Breaking Cultural Barriers to Health Care:
The Voice of the Deaf

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Abstract

This study, in collaboration with the Montreal Deaf Community, used an anthropological perspective to explore the health care experiences of deaf persons and identify the strategies they use to meet their health needs. Narratives were qualitatively analyzed. Deaf persons see their world as separate from the hearing world of health services. The latter is perceived as lacking understanding of deaf persons, leading to their feeling of exclusion and powerlessness. What is supposed to be a source of support becomes one of anxiety. Nevertheless, deaf people show courage and versatility in coping strategies including affiliation and the notion of culture. The health system focus on 'normalization' contradicts deaf persons' perceptions of deafness as a meaningful human reality. The differing values have implications for health professionals and the organization of services. The McGill Model of Nursing offers an organizational framework for planning accessible health services for deaf persons.

Résumé

Cette étude, en collaboration avec le Centre Communautaire des Sourds de Montréal, a utilisé une perspective anthropologique pour examiner le vécu des Sourds auprès des services de santé et identifie les stratégies qu'ils emploient pour répondre à leurs besoins. Les récits, analysés qualitativement, démontrent qu'ils perçoivent le monde différemment des entendants quand il s'agit du système de santé. Celui-ci se caractérise par un manque de compréhension qui entraînent des sentiments d'exclusion et d'impuissance. Ce qui devrait être une source d'aide devient une source d'anxiété. Néamoins, les Sourds font preuve de courage et utilisent un évantail de stratégies pour se débrouiller, particulièrement des stratégies collectives comme la notion de culture. Le système de santé, axé sur la "normalisation", empêche les Sourds de se réaliser pleinement comme entité significative. Ces écarts de valeurs suppose des changements dans le système de santé. Le Modèle de Nursing de McGill offre un cadre organisationnel pour plannifier l'accessibilité des services de santé aux Sourds.

This thesis is lovingly dedicated to
my father and to
the memory of my mother

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Introduction

Deafness has probably existed throughout the history of humanity (Moores, 1987). The congenitally deaf only constitute about 0.1 percent of the population; however, issues that arise from them are of great importance (Sacks, 1989). Deafness can lead to cognitive and emotional deprivation (Rodda & Groves, 1987) as well as difficulties in interpersonal relationships (Vernon & Andrews, 1990). It can isolate people from others (Israel, Cunningham, Thumann, & Arnos, 1992, Steinberg, Sullivan, & Loew, 1998) and from knowledge (DiPietro, Knight, & Sams, 1981; Kleinig & Mohay, 1990; Sawyer, Desmond, & Joseph, 1996). Deafness affects the behavior of a deaf person in all areas of life such as career, marriage, education, friends and emotional well-being (Vernon & Andrews, 1990). Deafness creates distinctive problems in families, problems calling for solutions which are not typical in modern family life.

Deafness, genetic or acquired, is not restricted to any racial group or to any type of social organization (Moores, 1987). Because there are many causes to genetic deafness and since deafness can be acquired in many ways, it is likely to be found in any large population. In Canada, over a million people have a hearing impairment, establishing this disability as among the most prevalent in the nation (Schein, 1992). The incidence will become more prevalent over the next few decades because of the increasing elderly population (Herth, 1998; Schein, 1992; Vernon & Andrews, 1990).

The World Health Organization's global strategy, "Health for All by the Year 2000" (1981), is based on the principle that health professionals, educators, scientists, politicians, government committees, and others must cooperate to enhance the quality of life for all people (MacDougall, 1993). Equity is fundamental to health for all (Maglacas, 1988) and all persons deserve and have the right to equitable access to health services (McIntyre & Rivard, 1995). Despite federal statutes mandating accessible health care for disabled persons and a recent supreme court ruling stating that the failure to provide interpretation services in health care settings violated the rights of deaf persons (Eldridge,1997), the health service needs of deaf Canadians remain profoundly

underserved (MacDougall, 1991; 1993). Deaf individuals and their families live in the community but do not receive the health services needed to achieve productive and independent function.

Traditionally, the medical model has been used to understand and describe deafness (Lane, 1992; Padden, 1980; Padden & Humphries, 1988). Consequently, deaf people have been primarily described in terms of their pathological condition: hearing loss. Deaf people, however, do not want to be treated as medical cases. Although hearing loss is a very real physical condition with important consequences, there are deeper aspects in deaf people's experiences of themselves and of the world (Padden & Humphries, 1988). Deaf people form groups in which members do not experience "deficiencies" and in which the basic needs of the individual members are met (Padden, 1980). Deaf people see themselves as fundamentally visual people, with their own visual language, social organization, history, values, knowledge, and expectations--in short with their own way of being, their own language and culture. Scholarly research in linguistics, anthropology, sociology, and history supports them in this claim (Lane, 1992).

In Canada, the notion of deaf community is used for describing those individuals who use American Sign Language (ASL) or/and Langue des signes québécoise (LSQ) to communicate and who consider themselves part of the Deaf culture (MacDougall, 1991; 1993). However, deaf persons' life experiences shape their sense of belonging to a particular culture. While some deaf adults are part of the deaf culture, other deaf individuals are part of the hearing culture (Israel et al., 1992). Members of this group share many of the frustrations and life experiences of the socioculturally deaf and utilize much of the same technology in coping with their deafness; however, they identify with the hearing population rather than with the deaf community. In reality, these individuals are culturally somewhere between the hearing and deaf worlds (Reagan, 1990).

Nursing is a health profession which focuses on understanding the health care needs and responses of diverse client populations and on delivering culturally competent care (Meleis,1992a). The McGill Model of Nursing is a specific approach to the delivery of health care that is inherently

responsive to the needs of a large variety of populations, including deaf people and other minority populations. Its focus on health and strengths and potential in lieu of deficits makes it particularly compatible with how deaf persons view themselves.

To promote access to health services to deaf individuals and their families, nurses and other health professionals require a knowledge base pertaining to deafness. However, most nurses have little knowledge about deafness (McLeod & Bently, 1996; Wright; 1993). In an inventory of statements to assess perceptions of deafness in a group of 85 nurses and a comparison group comprising 95 non-nurses, Darbyshire and Kraus (1983) found that an attitude of ignorance of the deaf and their difficulties was characteristic of both groups. Surprisingly, nurses showed no real awareness of deaf culture and the particular challenges deaf people faced. It is important for nurses to be aware of deaf people's perspectives and their experience with health services, the particular problems they face. It is also essential that nurses possess knowledge of the health care needs of deaf persons, as well as their strengths, resources and coping strategies.

There is a dearth of research which addresses accessibility of health services to deaf people whereby deafness is viewed within the context of the whole person and in relation to culture. Papers have described the special communication needs of deaf adults in medical settings (Chovaz, 1992; DiPietro et al., 1981; Ludders, 1987), barriers to the delivery of health care (DiPietro et al.,1981; Ebert & Heckerling, 1995; MacDougall, 1993) and the lack of accessibility to mental health services (Steinberg, 1991; McEntee, 1993; McIntyre & Rivard, 1995). Israel and colleagues (1992) addressed access to genetic counselling services and recommended that increased attention be given to cultural issues. In a recent study, Steinberg et al., (1998) investigated the knowledge, attitudes, and beliefs about mental illness and providers in a group of 54 deaf adults. The authors concluded that views of deaf patients needed consideration in planning services. However, comprehensive studies regarding general accessibility of health services for the deaf have not been found. The present status of the research on deafness and health means that

those who care for deaf people must presently rely a great deal on intuition with all the potential pitfalls of myth and speculation entailed in such an approach.

The present investigation was undertaken in an attempt to begin to fill these gaps in knowledge. The purposes of the study were to explore two complementary aspects regarding deaf people and access to health care. The first facet of the study explored the health care experiences of deaf people. The second aspect of the investigation identified the strategies and resources used by deaf persons to cope with the present gaps in the health care system and constraints encountered.

Literature Review

The literature concerning the health of and health services for deaf persons, can be organized around three main topics: deafness and the deaf community, deafness and health, and deafness and health services. In order to draw a picture of deaf people's situation and the potential contribution of nursing, two additional areas will also be covered: the organization of health services in Québec, and health, deafness, and the McGill Model of Nursing. To promote accessibility of health care to deaf persons, the concept of health is highlighted and a theoretical framework is proposed.

Deafness and the Deaf Community

The notion of a Deaf community has come to impose itself in the last decades. In order to understand its dynamics and its importance, it has to be situated against the context of the heterogeneity of deafness and the attitudes associated to deafness through history. It also has to be understood in the context of the debates surrounding the two main modes of communication available to deaf people.

Profound deafness is a physical entity but it is also a cultural phenomenon in which social, emotional, and developmental patterns and concerns are inextricably bound together (Higgins, 1980; Lane, 1984; Moores, 1987; Moores & Meadow-Orlans, 1990; Reagan, 1990; Schlesinger & Meadow, 1972). Due to the heterogeneous nature of deafness, it is exceedingly complex to define. The sociologist, Paul Schein (1987;1989), believes the issue of deafness to be one of communication: how hearing impairment affects one's ability to communicate with another. In this light, Schein defined deaf people as people who cannot hear and understand speech through the ear alone.

The term "deaf" is general, and it impedes consideration of numerous factors which mark the condition of deafness (Sacks, 1989). The essence of deafness can only be grasped through realizing the range of factors which influence the experience of being deaf. Among those, the differing degrees of deafness, age of onset, whether parents or family members are deaf or hearing, and what their primary language is, are particularly important to consider. Some deaf adults are part of the hearing community, while other deaf

individuals are members of the deaf community. Connection with the deaf community gives access to information, values and a history of solutions created for them by other people like themselves (Padden & Humphries, 1988). By contrast, other deaf individuals feel caught in between the hearing and the deaf community. Disconnection with either communities can result in a tremendous sense of isolation. Deaf peoples' experiences through family and school environments help shape their sociocultural orientation (Higgins, 1980; Israel et al., 1992; Padden & Humphries, 1988; Schein, 1989).

There are differing degrees of deafness, degrees that are of qualitative and "existential" significance. There are the *hard of hearing* who can manage to hear some speech using hearing aids and a certain amount of care and patience on the part of those who communicate to them. With the hard of hearing, the development of speech and oral language follows the same pattern as their hearing peers, although not necessarily at the same rate (Rodda & Grove, 1987). There are also the *severely* deaf, many as a result of ear disease or injury in early life. As with the hard of hearing, the hearing of speech is still possible especially with sophisticated hearing aids. Then there are the *profoundly* deaf who have no hope of hearing any speech, whatever imaginable technological advances are made (Sacks, 1989). Consequently, they cannot converse in the usual way--they must either lip-read or use sign language or both (Rodda & Grove, 1987).

It is not merely the degree of deafness that matters but, importantly, the age, or stage, at which it occurs (Moores, 1987; Sacks, 1989; Schein, 1987,1989). The *prelingual* deaf involves those whose hearing was absent at birth or prior to the development of speech and language (Moores, 1987; Rodda & Grove, 1987). Many such deaf individuals are congenitally deaf and have etiologies of genetic origin. In all cases, they have been subject to severe sensory, oral language and emotional deprivation. Considerable harm can result and has resulted from a failure to appreciate the special problems facing deaf children in infancy and in late stages of development (Rodda & Grove, 1987). *Postlingual* deafness refers to the condition of persons whose deafness occurred following the spontaneous acquisition of speech and language (Moores, 1987).

Although deafness is a heterogeneous phenomenon, the lack of communication is certainly common to all deaf persons. However, the difficulty of access to a language goes beyond a communication problem.

Deaf people interact with their environment in a different way than their hearing counterparts. For one thing, deafness affects speech development (Rodda & Grove, 1987). The beginnings of speech lie in the natural gestures of the body and verbal communication retains some aspects of this form of symbolization. In young children, gestures develop into a skill that enables the child to communicate specific meanings, such as pointing to an object. In the deaf child the gesture of pointing develops into a sophisticated communication system that is part of the syntax of sign language. The hearing child on the other hand develops speech sounds to fulfil a similar role, and so retains pointing only as a relatively unrefined part of the communication system.

Language serves social, emotional, and intellectual functions (Gallaudet, T.H., 1848: 1997; Gallaudet, E.M., 1887:1997; Sacks, 1989). In the early years, children's communication is usually aimed at locating and identifying self and exploring emotions and feelings (Rodda & Grove, 1987). It is often the mother's language, internalized by the child, that allows the child to move from sensation into sense and to ascend from a perceptual into a conceptual world. Language makes thought possible. It is an innate ability which needs to be activated by another person who already possesses linguistic power and competence. Through transaction and negotiation with another, language is achieved (Sacks, 1989).

If communication goes sour, intellectual growth, social intercourse, language development, and emotional attitudes, simultaneously and inseparably become affected (Sacks, 1989). The breakdown in family communication is often associated with a rigid commitment to oralism (use of speech only) for deaf children for whom this method is not always suitable. As a result self-identity and self-esteem suffer (Rodda & Grove, 1987). Additionally, when a deaf child of hearing parents enters elementary school, that child often lags behind children with normal hearing in the area of language skill (spoken or sign language), general knowledge about the world, and social adaptability (Israel et al., 1992). A cycle is established in which educational

underachievement becomes linked with lower socioeconomic status, and breaking the cycle becomes exceedingly difficult as lower expectations are set for the deaf student (Moores, 1987; Rodda & Grove, 1987). A small number of deaf children, perhaps ten percent, are born of deaf parents (Schein, 1987). These children have access to the acquisition of the natural sign language used by their deaf parents and have a greater knowledge base about themselves, their family, and the world around them (Israel et al., 1992; Johnson et al., 1989; Meadow-Orlans, 1990). Unless deaf children are in environments that use sign language, they are eventually deprived of all language input (Johnson, Liddell, & Erting, 1989; Moores, 1987; Reagan, 1985, 1990; Rodda & Grove, 1987).

Deafness has been met with a great deal of prejudice since antiquity. A core element in the experience of deaf people is the phenomenon of stigmatization. There is abundant historical and sociological evidence that deaf people are viewed negatively in this society, encountering discrimination, social distancing, paternalism, and authoritarian attitudes (Becker, 1980; Higgins, 1980; Lane, 1992; Moores & Meadow-Orlans, 1987; Preston, 1994; Rodda & Grove, 1987; Schein, 1989; Vernon & Andrews, 1990). Lane (1988), reviewed the literature on the psychology of the deaf and assembled a list of characteristics ascribed to deaf people. The author contended that trait attributions such as aggressive, hedonistic, immature, impulsive, rigid, lacking in initiative, stubborn, and suspicious reflect not the characteristics of deaf people, but the paternalistic posture of hearing professionals.

The sociologist Erving Goffman (1963) distinguished three kinds of stigma: physical, characterological, and tribal. According to Lane (1992), all three types have been ascribed to deaf people. Physically they are judged defective because of their hearing loss and this is often taken to give rise to undesirable character traits, such as concreteness of thought and impulsive behavior. Because the Deaf are an ethnic minority, they are also subject to tribal stigma (Lane, 1992).

Stigmatization refers to the marking of "outsiders" and is an aspect of marginalization. Marginalization is the process through which persons are pushed to the periphery on the basis of their identities, associations, experiences, and environments (Hall, Stevens & Meleis, 1994). Deaf people are

often seen as outsiders as they live in a world largely created and controlled by those who hear (Higgins, 1980).

Deaf persons and culturally and economically disadvantaged persons are often described similarly: both are seen as impulsive, immature and as having delayed psychosocial development (Schlesinger, 1987). An important aspect of the deaf experience which impacts on future development is a dependency on hearing people, fostered in deaf children in childhood and continued by the condition of deafness into adulthood (Meadow-Orlans, 1990). Schlesinger (1987) looked at the characteristics of disadvantaged and deaf children and contended that the similarities between the two groups relate either to a parental experience with powerlessness on a personal level or powerlessness due to membership in a group that is subordinate to the dominant portion of society.

This current situation is not new. Since the time of Aristotle, deaf people were thought to be "dumb." Lack of speech implied the inability to reason (Bender, 1981). This misconception lasted until the middle of the eighteenth century when it was discovered that deaf people were capable of reading and writing (Lane, 1984). Around the same time, the language of signs, was also recognized. These two events demonstrated for the first time that deaf people were not "dumb" but capable of intellectual thought and communication (MacDougall, 1991).

Until now, the form of communication used by deaf people continues to be a major source of debate and controversy. Natural Sign language has evolved over several hundred years and deaf people have always used manual language. However, the educational arena was and remains the locus of conflict between proponents of oralism who concentrate exclusively on oral (speech and hearing) means of communication and advocates for the addition of sign language (Steinberg, 1991). The two main orientations to communication pose a dilemma for parents of deaf children.

The development of speech and the understanding of spoken language is the major educational orientation for "oralist" deaf individuals, who are taught communication skills based only on residual hearing and speechreading (lipreading). Most oralists use only those modalities of communication however,

linguistic studies have demonstrated that only about 30 percent of spoken language is comprehensible through lipreading (Dubuisson & Nadeau, 1993); the remainder must be gathered from context and prior knowledge of the language being used (Steinberg, 1991). Few profoundly deaf individuals can rely on speechreading alone for complete information exchange (DiPietro et al., 1981). Other methods of communication include written communication and some form of signing. For most persons with a social and personal deaf identity, the optimal modality remains the use of sign language to communicate comfortably and unambiguously (MacDougall, 1991:1998).

American Sign Language/Langue des signes québecoise, the primary languages of the deaf community in Canada, are linguistically rich and complex systems with grammars independent of spoken languages. ASL/LSQ are natural sign languages with complex organizational properties found in spoken language, but with a moving and visual modality. They are not meant to be heard, spoken, or written. Words or signs are formed by the hands, arms, face, and sometimes by the entire upper body. A single sign can correspond to a single word, or may represent a phrase or sentence. Besides the obvious advantage of enabling deaf people to communicate with each other, sign language is perhaps the most affective of all language systems (Bellugi, Poizner, & Klima, 1983; Gallaudet, T.H.,1848:1997; Johnson et al., 1989; Vernon & Andrews, 1990). Oralism is perceived by deaf people as denying their deafness.

The present approaches to communication: oralism, total communication, and artificially developed systems for coding spoken languages are debatable (ADISQ, 1996; Johnson et al., 1989; MacDougall, 1991,1994). Several decades of intensive research and intervention programs have failed to raise the average reading level of deaf high school graduates above the 3rd or 4th level (Allen, 1986). Johnson and associates (1989) suggested that low academic achievement levels are not the result of learning deficits related to deafness, but of problems in the communication practices of teachers and the absence of an accessible language in the classroom setting. They advocated the primary use of Sign language in the classroom, the exposure of deaf children to deaf teachers and other adult role models and instruction in English as a second

language through reading and writing. Although the future impact of these experts' recommendations remains to be seen, few deaf students are currently educated in a linguistically accessible environment (ADISQ, 1996; Steinberg, 1991).

The history of deafness is one of denial--denial that the experiences of deaf people are different from those of hearing people (Rodda & Grove, 1987). Denial has led to the extremes of oral education advocated by such people as Alexander Graham Bell and his successors in the 19th century. In the first half of the twentieth century, sign language was a stigmatized and repressed language and its users deemed dysfunctional and illiterate. Many educators felt that their efforts to make deaf people like hearing people were thwarted by sign language (Mindel & Vernon, 1971).

A key concept that has arisen in the communication debate is the idea that signing deaf persons constitute a distinct society with a minority language, culture and social institutions (MacDougall, 1991; Lane, 1992; Padden & Humphries, 1988; Sacks, 1989). In the 1970's, with evidence supporting the view that Sign Language was a real language, Sign Language became a core emblem and a recognized vehicle of culture for the deaf community (Benderly, 1980).

Deaf people tend to socialize within their cultural group. Although ninety percent of deaf children are born to hearing parents (Schein, 1987) and although members of deaf communities are citizens of the larger society, most lifelong deaf adults socialize exclusively with other deaf people. It is estimated that deaf people have an 85 to 95 percent endogamous marriage rate (Schein & Delk,1974). Many deaf persons would prefer to have deaf children because of the communication ties that will exist and the strong desire to preserve deaf culture (Dolnick, 1993; Israel et al., 1992).

Deaf people are culturally distinct from their hearing neighbours also in terms of the behavioral norms that govern their social interactions. Examples of variations in behavioral norms between deaf and hearing people would be eye contact patterns, rules governing physical contact and touching, the use of facial expressions, gesturing, and so on (Gannon, 1990; Reagan, 1990). Such

variations in what would constitute socially acceptable behavior often results in misunderstandings between hearing and deaf people (Reagan, 1990).

A widespread misconception among hearing people is that deaf people live in a world of silence (Padden & Humphries, 1988). For hearing people, the world is discovered through sound. Deaf people, however, build their world around the resources of movement, form and sound. "The lives of deaf people are far from silent but very loudly click, buzz, swish, pop, roar, and whirl" (Padden & Humphries, 1988, p.109). "Metaphors of silence reflect two cultural standards: a hearing culture that reveres sound as the basis for communication, and a deaf culture that sees sound as an unessential and often unnecessary ingredient of communication" (Preston, 1994, p.122).

According to Padden & Humphries (1988), hearing professionals who work with deaf people have a different "centre" than their clients. The example they eloquently presented was of the meaning of *hard of hearing* . To those who can hear, hard of hearing typically refers to someone who *cannot* hear well. From a hearing point of view, it is better to be hard of hearing than deaf; someone who is a little hard of hearing is much less deaf than someone who is very hard of hearing. Deaf people see things the other way around. To a deaf person, hard of hearing usually means someone who can hear, even if only a little. When they sign that an acquaintance is a *little hard of hearing* they mean that the person has some of the ways of hearing people but basically is quite deaf. When they sign that someone is *very hard of hearing*, they mean that the person is very much like hearing people, scarcely like deaf people at all. Two cultures, two points of view, two different "centres" (Lane, 1992; Padden & Humphries, 1988)

Culturally deaf people do not see their deafness as a "disability," but as a cultural difference. Deaf authors Padden & Humphries (1988) state:

> The traditional way of writing about Deaf people is to focus on the fact of their condition--that they do not hear--and to interpret all other aspects of their lives as consequences of this fact. In contrast to the long history of writings that treat them as medical cases, or as people with 'disabilities' who 'compensate' for their deafness by using sign language, we want to portray the lives they live, their art and performances, their everyday talk, their shared myths, and the lessons they teach one another. We have

always felt that the attention given to the physical condition of not hearing has obscured far more interesting facets of Deaf people's lives. (p.1)

Culture is the symbolic system of a group of people and the link between what people are intrinsically capable of becoming and what they in fact become (Geertz, 1973). Culture consists of learned systems of meaning, communicated through natural languages, and reflected in daily cognitive, emotional, and social behavior. Meaning systems enable people to adapt to their environment and structure interpersonal activities (D'Andrade, 1984).

Although deaf people throughout the world often report feeling closer with each other than with hearing people, deaf cultures are specific to the nation or region. The political, historical, and social dimensions of the majority culture which is hearing, create a particular context for deaf people. Such differences result in distinct characteristics among deaf people from the community to the national level (Preston, 1994).

The view of Deafness as culture is reflected by the preference of the deaf community to use the term "Deaf" (cultural viewpoint) or "deaf/hard of hearing" (clinical viewpoint) rather than "hearing impaired." However, other individuals (deaf and hearing), including parents of a child with hearing loss, may prefer to use "hearing impaired," seeing this as a more polite, less threatening term. How individuals refer to themselves (or to a family member) can give important information about their cultural ties and perspective on deafness (Israel et al. 1992).

Most culturally deaf people have moderate to profound hearing loss since birth or childhood. Cultural deafness, however, is not just about hearing loss (Preston, 1994). Cultural deafness is an achieved status that depends on identification with the deaf world. Membership is largely based on a sense of cultural familiarity: having life experiences associated with being deaf; participating in social interactions with other deaf people; and sharing similar social behaviors, historical traditions, and a common destiny (Higgins, 1980; Padden,1980; Preston, 1994; Schein, 1989). A deaf person may be born into deaf culture, as is the case with those who have deaf parents, or may become enculturated later in life. Since the majority of deaf individuals are from hearing

families, in contrast to most cultures, the great majority of individuals who are part of the deaf culture do not join at birth but choose this culture themselves (Padden & Humphries, 1988). Through Sign Language, deaf people learn about their culture and share experiences. Most deaf and hard of hearing people who lost their hearing later in life are not members of the deaf community as they use verbal communication. The oral deaf that shun any use of sign language and the people who serve them are generally not regarded as part of this group (MacDougall, 1991).

Culturally deaf people generally disassociate themselves from speech. Among deaf people, speech is almost never used. The fact that a deaf person does not use speech may not be an indication of that person's ability to use speech, but may rather be a reflection of their deaf cultural values (Israel et al., 1992). Some deaf persons may use their speech in situations where they would not otherwise be understood, such as with hearing persons (Padden & Humphries, 1988).

Deaf communities are both a response to the negative experiences encountered by hearing-impaired people in the larger society (Lachance, 1993) and a positive means for deaf people to achieve a sense of wholeness and belonging. An important goal of deaf communities is to achieve public acceptance of deaf people as equals--equals in employment, in political representations, and in the control of institutions that involve deaf people, such as schools and service organizations (Padden, 1980). Deaf people are seeking empowerment in all aspects of their lives (McDougall, 1991).

Although deafness undeniably involves restrictions and accommodation, many authorities on deafness believe that the more deafness is approached as a social condition, the greater will be deaf people's chances for healthy overall development (Moores, 1987). The present orientation towards deafness, however, makes it difficult for families to understand deafness as other than a medical condition. Upon diagnosis, parents must cope with the shock of learning about an unexpected handicap and face the difficulties of communicating with their child in the absence of a common language. In many instances, the diagnosis confuses deafness with other kinds of impairments, such as mental retardation or emotional disturbance (Meadow-Orlans, 1990).

The diagnosis is usually made by a physician or audiologist who has extensive knowledge about the auditory mechanism, but little knowledge about deafness (Vernon, 1980). Hearing parents are rarely referred to the deaf community and thus do not get a chance to see and meet deaf people who are doing well. Because of lack of information about the psychosocial, educational, and cultural implications of deafness, health professionals often fail parents at the time of greatest need (Vernon & Andrews, 1990).

Raised in a society with a "disease" orientation toward difference, parents naturally assume that deafness can be treated in a way that is similar to how other diseases are treated--with medicine or surgical technique (Moores, 1987). Similar lines of thinking have brought about great interest in cochlear implants, direct electrical stimulation of the inner ear. However, the psychosocial benefits of implants to the profoundly deaf child and adult have been and remain controversial (Crouch, 1996; Lane, 1992). For most deaf children, there are no cures and it takes a great deal of adjustment for a parent to realize that they and their child must prepare for a lifetime of deafness (Moores, 1987).

The notion of deafness as "disease" or "handicap" can have deep implications for a child's growth and development. As early as seven to eight months, babies are tuned into the different emotional expressions of adults (Dunn, 1988; Stern, 1985). The importance of early close relationships for children's social, cognitive and emotional development, has long been assumed (Bowlby, 1982; MacTurk, Meadow-Orlans, Koester & Spencer, 1993). A secure relationship between a child and parent is the foundation for a child's developing sense of confidence and affects how he or she will learn to know and deal with features of the environment including other human beings (Ainsworth, Blehar, Watters & Wall, 1978).

Many health professionals who have worked extensively with parents and children believe that the diagnosis of a handicap in a young child evokes a response of grief in the parents similar to the grief felt for the death of a loved one (Meadow-Orlans, 1990; Vernon & Andrews, 1990). The response to the diagnosis of hearing loss has been described as similar to the reaction to other kinds of crises: shock, recognition, denial, and acknowledgement, followed by constructive action (Vernon & Andrews, 1990).

Schlesinger (1987) observed a sense of powerlessness in parents of a newly diagnosed deaf child. When parents are told by medical specialists that "nothing can be done" their sense of being unable to influence the destiny of their deaf child becomes overpowering. The sense of powerlessness continues beyond the child's infancy and becomes particularly intense when parents are unsuccessful in attempts to communicate more extensively with the child. Parents become domineering as they increase their efforts to break through the communication barrier. Hearing mothers of young deaf children are rated as more controlling, intrusive and less approving or encouraging in comparison with mothers of young hearing children (Schlesinger & Meadow, 1972). Parents of deaf children also reported a constant concern over whether they were being overprotective or underprotective. These parents tended to use a narrow range of discipline techniques, with more reliance on spanking, and exhibited more frustration with respect to their children. Meadow (1980) concluded that the protectiveness most families exhibited toward their deaf children likely inhibits their social development.

For those children who are born of deaf parents, the situation is very different. For deaf parents, deafness is a familiar situation. Unlike parents with normal hearing, they can anticipate rearing their deaf child in a way similar to how they were reared or with changes based on experiences they want to avoid (Meadow-Orlans, 1990). Deaf parents tend to have a greater range of coping strategies for dealing with typical problems confronting a deaf child (Schein, 1987). Jones (1995), compared deaf and hearing parents' perceptions of family functioning and found that deaf parents ranked leisure/recreational activities as more important than hearing parents. For parents with normal hearing, their own family experiences however provide few guidelines for the socialization of their deaf child. From their first suspicion of their child's hearing loss, through their contacts with medical, audiological, and educational specialists, into the child's educational experience, the deaf parents and the hearing parents of deaf children will have differing experiences, understandings and expectations (Meadow-Orlans,1990).

In his book entitled The Mask of Benevolence, Lane (1992), a psychologist and chief theoretician of the deaf culture movement, has made his

case clear. He sees the lack of communication at home, inferior education in school and discrimination in employment as obstacles placed by hearing people, who, if they came to know the deaf community, could readily remove them.

Deafness and Health

A national survey, the "McGill Study of Deaf Children in Canada" (MacDougall, 1990) documented demographic information and characteristics of 8,000 deaf children. Age, sex, cause, degree of hearing loss, age of onset and additional disabling conditions were identified. The prevalence of deaf children (birth to 21) in Canada was found to be 1/1000. The cause of deafness was unknown in half of the cases, chronic otitis media being responsible for 6% of children with hearing impairment and residual effects from meningitis causing 6.1% of deafness. MacDougall also found that 30-35% of deaf children had additional physical and psychological impairments. Knowledge of degree of hearing loss, age of onset, etiology, and the presence of additional disabling conditions can be used in the development of health services suited to the needs of deaf children.

Within the health care system, the attention given to deaf clients has been principally of a physical nature. Specialties have evolved to identify and diagnose deafness, offer therapy for remedial conditions of the ear, conduct hearing aid evaluations, develop and implement programs for the prevention of hearing loss and provide special education and rehabilitation to hearing impaired people. Such specialties deal principally with only one component of health care delivery to the deaf person--the ear and its dysfunction. However, the health care system is most frequently called upon to provide care for the deaf individual when their concerns are unrelated to the ear (Chapman, 1975; DiPietro et al.,1981; Vernon & Andrews, 1990).

The condition of deafness impacts on health in varied ways. Studies in the domain of mental health indicate that deaf people may be more vulnerable to mental health concerns as compared to hearing persons (Vernon & Andrews, 1990). Hindley, Hill, McGuigan and Kitson (1994) found that the prevalence of mental disorders among deaf children was approximately one and a half times that of a comparable hearing population. Similarly, Lou (1991) found that deaf

children were more likely to experience serious mental health problems as compared to children with or without other disabilities. In most cases, the problems appeared related to the quality of communication. In contrast, deaf children of deaf parents are less frequently identified as exhibiting problems in emotional and behavioral adjustment than are deaf children of hearing parents (Paul & Jackson, 1993).

Besides issues of mental health, deaf persons also face higher incidences of common societal problems such as alcohol, substance abuse and sexual abuse. Within the deaf community 1 in 7 people have a substance abuse problem compared to 1 in 10 people in the hearing community (Vernon & Andrews, 1990). Contributing factors include poorer self-esteem, isolation, learned dependence, and lack of social skills (Steitler, 1984). Children who are deaf, have been found to be at a greater risk for sexual abuse or incest than their hearing peers (Sullivan, 1987). Communication problems, fear of authority, and doubts of not being believed all contribute to the fact that deaf children are less likely to report a situation of abuse (Peinkofer, 1994). Sawyer, Desmond and Joseph (1996) surveyed a deaf and hearing group of university students and found a significantly higher rate of forced sex in the deaf population (24%) as compared to the hearing population (14%). According to Langlais and colleagues, deaf women, if victims of conjugal violence, are doubly jeopardized because they are generally isolated and destitute (Langlais, Larochelle, Lemieux, & Racine, 1995). They add that the absence of adapted communication technology and lack of training of health professionals regarding deafness make shelters inaccessible to deaf women. The above literature indicates that deaf persons are vulnerable in relation to their health status.

Most studies have focused on the particular health concerns of deaf people. However, Magilvy (1984), investigated the quality of life of 66 hearing impaired older women, 27 of whom became deaf before nineteen and 39 who became hearing impaired after the age of nineteen. Results indicated that early onset deaf subjects, most of whom identified with the deaf community, noted more difficulty communicating with hearing people, but felt that deafness itself did not limit their lives. In contrast, later onset subjects expressed more

emotional and situational problems stemming from their hearing loss and had an overall lower perception of quality of life. Similarly, using a cross-sectional survey, Zazove, Niemann, Gorenflo, Carmack, Mehr, Coyne, and Antonucci, (1993) investigated the self-reported health status of 87 deaf and hard of hearing members of various organizations in Michigan and 88 hearing patients from a family practice unit. The researchers found that deaf and hard of hearing persons reported a lower subjective health status as well as substantial communication difficulties with their physician as compared to their hearing counterparts.

The effects of hearing loss, creates stress no matter the extent of the hearing loss, and deaf people often lack opportunities to talk through their stresses and gain insight and coping skills (Fellinger, 1995); Vernon & Andrews, 1990). Fellinger attributed these high levels of stress to permanent high level of attentiveness and concentration required of deaf people in their daily encounters with the hearing world. Another attributable factor was that of having experienced communication difficulties ever since childhood (Fellinger, 1995).

Deafness and Health Services

The condition of deafness creates barriers to the delivery of health services. Communication difficulties (Casey, 1995; Chovaz, 1992; DiPietro et al.,1981; Ebert & Heckerling,1995; Higgins,1980; Ludders,1987; MacDougall, 1991; Schein, 1989; Vernon & Andrews, 1990), inadequate interpretation services (Lotke, 1995; McEntee, 1993; Steinberg, 1991), lack of training of health professionals in Sign language, and lack of knowledge about deafness and the deaf community (MacDougall, 1993), lead to poor understanding of deaf people and their health needs. Other significant barriers to health care include, the invisibility of deafness and negative, paternalistic and authoritarian attitudes towards deaf people (Vernon & Andrews, 1990; Lane, 1992). As a consequence of deafness, health information is not easily accessible (DiPietro et al., 1981; Israel et al., 1992; Lass, Franklin, Bertrand, & Baker, 1978; Ludders, 1987; MacDougall, 1993; McEwen & Anton-Culver, 1988; Peinkofer,1994; Sawyer et al, 1996; Vernon & Andrews, 1990; Zazove et al., 1993).

Several authors have commented upon deaf peoples' lack of health knowledge. Gibbons (1985) found that deaf children could name fewer body

parts than hearing children. Kleinig and Mohay (1990) compared the health knowledge of high school students and found that the level of health knowledge of hearing students was superior to that of the hearing impaired students. Similarly, Sawyer, Desmond and Joseph (1996) found that hearing university students were significantly more knowledgeable regarding sexuality than deaf students. The lack of health knowledge appears to be a reflection of the lack of exposure of deaf persons to medical terms and discussions of health at home, work, school and from television and radio (Kleinig & Mohay, 1990).

Sensory-neural deafness is associated with significant difficulties in the area of literacy (MacDougall, 1991). Reading is a complex perceptual, cognitive and linguistic process which under usual circumstances, is involved with the ability of the brain to receive and process auditory and visual signals, and is tied to the complex speech process (Litowitz & Liben as cited in MacDougall, 1991). Deaf individuals lack fluency in written English and/or French because they cannot hear spoken languages. Lacking in English and/or French vocabulary and syntax, most deaf people do not read much as reading is difficult and a slow process. This translates into barriers for deaf persons in their interaction with the health care system. For the health system it means that although printed materials about health care topics may be available to the deaf person, the information may not be written at a level appropriate for the average deaf adult (Israel et al., 1992). Without the reading skills needed to understand printed materials, many deaf people have a limited understanding of health related issues and of the health care process (DiPietro et al., 1981).

Deaf people's lack of health knowledge affects the quality of communication with health professionals as the latter are likely to use words and medical terminology unfamiliar to deaf persons. Interpreters can offer one of the most effective ways of facilitating communication between hearing and deaf persons (Israel et al., 1992). The role of the interpreter is to convey accurately all messages between deaf and hearing individuals. The interpreter serves as the (visible) voice of the health professional and the ears of the deaf person. As such, the interpreter does not counsel, participate in discussions nor edit conversations. The interpreter has the obligation to interpret everything that is said in the deaf person's presence (DiPietro et al., 1981). Although interpreters

can greatly facilitate communication, they are unfortunately not always made available (Lotke, 1995; McEntee, 1993; Steinberg, 1991). A survey by Ebert and Heckerling (1995) demonstrated that although physicians were aware that signing should be the initial method of communicating with deaf patients who sign, writing was the method used most to communicate. Overall, the studies overwhelmingly point to a lack of accessibility to health care services. According to Steinberg (1991), the majority of hospitalized deaf individuals remain isolated, confused, and, often, abused in systems that do not comprehend their special needs.

The organization of health services in Québec

In Québec, there exists a fundamental dilemma regarding the organization of health services for the deaf. The predicament is about whether or not services for the Deaf should be integrated or separated. In Quebec, until the early 1970's, services were separate, under the authority of religious orders. Besides serving as an educational institution, the convent or residence as it was commonly called, was a central reference centre for deaf people. It was also a protected place where deaf people gathered together to exchange and share experiences. In this aspect the Deaf felt self-sufficient, not isolated. These residences were abolished in favour of integrated services.

Carbin (1996), an educator and author who is deaf himself, looked at the history of the Deaf in Québec. The province of Quebec is populated by a majority of French-speaking and a minority of English-speaking residents. Most people who speak French are Catholic. Until recently, educational placement was largely determined by the family's religion and language preference. In the 19th and most of the 20th centuries, deaf children from Catholic French families as well as some Catholic English deaf children, attended one of the two schools run by the Catholic Church while deaf Protestant anglophones usually attended the Mackay Institution. The Catholic schools for deaf children were further segregated by gender, with the boys attending the Institution Catholique des Sourds-Muets (Catholic Institution for Deaf and Dumb Males) and the girls attending the Institution Catholique des Sourdes-Muettes (Catholic Institution for Deaf and Dumb Females).

Between 1940-1950, the Institution Catholique des Sourdes-Muettes began to offer a variety of educational as well as social programs (Carbin, 1996). These included the School of Domestic Arts, a preschool for children between ages of five and eight and a school of family and feminine education. In addition, the school housed deaf women who had completed their education, but for varied reasons, wished to remain at the residence. They became part of the housekeeping staff. The Institution also established a social program for deaf adult men and women who were not residents of the Institute.

Located in Montreal, Quebec, these residential schools thrived for many years, but eventually came under the influence of integration (the practice of mainstreaming deaf students into local schools with hearing students), the secularization of Quebec, the development of new technology and the arrival of rehabilitation professions in the work force. The integration of services for deaf persons into general services took place under the influence and the philosophy of normalization, which was applied in the context of oralism. In 1964, responsibility for Catholic schools was transferred from the Catholic Church to the newly created Quebec Department of Education. This change led to the beginning of officially sanctioned co-ed Catholic education in the province and the eventual closure of the two schools for Catholic deaf students. In the early 1970's, the provincial government passed legislation on health and social services that forced the various religious communities of the province to give up their hospital work and their centres. One of the six "centres" within the municipality of Montreal that fell under this decree was the building housing the Institution Catholique des Sourdes-Muettes (Carbin, 1996). The building that once housed the school and served as home for deaf students and nuns alike now houses the Institut Raymond-Dewar, a rehabilitation centre for persons with communication difficulties and physical handicaps. The focus of the institute is primarily on auditory/oral communication. The Institution is part of Quebec's ministry of health and social services public network.

The closure of the Institution Catholique des Sourdes-Muettes, led to the transfer of its department of social services to the Centre Régionale de la Santé et des Services Sociaux (Regional Centre for Health and Social Services). In the early 1980's, with the advent of the health care reforms, the social services

for the deaf were once again reorganized and deaf persons were required to seek services at their local community health clinics (CLSC), which had come to being in the 1970's.

The integration of services led to the creation, in 1978, of l'Associaton des Adultes avec Problème Auditif which was later named the Montreal Metropolitan Deaf Community Centre, (MMDCC). The centre is open to deaf and hard of hearing persons and any hearing person interested in deafness. Objectives of the centre include: identification of needs, advocacy of rights and interests of deaf persons, training of deaf leaders, the support of projects created by deaf persons, sensitization of the public toward deafness, relaying information regarding community resources and legal issues and so on. The centre advocates for workplace accessibility and an educational system adapted to the real needs of the Deaf. It also organizes social activities. The centre seeks to empower deaf people in all aspects of their lives. The promotion of well-being of deaf people and accessibility of health services is of utmost importance to the organization. The Montreal Deaf Community Centre is a non-profit organization funded by Centraide.

In 1960, the Mackay Institution for Protestant Deaf-Mutes became the Mackay Centre as a result of an amalgamation with the School for Crippled Children. The centre provides education and rehabilitation to children with various disabilities and sensory deficits. The objectives of the centre are to maximize abilities and independence and to facilitate community integration. Today, in Montreal and surrounding regions, anglophone deaf persons are often referred to the Mackay Centre for psychosocial services while the francophone population is referred to l'Institut Raymond-Dewar.

Health, Deafness, and the McGill Model of Nursing

Nursing is concerned with health and illness and the experiences of human beings, experiences shaped by history, significant others, politics, social structures, gender, and cultural heritage (Meleis, 1992b). These experiences become more complex as individuals navigate their way through the health care system, with its complex organizational structure (American Academy of Nursing, 1992) and culture-laden components (Kleinman, 1980). In making their way through the health care system, members of minority groups tend to

encounter the most difficulties. Nurses are central to the potential of developing and maintaining programs that deliver culturally competent health care. There is global support in nursing for reaching vulnerable, disenfranchized populations and for maximizing their access to care (AAN, 1992).

Health as a central concept in the discipline of nursing is strongly evident in the nursing literature. Emerging as a nursing goal in the mid-19th century, the issue of its significance is less debatable than its nature (Jones & Meleis, 1993).

The concept of health as a disease-free state followed the Cartesian separation of mind and body (Engel, 1977). In an attempt to return to the Greek holistic view of health and block Western medicine's disease orientation or capitalism's view, the World Health organization defined health as more than the absence of disease and acknowledged the social and psychosocial aspects of health (Allen, 1986; Webster & Lipetz, 1986; WHO, 1947). Although the definition has been considered by some to be utopian (Keller, 1981; Seedhouse,1986), it was also recognized as emphasizing the positive qualities of health (Payne, 1983).

Until now, the biomedical perspective has influenced most theories of health and well-being (Meleis, 1991). As a framework for health, the biomedical perspective has been challenged because of its limited effectiveness (Engel, 1977), professional bias (Kleinman, 1980) and inappropriateness for the goal of nursing (Allen, 1979; Allen & Hall, 1988; Meleis, 1991; Shaver, 1985; Winstead-Fry, 1980).

In nursing, health has been defined in many ways. It has been conceptualized as a state, a process of development, an actualization, an outcome, a style of life (Jones & Meleis, 1993), a dichotomous variable, a continuum, and a more inclusive holistic state (Tripp-Reimer, 1984). Some nurses argue for more unity in nursing's view of health to avoid confusion, while others argue for diversity to encompass the variety of clients (Jones & Meleis, 1993). Seedhouse (1986), contends that health is a word with a wide range of different meanings and that it is impossible to decide on a single common meaning. Definitions of health in any society are culturally determined (Boyle & Andrews, 1989) and are bound by access to health care and how options for health care are perceived (Meleis, 1990).

One predominant theme in the discussion on health is that health is frequently viewed as a personal matter. The underlying assumption is that individuals are responsible for their health; families, communities, and societies are not as accountable (Meleis, 1990). Meleis challenged nurses to consider constraining social conditions that limit achievement of clients' health potential in some communities and societies. "Health may be a personal matter for privileged individuals, but not for those without access to health care. Furthermore, as long as diverse, underserved, and disenfranchised groups face overwhelming obstacles to achieving their health potential, nursing cannot afford to focus too long on attempts to develop definitions" (Jones & Meleis, 1993, p. 3).

In addition to the potential problem of conceptualizing health as a personal matter, there is a tendency to reduce the conceptualization of health to one's bodily function (Meleis, 1990). For instance, health for deaf persons has become synonymous with a physical problem, hearing loss.

An alternative to this model is to look at deafness from the perspective taken in the McGill Model of Nursing. Instead of viewing deaf people as sick or disabled and in need of help or a cure, the McGill Model focuses on the health potentials and health maintenance for all groups of people and in this situation, for deaf individuals and their families. Research has shown that the popular sector, the central part of the health care system which includes the individual, family, social network, and community beliefs and attitudes, is not preoccupied with sickness and care but with "health" and "health maintenance" (Kleinman, 1980). Until now, the health and health maintenance functions of deaf people have been totally neglected in the health care system.

The McGill Model of Nursing is a useful pragmatic organization plan for accessible health services. The model has evolved over 20 years and continues to be developed by faculty and students at the McGill University School of Nursing (Gottlieb & Rowat, 1987; Kravitz & Frey, 1989). The model reflects the unique perspective of Dr. Moyra Allen who believed that the strength of the health care system lay not solely in the expansion of technology and consumption of resources, but, more appropriately, in the development of human resources: healthful living styles, healthy families and healthy

communities (Allen, 1979). The beginnings of the conceptual framework were first conceived in response to an identified gap in the Canadian health care system (Gottlieb & Rowat, 1987). While a strong community voice was emerging advocating the need for universal, accessible family health services in the community, health care services continued to focus on acute, episodic care in hospitals and some preventive programs in the community. The gap in services provided the impetus to demonstrate the role of nursing in facilitating and promoting family health throughout the lifespan (Ford-Gilboe, 1994).

Health is the central component of the McGill model and the focus of the practice of nursing (Gottlieb & Rowat, 1987). It is a social process based on interpersonal attributes and learning phenomena. Unlike most definitions of health, health in the McGill Model is not viewed as being part of the health-illness continuum but as a variable distinct from illness (Allen,1979). Health and illness are seen as separate concepts which coexist (Gottlieb & Rowat, 1987). The concept of health is viewed as a dynamic process: a way of being, living, and becoming (Allen, 1981). Health is related to potentials, strengths, and aspirations and not to inadequacies and limitations (Allen, 1979). Conceptually, health is seen as multidimensional construct which encompasses a number of processes. Two processes, coping and development, are proposed as particularly important attributes of health. Coping is a function of effective problem solving (Kravitz & Frey, 1989). Unlike coping, development is directed toward the achievement of life goals and involves acts of recognizing, mobilizing, maintaining, and regulating potentials and resources that reside within the individual, family and the larger social context (Gottlieb & Rowat, 1987; Warner, 1981).

In the McGill Model, environments are viewed as contexts for learning about health. Although the family is considered the prime context of learning, it is acknowledged that learning about health also occurs in other social settings such as the school, the workplace, community group, the hospital, or the clinic (Gottlieb & Rowat, 1987; Kravitz & Frey, 1989). Allen (1979) proposes features of a supportive learning environment which includes the usual events of family life as opportunities for growth, availability of knowledge and resources, access to role models (nurses), access to families with similar concerns, and the

provision of opportunities for families to view health as an important part of family life and to experiment with new ideas and modes of expression. Nursing takes place within a collaborative relationship where both the family and the nurse share responsibility in the search for health (Gottlieb & Rowat, 1987). A major role of nursing is to structure learning experiences that empower families and enable them to define their concerns and arrive at approaches to meet their goals (Gottlieb & Feeley, 1995).

Webster and Lipetz (1986) claim that people's experiences of wellness and illness can only be understood in the context of their daily lives and with information about their usual health practices and health beliefs. People's descriptions of their health concerns in their own words are essential in assessment, planning health care, implementing interventions, and evaluating their effectiveness. How health is defined, how people tend to maintain their health, and what health promoting behaviors are used by different cultural groups were described by Clinton (1982) as the conditions that determined health seeking behaviors.

Research in nursing and other related fields support the proposition that health and illness are culturally bound and that there are differences in how health and illness are perceived, described, responded to and dealt with, based on the cultural or ethnic heritage of clients. In order to refine the conceptualization of health that is congruent with societal needs, nurses need to focus on understanding the health care needs of underserved populations and the integration between a static conception of being healthy and a process/dynamic/ becoming conception of health (Meleis, 1990).

This study concerns deaf people and access to health care. Deaf persons encounter tremendous difficulties when seeking health services. Consequently, their health concerns go largely unmet. The main obstacles identified are: communication barriers between deaf persons and health professionals, lack of information about health issues, negative attitudes of some health professionals, and lack of knowledge about the realities of the deaf community on the part of professionals.

We have less information regarding the coping strategies developed by deaf people in order to meet their health needs: the way they get information

about health issues, the availability of resources, and the way they are able to use resource materials. To these difficulties, new ways of working with deaf people need to be developed. The success of community health services is largely dependent on the development of culturally appropriate interventions. For this to occur, deaf persons must participate in the development and delivery of appropriate health care programs. An anthropological orientation to culture was used so that deaf people could respond in a way that represents accurately and thoroughly their experiences, concerns, coping strategies, and points of view.

Therefore, the research addressed two major questions:

(1) What is it like for deaf persons to seek health care?

(2) What strategies and resources do deaf people use in order to meet their health needs?

Methods

The global perspective of this study was to contribute to the development of appropriate health care for the deaf population by examining deaf persons' health care experiences and by exploring strategies developed by deaf people to meet their health needs. The purpose of the study was to explore two complementary aspects regarding deaf people and access to health care: the health care experiences of deaf people and the strategies used by deaf people to cope with the present gaps and constraints in the health care system.

This exploratory study followed the inductive approach of a qualitative design. Qualitative research seeks the insider's view and reflects the complexities of the natural world (Hammersley & Atkinson, 1983). Understanding and meaning emerge from in-depth analysis of detailed descriptions (Patton, 1987). In collecting qualitative data, the investigator seeks to capture the richness of people's experiences in their own terms.

This study was undertaken in collaboration with the Montreal Metropolitan Deaf Community Centre (MMDCC) and the Canadian Deafness Research and Training Institute (CDRTI). The MMDCC and the CDRTI were involved in the development of the study. This research was part of a research grant funded by the Ministry of Education. Facilities that participated in this study were informed that they would receive a copy of the final report. Respondents were informed that a summary of the report would be made available to them at their request. Presentation of the findings to the Deaf Community Centre is planned.

Open-ended interviews, ethnographically oriented, were used to reconstruct deaf person's perceptions, understandings, and concrete behaviors as they pertained to the issues of health and health care while remaining as close as possible to their actual experiences. This approach served to uncover the central dimensions which structure their vision of the world, their values, and practices in the domain of health. Given this orientation, the present study was situated within the method of ethnography.

Individual as well as focus group interviews were carried out. The object of focus group interviews is to get high quality data in social context where

people can reflect on their own views in light of the views of others (Patton, 1990). Within a group, participants provide checks and balances on each other and weed out false or extreme views, thereby enhancing data collection. In this study, the cost of interpreters was also a factor; thus, focus groups, while being an excellent means of data collection, were also cost effective.

A semi-structured interview guide was used with open-ended questions to guide participants as they related knowledge pertaining to the phenomena of health and deafness (Appendix A). The comprehensibility and cultural relevance of questions were verified by three deaf persons, one of whom assisted me throughout the study.

A process of translation occurred throughout the interview allowing me to follow what was being said and to adapt questions accordingly. Having basic knowledge of LSQ and ASL also allowed me to follow the general flow of the interviews and to enter in communication with the people. A qualified interpreter facilitated exchanges during interviews. To the role of the interpreter was added that of cultural broker. The culture broker enabled me to overcome barriers linked to the fact that deaf persons and I participate in two, partly distinct, cultural worlds. The cultural broker added comments which helped to interpret cultural meanings. For me, the challenge was to assure that translations were accurate while also having access to comments which contributed additional information relating to discrepancies between both cultures. All interviews were videotaped.

A more formal process of translation occurred after one of the interviews and involved an interpreter who translated the entire interview including the comments of the cultural broker. This information enabled me to evaluate any bias introduced by the cultural broker, to validate the quality of the interpretation and to utitilize this information as a source of additional information concerning deaf culture.

From the interviewees responses, categories were inductively derived and represent recurrent themes surfacing throughout most narratives. I looked for relationships between categories and systems of meanings associated with the categories. Knowledge was gained directly from the persons interviewed.

<u>Sample</u>

The population of interest, included all deaf persons living in a large metropolitan city. The accessible population was comprised of severe to profoundly deaf persons who frequent the Montreal Metropolitan Deaf Community Centre.

In keeping with the design of the study, a purposeful sampling technique was employed. The logic for purposeful sampling lies in selecting information-rich cases for study in depth (Patton, 1990). Maximum variation sampling was used to represent the heterogeneity of the deaf population with respect to key variables and to capture and describe the central themes that cut across participant variation. To ascertain that the sample was not biased and to assure adequate variation, two important variables were selected relating to deaf culture: age of onset and whether parents were deaf or hearing.

The sample was selected in collaboration with the Montreal Metropolitan Deaf Community Centre because the centre has access to a large number of people who are deaf and could act as a cultural broker with the deaf community. These deaf persons generally came from differing backgrounds and also frequented other centres involved in deafness besides the Deaf Community Centre. Participants were selected because of their deafness and their willingness to share their experience. Because the participants were all known to the Deaf Community Centre, a certain bias was present. The sample included participants who were readily accessible, available, and satisfied the inclusion criteria:

i) use sign language as their main mode of communication

ii) be at least 19 years of age

iii) be able to provide detailed experiential information about their experiences with the health care system

iv) agree to a videotaped interview.

A letter explaining the study was sent to the centre's president, director and health project coordinator (Appendix B). The coordinator of the health project was asked to participate in selecting potential participants who could meet the inclusion criteria.

Once the potential participants were selected, the coordinator and I discussed the list of potential participants, taking into consideration the criteria and the heterogeneity of variables. Selection of participants was modified later as needed.

The final sample included ten deaf persons: three women and seven men. Two women and one man were interviewed individually. The remainder of the participants took part in one of two focus groups. One group comprised of three men while the larger group of both men and women. The mixed group was generally characterized by a low literacy level. The men's group was chosen because of their known capacity for reflection and pertinent experiences. In the mixed group, one woman had to leave early therefore was later interviewed alone. While she talked about her life, she did not add anything further about health care information and access to it and therefore no additional data were included. A second man was also interviewed individually, but provided no information about health care. An additional group of women were interviewed, but their data focused entirely on their perinatal care. It was decided not to include them in this sample, but to keep this as a separate entity. Their data will be used subsequently. Since I was seeking in-depth information, the size provided reasonable coverage of the phenomena. This decision was supported by Patton (1990) who stated that the validity, meaningfulness, and insights generated from qualitative studies have more to do with the information-richness of the cases selected and the observational/ analytical capabilities of the researcher than with the size of the sample. The author added that a small diverse sample is often desirable as it leads to two kinds of findings: (1) high-quality, detailed descriptions of each case which are useful for documenting uniquenesses, and (2) important shared patterns which cut across cases and which derive their significance from having emerged out of heterogeneity (Patton, 1987). Descriptions depicting experiences and strategies were elicited from both men and women.

Profile of Participants

Since the Montreal deaf community is small, most deaf persons know each other. This prohibits giving too detailed information about the persons I

have interviewed. To assure anonymity, certain detailed information is not revealed.

Table 1 (Appendix E) concerns general information. Out of ten participants, four had primary education only, three had completed secondary education, and three had pursued post secondary education. Participants over 40 years, were generally educated in institutions at a time where education was oriented towards oralism. Some of the younger participants had been mainstreamed with hearing students. The sample indicates a higher level of education than the average deaf Canadian person. Nevertheless, seven participants were unemployed at the time of the interview. According to Schein (1992), only 1.7% of Canadians with severely impaired persons have university degrees as compared to 10% of the non-disabled persons. He also noted that the hearing impaired persons' participation in the labour force was one third lower than the non-disabled persons.

Table 2 (Appendix E) highlights certain characteristics of the participants. Although the degree of deafness was not measured audiometrically, our participants informed us that they had severe to profound deafness. Six participants were deaf from birth, two prior to age three, and three became deaf between the ages of 4 and 18. The cause of deafness was unknown in four of the cases, illness was responsible for four participants, one resulted from a birthing complication and one was genetically based. All but one participant had hearing parents. Five had deaf siblings. All participants were more comfortable in sign language; however, two participants had difficulty signing. One person in particular had very basic signing ability and possessed no complete language. With a few exceptions, most of their parents did not know sign. This included the two participants who were not raised by their parents of origin. Most of the participants were single at the time of the study.

All but three participants were born in Québec. One participant had immigrated to Québec as an adult while his family remained overseas and the other two participants have moved to Québec from elsewhere in Canada.

Interviewing

Interviewing allows the investigator to enter the other person's world and to understand that person's perspective (Patton, 1987). An interview guide was

written in both French and English, and was divided into two broad topics for discussion: health care experiences and strategies and resources. These topics were further subdivided into underlying themes, each theme addressed by pertinent questions. To capture deaf persons' experiences with health care, experience, difficulties and constraints, satisfaction, expectations, and recommendations in relation to health care were initially explored. The themes of interpreter and written communication were added after the pilot study. To understand how deaf persons coped with health concerns and difficulties encountered in the health care system, coping strategies and social resources were investigated. To approach the topics and underlying themes, I searched for information concerning the problem encountered, its significance, the way deaf people manage the problem, the accessible resources, and the potential resources available to deaf persons. To ascertain validity, these topics were discussed with deaf persons prior to the study. The same guide was used for both individual and group interviews.

To get into the area of interest during the interview, I asked general open-ended questions at first in order to let participants express what was the most important for them in a particular domain. In a second step, if the information was not sufficient, framed probe questions with more specificity and in a language that reflected the participant's language were asked. In this way I sought clarification and elaboration until I began to understand the participants' meanings, as the perspective was distinct from prior knowledge gained from the literature.

Sociodemographic information, identified in the literature, were addressed at the end of the interview (Appendix D). Age, etiology of deafness, age at which deafness occurred, socioeconomic status, marital status, educational background and family background with respect to deafness were examined for their contribution to the study.

Since access to deaf participants is not straightforward and since the topic could be readily covered in one contact, interviews were done on a one-time basis with the exception of one participant. She was interviewed twice.

Translation

Since the structure of Sign Language differs significantly from English and French, interview questions were translated into Sign Language prior to the interviews. Translation of interview questions into Sign (American Sign Language and Langue des signes québecoise) were carried out by an experienced deaf person. To ensure loyalty of meaning in both languages, a back-translation (from Sign to English) was carried out by a second deaf person adept in both languages. Back-translation served as a validity check. Translators and I discussed and resolved any discrepancies. Back translation informed me of what part of the content could be successfully asked and what part was incommunicable. To gain a good grasp of the study, the translators were trained regarding the research plan and the philosophy and rationale of the research. According to Werner and Campbell (1973), translation of a source language into a target language is crucial in cross-cultural research. Translation aims at loyalty of meaning and communicates fundamental information regarding cultural differences. Translation also means providing an understanding of cultural empathy, where content, context and style may have to be adjusted to the receptor culture. The authors add that a translator is central to the success of a "cross-cultural-cross-language" project and should be chosen on the basis of competence in the target language (Werner & Campbell, 1973).

During interviews, a qualified interpreter who also played the role of cultural broker, assisted me in the interviews by transmitting the information from me (who is hearing) to the participant and back to me. Culture brokering, a concept evolved from anthropology and adopted in nursing, is defined as the act of bridging, linking, or mediating between groups or persons (Jezewski, 1990; 1995). Cultural brokerage relates to the process of establishing meaningful, strategic, or significant linkages between separate cultural systems (Weidman, 1982). The person who engages in such mediating processes functions as a culture broker. In this study, the cultural broker was a qualified interpreter, knowledgeable about the culture of deaf people, and well informed regarding the objectives and perspectives directing the research.

Individual interviews as well as focus group interviews were used to collect data. I carried out five of the six individual interviews and a trained deaf interviewer carried out one of the interviews. Two interviews were carried out in American Sign Language while three were carried out in Langue des signes québecoise. Although the same two interpreters (one ASL and one LSQ) were used for most of the interviews, because of gender preference, a third interpreter was also used.

The focus group interviews took place in LSQ. Because the persons were known to the deaf community, it was possible to create groups that were homogeneous. A number of reasons may be attributed to the success of the groups. To begin with, participants appeared comfortable with the interpreter who had been chosen with great care and in accordance with the needs of the individuals in the group. The interpreter was a sensitive, well respected competent professional who was knowledgeable about deaf culture. Prior to the interviews, the interpreter took time to explain his role and how he would proceed in a group. During the interviews, he would point to the person he was attending to. When all participants joined in, he would remind them to proceed one at a time. When the information was not clear, he clarified the ambiguity with the participant in question. During the breaks, he could mingle with ease with the participants, although most of his break time was spent answering my questions. The success of the groups can equally be attributed to the presence of a deaf cultural broker who facilitated communication. The deaf cultural broker instilled confidence in the group. Being well-known and respected in the community, people felt at ease to express themselves. They also felt that the research could be trusted as the deaf cultural broker had agreed to take part in it. Being deaf and having experienced similar life experiences, the cultural broker understood what the persons were trying to say and could therefore add very pertinent comments, which triggered other thoughts and permitted the uncovering of various levels of knowledge. Some of the participants had very poor signing ability which made it difficult for the interpreter to understand. Being deaf, the cultural broker could figure out what the participant was trying to say and thus convey it to the interpreter and me. During breaks, the interpreter,

the deaf cultural broker, and I would gather together to discuss how the interview was going and to make adjustments if needed be.

Pilot Study

A pilot study was conducted in ASL to verify the effectiveness of the interview guide in eliciting information relevant to the research questions. During the pilot study, I became familiar with conducting a videotaped interview along with an interpreter.

A preliminary analysis of the data was carried out after the first two interviews. Two videotaped interviews were adequate to identify salient dimensions of certain topics and to indicate what refinement in the interview technique was needed. Since only minor adjustments were necessary, the pilot study became part of the study.

Setting

Interviews took place at the Metropolitan Montreal Deaf Community Centre where I had been involved in activities. Working with the deaf community had enabled me to cultivate relationships and gain a better understanding of the prevailing health concerns. It also has provided an entrance into the social group under investigation and permitted me to establish rapport and trust within the group. According to Leininger (1985), unless entry and trust of the group has been gained, the researcher will typically be restricted to front stage knowledge instead of the true realities of the group's experiences and behaviors.

Conducting research in a deaf environment was a challenge as everyone around me signed. Although I felt very welcomed at the centre, since I could not sign fluently, I was unable to fully participate in people's animated conversations unless the interpreter was nearby. Waiting for the interpreter was not always practical nor pleasant as I was used to communicating spontaneously. This research enabled me to experiment within myself what it means to feel marginalized from a surrounding communicating environment.

Data Collecting Procedures

With the aid of a Telephone Communication Device for the Deaf, interview schedules were arranged with participants. Participants were told that the interviews were expected to be of a few hours in duration.

Interviews were conducted in a private area and were videotaped to assure accuracy of data collection. Videotaping permitted me to address major themes and be more attentive to the interviewees, while capturing all that was said. Since the interviews were conducted in Sign, angles were a major importance. The use of one video camera necessitated that groups remain small.

Besides videotaping, note taking took place. Note taking by the investigator can serve to formulate new questions and also facilitate later analysis (Patton, 1987).

Following the interview, I recorded observations and inferences. These fieldnotes were used to assess emerging ideas, identify and sketch out research strategies. All but three videotaped interviews were transcribed by me. All transcriptions were verified word for word. A translator validitated one of the interviews. These transcripts constituted the data base.

Rigor, when well understood, is the essential basis of good research. In 1993, Sandelowski alerted qualitative researchers to the "inflexibility, uncompromising harshness and rigidity (implied in the term rigor) that can lead to loosing the "artfulness, versatility, and sensitivity to meaning and context that mark qualitative works..." (p.1). She also outlined the difficulty of arriving at one set of criteria for qualitative research when in reality, it encompasses a range of approaches and methods.

In qualitative research, rigor can be addressed by paying attention to trustwhorthiness (Morse & Field, 1995; Sandelowski, 1986). However, according to Sandelowski (1993), the measures taken to safeguard trustworthiness are complex and must be closely examined by the researcher before selection. For instance, member validation may be a threat to validity rather than a safeguard when both member and researcher have stakes in the research process (Sandelowski, 1993).

Four factors relating to tests of rigor can be useful as a framework for evaluating qualitative and quantitative research: (a) truth value, (b) applicability, (c) consistency, and (d) neutrality (Lincoln & Guba, 1985).

Truth value or credibility of a qualitative study generally resides in the uncovering of experiences as they are lived and perceived by participants

(Sandelowski, 1986). In qualitative research, there are multiple realities and it is the researcher's responsibility to report the perspectives of the participants as clearly as possible (Morse & Field, 1995). In this study, truth value was accomplished by remaining as close as possible to people's words and expressions. The research report includes a large number of excerpts giving the reader a good sense of the main articulations of the lived world of deaf people and the data for understanding the context within which difficulties and strategies have to be situated.

A major threat to the truth value of qualitative study lies in the closeness of the investigator-participant relationship (Sandelowski, 1986). In this study, truth value was also maintained by distancing myself from the affective weight of the interviews and interactions while at the same time retaining a sensibility to the affective quality. Reflecting on my experience was also used as an additional path of understanding.

Applicability is the criterion used to determine whether the findings represent what they are supposed to represent. Applicability in this type of research, was handled by a sound theoretical orientation, back-translation of interview questions, testing of the interview instrument with deaf persons, conducting a pilot study, developing a good rapport with participants, videotaping interviews, and sensitivity to participants during interviews.

'Elite bias' can be a problem in qualitative research because chosen participants are frequently the most articulate, accessible, or high-status members of their groups (Sandelowski, 1986). In this study, maximum variation sampling was used to represent the heterogeneity of the deaf population. Furthermore, the various levels of literacy in the sample was considered to represent the larger group. Representativeness was also established by presenting the converging and diverging responses of the participants.

Consistency refers to whether the findings would be consistent if the study were replicted with the same participants or in a similar situation (Morse & Field, 1995). In quantitative research, reliability refers to the consistency, stability, and dependability of a test or testing procedure. Inherent in the goal of

reliability is the value of repeatability as the same measurement over time lends credibility to the findings and confidence in the generalizability of the study (Sandelowski, 1986).

In contrast, the issue of reliability is debatable in qualitative research (Sandelowski, 1993). Qualitative research emphasizes the uniqueness of the human situation so that variation in experience rather than identical repetition is to be expected (Morse & Field, 1995). Globally, whether reliability is pertinent in an ethnographic oriented study such as this one is disputable as repeatability is not seen as essential. When collecting data, the observer or interviewer cannot abstract from the observations what he is doing. Narratives and comments are always produced in a particular context and addressed to particular persons. What can only be done from that perspective is to ensure a context most appropriate for the person expressing him or herself. An analogous process takes place in analysis and interpretation: one retains or accentuates particular elements of what is said from the perspective of a particular research question, personal interests, and past experiences. This does not mean that interpretation is purely subjective. It is essential to frame the analytic process as much as possible by being very clear about the analyzed steps followed, providing excerpts given by different persons showing the base on which we have built our understanding. One could say that these two levels of difficulties apply to all research but they are more on the forefront in qualitative research and they often remain untold or dissimulated in quantitative research.[1]

Another criterion to establish rigor is the notion of *neutrality*. *Neutrality* refers to the freedom from bias in the research process and results. In empirical research, objectivity is the criterion of neutrality and it is achieved when reliability and validity are ascertained (Morse & Field, 1995). In contrast, Guba and Lincoln (1981) suggest that confirmability be the criterion of neutrality in qualitatiave research. Confirmability is achieved when auditability, truth value, and applicability are established. In this study, confirmability was established by the participants narratives, the techniques employed to collect the data, the purpose of the study, and the techniques of analysis used.

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[1] These reflections on reliability follow from a discussion with Ellen Corin

Data Analysis

The process of data analysis is a creative process (Patton, 1990). It involves uncovering patterns, themes, and categories and requires making carefully considered judgments about what is really significant and meaningful in the data.

The first step in the process of analysis entailed a thorough reading of the data. By going over the data a number of times, I gained familiarity with the content and could see if themes and patterns could be identified. It also permitted me to discern whether anything stood out as surprising, how the data related to what might be expected, and whether there were any apparent inconsistencies or contradictions among the views of different individuals. The first reading of the data occurred after the pilot study and clearly indicate frustration and dissatisfaction with the services, but did not clearly bring forth the coping strategies used to meet their health care needs. Subsequently, questions regarding the support system were asked throughout the interview.

The themes of interpreters and written communication were highlighted during the pilot study and were integrated in the following interviews.

The second step involved looking for dominant themes in the data and their variability. This required analysis of the themes used by participants in order to break up the complexity of the information into parts. In this study, analysis of the themes was carried out by going through the narratives to gain a descriptive picture of converging and diverging opinions.

Once dominant themes were identified, I considered the semantic context. Attributes or characteristics that distinguished one element or detail from another were identified to differentiate how people construed their experiences from the way they communicated about them.

The fourth step involved looking at relationships between themes and defining these relationships. Recognition of patterns led to greater clarity and a deeper understanding of the phenomenon of interest.

The final operation involved attaching significance to the major themes found in the interview. The key theme of separate worlds captured the significance of the themes for deaf people and came out as a unitary frame.

Coding was done by me, from the perspective provided by my research questions and my previous contacts with the deaf community. In order to let the reader control the process of inference, as much as possible, used and detailed narratives are included in the findings. Stern (1991) maintains that there is no reason why any reasonably bright, trained, mature individual cannot code data accurately, meaningfully, coherently, and solo.

Ethical Considerations

Each potential participant was asked by the health project coordinator to participate in the research. The purpose of the study was explained and any questions the participants may have had regarding the research were answered. The participants were informed that the interview would be videotaped and would take approximately a few hours of their time.

Confidentiality of the respondents was strictly maintained. Participants were made aware that participation in the study was on a voluntary basis. They were also advised of the right to withdraw from the research at any time and that they were not obliged to give me an explanation if they decided to withdraw from the study. Participants were informed that there was no obligation to answer all questions; however, they were encouraged to do so.

Participants were made cognizant of the fact that there was no personal benefit in participating in this research, but at the same time they were informed of the potential benefit of the study, which was to make health services more accessible to deaf individuals and their families. Participants were made aware that the study is part of a research grant funded by the Ministry of Education. Written consent was obtained immediately prior to the interviews.

To guarantee confidentiality, videotaped interviews were identified by date, time, and a research number. The first name of the respondent was recorded and retained, along with the research number, in a location separate from the interviews. Only the researcher and the deaf cultural broker had access to the participants' names. Names mentioned in the data are pseudonyms.

As a token of appreciation and as a means of compensating for any costs associated with participating in the study, participants were informed that they would be given $40 for granting the interview.

Culture must be seen through the eyes of those who live it (Edgerton & Langness, 1974). The nature of the study involved deaf people in all aspects of the study: as participants and as consultants. According to Meadow-Orlans (1990), collaboration with members of the cultural group under study can lead to increased sensitivity, knowledge, and insight with which the research was designed. Additionally, research that takes only the perspective of the hearing world can lead to an ethnocentric point of view (Meadow-Orlans, 1990).

Separate Worlds

This chapter presents the results of the analysis of data. Several themes appeared central in the interviews and run throughout the responses given to the various questions. These themes enabled me to fully capture the difficulties experienced and the solutions created in accordance. The themes echo one another and there are many overlapping areas across these. I have focused on each of these and examined the meanings, connotations and clusters of meaning associated to these themes. Three main themes were highlighted: the health care system as a source of alienation and suffering; communication as the link to both worlds; and marginalization as a stimulus to look within. Relationships between these themes enlighted the importance of a salient topic which provided the central unity to the narratives: the feeling of inhabiting a separate world. The latter was marked by a feeling of marginality and exclusion but was constructed in a positive way through the resort of the notion of culture.

A guiding thread throughout the analysis is the notion of a separate world of the profoundly deaf, a world outside the world of others. Most of us live in a world of sounds. Most importantly, we communicate through sounds--by means of telephones and radios and just by talking. We depend on sound to get through our daily lives. Furthermore, much of our everyday lives is based on the assumption that everybody can hear. Yet, what becomes of the Deaf? They live in a world of sounds but are not fully part of that world. In this very obvious sense, they live in a separate world.

The deaf people interviewed are people who see themselves as visual people, who communicate with a visual language, Sign, a rich and expressive language, is not meant to be written and, therefore, has no written form. Sign language provides a myriad of possibilities for people who cannot hear as it unlocks a person's capacities, allowing him to think while also serving as a medium for development and rich interaction. Although there is a 'medical' status to deafness, there is also another dimension, not biological but cultural. Deaf people see themselves as people with a distinctive language, sensibility, and culture.

In contrast, the health care system is perceived as focusing on deafness as a 'condition', a deficit that needs treatment, a negative image. Since deafness is seen as a disability, instead of whole people adapted to another sensory mode, efforts are put into rehabilitation in lieu of adaptive services. The desire to have the Deaf speak and the insistence that they speak, has created tension between the world of the Deaf and that of the Hearing. The Deaf contest the biomedical, reductionist conception of deafness as much as the models of rehabilitation inspired by an objective of normalization. According to people interviewed, the present ideology leads to alienation, rejection, powerlessness and separateness. This second notion of separateness is the source of tremendous suffering.

The narratives indicate that for deaf people, a central challenge becomes one of communication, to build bridges linking the two worlds. These links are presently created by various means of communication, such as the use of interpreters and written communication. However, the strategies put forward to bridge the two worlds are themselves problematic and negatively perceived by deaf people interviewed. The narratives bring forth some of the difficulties associated with the present strategies, what may be contributing factors to deaf people's negative reactions, what they try to put in place as other means of communication and how they try to cope on a personal level with the difficulties encountered. Finally, the narratives highlight how the shared experiences and complex relationships with the hearing world have led them to live in a separate world, a world where the negative is transformed into systems of meaning that are positive and empowering.

The difficulties encountered in interaction with the health care system cannot be isolated from a larger context of experiences and situations, which have contributed to positioning the person in his present world. It is in this larger context that the strategies elaborated and resources utilized take on their meaning. This result section gives a large place to excerpts of the narratives because it is only through the detailed descriptions that the personal and social meaning associated with the difficulties can be appreciated.

Struggling to find one's way within the health system

The narratives highlight the emotional charge associated with seeking health services. They also indicate a paradoxical effect since what is supposed to be a source of help and of support becomes a source of tremendous stress for deaf persons. In the case of Jean, the stress associated with consulting takes on monumental proportions. *"Je déteste l'hôpital parce que ça me crée du stress. Ça m'endommage aussi corporellement parce que j'ai de l'anxiété...* Similarly, Denis' mood changes when having to consult. *"Quand je suis malade, c'est automatique, je deviens négatif parce que quand on va là bas, ça va pas bien. C'est tout le temps la même histoire."* It appears that things that may seem simple and banal to people who hear, are transformed into considerable sources of stress in which we can hardly envision the emotional charge.

The narratives demonstrate that the very process of consulting is stressful and that many difficulties lie at the root of this stress. The analysis draws attention to the difficulties deaf people encounter from their first contact with health care services and illustrates how they permeate the various stages of their contact with health professionals. The narratives also indicate that the difficulties encountered with the services have extensive repercussions on the persons themselves, their perceptions of themselves and of the world.

Feeling excluded

The participants' narratives bring forth a first level of constraints characterized by a health care system based on an environment that is by and large sonorous. Deaf people must continuously contend with the orientation to hearing in health care settings. The difficulties associated with the present focus begins at the reception. Vivian comments: *"Every time I have to fill out a form. I mean I'm born deaf. I'm not going to become hearing, right! I'm deaf only once in this life. It should be automatic that on this card, it says something about me being deaf so that an interpreter can be called right away. Their system needs to be changed."* Although a logotype on her health care card representing an ear was conceived to identify deaf persons, she is still treated as a hearing individual as she is asked to write. Her need to communicate visually, to have an interpreter present goes unrecognized.

The focus on sound and speech has the effect of excluding Deaf persons from the health care process. In the waiting room, it makes control ephemeral. Jean talks to us about what it's like to be in an environment aimed at people who hear. *"... Là le médecin peut-être il sait pas que moi je suis sourd. Peut-être qu'il pense que je suis un entendant. Fait que là le docteur me parle mais moi je réponds pas. Là il passe à une autre personne."* He adds: *"Moi mon angoisse c'est de ne pas savoir c'est à qui le prochain tour. J'attends qu'on m'appelle. J'attends, j'attends. Je sais pas quand ils vont m'appeler parce que j'entend pas. Il y a rien qui m'avertit qu' ils vont m'appeler. Il y a des personnes qui se rendent. Je sais pas qui au juste est arrivé en premier. Moi j'attends, j'attends, j'attends, j'attends. Ça m'angoisse. Et puis là ils passent au suivant. Fait que là, j'ai encore perdu mon temps!"* The inability to understand and have some control over what goes on in one's environment makes the waiting period appear exceedingly long and stressful.

All participants echo in one way or other this impression of limited control in health care environments. Vivian talks about what it's like not to know what is going on: *"If I go into a health setting and I have an appointment, I'm told to go sit down. There's a room of people. I see their mouths moving but I dont know what they're saying. I see some people spontaneously get up and go to a room..."* Inherent in Vivian's narrative is a also the sense of exclusion. In Denis' case, the inability to master what is going on initiates reflection and a series of suppositions in an effort to make sense of the situation. *"Mais pourquoi ils me passent pas tout de suite? C'est tu parce que je suis sourd? Qu'ils savent pas quoi faire avec moi? Si c'est un entendant, ils ont le service tout de suite. Mais quand c'est un sourd... Fait que là, c'est comme parce que t'es un sourd et muet, ils m'ont fait attendre. Ça veut dire qu'ils savent pas comment se débrouiller avec un sourd...."* Denis perceives that there are double standards of care and that his inferior treatment stems from the fact that the health care personnel is at a lost as to how to manage when faced with deafness.

The perceived discomfort of heath care professionals in regard to deafness is a recurrent theme in the narratives and a rationale often given to explain the sentiment of exclusion from the health care system. Jean gives us his perception of the dynamics of the interaction. *"Les CLSC, quand ils*

rencontrent un sourd, ils savent pas quoi faire. Je leurs demande, est-ce que ça va bien? Bien là je regarde ça et puis c'est comme ils me renvoient. Et puis, c'est toujours la même histoire. Ah, ils disent ah oui c'est correct, ça va bien. Fait que là ils sont nerveux. Ils savent pas comment s'y prendre. Ça leurs devraient déjà avoir été expliqué tout ça." Jean internalizes their quick response as rejection and further relates their behavior to a lack of knowledge about how to communicate with a deaf person. Ann, on the other hand, attributes the behavior of some professionals to sheer bewilderment. *"They think, 'Oh my god there's a deaf person here'. They just can't open their mind or stretch their imagination that yes they can actually communicate with a deaf person."*

The narratives indicate that the waiting period is often perceived with a deep sensation of inequality and rejection. Jacques signs that he is generally made to wait longer because he is deaf. *" Il m'a fait attendre. Il y a des clients qui ont passé à l'urgence et puis moi j'attendais, j'attendais et puis j'attendais. Parce que je leur ai dit que j'étais sourd, ils m'ont fait attendre, attendre."* The sentiment of exclusion during the waiting period is perhaps best captured in Denis' narrative. *"Quand j'arrive avec ma carte d'assurance maladie et puis je dis que j'entend pas, ils me mettent de côtés. Ils vont en passer d'autres. Et, tu sais, je suis un client. Je suis un humain comme les autres. Ils devraient me passer tout de suite. J'étais le premier. Et puis là quand il y en a d'autres qui arrive, ils me font attendre. Eh, ils sont pas gênés. Et puis, souvent ils me font ça."* It appears that the inability to master what is going on leads to a feeling of rejection, of not being treated fairly like others.

In other narratives, one gathers that the waiting period is a very isolating experience. Denis comments: *"Je parle pas et puis c'est plate. L'entendant me parle. Je lui dis que j'entends pas. Il me quitte. Alors je suis pas avec les gens. J'attends et puis j'attends. Là je leur dis, c'est bien long, c'est bien long. Ils disent, oui, attends, attends. Je sens que j'ai le goût de partir et puis là je peux pas parce que j'ai mal au bras."* Jean echos:*" Moi quand je vais à l'hôpital, j'aime jamais ça parce que quand je vais à l'hôpital, je me sens comme seul."*

Struggling to be heard

The narratives indicate that the difficulties related to the waiting period carry over into the consultation and into a feeling of a general lack of understanding of the deaf person. Georges shares an experience where the professional had great difficulty making sense of his concerns and his needs. "*À l'hôpital, ils arrivaient pas à me comprendre parce que j'étais sourd. ...Il y a une femme qui me parlait. Je lui ai dit, écoute, je suis sourd. Je lui ai dit que j'avais des bobos. Elle dit, mais où ça t'as des bobos? Et puis là je comprenais pas. J'ai dit, là, là. Elle dit, c'est peut-être cassé, c'est quoi? Elle dit, t'as tombé? J'ai dit, non, non, non. J'ai dit, c'est comme enflé. Mais elle me comprenait pas. Elle comprenait pas mes signes, la femme entendante. Fait que là j'ai dit il faut avoir un interprète. Mais l'interprète ne venait pas. J'ai attendu deux, trois heures pour que l'interprète arrive. J'attendais, j'attendais.*" Georges is illiterate and furthermore, he barely signs. In light of his limitations and capabilites, he has special communication needs. More precisely, he needs a particular interpreter. It appears that his needs are not well understood.

In some narratives, the professional's distress in regard to communication appears to lead to a systematic negation of the fact that the person is deaf. The fact that the Deaf person does not understand seems to be irrelevant. What matters is that the person speaks. Such disconfirmation also contributes to feelings of rejection of the person. Vivian recalls a hospital experience where it was impossible to communicate. "*This woman kept on talking to me. I indicated that I couldn't hear, however she kept on talking to me. I indicated that I would like to write to communicate but she kept on talking to me. I asked her to repeat and I still didn't understand. And she didn't understand that she had to write in order to get through to me. She was a very difficult person do deal with. Finally, she pointed to where I was supposed to go but she certainly wasn't kind and polite. She was very cold with me. I was very disturbed by the lack of communication.*" The narratives demonstrate that the present focus on speech renders any significant exchanges with health professionals virtually unattainable. Georges' narrative further exemplifies this point. "*Moi j'ai de la misère avec ça. Comme ils posent une question et puis moi je les comprends pas. Mais tu sais, parfois on parle et puis moi je dit que je suis*

sourd. Il dit qu'il a de la misère avec moi. Un visage pas souriant. Il a l'air pressé. On va passer des radiographies. Il m'explique pas. Comment est-ce qu'on fait pour communiquer par signe?"

The feeling of absence of communication with professionals is reinforced by the lack of technical devices that would enable the Deaf to enter in contact with the exterior world, particularly in cases of emergencies and hospitalization. The unavailability of closed captioning on television sets and the lack of telephone devices for the deaf (TDD) means that at a time when support is often beneficial, Deaf persons are unable to make outside contacts and are left alone to face the problems they encounter. This leads to a doubling of the isolation felt as in Thomas' narrative. *" Moi, je suis allé à l'hôpital. Je suis resté un mois à l'hôpital. J'ai resté au lit pendant un mois. Là, l'entendant a téléphoné et puis j'avais besoin d'un appareil téléscripteur pour sourds. Il avait pas d'ATS. Et puis, moi je voulais téléphoner à ma famille parce que ma famille savait pas que j'étais à l'hôpital. Moi mes parents sont pas ici au Canada. Je n'ai pas de famille. Je suis tout seul de ma famille. J'ai quelques amis au Canada que je me suis choisis mais comment je fais pour entrer en contact avec eux. Eux autres sont chanceux les entendants. Ils peuvent communiquer par téléphone. Moi là, je me sens frustré parce que j'aimerais ça avoir un appareil ATS pour communiquer avec mes amis moi aussi. Et puis, ils m'ont dit qu'ils en avaient pas, qu'ils en avaient pas. Ah là j'étais frustré!"* Thomas' critical claimant's discourse makes no mention of health professionals, but social support appears to play a critical role and could provide some reassurance for facing the difficulties inherent with health services.

On another note, the narratives also indicate that positive experiences are highly associated with the presence of a shared communication. Thomas' experience demonstrates this point. *"Je suis allé voir le docteur parce que j'avais mal au nez. J'ai demande, peux- tu signer? Il signe que oui. J'ai dit, j'ai mal au nez, je suis malade. Là il m'a dit de prendre des pilules. Eh, il avait des bons signes. Il les avait appris les signes. Je lui ai demandé comment ca se faisait qu'il signait. Il m'a dit que ses parents étaient sourds. Fait qu'il avait appris un peu des sourds. Fait que là j'aime le médecin."* The fact that the physician shares the same language automatically sets the stage for a working

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relationship as there is a certain linkage of cultural backgrounds. For Thomas, it is also indicative that the physician is genuinely interested in him, a deaf person. The importance attributed to professionals who can sign is further exemplified in Ann's narrative. *"I worked at a veterinary hospital and doctors were interested in learning sign language. I taught them sign language in the workplace. The one doctor was very open and warm to deaf people and it made it such a wonderful experience. Unfortunately, he was a rare breed and I never met another person like that."* Knowing how to sign makes a professional highly sought after. Antoine has tried to meet with the few physicians who sign in Montreal but was unsuccessful. *"Le médecin m'a refusé. Il avait trop de clients. Et puis, à une autre place aussi, la même réponse. J'etais frustré..."* He adds: *"J'aurais aimé ça communiquer avec le médecin. J'aurais aimé ça le connaître. Je lui aurais posé des questions de santé pour avoir des éclaircissements. Fait que j'ai laissé tomber. Mais c'est important pour ma santé d'avoir une communication claire. C'est important d'avoir un médecin qui signe. On est plus confortable pour communiquer. J'aurais bien compris. La avec un interprete c'est mediocre."* For Antoine, knowing someone who can sign means being able to access health information. It also means the possibility of establishing a rapport with the treating physician. The lack of professionals who can sign is a significant barrier to health care.

In other narratives, it appears that knowledge of deaf culture facilitates interactions between health professionals and their Deaf patrons. A key person in the deaf community signs: *"... si une personne connait la culture sourde, ça nous permet d'accélérer. Mais si je compare avec un médecin qui connait pas la culture sourde, bien il y a comme un mur. Et puis là on essait de franchir ce mur la. C'est comme il ne sait pas quoi faire, comment communiquer. Lui même, il est surpris. Parfois il sait pas comment faire. Il va essayer de communiquer au niveau de l'oralisation, et puis là, ah, la solution, c'est d'écrire. Et puis la, finalement, il va me poser des questions et puis je vais lui expliquer et puis il va finir par comprendre. Et puis la deuxième fois, il sait et ça va aller un peu mieux. Là il commence déjà à avoir l'experience. Le médecin qui a déjà la culture sourde, il va dire: ah oui, oui, oui, oui. J'ai compris. J'ai compris,*

oui, oui. C'est excellent. Tu sais, c'est comme automatique, il le sait. Ça va bien dans ce temps la." (Alexandre)

According to Vivian, understanding the Deaf perspective and their absolute need to communicate, would come a long way towards resolving the numerous problems inherent with health services. As it stands, misunderstandings abound. *"They claim to understand me but they don't. Most of the time there are misunderstandings. They are lacking information about Deaf culture. For example, I tell the hospital that I need accommodation because I'm going to be requesting interpreting services. They say they cannot be flexible. So they obviously don't understand Deaf culture and our needs. They don't understand that an interpreter has to be present and that it's not easy to find an interpreter around here. They always tell me when I'm supposed to be there so I have to go with or without an interpreter. Most of the time it's without. "* For deaf persons to exchange in any significant way, an interpreter is generally required. However, the necessity of having an interpreter often goes unrecognized by health professionals as well as by administration.

As an alternative, some professionals will try writing to communicate. However, written communication is often problematic. It can impose stress on Deaf persons that is inconceivable to hearing persons who, paradoxically, by virtue of being able to hear, can accommodate much more easily to written communication.

Health professionals have difficulty understanding the needs of their Deaf patrons so there is a great tendency to refer. Georges comments: *"Ils m'ont dit, il faut que tu ailles à une autre hôpital. Ils ont dit, là bas, ils sont bien pour ça. Nous on comprend pas ton mal. Là, j'ai mal à l'oreille et j'ai mal à l'estomac. J'ai mal aussi à..."* Constant referrals create confusion and place additional demands on a Deaf person, demands which can seem unsurmountable in the midst of other concerns. Jacques shares his perception and sentiments regarding being referred. *"Il y a une fois, j'étais allé à une place et puis il m'avait envoyé à une autre place et puis une autre place et puis je comprenais rien là dedans. C'était tout à l'envers. Ils ont envoyé un interprète à une autre place. Fait que là, j'ai laissé ça."* He adds: *"Je deviens nerveux dans*

ce temps-là. Oh, c'est pas drôle ça. C'est pas comique...J'ai trouvé cruel de faire ça. J'ai trouvé ça cruel. Oui moi j'ai trouvé ça cruel."

It is clear that frequent referrals make seeking health care exceedingly stressful for Deaf persons. Equally stressful is the nature of the referral. Many deaf persons are referred to rehabilitation centers. However, such referrals are often met with great resistance. Jean comments: *"Ils m'ont dit d'aller au centre de réadaptation. Moi je voulais pas aller là. J e suis pas confortable d'aller au centre de réadaptation. Eux, ils s'axent sur les problèmes au niveau de l'audition, d'oralisation et puis les devenus sourds, les prothèses et les projets d'école. Moi je suis pas intéressé. ...Comment communiquer dans la langue des signes, c'est ce qui est important pour les sourds."* In the same context, Antoine states: *"Et puis ils signent pas tous, ah! C'est plus l'oralisation, communiquer par écrit. Il y a pas d'utilité finalement pour les sourds."*

Tied to the problems with communication and the lack of understanding regarding the realities of the Deaf, is the notion of attitude. All persons interviewed placed a great deal of importance on the attitude of health professionals. A positive attitude is generally interpreted as acceptance of the person and facilitates communication, whereas a negative attitude is often perceived as rejection and impedes communication. Negative attitudes are generally attributed to a general lack of knowledge of health professionals regarding Deaf persons. Unfortunately, it appears that poor attitudes prevail. The consequences of a poor attitude are captured in Jean narrative. *"Bien je sens qu'il est ignorant là dedans. Il sait pas comment communiquer avec les personnes sourdes. Il sait pas. C'est comme il me trouve comme un achalant et puis il aurait comme le goût de m'envoyer, de m'envoyer chez les sourds. Tu sais, va-t-en, tu es sourd. J'ai pas besoin de toi. C'est comme ça que je me sens. C'est comme je suis une personne inutile et puis c'est pas correct ça."* Jean expands on the differences in attitude. *"Ca va arriver une personne sur cinq qui est gentille avec moi. Les quatre autres, ça va mal. S'il a déjà connu une personne Sourde, il va changer son attitude. Mais s'il a jamais été en contacte avec un Sourd, c'est là le problème. Il est là. Moi là, je suis de la merde. Moi je te le dit par expérience."* The importance of a positive attitude, of being acknowledged, is further stressed by Denis. *"Ça m'est arrivé 2-3 fois que*

j'ai eu un bon service. Elle me laisse savoir quand c'est à mon tour. Tu sais, la fille est gentille. C'est comme ça que j'aimerais ça mais ça arrive pas souvent. Tu sais, que je me sens au même niveau qu'elle, comme un entendant, mais là souvent ce qu'on ressent c'est qu'on est plus bas." From Denis' narrative, it can be advanced that in general, he perceives that he is not 'really' accepted and that most health workers are not ready to make contact with him on equal grounds. Denis, on the other hand, still longs for a good service. *"Moi ça m'est pas arrivé. Lui, il est chanceux que ça lui est arrivé. Moi ça m'est jamais arrivé."*

The above narratives indicate that poor attitudes towards deaf persons along with a lack of understanding of the needs of deaf persons and problems with communication barriers contribute to unsatisfactory encounters. In addition, it leads to information deprivation.

<u>Fighting to understand</u>

From the perspective of the persons interviewed, the difficulties in communication result in few explanations and rapid closures. Consequently, people feel deprived of health information. Vivian, who is tremendously frustrated by the difficulties in communication, elaborates: "*I tried to explain to the dentist what the problem was but he was talking to someone else and I have no idea what he was saying but this other person beside me was taking notes. And I wrote down tooth and then I was told to take some pills. I was given a prescription and told that I should come back when the infection would be gone. But when I left, you know it really hit me that there wasn't any communication. I was not an informed patient. I didn't know what was going on. I was just handed a prescription and not explained anything. So when I left, I felt very disturbed by the lack of communication.*"

The difficulties of communication are often perceived as leading to an automatic dispensing of pills, a quick and easy solution. Although this may not be unique to the Deaf, it is largely perceived as uncaring. Georges comments: "*Ils essayent de vérifier avec des pilules. C'est pas bon quand ils nous donnent des pilules. Aussi, quand ils nous passent des rayons X, les noms des malaises, les enflements à l'''intérieur, ils devraient nous aider.*" Charlotte is equally disillusioned by the care she receives. "*Il m'aide même pas. Il me dit en*

bref, bon bien on va te donner des crèmes pour mettre sur ton allergie. Mais tu sais, j'ai pas vraiment confiance aux medicaments. Je ne suis pas satisfaite."

In the narratives, it appears that little effort is made to convey the information in a form that people can understand. Antoine explains: *"C'était pas expliqué clairement. Qu'est-ce que ça voulait dire ce qui se passait? Est-ce que c'était dangereux? Est-ce que c'est un cancer, un tumeur? On a pas toute l'information. C'est comme s' ils nous laissent à nous même..."* For Antoine, the lack of clear explanations provokes unnecessary anxiety and is interpreted as uncaring behavior. He adds, that others experience similar difficulties. *"Il y a beaucoup d'amis Sourds qui disent qu' ils sont frustrés parce que le médecin n'a pas été assez clair ou ils ont pas donné le remède qu'il fallait."* The lack of explanations can be detrimental as Ann recounts a women's postpartum experience. *"The child was diagnosed with Down's Syndrome and the mother didn't know what was going on. They were just saying hold on, hold on. There was no communication. She didn't know what was going on. All the doctors and profesisonals were talking amongst themselves. She was left out. These types of experiences are horrible."*

In other narratives, we see how persons come to construct physiological idiosyncratic representations in order to explain to themselves what is going on in their body. Charlotte had no idea of the duration of a normal pregnancy, she associated difficulties in labor with not having drunk adequate amount of water during her pregnancy. She recounts: *"... Moi, ma grossesse, je pensais qu'elle aurait duré 1 ans, 2 ans mais elle a duré 9 mois et puis j'ai trouvé ça difficile.... Et puis, j'avais pas d'eau qui a commencé à couler. Oui, il manquait d'eau. J'avais pas bu assez d'eau. J'ai pas été prévenue de boire beaucoup d'eau pour que l'accouchement soit plus facile".* Since her cesarian delivery, Charlotte has been experiencing abdominal problems and although she has been to three physicians, she has been unable to have her concerns solved. Meanwhile, she comes up with possible explanations for her symptoms. Her lack of knowledge and her mistrust of the health care system leads her to fear the worse. *"Ça continue d'enfler. J'arrête pas de souffrir. ...Ça m'inquiète. C'est probablement dû à l'opération. Il a dû y avoir une ouverture qui se fait par en dedans, que les points ont été mal fait, et puis qu'il y a de l'air qui passe et puis*

là je me mets à enfler. Je pense que c'est une deuxième infection et puis j'ai assez peur de mourir là. Le médecin, j'ai pas confiance."

The destructiveness of broken communication

According to Jean, communication is cut off between Deaf and hearing persons. And in a world where daily activities are strongly related to being able to hear and speak, broken communication lines can cause a great deal of emotional pain. Jean's narrative is particularly revealing. *"T'essaies de faire fonctionner ça et puis ça fonctionne pas. Et puis là on attend l'interprète. Et puis le sourd, il emmagasine tout ça en dedans. Il accumule ça et ça lui cause des dommages. Ça lui cause des dommages. Ah oui, des dommages mentals. Ça le détruit mentalement--le stress, les émotions, dans la tête, il est démoli. Et puis la par la suite, bien les sourds sont tous habitués à ça. Mais c'est notre vie et puis c'est pas mieux."*

In certain cases, it seems that the problems with communication evolve in situations where the persons feel victim of violence. Jacques talks to us about his perception of being abused. *"Il y en a qui veulent nous abuser. Moi je veux pas me faire abuser. Moi j'aime ça quand c'est droit. Il faut que je sois franc et tout ça. Il faut etre franc. Il faut pas etre croche dans la vie. Je veux pas me faire abuser moi. Me faire mettre à part, moi je veux pas ça."*

It appears that the feelings of abuse reinforce the absence of recognition. Vivian signs of her dental experience which profoundly marked her. *"The dentist told the interpreter to stand back. If I had been hearing and the doctor was looking into my mouth, then he would be warning me, 'this is going to hurt, or you're going to bleed.' You know what to expect. So you don't get so nervous psychologically. And if they're inserting a needle in your mouth and you don't know what's going on, you're going to react. ...I was telling him that the pain was just immense but he still was looking at my mouth. I told him that whatever he was doing, it was hurting. And I wanted him to stop. I could not see what he was doing. It really hurt. My interpreter was standing in the corner. He wasn't accessible. It just made my stomach turn. It was really painful. It lasted for about an hour and a half, two hours. And I kept on signing stop, stop, and he wouldn't. He kept on... I don't know how to have this dentist change his attitude. Ah,*

maybe I'm too sensitive. Regardless, I don't know that some problems can be resolved."

In the case of Antoine, his request to have an interpreter present in order to understand the medical situation during his wife's birthing process was simply brushed off. He recounts: *"Ma femme a eu une césarienne et est restée une semaine à l'hôpital. J'avais averti qu'on avaient des problèmes de communication et que c'était important d'avoir un interprète. Et puis ils ont dit qu'il fallait expliquer tout de suite, qu'il fallait s'écrire. J 'ai dit non, on est mieux d'attendre à demain. Ils ont dit tout de suite. Ils me forcaient à prendre la décision tout de suite.... Là j'avais pas d'information. J'avais pas compris. Ma femme non plus. Fait que là on a signé. ... Tu sais, ç'était mélangé. On était pas confortable."* The difficulties of not being able to communicate in emergency situations is frequently brought forth in the narratives and is addressed later in the analysis. However, this cesarian birth was not an emergency caeserian. It appears for some professionals, it is easier to ignore the difficulties than to deal with them. The problem with this approach is that the memory of such an experience can linger on forever in a patient's mind.

The narratives indicate that professionals' lack of understanding of the needs of the Deaf leads to tremendous anxiety as well as fear. For Jacques, his fears turn into a sentiment of impending doom, which takes on a life in itself. *"Mais c'est pas de ma faute. Ah oui, j'ai des problèmes parce que maintenant j'ai des maux de têtes et puis là je commence à avoir mal à une dent. Et puis j'ai pas d'aide d'un interprète. J'ai peur. Si j'y vais pas ça peut devenir pire mon affaire. Ça peut devenir soit un cancer ou je peux avoir des problèmes cardiaques. Moi je sais pas. J'ai des problèmes presentement. Je suis inquiet...."* He adds: *"Là quand je vais mourir, c'est qui va être responsable? Ca va être le médecin? C'est tout moi. Il y a une fois que j'ai rasé proche de mourir, j'étais en train de m'étouffer. J'avais mal au sinus et puis c'était à cause du médecin parce qu'il voulait pas s'occuper de moi...."*

One also gathers the impression that the lack of understanding translates into an increase in physical symptoms as unresolved problems lead to chronic worrying. This feeling is particularly accentuated with those who are illiterate as they are unable to express themselves clearly. Although it was only a few

weeks since Georges sought health care, his numerous symptoms indicate profound anxiety and unresolved issues. "*Là j'y vais en juin. Je suis obligé d'aller à l'hôpital. Ils vont m'examiner l'oreille. J'ai comme des caillots de sang dans mon oreille. Juste un petit peu de sang. Ils vont m'examiner la gorge aussi et puis peut-être me faire passer des rayons-X parce que j'ai mal a l'oreille et j'ai mal à l'estomac. J'ai comme une boule qui grandit. Ça me serre l'estomac et puis j'ai des problèmes pour manger. Ça c'est à cause de ma boule ici. Je pense c'est plus mon problème à l'oreille et de la gorge et mon mal de tête et au ventre aussi. J'ai le bras aussi qui me fait mal. Et puis là c'est cinq places differentes*" The stress associated with the language limitations, with the fact that they cannot effectively communicate their problems, appear strongly related, whether directly or indirectly, to the symptoms voiced. It appears that the initial symptoms are transformed into a malaise that is much more vast and profound and which compounds the anxiety.

In many of the narratives, we see that the difficulties with the services have far reaching repercussions. Jean signs of how his experiences affect him. "*Moi quand je sort de là, je pense qu'au lieu d'y aller, que j'aurais été aussi bien de mourir à la maison que d'aller là parce que c'est toujours des problèmes. Soit qu'ils sont froid ou ils nous trouvent achalant. On les dérange. On le voit par leurs expressions. Chaque fois que je vais là dans un CLSC, à la clinique, l'hôpital, je suis jamais satisfait.*"

The narratives show that interpersonal encounters are inundated with difficulties, giving the person the impression that walls are erected everywhere. Every effort to break through to the other side, to the hearing world, is met with a series of hurdles. The resulting effect is a deep sense of frustration, rejection, loneliness, and an overwhelming feeling of powerlessness. Jean tells: "*Les entendants eux, ont des services. Ils ont pas de problèmes. Ils ont des alternatives. Mais nous les Sourds, on est limité. Tu sais, on a pas d'autre alternatives. Si on regarde dans notre courte vie, les Sourds on est tout seul face à un monde d'entendants. Comment on peut arriver à communiquer?*" Charlotte echoes: "*Il y en a pas d'interprètes. C'est difficile. J'en souffre beaucoup. Là je garde ça pour moi. Tu sais, j'ai pas personne pour m'aider. Et puis là je suis toute seule. Et puis là je me promène et puis je pense à tout ça et*

puis je pense au médecin qui m'aide pas. Tu sais, parfois on arrive à se comprendre et puis parfois on se comprend pas. Il me dit tout simplement pas tout en profondeur. Tu sais, c'est pas normal. Ils devraient nous aider un peu."

After a while, the slightest obstacle seems insurmountable, reinforcing the anxiety or requiring energy that is not available. Many deaf persons wait until their problems have reached a point of urgency before consulting. Meanwhile a minor problem can potentially become very serious. Georges talks about his dilemma. *"Là, j'ai de la misère à dormir. J'ai mal. J'ai eu du sang pendant trois jours à l'oreille. Je sais pas c'est quoi. Je sais pas si c'est dangereux. Là peut-être en juin* (in two months time), *je vais passer des rayons-X à l'hôpital . Mais j'ai dit j'ai pas d'aide. Est-ce que c'est vous qui allez m'aider? Comment est-ce que ça fonctionne?"*

On a day to day basis, Deaf people face many roadblocks. After a while many will give up trying to access information and services. Vivian states: *"I have tried to ask for information, even when I was at the bank, I was looking for information but I never got an answer. I called the headquarters and I still didn't get anywhere. So I've given up on trying to access information. I would prefer to have some kind of language between the deaf and hearing communities."* Ann, an assertive deaf woman, will fight for services but after a while, frustration takes over and she too begins to give up. *"Well I'll fight for it. I have yet to go into a service where I go in and the service is readily accessible for me. I have to go and I have to complain. I have to write to them. I wish I could just get a video camera, I'd videotape my complaints and send it to the government and let them worry about interpreters and interpret what I've said. Rather than writing a letter to them. And put them in my situation. If you don't understand what I'm saying, it's your responsibility to find out what I'm trying to say. Put them in my shoes, to see how I feel. ... And there are times that I get fed up. At this point, I've given up somewhat. Letting other people and other groups fight for these rights..."*

In all the narratives, one senses a profound longing to be acknowledged, understood and most important of all, accepted. Because of the invisibility of deafness, deaf people go unheard and unseen. Furthermore, because of a lack of knowledge regarding the realities of the Deaf and their means of communication and the lack of technical devices leads to a redoubling of the

isolation and absolute solitude. The present system leaves Deaf people feeling marginalized and isolated rather then supported. The exclusion leads to tremendous suffering. At times, the slightest problem becomes a tragedy because deaf persons do not have the key to translate what is being said.

Maintaining control

Until now, the narratives unveiled the difficulties lived by the Deaf in their interaction with health services. The narratives also surfaced the ways in which they seek to confront these difficulties, the strategies which they develop and the stress inherent in using them.

The narratives demonstrate the importance of being able to predict and have some control over one's environment. Health care settings are geared for people who are hearing, and unless one is hypervigilant, there is a great probability of being overlooked. Deaf persons have, therefore developed special abilities of observation and concentration. At a visual level, little goes by without their noticing and they are highly sensitive to people's non-verbal behaviors. However, because they cannot hear, the information received is not always complete and they are obliged to remain in a state of hypervigilance that is exhausting. To complete the picture and thus understand what is going on, deaf people must often resort to guessing. However they are unable to verify their perceptions, and, therefore the real picture often eludes them even though they have done everything in their power to have some control over events. When the picture is clear, the fact that they do not speak makes control evanescent.

In Jeans' narrative, the efforts required to maintain control in a health clinic appear monumental as compared to those who hear, as the latter simply need to be attuned to their name being called. Jean tells: " L'autre personne arrive et puis elle parle. Moi je vais oraliser. Je vais essayer de regarder. Je suis pas fou mais je deviens fou par exemple, d'essayer de toujours regarder sur les lèvres. Tu sais, essayer de voir. Je peux pas toujours me concentrer sur elle. Je compare avec d'autres personnes, d'autres entendants, ils sont là, ils jasent. Ils se promènent . Tu sais les autres ils savent. Mais moi, il faut que je regarde toujours la même porte. Il faut que je me concentre au cas où la personne sort. Tu sais, pour essayer de voir. Moi je compte les personnes. Là

je sens que ça va être à mon tour. Je la regarde. Je sens que ça va être à mon tour. Là je la regarde et puis je devine. Là c'est moi. Mais ça me crée du stress. C'est pas le fun pour moi ça....Tu sais, je suis sourd. Ah je vis plein de frustration comme ça. C'est effrayant." Strategies such as: lipreading, concentrating on key areas, monitoring the movements in the clinic and guessing as to their turn, are common strategies used by deaf people in an effort to follow what is going on in the clinics and to assure that they will not be forgotten or overlooked.

Faced with a similar situation, Antoine describes how he uses his keen visual skills to monitor the movements in a hospital's emergency room. *"Là j'avais mal aux doigts. Et puis là mes doigts ont enflé et puis j'avais mal. J'avais mal. Fait que là les tours s'en allaient. Là moi, j'entends pas eh. Fait que là les appels, je les entends pas. Fait que la il y a une autre personne qui est arrivée. La je la regardais. Moi j'observe beaucoup, ah. Je regarde, j'observe et puis là j'avais mes deux doigts de suspendus. Fait que là j'observe, j'observe toujours. Fait que là j'observe et puis la de mémoire, j'étais à veille de passer. Je le savais moi-même. Fait que la il y a une autre personne qui est arrivée et puis elle a passé. Eh, là je me suis fâché. C'est normal! Ah ça, ça m'a fâché. C'est normal."* Ironically, no matter how much effort goes into trying to gain some control over what is going on in the clinic, he still ends up defeated as he does not have the necessary information about the running of a clinic. Similarly, while sitting in the dentist's chair experiencing excruciating pain and unable to access her interpreter, all Vivian could do was observe in order to try to grasp what was being done to her. *"And I kept on trying to watch him and trying to watch his hands, see what he was doing. It was very difficult. I didn't know what was going on."*

On a more personal level, many people have developed skills enabling them to have some control, such as trying to develop a relationship with the other and create a climate favourable to communication to permit exchanges to take place. Because health professionals are often reluctant to write, deaf persons must try to motivate professionals. Denis, for instance, will try to be 'extremely nice' in order to get his concerns addressed. In a similar line of thought, to avoid being observed and going through a series of explanations

and behaviors in order to be accepted, Denis will try going to familiar places. *"Si tu vas toujours à la même place, ça va bien. Mais si c'est un endroit que c'est rare, il faut travailler ça et puis c'est achalant."* For Ann, confrontation is sometimes an effective way to get her concerns addressed. *"Well I guess it depends on the individual doctor. If I had a good relationship then I'm willing to let bygones be bygones. But if it's someone I don't get along with, then I'm not willing to deal with it and sometimes I'll be very confrontive with some people and I won't give up until I get an explanation. Sometimes, I have to pay for the interpreter myself out of frustration, and to make sure I get a clear, concise explanation of whatever it is I needed. It really depends on each individual situation."* In the past Ann has gone to great lengths to find a suitable physician. *" I remember one doctor I didn't like, then a second doctor I didn't like, and I went through a couple until I found one I really liked and we really worked well together as he had an open mind. He understood me and my concern and about me being Deaf. He worked well with me as a Deaf client. So that relationship was developed. It was good but it took awhile."*

In this context, certain persons also develop another level of strategies in order to overcome the stress of the situation and to remain in control of one's own emotional reactions. In the case of Vivian, positive thinking enables her to muster enough courage to get through. *" My feeling is that something will go wrong but I try to be very positive when I walk in there. ...I do not have any other options."*

Since encounters with health professionals often leave people devastated, people must not only cope with whatever concern they have, they also have to deal with the psychological effects of the encounter. Jean explains: *"Quand je sors de là, tu sais j'ai l'habitude, je reviens au positif assez vite. Mais tu sais, à l'intérieur, je me sens toujours joué avec mes sentiments. C'est pas une vrai communication ça. C'est pas bon."* He adds, *"Fait que là on recommence. Là on recommence la vie. On rediscute de nos affaires et puis là c'est okay."* Although Jean is able to move on after the encounter, deep inside he remains affected by the lack of communication. Others, on the other hand, may not be as able to move on. Denis explains: *"Mais tu sais là, l'angoisse, là, comment solutionner tout ça. C'est vrai mais il y en a des sourds là quand ils*

sortent, ils continuent 2-3 semaines. Eh, j'arrive. Je dis eh, oublie ça. Oublie ca. Mais non. Ils sont tout angoissés là dedans. Sont poignés dedans. Lui là, (points to Antoine) eh lui, il est pire que moi. Moi c'est grave mais lui est encore pire que moi. Imaginez-vous!" Knowing that others are worse off also enables Jean and Denis to maintain some control of their situation. Antoine deals with a difficult encounter by removing himself from it all. *"Bon, moi, comment j'arrive à contrôler tout ça, c'est quand je me couche. Quand je me couche, j'essaie de diriger toute ça. C'est comme ça que je le contrôle."* Jacques does the same when all efforts appear futile. *"Mais là je m'en vais chez nous. J'ai personne pour m'aider. Tu sais, j'ai pas personne pour m'aider. Qui c'est qui va m'aider? J'ai pas personne. Alors je m'en vais me coucher. "*

Because the 'support' offered by health professionals is so difficult to obtain and is not always helpful, Deaf persons often try to manage on their own or rely on other systems of support before turning to professionals. Jean comments:*"J'essaie de me debrouiller et de solutionner mon problème. J'essaie de pas y aller à l'hôpital. Ça je déteste l'hôpital parce que ça me crée du stress. Ça m'endommage aussi corporellement parce que j'ai de l'anxiété...."* In the case of Charlotte, she has given up on consulation with health professionals and has taken the matter in her own hands even though she is uncertain as to the etiology of her physical ailments. *"Ah bien là j'ai demissonné. Là j'essaie de tremper ça dans l'eau. Et puis là je prends mon bain et puis là je resors du bain et je me remets à me gratter. Là dans l'eau je sens que ça me chatouille. Et puis les crèmes, je sais pas. J'ai pas confiance."* Others like Ann may decide to make their own lay assessments of the medical problem. *"I've had a problem with my elbow but I sort of worked it out myself by doing some self-diagnosis because I know when I go to the doctor without the access, I'm just going to get a short and sweet minute and that's pretty much it."*

The narratives also highlight the tremendous resilience of some Deaf persons. *"Et puis moi quand je suis blessé, et puis je suis sourd, je le sais, il faut y aller en double, en triple. Bien oui. On a pas le choix. On a pas le choix. Moi je le sais quand on a un accident, on peut pas parler, il faut signer, ça je le sais. Il faut avoir une volonté additionelle. On l'a à l'intérieur de nous."* And for

Charlotte, whose life story is a difficult one, courage has perhaps been her best ally. *"Et puis il y a des hauts et puis des bas. Je sens qu'il se passe de quoi. En tout cas, il faut que j'aie du courage."* Along with the need to be courageous, patience also becomes a means of survival for as Georges states, *"Il faut que je sois patient. Bien je peux pas me suicider. Il faut que je sois patient. Bien oui. Il faut que je sois patient. Eh, j'ai 66 ans moi."*

Communication: an uphill battle

We have seen that the present orientation of services creates a great deal of tension and that this tension leads to alienation, powerlessness and separation. To ease the tension between the world of the deaf and the world of the hearing, communication strategies have been put into place to build bridges between the separate worlds. However, according to the Deaf, these solutions are themselves problematic. The following analysis brings forth what is negative with the present efforts, what may be contributing factors, and what the people have put into place to deal with the present communication constraints.

The voice of the Deaf

The need for a voice is a recurrent and pervasive theme throughout the narratives. The accounts repeatedly demonstrate that the desire and need to communicate and to be heard is so profound as to be resonant. The emotional pain resulting from the lack of a voice is somewhat captured in Antoine's comment. *"Tu sais, je peux pas crier fort mais j'aurais beaucoup de chose à sortir en dedans de moi. Ça me provoque des douleurs."*

Sign Language is the natural language of deaf people. However, because the health care environment is based on a hearing world and because sign language is only known by few professionals, interpreters are usually necessary for any significant exchanges to take place. The interpreter then, becomes the voice of the Deaf, at least in theory.

In 1992, the Montreal Deaf Community Centre created a pilot project for a permanent interpretation service where the qualifications of interpreters were well defined. A document explaining the project was passed to the Regional Health Board for consultation. The idea never got off the ground as the Board created an interpretation service that same year without apparently consulting the centre. The new service was named 'Le Service d'Interpretation Visuelle et

Tactile' (Sivet). Through an understanding with governmental services and the health care system, Sivet aims to provide visual communication services to deaf, hard of hearing and deaf-blind persons in order to facilitate communication between deaf and hearing persons. Sivet provides services for people in Montreal, Laval, Monteregie, and the Laurentians. Request for services must be made on weekdays between certain hours and at least 48 hours in advance. An emergency service for health and social services is also available.

The narratives indicate that there are many constraints related to the interpretation services. The participants' narratives bring forth, at a first level, serious difficulties related to the accessibility of services during emergency situations or in moments of crisis or great need. In fact, it appears that interpreters are not always provided in such situations. Vivian comments: *"If a woman is pregnant, is about to give birth, if someone suddenly falls extremely ill, any kind of emergency situation, we don't have interpreting services available for that. You know, it's just not fair because hearing people go into health services and have automatic communication happening."* In the case of Ann, the lack of access to an interpreter while residing in a shelter compounded an already difficult situation. She finds the availability of interpreters in Montreal much worse than in another province where she lived before.

By contrast, the remembrance of positive experiences indicate the extent of expectations and the emotional importance associated with the presence of good interpreters. Ann remembers a hospital experience that took place out of province. *" I had an operation before and that time I did have access through an interpreter. I had an interpreter with me. I had everything explained to me. What was going to happen, the consent form. Everything was explained to me in great detail. I also wanted to keep the gallbladder for myself and they said sure no problem. I was able to tell them that. I went through all the things that I wanted to make sure I knew what would happen and we went into the surgical room. I said good-bye to the interpreter and had a shot and I went to bed feeling comfortable. Then I had surgery. After the surgery, I went back to the recovery room and when I woke up, the interpreter came and checked to see how I was feeling. I was feeling good and of course, tired. And then I got my gallbladder.*

I got to see my gallbladder! We had a little chit chat and then I rested. The interpreter left me to do that. So it was a very good experience."

It appears that scheduling an interpreter can be a lengthy and even annoying process. To begin with, services must be booked 48 hours in advance. This may not be a problem in some cases, but it can be in others as not all situations are predictable nor are all situations the same. Then one must try to reach the services. Antoine explains how he has had to present himself at the office in order to obtain services. *"J'ai été obligé d'aller au bureau des interprètes. La ligne était toujours occupée. J'ai dit, j'appelle, j'appelle et puis j'avais un cas d'urgence."* Once the person has reached the services, he or she must then wait for confirmation. Jean explains: *"Maintenant moi j'appelle l'interprète mais le service nous répond jamais tout de suite. Je leur dis l'heure, l'endroit et puis là ils vont dire, attendez-moi. On va vous donnez une réponse dans une heure. Là moi j'attends, j'attends, j'attends. Là dans une heure, ils m'appellent. Bien moi je peux pas quitter. Je dois rester la la maison pour avoir la confirmation si je vais avoir le service d'interprète. Il y en a à peu près pour une heure. Fait que là le sourd, il perd du temps. Là l'entendant, il perd pas de temps lui. Il va au CLSC, c'est direct. C'est ça la différence."* The lack of efficient and direct services during emergency and other important situations is a major barrier to health care.

The narratives also indicate that a great deal of time is spent trying to schedule an interpreter. Indeed, the notion of 'wasting time' is a recurrent theme in the narratives. Antoine: *".... On perd beaucoup de temps. Fait que on prend du recule. Parfois ça prend 2-3 jours avant de trouver un interprète. Là c'est lent. C'est long. Fait que tu sais, ça fonctionne pas."* Jean compares his situation to those who hear. *"Si je compare ça, les entendants à l'heure actuelle, ils ont le service tout de suite mais moi je suis obligé d'attendre 48 heures pour un interprète. Penses-tu que c'est juste ça? C'est pas juste. Moi je suis obligé d'attendre 48 heures. Et puis là pendant ce temps là, en dedans de moi, il se passe plein de chose. Eux ils ont l'accès direct... Comment je vis moi? Les sourds c'est comme ça."* The lack of accessibility to interpretation services is felt as a great injustice.

In Quebec, the problems of access to interpreting services are compounded by the fact that there are two main sign languages, American Sign Language (ASL) and Quebec Sign Language (LSQ). The narratives indicate that there is a paucity of ASL interpreters available to the deaf anglophone community. Vivian tells the story of a deaf/blind person's experience at a French hospital. *"They had an appointment to see the doctor. They gave the hospital the information that they needed an interpreter. T hey were told that LSQ interpreters were funded, that they were accessible, but that ASL interpreters were not. Well this person was very angry. And then Sivet was contacted, they couldn't provide that person with an ASL interpreter either. So this deaf/blind person ended up by using her husband as an interpreter but that created alot of fights because the deaf/blind person did not want to rely on her husband all the time. She would of preferred to have an interpreter but it didn't happen. And when I look at situations like that, the hospital should have services available to the anglophone community by providing ASL interpreting services. That shouldn't be the main question."*

The problem with the lack of ASL interpreters is often resolved by providing someone who uses a combination of ASL and LSQ. However, this is not deemed acceptable for most persons. In emergency situations this make shift solution usually leads to misunderstandings and is seen as highly discriminatory. Vivian feels strongly about the need to provide ASL interpreters to the anglophone community. *"I tell people that their language needs to be respected but in the health care field, often people do not respect the use of ASL. They'll say they'll provide an amalgamation of ASL and LSQ but that's not good. So it means that the deaf person can't go there and really express themselves because there is no one there to understand them. So I act in a supporting role because I don't like to see other deaf people oppressed. I mean, deaf people have been oppressed all their lives and they're very sensitive to oppression. And it's important to lay down the ground rules you know, to tell the health professionals that they can't provide a mixture of ASL and LSQ to do a half decent job. They need to give them a half decent communication. They have to provide communication that works."*

In some narratives, the legal repercussions associated with the failure to provide adequate interpretation services were brought forth. Ann recounts a situation where a mother gave birth to twins and no interpreters were provided. The babies were taken away for medical reasons; however, the parents were not informed as to what was going on with their babies. The situation ended up in court and the hospital was sued for not providing interpreters.

The narratives also indicate that many deaf persons are ill informed and confused about the interpretation services. For Jacques, the inability to make sense of the services is perplexing and leads to a general state of anxiety. *"Là maintenant j'ai des problèmes parce qu'il n'y a plus d'interprète."* Indeed, the narratives show that the re-orientation of services has created havoc for Jacques, who is illiterate, and others like him. *"Avant c'était facile, mais maintenant c'est difficile. Avant, on avait de l'aide, on avait des interprètes mais là ils font des coupures."* From conversations with other deaf persons, Jacques concludes that the problem of access to interpretation services is a function of government cutbacks . *"J'ai entendu dire que le gouvernement faisait des coupures. Il y a des sourds qui m'ont dit ça. Ils m'ont dit que le gouvernement aime pas les sourds. C'est comme ça. C'est ça que j'ai entendu parler."* These cutbacks are then interpreted as a direct expression of his differentness and the lack of acceptance of this difference on the part of hearing officials.

For those persons residing beyond the boundaries outlined by Sivet, access to interpreters is even more remote as it is up to the health organization called upon to pay for the interpreter. According to the persons interviewed, many organizations do not budget for the cost of interpreters. Hence, deaf people must either go without an interpreter and attempt to have their needs understood, or pay for the interpreter themselves. The second option is not feasible for most deaf persons as many are on social assistance and therefore cannot afford an interpreter. Jean comments about the lack of accessible services where he lives. *" Là je suis déménagé en campagne et quand je viens ici, ils me disent non, en dehors on les accepte pas. Fait que ça me crée encore bien plus d'angoisse. On a pas de service nous autres dans note coin. Et puis là ils disent qu'ils ont pas d'argent. Là c'est moi qui paye l'interprète. Eh, ça me*

tâche. Il me semble on est dans la province de Québec, on devrait avoir des services. On en a seulement à Montréal..."

The people interviewed expressed the feeling that interpretation services have deteriorated over the years and that the current reorganization of health care services is both confusing and frustrating and not adequately serving their needs. Jean complains: *"Je préferais le système d'avant parce que au couvent, les services étaient plus rapide."* Most of the men interviewed in the study agreed that the services for deaf persons were better prior to the beginning of the health care reforms. The discrepancy is attributed to the fact that interpretation services are presently a separate organization, administered by a majority of persons who are hearing and who, it is felt, do not fundamentally understand the needs of the Deaf. Consequently, the services are felt to be fragmented, leading to inefficiency and dissatisfaction.

In contrast, when the convent served as a central reference center for deaf persons and even when their social service department was transferred to a new location on Henri-Bourassa, many services for the Deaf, including interpretation services, were combined under one roof rendering the services both efficient and adapted to one's particular needs. The transfer to Henri-Bourassa included the transfer of nuns who not only knew the Deaf but understood sign language. This made information easily accessible for someone who was deaf because someone could explain and guide the deaf person through the health care system. Furthermore, knowing the deaf person made it possible to tailor the interpretation services according to individual needs. Deaf persons felt both informed and protected. Jean explains: *"Avant, quand c'était à Henri-Bourassa, c'était différent. Ils connaissaient déjà les sourds. Ils nous informaient. J'avais pas besoin d'amener un interprète. C'était déjà près. C'était sur place. On avait l'information. Fait que là on comprenait tout. Ça allait bien. Ça allait vite. Là maintenant c'est different. C'est fermé à Henri-Bourassa et maintenant c'est au CLSC. Et puis là les sourds, bien, ils les connaissent pas. Ils savent pas quoi faire avec eux"* He adds: *"Fait que là le service pour les sourds, il est pas bien bon. Bien non, il est pire qu'avant. C'est pire qu'avant. Là on ne sait pas ce que le Sivet nous offre comme compétence d'interprète. Je suis pas satisfait du tout des interprètes et souvent, c'est le*

Cegep du Vieux Montreal qui a les meilleurs interprètes." It appears that the most qualified interpreters often get recruited by educational institutions who offer better incentives, leaving few available qualified interpreters for deaf persons in need of health care. *"Là je regarde aujourd'hui, le gouvernement il décide qu'il faut qu'il y ait intégration des sourds okay. Bon bien il faut qu'il accepte de payer certains interprètes comme $40.00 de l'heure dépendant de leur compétence."* (Jean)

From the point of view of the people studied, it appears that the change in orientation, the move towards integrated services, has created a great deal of turmoil in the lives of many deaf persons. The narrratives indicate that beyond the philosophical orientations, what was most important was the certitude of having someone known who could sign and would be able to orient them in the system as well as help them find the necessary resources. The existence of a segregated center and dedicated nuns constituted a structure which permitted the assurance of this function. Since the changes, many deaf persons feel abandoned and at a loss to manage. Jacques talks to us about the changes and how they have affected him. *"Avant, en 1973, il y avait Madame ___ qui est venue m'aider. Elle était responsable d'aider les personnes sourdes. Parce que moi je pouvais pas arriver. On pouvait pas me comprendre. J'avais besoin d'un interprète. J'allais la voir. Là il m'envoyait un interprète et puis là, elle me disait quand c'était le rendez-vous. Effectivement, la personne se rendait. Oui, avant ça allait bien la communication. L'échange se faisait bien avec l'interprète. Et puis là quand elle est décédée en 1982, ça commencé à diminuer. Là on dirait que ça va mal maintenant. Qui va m'aider maintenant? J'ai plus d'aide. J'ai plus d'aide.....Je suis allé à la clinique et puis là on arrivait pas à se comprendre. Je comprenais rien. J'ai dit, qu'est-ce que je vais faire? ... Parce que moi je n'ai plus de parents."*

In the narratives, all voice in one way or other, a longing for the past, for what used to be. Jean talks to us about the organization of services and their accessibility prior to the 1970's. Inherent in his discourse, is a sense of acceptance, familiarity and belonging and not one of isolation, rejection and anxiety as he feels today. *"Moi ce que je préfère, c'est revenir comme avant. Quand c'était au couvent, on avait déjà tous les services sur place. Il y avait*

toutes les compétences nécessaires pour communiquer dans la langue des signes. Tu sais, qu'on soit tous les sourds pareilles..." Denis talks about the impact of the changes on his general sense of well-being. *"Moi je suis d'accord avec lui. Avant, quand on avait le couvent là, on était bien. J'avais pas de maladie. Quand ils ont déménagé à Henri-Bourassa, les règlements ont changé mais je pouvais arriver à m'exprimer quand même, moins mais c'était pas grave. Mais là quand ça fermé, bien là c'est pire."*

From the above narratives, it is clear that one cannot talk about accessibility of services without looking at availability of services and vice versa. Furthermore, it is not simply a question of whether or not the services are present but in the use of interpreters, equally important is the quality of the interpreter.

Il connait pas mes mains!

Interpreters are not equal nor are they inter-changeable. Deaf people complain about the lack of discrimination in selection of interpreters. In concrete cases, the difficulties encountered occur on several levels: the degree of fit with particular interpreters, professional training and the attitude of the interpreter. They argue that interpreters are not chosen according to their qualifications and the nature of the request. The result can be disastrous. Jean talks to us about the nature of the services. *"Ici, ils envoient des bons, des moins bons. Ils envoient n'importe qui. Quand c'est important ou c'est moins important, bien c'est tout le monde égal. ...Ils donnent n'importe quel interprète. "*

The "goodness of fit" between the interpreter and the deaf person appears to be very important. Deaf persons have different signing abilities. They also have differing styles of signing and their individual style is very much linked to who they are, to their personality. The quality of the interaction largely depends on the interpreter's familiarity with the deaf person's signs. Unfortuately, this important point is not always recognized. Jean expands: *"La semaine passée, j'avais un problème avec un nouvel interprète. J'étais pas satisfait. On arrivait même pas à se comprendre tout les deux dans la communication. Il connaissait pas mes mains! Il connaissait pas ma façon de signer. Il m'avait jamais vu signer. Là il me regardait signer et puis il m'arrêtait, il m'arrêtait, et puis il m'arrêtait. Moi là mon fil d'idée, je le perdais finalement! Là*

j'ai dit qu'est ce que c'était que j'avais dit? Je voulais m'exprimer mais il comprenait pas la façon que je m'exprimais. Là je descendais mes émotions. J'expliquais. Là tu sais, j'étais tout melangé déjà moi-même. Tu sais, j'essaie de faire le balancement et puis j'y arrive pas. Donc, c'est pas naturel. Il fallait que je m'adapte pour lui." He adds: *"Alors tu sais, ma vie là, je me sens toujours vidé... A l'intérieur, je me sens joué avec mes sentiments. C'est pas une vraie communication ça. C'est pas bon."* What is dominant in Jean's narrative is the idea that the lack of a 'real' communication has an immeasurable impact on his life, on his emotional well-being.

The problems related to the lack of familiarity with a deaf person's signs are frequent upon first encounters and can lead to a myriad of difficulties for all parties involved. Jean talks to us about the obstacles often inherent in first encounters: *"Mais si c'est la première fois que je le rencontre, bien il doit s'adapter. Bien là ça me pose des problèmes avec le CLSC. Ça veut dire qu'en premier temps, j'ai attendu une heure pour avoir la confirmation de l'interprète. Là je suis un sourd. J'ai déjà perdu une heure de ma vie. Deuxièmement, au CLSC, si l'interprète a pas les compétences, bien là j'ai encore perdu du temps de ma vie parce qu'il faut arriver à se comprendre pour que ça fonctionne entre moi et lui. "*

By contrast, Ann's narrative indicates a very satisfactory experience. *"The interpreter with whom I was involved with here is a certified interpreter whom I know and so communication in that sense was very clear as she was familiar with my signs. It was a very comfortable situation for me because I didn't have to change my way of signing when I saw that interpreter. I know that in Montreal there are different signs that I would have to use but in that situation, I didn't need to."*

In a similar light, the narratives demonstrate that the particular needs of people with regard to interpreters may not be given adequate consideration. For instance, a deaf person may have a preference for a certain interpreter because of a known ease of communication. However, the interpreter may not be available and another interpreter is sent in his or her place. This is generally well accepted if the interpreter is proficient, but it creates a problem when he is not. Unfortunately, it appears that deaf persons have little say in the choice of

interpreters and they may even be penalized if they disagree with the rendered services. Antoine speaks candidly about a problem he has had with the services and the threats of being 'black listed'. *"Au Sivet, s'ils me disent qu'il est occupé, ils m'en envoient un autre. Bon bien là okay, je le connais pas mais tu vois que l'interprète est pauvre dans ses signes. J'arrivais pas à le comprendre alors je le refuse. Il me demande de signer son contrat et là on se chicane parce que je veux pas le signer. Je lui dis de s'arranger avec le bureau. Fait que là je suis allé au bureau et puis il m'ont dit que si j'étais pas content, on allait me mettre sur la liste noire. J'ai dit, oh! J'en revenais pas de ça moi là. C'est mon droit! C'est mon droit! Mais j'ai dit, écoutes, il faut que ce soit des LSQ V. Ils ont dit, écoute, on va perdre notre temps là."* When a deaf person is put on the black list, it means that if he refuses an interpreter, then the next time he asks for an interpreter, he will be denied access. Antoine, therefore, has little choice but to agree. To Jean, this is just another situation where the needs of the deaf come second in favor of the interpreter. *"Oui mais c'est comme primordial l'interprète plutôt que la personne sourde. Ils disent qu'il faut que ça soit égal, qu'il y ait de la formation. Qu'ils progressent, c'est plus important que toi, le sourd! Ça veut dire, toi attends là. On va favoriser l'interprète. Pourtant, c'est toi qui es important."*

All the narratives touched on the lack of professional interpreters. It appears that many perform the work of interpreters without having adequate training and the necessary skills. Ann feels strongly about the importance of having qualified interpreters." *There are very few ASL interpreters. There are some CODA (children of deaf adults) who function as interpreters but they're not trained. Their first language is ASL and they grew up with deaf people but they haven't received proper training to become interpreters. They say they are interpreters but they're not. I as a deaf person would prefer that they get training so that they know the code of ethics and the process of interpretation. Because you know a language, it doesn't mean you can interpret. Also, there are many people who are taking an evening course in sign language and say "hey, hey, I'm an interpreter. I can interpret for you." That's very dangerous. What happens if a misunderstanding happens in a hospital setting? What if they take the wrong medication and die? "*

The notion of professionalism is not merely a question of technical competence but is also related to ethical as well as human qualities. Interpreters not only translate information but also act as a real gate-keeper between the world of the deaf and that of ordinary people. In some instances, a qualified interpreter can prevent abusive situations. Vivian's experience demonstrates the importance of having a professional interpreter. *"The interpreter was not professional. So the person was being spoken to for me and this interpreter was not aware of professional ethics for interpreting, the code of ethics for professional conduct. And when the dentist was examining me, the interpreter stood way back and I couldn't see her. ...I would prefer the interpreter to know the rule, to tell the doctor whatever the deaf person is saying, what the role of the interpreter was. So the dentist would be better informed knowing what the interpreters role is and that I am equal to my hearing counterparts. It was a very bad experience ."*

Deaf persons attribute various qualities to a professional interpreter. For Jean, the interpreter's attitude is crucial. The attitude sets the ambiance for the interaction that lies ahead and enables communication. *"C'est primordial son attitude....par exemple dans ses expressions, ah il est fatiguant lui. Ah, il dérange ou dans ses signes, il comprend pas. Ah tu sais! Ça c'est la question d'attitude. Ça c'est écoeurant. Quand tu vois dans son air qu'il fait ça, moi j'ai pas le goût de travailler avec une personne comme ça."* Antoine speaks of how some interpreters are cold and lack human warmth. They do not go beyond their work.

Tied to the notion of attitude is that of respect and colloboration. Jean talks about the importance of mutual respect. *"Je le respecte. Il me respecte. Si le sourd a pas compris, bon il dit écoutes, allez pas trop vite. Allez pas trop vite. Bien il a du respect. Il faut qu'on ait une bonne collaboration, qu'on ait des bons accords, que ça aille bien et puis que ça avance. Ça c'est excellent."* He adds: *"Ou s'il dit, ah c'est ta faute parce que t'as pas été plus haut qu'en secondaire deux. Bien il faut être positif quand même. Il faut avoir une bonne attitude. Il faut avoir du respect. Si il est faible en français, il faut le comprendre et faut le respecter dans ça."* Inherent in Jean's discourse, is a general feeling

of weakness regarding his writing capabilities and a fear of being disqualified and marginalized because of his limitations.

In the case of Charlotte who was abandoned as an infant and whose childhood was spent in and out of foster homes, a professional interpreter is seen as somebody who can also be a confidante, someone who, having the knowledge of the hearing world and of sign language, can guide her in life. She tells:"...*Et puis aussi, d'avoir un interprète qui pourrait m'aider à me corriger parce que j'ai pas de parents alors s'il y avait un interprète qui serait comme ma soeur, elle pourrait m'aider parce que là j'ai pas eu d'aide de mes parents. Ils sont loin. En plus, ils sont plus intéressés avec moi fait que moi je trouve ça difficile parce que moi je suis toute seule à tout commencer ma vie. Et puis j'ai plein d'erreurs dans ma vie. Comment corriger mes erreurs?.... Fait que moi je pense que ça serait mieux d'avoir un interprète soit du service social qui pourrait m'aider à me corriger. Mais il en a pas d'interprète. C'est difficile. C'est pas drôle. J'en souffre beaucoup. Là je garde ça pour moi. Tu sais, j'ai pas personne pour m'aider. Et puis là je suis toute seule. Et puis je me promène et puis je pense à tout ça et puis je pense au médecin qui m'aide pas...*" As a result of the lack of professional training and the lack of trust that confidentiality will be maintained, many deaf people will only call upon an interpreter if it is absolutely necessary. For instance, they may pull in an interpreter when physicians give them little information about their health concern(s) or when they cannot make out the physicians' writing or vocabulary. Ann talks about her mistrust of interpreters. "*I've never brought in an interpreter when dealing with a doctor. I've always written in order to communicate and when I don't understand a word that's written, I ask for an explanation because I don't trust interpreters. I really don't.*" For reasons of confidentiality, professionalism, and personal preference, free lance interpreters may be asked to interpret. This is often the case with deaf organizations who can afford to pay for an interpreter of choice.

Besides the issue of professionalism, lies that of gender. Because of the intimacy of certain medical situations, a female interpreter may be preferred over one who is male or vice versa. However, the scantiness of professional interpreters makes selection of one gender over another difficult. The

importance of gender is highlighted by Vivian. *"I'm a woman. I need a woman interpreter. We don't have anyone who's that proficient in ASL. But when it comes to a health setting, I do not want to use a male and I don't trust interpreters."*

Despite the critiques formulated by the narrators in regard to specific interpreters, the idea of having an interpreter at one's disposal in case of a crisis or of problems retains a central importance and remains a fundamental solution for deaf persons. The fact that deaf persons tend to seek health care as a last resort, when all other avenues have been exhausted and when the problem can no longer be ignored has already been raised. In such situations, the primary concern becomes one of communication. Interpreters play a critical role as they make communication with health care providers possible thereby, decreasing the risk of errors and ineffective treatment. Thus to overcome the communication barrier, accessing an interpreter becomes an emergency in itself. Ann recalls her initial response after a car accident. *"When I was in the accident, the first thing I said was "interpreter, interpreter" because I have no other way of communicating. If I'm debilitated how are you going to know what I need or what I want. That instance when I was talking to myself at the accident, who was going to understand me? No one is going to understand me. All I can think about is an interpreter. I need an interpreter. I have to communicate. I need an interpreter. That's always a priority in moments of crisis."*

For many profoundly deaf persons, the issue of interpreters is presented as one of necessity and efficiency and not one of disability as is the popular view. Vivian comments: *"If it's something that is essential, I would first inquire about interpreting services within the hospital so that I could have the right message and not go off the point and not be grouped into the handicapped category, not wheelchair bound or not other things. We're looking at interpreting services for me because I'm deaf."* Vivian's comment stresses not only the importance of having an interpreter for clear communication, but points out that even though she may need the services of an interpreter, in no way does she wish to be considered or categorized as handicapped. The notion of deafness as disability is devaluating to Vivian as it is to many deaf persons.

On a personal level, there is no doubt that an interpreter can play a key role in the lives of deaf persons. Where languages and ways of being differ, an interpreter can become the voice of the deaf and the link to the outside world as he enables and facilitates communication, therefore, making the world of the Deaf a little easier and more pleasant. For deaf persons, a good interpreter is in effect a cultural broker. This implies sensitivity, respect and knowledge of the culture. It does not mean control. In emergency health situations, an interpreter can ultimately mean survival.

An interpreter is not always deemed necessary by the deaf person. In situations where health professionals are receptive to the Deaf, when a certain warmth is felt on the part of the individual seeking care, where effort is put into communicating with the person, the importance of having an interpreter may become secondary. Such situations usually necessitate that the deaf persons be literate which is not the case for the majority of deaf persons in Québec.

Although interpreters are very important to the Deaf, they are also not a panacea. Deaf persons long to be able to communicate in their native language, Sign. Being from out of province, Ann has had this opportunity and explains the difference. " Where I'm from, fortunately the counsellors are fluent in ASL so we don't need interpreters. That's even a better situation because going through an interpreter it becomes problematic, it becomes tedious. I had a deaf counsellor for myself. When there is an interpreter, there is a lag time and sometimes you can't have real communication. Sometimes when a deaf person is very emotional and loosing control or becoming very upset about something, the interpreter can't keep up because of the interpretation process. Whereas if it's just you and me and you understood sign language, I can say whatever I want as fast as I want and you're right there with me."

Family and friends as facilitators

In real life, we have seen that interpreters are not always available and that deaf persons often feel dissatisfied with their services. For deaf persons, it becomes very important to have an immediate circle who can be relied upon and who has a certain familiarity with the language of the Deaf, however limited. In emergency situations, many persons rely on their children for interpretation.

Jean relates: *"Et puis dans les cas d'urgences, on prend les enfants mais c'est pas correct."* At times, there is preference for an interpreter from the family for concerns of a certain nature and especially for intimate situations. Denis talks to us about how his sister-in-law served as interpreter in the course of his wife's hospitalization. *"Quand on a eu sa soeur, elle était tres bonne comme interprète. Je lui ai demandé d'interpréter et puis elle a accepté. Parfois, elle était occupée mais quand elle avait rien, elle venait. Elle avait pas beaucoup d'energie mais elle venait comme ça. Quand elle venait, ça me faisait du bien. Je voulais pas la forcer. Si elle avait rien, je lui demandais, viens-tu s'il-vous-plaît. Et puis là, elle venait. Et puis la, quand c'était finis, elle s'en retournait."* Although the family may be called upon to interpret in situations where there is a problem of a particular sort, relying on the family has its limitations as one does not wish to impose nor exploit. For others still, having to depend on family to interpret becomes inconceivable as there is often the fear of being perceived as dependent and therefore weak, a stigma which many deaf persons continuously face.

In other narratives, we see that family and friends serve as links to institutions as well as informational sources. For instance, after the baby's birth, it was Denis' aunt who provided him and his wife with helpful postnatal information. At other times, Denis will ask his brother to interpret. *"Il y a mon frère parce qu'il connait la culture. C'est facile avec lui. Mon gestuel il le connait bien."* There is an affective bond between Denis and his brother. His brother understands his signs and understands his deafness and can serve as a bridge to the hearing world, which is often perceived as threatening and frightening. In this way, his brother becomes an important source of emotional security.

Family members are called upon to interpret in various situations. Faced with the need for an interpreter regarding his son's school, Antoine will sometimes rely on a family member. *"Bien là ça depend. J'ai mon beau frère. Mon beau frère signe un peu parce que lui a un frère sourd donc ça aide un peu. Parfois je vais l'appeler mais c'est rare. Mais si par exemple mon fils a des problèmes à l'école, il est pas content, là j'appelle mon beau frère. Il reste tout près de chez moi et puis là bien il va m'expliquer les choses et il va l'expliquer à mon fils. Mais je vais l'appeler seulement en cas de gros problèmes. Mais tu*

sais, il a parfois qu'il va me l'expliquer sans interprète parce qu'ils nous refusent des interpètes pour ça et moi j'ai pas le moyen de payer des interprètes au moin que c'est des besoins spécifiques."

The narratives also demonstrate that in some cases, deaf persons develop particular friendships with interpreters. This increases the trust in the interpreter and is the source of emotional as much as instrumental support. As well, knowing an interpreter gives one the sentiment of having some kind of a safety net in case of emergencies. Thus, Jacques called upon his friend when admitted in emergency. *"Et puis là ils ont fait venir un interprète par paget, je connais Jimmy, fait que là j'ai appelé Jimmy. Il a rappelé et puis là ils ont dit c'est correct. Là il est venu."*

However, having to appeal to close relatives or a friend as interpreter can be the source of confusing roles or the muddling of barriers between the private and the public. Ann feels fortunate to have a friend who is also a qualified interpreter; however, she does not always feel comfortable asking her to interpret. *"In an emergency, I tend to ask a friend who's an interpreter if she would mind coming with me and of course she gets annoyed! It's not fair because that's her profession. It should be the case that if there's an interpreter with me, the hospital should automatically pay the interpreter."*

The narratives indicate that even though family and friends can sometimes serve as interpreters, they cannot always be relied upon to help nor can confidentiality be assured. Furthermore, many persons prefer to go about their affairs independently.

Writing, a limited system of communication

In our society, writing is generally perceived as inherent to communication and people tend to perceive written communication as the most appropriate response to the difficulties mentioned above. However, the narratives demonstrate immense emotional stress associated with written communication, exacerbating an already difficult communication problem.

We live in a largely 'oral' society so there is a bombardment of written information. This is understandable given that the majority of the population is hearing; paradoxically, it is extremely problematic for deaf persons. Vivian talks to us about the strain inherent with written means of communication: *"I'll be*

reading the pamphlet but not getting through it because I'm tired of not understanding certain words. When I'm watching television, I read the caption so I'm always reading. Deaf people always have to read. Like watching television, you can watch television, let your auditory system kick in and you can totally relax. Whereas if I want to watch television to relax, I have to read the caption all the time and it takes effort. Although many deaf persons despise reading and writing, it appears that their difficulties with reading and writing are often overlooked. *"But deaf people are forced to read all the time. Go to the CLSC, they give you some information because they can't sign so you have to write back and forth. It takes alot of energy. Very energy consuming. Then they give you pamphlets. I go well, on top of all this reading and writing, we have to do more. And they're still talking to me, talking to me verbally and I don't understand. So we're always forced to accommodate them, to read a book, read a pamphlet, write here, write there. I'm very tired of it. I wish that sign language was accessible."* The pressure imposed by the necessity of having to write and read constantly, combined with professionals resorting to a complementary oral form of communication, provokes an anxiety that takes on a life in of itself.

In many situations, explanations are perceived as much too lengthy for deaf persons. People who use sign language tend to be concise and to the point whereas people who speak are inclined to be lengthy. Jean, *" Le problème c'est que les entendants pensent que moi je suis comme un entendant. Ils nous communiquent par écrit comme un entendant. Mais c'est impossible! C'est pas pareil. Ils me donnent peut-être de l'information que j'ai même pas besoin, qui me retarde finalement. Fait qu'ils connaissent rien des sourds. Il y a des choses que les sourds ont pas besoin. Peut-être que les sourds ont besoin de choses et que les entendants on besoin d'autres choses."*

The narratives also illustrate that the effort and time required to communicate one's health concerns in writing can be overwhelming and emotionally draining. Jean talks to us about his recent experience at a CLSC: *"Je communiquais par écrit et puis je me suis aperçu que j'avais de l'angoisse qui montait. Fait que là on écrivait lentement. J'avais posé une question et puis là il me répondait par écrit lentement, une page et demi. Une page et demi! Là il dit, attends une minute et puis il écrivait. Moi je cherchais comment formuler*

mes phrases, lui cherchait ses phrases. J'ai dis, envoie. Tu sais, ça nous envahit..." In contrast to the laborious exchanges associated with writing, Jean can communicate with great efficiency in sign. *"C'est lent. Si on était deux sourds, ça prendrait 20 minutes mais on a passé deux heures. Imagines-toi au cours d'une vie, tout passe tellement vite. Fait que tu sais, ma vie, je me sens toujours vidé. Je me sens toujours joué avec mes sentiments. C'est pas une vraie communication. C'est pas bon."*

The narratives demonstrate that writing often leads to misunderstandings because mastery of written language and knowledge of basic health concepts often eludes deaf persons. Ann talks to us about some of the difficulties inherent with reading and writing. *" I don't even have the basic knowledge. Other deaf people have complained about that because they never had the health education or medical education that other hearing students get in high school. I never got that basic information in high school because access was not provided to me."* She expands: *"Many times I don't understand written communication because I may not know what certain words mean or the structures of the sentence. I have to get them to explain things to me in simple terms. Also there are alot of misunderstandings that happen because of the difference in both of our English. So what happens is that communication breaks down. Also, in written form, the process is bogged down. I can't understand their spelling or their chicken scratching and I have to ask them to write it again and they get upset and annoyed. I apologize and they of course become impatient. It gets me down, even depressed. I want to know."* Writing is clearly a very tedious means of communication for someone who is deaf. To speed up the process, situations are often summarized and relevant explanations and details left out, leaving the person confused about their health situation. *"When I go see the doctor, I want to know what's going on. The doctor will do some writing for me but I don't totally understand his writing and I don't understand the vocabulary being used. Then he tells me I have to go for an X-ray. I want to know why. His answer is don't worry. Well, that's not good enough for me."* (Vivian) Writing often leads to confusion and misunderstandings, so it can also increase the probability of errors.

The narratives indicate that most deaf persons tend to go along with treatments that they do not fully understand. Unfortunately, unanswered questions feed uncertainty, fear and often lead to catastrophizing. The devastating effects of constant anxiety can best be seen among those who are illiterate. Jacques talks to us about his fear of medical errors. *"Moi je sais pas écrire. Je peux pas lire. Je sais pas le français. Moi je suis analphabète. Si je vais tout seul et puis je parle, bien on se comprend pas. Et puis si on s'écrit bien je comprends pas. Si il y a des erreurs, si je meurs, qui va être responsable? Est-ce que c'est le gouvernement qui va être responsable? Je suis nerveux. Présentement je suis encore nerveux. Ah oui, ça continue. Là j'ai mal aux sinus et puis j'ai mal à la tête et puis j'ai mal aux dents. Qui va m'aider?"* It appears that the stress of not being able to communicate leads to an increase in physical symptoms.

The participants' narratives bring forth another level of constraint that is perceived as affecting their inner being. For someone who is deaf, writing can be a very restrictive and unnatural form of communication. Vivian explains: *"Writing is one form of communication and we can understand each other that way but it is not sufficient...Because when you write something, your emotions are not in the writing. The intonation isn't there. If the hearing person agrees to speak to someone, their intonation, their emotion, everything can be heard. When you're writing, very limited information gets across."* Signing, on the other hand is a very expressive, spatial language. Being multidimensional, it is also a very powerful way of expressing thought. Jean finds writing particularly taxing when upset. *"C'est dur d'écrire quand on est fâché. Moi je préfère signer parce que on peut exprimer nos émotions. Mais quand je suis obligé d'écrire, il faut que je contrôle mes émotions et puis j'arrive pour écrire et puis je peux pas. Je suis limité. C'est mes mains. Je peux pas arriver et puis écrire, aller vite par l'écriture parce qu'elle va rien comprendre. Il faut que je pense à ma structure française. En dedans là eh là, c'est de me ramener à ce niveau là. Tu sais c'est ça le problème...Eux les entendants, ils sont chanceux. Ils sont confortable là-dedans. Ils peuvent s'exprimer. Ça c'est pas pire. Nous on perd ça."* For Denis, having to write in order to communicate can be disheartening. *"C'est vrai ce qu'il dit. Tu sais, quand on est en colère, on a plein de choses qu'on voudrait*

dire. Là quand on arrive pour écrire, bien là on perd toutes ses choses-là. On a comme le goût d'abandonner. Tu sais, on leur fait cadeau de ça." The narratives clearly indicate that for deaf persons, writing is a very limited way of expressing one's health concerns. Deaf persons long to communicate in their language, which like speech to persons who hear, would enable them to fully express their concerns.

Deaf people's own difficulties in writing can be aggravated by what they perceive as professionals' negative attitude or resentment of having to write. Jean talks to us about the impatience of some professionals in regard to written communication and the impact it has on his sense of self. *"Aussi au niveau de l'écriture, il y a des entendants qui ont des problèmes d'attitude. Il y a quelques entendants qui vont comprendre les sourds, on va utiliser l'écriture. Mais il y en a d'autres, bon je vais leurs demander par exemple, as-tu un papier et un crayon? Là il me regarde et puis il dit, ah c'est écoeurant ca! Il me garoche le papier et le crayon. C'est comme eh, eh, dépêche-toi là, dépêche-toi. Et puis il dit, écoutes, peux-tu me lire sur les lèvres d'abord? Ah bien je lui dis que je comprends pas ses lèvres. Bien d'abord on va s'écrire! Là eh, ça le force . Bon tire le papier et puis on écrit. Tu sais, il est comme fâché d'être obligé d'écrire. Et puis là, il me donne ça et puis je lui réponds par écrit. Tu sais la communication là! Pourtant il sait que je suis sourd. Je peux pas devenir un entendant moi. C'est impossible. Mon rêve c'est ça."* Jean's narrative suggests that the refusal to acknowledge his means of communication is a personal rejection and undermines not only his particular abilities to communicate, but also his identity. This problem in communication is interpreted as a further evidence of rejection by health professionals and as evidence of their lack of knowledge and understanding of deaf people. *"Et puis il peux pas m'oraliser. Je suis un sourd. Je suis fait comme ça. C'est ça qu'il faut qu'il comprenne. Mais ça le dérange ça tu sais. C'est comme ma personalité le dérange. C'est comme si je suis achalant d'être obligé d'écrire, de lire. Pourtant c'est son mandat de communiquer avec moi. Comment communiquer avec un sourd. Il a pas appris ça."*

Having to write is also perceived as contributing to a larger feeling of being identified as a deaf person and marginalized. This adds to the deep

sense of oppression and loss of personal control experienced by deaf people. Denis recalls an experience at a convenience store and explains his unease with written communication. *"Bon quand je prends le papier et puis le crayon, je suis un peu gêné parce qu'ils me regardent écrire et puis quand j'arrive pour écrire, j'écris pas bien. Et puis il y a parfois que je me fâche mais il faut que j'accepte quand même d'écrire. Quand les gens me regardent et puis j'ecris, tu sais, j'ai comme un manque de contrôle. Tu sais, avoir la flexibilité d'ecrire. Comme les entendants eux autres, quand ils signent un papier, ils sont pas à l'aise . Moi c'est la même affaire. Je me sens comme ça."* The invisibility of deafness makes it easy to go unnoticed. But written communitication is very visual and nakedly exposes him to invasions of privacy. *"C'est parce qu'ils me regardent écrire et puis ils m'identifient comme un sourd tu sais. Fait que là, les gens n'ont pas d'idée sur les sourds."*

Beneath the fear of being recognized as deaf is the concern about how he will be identified and received by hearing persons. *"Bien tu sais, c'est comme par exemple, si c'est un handicapé. Je le regarde, tu sais, il fait pitié. Mais moi je fais pas pitié. Bien tu sais, moi en fait, je suis identifié comme un handicapé. ...Oui je me sens plus bas que les entendants. Les gens font un coup de tête. C'est pas un préjugé mais on le voit dans la façon qu'ils nous regardent."* Denis is uncertain as to what status he will be given; however, it is clear he does not wish to be identified as 'handicapped' and needy. To get beyond his situation, Denis approaches others with doubting courage. *"J'arrive dans le dépanneur et je leur demande par écrit pour des tylenols. Là les gens me regardent. Tu sais, c'est pas facile et puis c'est toujours comme ca. Je me sens pas confortable. Je leur fais un signe de tête comme je suis gentil. Et puis là je pars. Et puis là, je leurs envoie toujours la main."*

Deaf people often prefer to go unnoticed. Because deaf people are visual people with a visual language, there is no way to communicate this difference, to share one's uniqueness, one's difficulties in any detailed way as both parties do not share the same language. There is thus a mutual lack of awareness in regard to each other's ways of being. However, being a minority, without an acknowledged voice, it is deaf persons who are left void of satisfactory services.

For those who have some literacy skills, reading is used to a limited extent to access information. Charlotte, for instance, proudly states that she gets her information by focusing on headlines, key words, and through guessing. *"J'ai pas de problèmes avec la lecture. S'il y a des mots que je compends pas, je vais m'en tenir au plus important. S'il y a des mots trop avancés, c'est pas grave, j'arrive à savoir ce qu'ils veulent dire."* *Comme prendre une tasse, deux tasses, trois tasses de telle chose pour faire mes affaires."* This way of getting information is haphazard. In some situations, it may even be problematic.

The narratives demonstrate the importance of signing for deaf persons as when all communication strategies fail, deaf persons generally turn to signing to communicate. Jacques tells: *"Comme là c'est difficile. J'essaie d'expliquer, de savoir pourquoi et puis tu sais, parce qu'on a plus d'interprète, j'essaie d'oraliser mais on arrive pas a se comprendre. Je peux pas lire ou écrire. Fait que là moi j'essaie d'autre chose. Comme là, je signe comme si j'ai mal dans le dos ou..."* When interpreters are unavailable and when writing is futile, Jean improvises by signing. *"Si on ne peut pas écrire, bien là je vais dire, assis-toi ici et puis je vais essayer de signer. J'ai pas le choix. Il faut que j'improvise. J'ai plein d'improvisation.... Je peux pas attendre de me faire comprendre, envoie-là, il faut que je participe. Envoie, j'y vais. Alors je prends ce que je peux. J'improvise. Ça peut m'arriver que souvent je suis tout seul. C'est rare que j'ai de l'aide."* When Vivian needed emergency dental care but could not access an ASL interpreter, she too relied on some form of signing in an attempt to be understood. *"...So I ended up going on my own and using some gestures showing that I had some problems with a tooth, and that it was infected, it was inflammed."* Faced with a similar situation, Antoine, who was born profoundly deaf, uses basic gestures along with exaggerated expressions to get his point across. *"Ah oui, j'avais beaucoup d'expression. J'ai mis beaucoup d'expression. Eh, j'ai mal au doigt. Ça me fait mal. J'y touche, j'ai mal. J'ai dit que c'est sûr que c'est cassé."* Thomas, an immigrant, fluent in his native sign language and increasingly comfortable in Quebec Sign Language, speaks of how he relied on gestures to communicate his needs during a recent course of hospitalization. *"Ah bien je faisait la gestino. Par exemple, quand ils amenaient les cabarets de manger, moi je faisait signe comme ça. Eh, ça j'en veux ça. Ça j'en veux. Là elle*

me l'a donné. Ça me soulageait. Ça fait que je pointais du doigt pour montrer ce que moi je voulais. Là, elle voyait le cabaret Comme cochon, manger. Ça j'ai dit, non, non, non, non. Moi j'ai dit je peux pas en manger. Moi c'est du boeuf que je mangeais. Là, elle m'a montré ça parce que en Europe et puis ici au Canada, c'est différent."

To be Deaf in a hearing world

We have seen that although ironic, the present health care orientation engenders many difficulties for persons who are deaf. Consequently, anxiety dominates any contact with the health care system. Furthermore, the difficulties create tremendous frustration and lead to alienation and powerlessness. Amidst such adversity, we have seen that deaf persons find ways to survive the negative forces inherent with the present system of care. This, however, is only the partial story.

Deaf persons have difficulty finding their place in the hearing world. The difficulties are also frequently present at the family level. In that context, there is a tendancy to stay close to other deaf persons and to mobilize them in case of problems however, this solution also has limitations. Deaf people often rely on more collective type of solutions such as recourse to the deaf community.

A generalized feeling of exclusion

The narratives denote that the situation with the health care system is only an example of generalized feelings of exclusion and marginalization lived by deaf persons. Jean signs that, in general, hearing persons do not understand him, do not understand what he is trying to convey, and that these misunderstandings lead to prejudices against him. He tells: *"Ils comprennent pas vraiment ce qui se passe en dedans de moi. Une fois j'ai eu un problème avec l'assurance chômage. Dans mon dossier, c'était écrit que j'étais aggressif, que j'étais violent dans mes entrevues....Et puis c'est pas vrai. C'est parce que moi j'attendais, j'étais nerveux. Fait que là j'étais fâché. J'ai dit, eh, dépêches-toi là. Elle m'a dit, ho, ho là. Elle s'est fâchée. Là on a utilisé l'écrit. Là elle me considerait violent ah. Et puis c'est pas vrai en faite. Je signais. Mais de la façon que je signais, moi je me suis fâché et puis tu sais, c'est comme si il faudrait que je me croise les bras. Tu sais, qu'on écrive. Ah ca c'est dure d'écrire quand on est fâché. Et puis il faudrait que moi je change. Elle a déjà des préjugés sur moi.*

Signing is very expressive and has a physical component which, apparently, is not well understood. He adds, *" Par exemple, dans mes expressions, lui va me dire, eh, t'es aggressif, t'es frustré et puis tu donnes une mauvaise image des sourds. Bon, les sourds c'est tout le temps des gens en colère. Pourtant je suis gentil. Il faut qu'ils comprennent. J'étais en colère devant cette personne là. Et puis je peux pas rien faire avec ça. Moi j'ai l'habitude."* As a result of such encounters, Jean feels very self-conscious and is careful about the impression he is making when signing. For Jean, such an experience leads not only to a feeling of rejection but also to a sentiment of oppression and powerlessness. *"C'est comme s'il me rejettait. Moi j'ai déjà fait une plainte et puis ils pouvaient pas m'aider parce qu'ils me consideraient comme une personne dérangeante."*

The narratives also bring forth the sentiment that others have a representation of the Deaf that is depreciating, that underestimates their capacities. They find a confirmation in their feeling by being confined to subordinate jobs and in the fact that they are not encouraged in their desire to fulfil themselves. Antoine recounts an experience with an employment counsellor. *"Une fois j'avais un problème. J'ai dit à Mr. M, écoutes, moi j'aurais le goût de travailler dans quelque chose d'autre, je sais pas moi, dans un bureau de poste, dans une brasserie Molson. Il me dit, non, non, non. non. Fait que là j'ai essayé de trouver autre chose, d'étudier autre chose. Là il dit, toi tu es sourd, tu es limité. Tu peux pas faire bien bien d'autres choses. Fait que là il m'encourageait pas. C'etait pas bien bien motivant. Fait que là moi-même j'ai mon secondaire trois et puis il m'a dit que j'étais mieux de travailler dans les souliers. J'ai dit, ça m'intéresse pas bien bien pour le futur. Moi j'aurais le goût de travailler dans d'autre chose. Il m'a dit, tu peux pas parce que ça c'est du travail d'entendant. Il faut que tu sois entendant. Avant on avait pas d'interprète. Bon bien j'ai dit okay. Là je suis allé sur le marché du travail. J'ai fait plusieurs compagnies et puis là j'étais découragé. Ça changeait plusieurs fois. J'ai changé douze fois de suite dans les souliers. Là j'ai laissé tomber ça. ...."* There seems to be few employment opportunities for deaf persons. Any aspiration to go beyond the traditional areas assigned to the Deaf is met with resistance. Antoine is not the master of his destiny. Time and time again he is undermined by those who have power over him. Although Antoine is an

assertive person, being deaf in a society that regards deafness as a deficit, makes it very difficult for him to have a voice. His lack of education further compounds the problem.

Some deaf persons blame governmental orientation for their confinement in secondary jobs. Antoine gives us his perception of the situation: *"Les sourds ont des moins bons travaux. On les retrouve chez le cordonnier, dans la menuiserie. Mais des professionnels dans les ordinateurs, des spécialistes en électronique, il y en a pas. Chez les sourds, on en voit pas. Là, ce qu'on remarque de plus en plus maintenant, il y a plus d'aide sociale, oui. Parce que moi je regarde ça, sur quinze de mes amis, il y en a trois qui ont trouvé du travail. Le reste sont sur l'aide sociale. Comment ça donc? L'idée de faire l'intégration. La politique d'intégration, ils s' amusent avec nous autres comme des marionnettes. Ils rient de nous autres. Tu sais, on est comme des marionnettes."* The deterioration of people's quality of life can only serve to further alientate deaf persons from society.

The narratives indicate that deaf persons must 'go the extra mile' in all aspects of their life whether it is to access health services, employment or education. Antoine gives us a glimpse of what he went through to secure employment. *"...J'ai fait à peu près 200 compagnies. ...Là il y avait une petite compagnie! J'ai dit je vais entrer pareil. Là il a appelé au bureau du Centre de la Main-d'oeuvre et la eux, ils m'ont rappelé. Là je suis allé au centre avec un interprète passer l'entrevue. Dans l'entrevue, j'ai compté des mensonges. J'ai essayé de m'arranger pour que je sois accepté. Finalement, ils ont signé le contract et ça fait huit ans que je suis là. "*

These experiences of living in a hostile world often prolong a more profound experience in the immediate family of having been rejected, marginalized and excluded from familial activities. The issue of abandonment was brought forth on a few occasions by different narrators. In a world which cannot be mastered, everything takes on the sense of rejection. But often, this feeling stems not only from internal perceptions but also from a true marginalization arising from life experiences. Charlotte recounts: *"Moi j'ai plus de parents. A 4 mois, mes parents m'ont abandonné et à 9 mois je suis allé en foyer. Et puis là je me sentais pas bien parce que j'avais plus de parents. Ça*

veut dire que mes parents m'aimaient pas. Ils m'aimaient pas parce que j'étais une personne sourde ou peut-être ils pensaient que j'étais une personne sourde et aveugle. À 17 ans, j'ai rencontré ma mère. Là elle s'est remise en question pour savoir pourquoi elle m'avait abandonnée. Elle disait que mon père buvait beaucoup. Il y avaient des problèmes d'argent et puis ils avaient deux enfants. Fait que là ils ont decidé d'abandonner la personne sourde."

Beyond such tragic cases, just the fact of not being on the same level as others leads to feelings of alienation. Antoine signs that because of his deafness, he is set apart from his family in terms of the family's social hiearchy. *"Ma soeur, elle travaille à l'impôt... Elle est une haute-placée. Mon frère, il est un haut-placé aussi. Il est député au gouvernement. Mon autre soeur est partie en France. Elle est une haute-placée aussi en France. C'est ça. C'est tout. Ma famille sont tous des savants et ma mère aussi. Dans ma famille, ils sont tous bien placés tandis que moi je suis sourd fait que je suis à un niveau plus bas. Si j'avais été entendant, j'aurais été bien placé."* He adds that he is not included in family affairs. *" Dans ma famille, on est quatre enfants. Je suis le seul sourd. Ils viennent presque jamais m'aider. Ils sont toujours occupés, occupés, occupés. Je les vois presque jamais. On les voit seulement aux occasions comme Noël, Pâques, c'est tout. Après ça, bien c'est ça, moi je suis dans ma voie avec les sourds."* Thomas also entertains a distant relationship with his parents. *"Mes parents eux-autres, ils signent pas. Il me mettent de coté."*

Although families generally want what is best for their deaf child, many have difficulty understanding what this is. This can influence the child's possibility of mastering a system of communication which would permit access to a resource from the deaf community. Denis' wife for example, who is also deaf, rarely frequents the Deaf Community Centre because of difficulties in communication. *"Non, elle vient pas souvent. C'est rare qu'elle vienne parce qu'elle signe pas beaucoup. Moi je l'encourage à venir pour qu'elle prenne des cours de français. Mais c'est long avant qu'elle se decide. Elle m'avait dit qu'au couvent la soeur sourde l'avait beaucoup aidée. Elle l'encourageait beaucoup. Elle lui montrait les signes. Elle lui a montré à faire du tricot, la cuisine, la couture. Ça, ça va bien. L'écriture, elle est pas pire aussi. La soeur a fait venir les parents pour expliquer tout ça. Les parents ont dit, c'est pas de vos affaires.*

Mêlez-vous de vos affaires. Elle a commencé tard à aller à l'école. Elle est entrée à l'école à l'âge de dix ans. Elle est entrée tard parce qu'elle était en campagne. Ils l'ont trop isolée. Quand un prêtre l'a vue, le prêtre l'a devoilée aux soeurs et les soeurs sont allées la chercher et ont dit qu'il fallait qu'elle aille à l'école. Finalement, elle est allée à l'école et puis là elle a commencé. Elle est intelligente mais il reste beaucoup de choses a l'intérieur qui sont pas reglées."

A homogeneous social network

The feeling of marginality experienced by deaf people towards the hearing world is reflected in the compositions of their personal resource network. They mention very few contacts with neighbours, except in emergency situations, and family is rarely perceived as a source of support. The most effective social resource narrows down to deaf friends who often experience the same difficulties. This increases the importance of a Deaf Community Center created and administered by deaf persons.

We have seen previously that, for many, the family is seen as a source of tension rather than a source of support. In cases where certain family members are ready to lend some support, the support does not always go over well and is largely perceived as insufficient or as not sufficiently pertinent because it comes from hearing persons. They are perceived as unable to understand what a deaf person lives through, his real needs, and people question their capacity to respond in a satisfactory manner. Furthermore, one does not always want to depend on family for fear of engendering pity or appearing needy, a concern expressed by a few of the participants whose families were hearing. In that context, the most effective source of support is associated to the network of other deaf persons as well as deaf friends. *"Pour ma soeur, par exemple, m'exprimer à ma soeur, non. Non, seulement avec mes amis, des bons amis, là je vais m'exprimer. On va discuter. Quand c'est des personnes en qui j'ai plus confiance, ils sont capable de garder le secret."* (Denis)

Deaf friends: an integral source of support

The persons interviewed found the support from friends essential, particularly from deaf friends. More generally, the narratives indicate that close relationships are generally with deaf friends. It appears that deafness leads to a

shared connectedness and traits similar to what may be seen in families or communities. Denis, who became deaf at the age of eight, tells us about the nature of his friendships. *"Des amis entendants, j'en avais autrefois mais là j'en ai plus. Là c'est plus des sourds parce qu'on est plus en lien. C'est plus vrai. Quand c'est des entendants, tu sais, c'est pas comme en famille. Avec les sourds, on est capable de rester lié jusqu'a la mort. C'est différent. C'est différent."* Denis compares the exchanges between deaf persons to those generally seen in families. *"On s'entraide. On est comme une famille. Par exemple, comme là, il m'a rencontré, il m'a parlé parce que là il s'est séparé. Il m'a demandé de l'aide. J'ai dit oui, je vais t'en donner de l'aide parce qu'avant, il m'avait déjà aidé. "*

Deaf friends appear to play a significant role in matters of health. Antoine explains how his friends were the most helpful in the initial postpartum period. *"Et puis là il avait des amis sourds qui avaient de l'expérience avec l'accouchement alors on a demandé, on a posé des questions, on s'est échangé. Fait que on a eu de l'aide. ... parce qu'eux ont déjà eu l'expérience d'une accouchement. Je savais qu'ils avaient un enfant de deux ou trois ans alors j'allais les voirs. Ils acceptaient de me donner l'information..."* When in need of information, deaf persons frequently contact one another. Jean tells us how he goes about getting his information. *"Par exemple, moi ce que je vais toujours faire, je vais téléphoner à un sourd, le premier. C'est primordial. Oui. C'est la première chose que je vais faire à cause de la communication. C'est important la communication... s'il y a un sourd qui est compétent, je vais aller vers le sourd. Ça je le préfère..."*

The fact of being able to exchange on issues with other persons who also live similar experiences, and can thus understand the difficulties, is in itself a source of support. Antoine gives us an example of the nature of his exchanges with other deaf persons. *" Il a parfois que je vais leur dire, eh, j'ai pas eu d'interprète. L'autre va dire, ah oui, je sais j'ai la même chose que toi. Je vis la même chose que toi. Il y en a qui sont satisfais avec l'interprète, parfois il y en a qui sont pas satisfais. Il va me dire l'interprète était pas bien bon. L'autre va me dire, écoute, il y a un médecin qui a de l'expérience pour signer..."*

The narratives also indicate that it is not necessarily the quality of friendships per se that is important but the fact that these friends are themselves deaf and are likely to understand what the other person is living, to share their experience. Furthermore, sharing a language makes for easy and more significant interactions.

Many of the participants mentioned trust as an important element in their relationships and explained that trust is more likely to develop with deaf friends. Antoine makes it a point to mention that he has a number of trustworthy friends. *"On s'échange. On est habitué parce qu'on est sourd. On peut s'echanger. Je le rencontre. J'ai des amis de confiance. J'en ai à peu près dix amis de confiance."*

The narratives demonstrate the importance of sign language to deaf persons. Antoine brings forth signing as a foundation point to his friendships. *"Ah mes amis c'est des sourds. Moi j'y vais par habitude avec les sourds parce que c'est pas de ma faute, moi je communique jamais avec les entendants. Je suis pas habitué. Moi je suis habitué avec les sourds parce que moi je signe naturellement. Je suis sourd profond, LSQ pure. Moi je rencontre presque jamais les entendants."* He adds: *"Si par example, un jour les entendants sont là et j'en rencontre et puis qu'ils comprennent un peu mes signes, bien là je vais être intéressé. S'ils se forcent à signer avec moi, bien là je vais essayer d'échanger avec eux. J'aime bien ça accepter mais c'est rare. C'est rare."* Antoine, like many others, would welcome the opportunity to exchange with hearing persons but unless the other party can sign, significant exchanges are unlikely. It is not because Antoine does not wish to make the effort to communicate by oral means, it is because he is profoundly deaf.

The opportunity to rely on friends for support rests on the sharing of a similar means of communication. This signifies that deaf persons who do not share the language of Sign can feel as marginalzed with respect to the deaf community as they are with respect to the hearing world. There stems the difficulty for those who resort to oralism and find themselve doubly marginalized. Charlotte, who was educated in the oral method, talks to us about the nature of her friendships. *"Non, je suis seule. Mes amies m'aiment pas à cause de la communication. ... Moi je suis habituée avec l'oralisme et puis de signer en*

même temps parce que je signe moins avec les enfants mais je rencontre pas souvent les personne sourdes non plus parce que je suis toute seule. J'ai de moins en moins d'amis sourdes. Et puis je trouve ça difficile avec des personnes sourdes gestuelles. Moi j'aime mieux être seule pour me débrouiller toute seule, rencontrer le médecin et puis tout ça."

On the other hand, the support system constituted of deaf persons has a number of limits. At a first level, these persons have similar problems. Other deaf persons have themselves only limited access to necessary information. There is therefore risk for confusion and incomprehension. When Jean was asked how deaf people obtained information on children's development, he replied: *"On l'a pas."* When Vivian was asked about how women learned about subjects such as menopause, she replied. *"I don't know. I don't know. I really don't know. There isn't enough information out there that's accessible for me."* Contacting a deaf friend is not always what is needed as situations are reported where the message conveyed by a third person led to misunderstandings and further health concerns.

Other deaf people signed of feeling distant from their deaf friends in light of their problems. Such feeling accentuates their vulnerability. It also makes it difficult to depend on others as there is an underlying apprehension that they cannot communicate their weaknesses. These feelings further accentuates the isolation.

At another level, there is an objection to the principle of resorting to deaf people for help. In effect, some deaf persons object to the idea of having to fill the functions that should be filled by health services. Jean will gladly help a fellow deaf person regarding his child's development, but has reservations regarding who should be responsible for certain information. *"Moi je connais un couple et puis ils sont venus me rencontrer parce qu'ils savaient même pas comment s'occuper du bébé, comment nourrir le bébé. Un petit bébé de trois mois, ils savaient même pas comment faire. C'est moi qui les a aidé. C'est une perte de temps pour moi... Alors je les ai rencontrés à deux reprises parce que c'est des sourds alors j'ai essayé de leur expliquer. Et puis c'est pas mon travail. Ça serait le mandat du CLSC ça normalement."* It should be noted that Jean obtained his information on infant nutrition through his wife who is hearing

but also signs. *"Bien là ma femme c'est une entendante. Et puis elle a déjà les services. Elle est capable de parler. Elle est capable d'entendre donc ça m'a aidé moi. Mais si j'avais une femme sourde, oh, oh, la..."*

The Deaf Community Centre as support system

From their difficult encounters, marked by sentiments of rejection and oppression, all persons long to be accepted, understood and reassured. One gets the sense that only once these basic requests are assured, can the effects of the difficulties on the persons themselves and on their perceptions of themselves and the world be worked through.

Georges relies on deaf organizations to help him link up with appropriate resources and alleviate the void in communication. *"Le Centre des Loisirs des Sourds de Montreal vont écrire au médecin. Là je vais leur dire que j'ai mal en dedans, que je dors pas bien la nuit, que je dors mal, que j'ai des problèmes à l'oreille, que ça continue encore. Et puis là j'avais plein de sang après mon Q-tip donc j'ai mal à l'oreille."* As for Antoine, although he will gravitate towards his friends, he will also rely on the deaf community centre in order to compare the information. *"Je vais aller vers des amis en premier et je vais venir au CCSMM (Montreal Metropolitain Deaf Community Center) aussi en même temps. Je vais faire un balancement avec tout ça. Ça me prend plusieurs témoins parce que je veux verifier l'information. Quand j'ai la même information, je vais faire mon idée. Je suis toujours comme ça."*

The narratives indicate that in Montreal, the Deaf Community Centre provides a safe place and a refuge for the Deaf persons interviewed. For Charlotte, the centre is a place where she feels respected and protected. *" Notre leader Sourd, il est sérieux dans ses choses et puis les heures sont respectées. Il fait venir les gens. Il prend les rendez-vous. Et quand quelque chose manque, il est pas content."* Antoine talks to us about the centre as a place where he can safely express his feelings and discontent regarding the present services. *" Ils (les professionnels) me comprennent pas alors je suis obligé de les laisser et je m'en vais. En plus j'ai de l'angoisse. Je suis angoissé. Je m'en retourne et puis là j'en fais part au CCSMM . Je fais plainte de mon mécontentement."* For Jacques, a sense of relief in having found the center is also apparent. The fact that he can have his needs attended to without being constantly referred back

and forth from one institution to another is reassuring. *"Ah je me sens heureux de venir ici. Si j'ai des problemes de maladies, de sinus, de bien-être, de chômage, je vais venir ici. J'aime mieux venir ici au CCSMM à cause qu'ils m'envoient pas partout."*

The narratives outline the various levels at which the Deaf Community Centre reaches people and enables them to face the numerous constraints brought forth. Themes include: an opportunity to communicate one's feelings and concerns and thus look forward to the future; clear communication leading to fewer misunderstandings; provision of competent and accessible interpreters; resource center and link to other community resources.

The importance of having a place where one can communicate comfortably is highlighted throughout the narratives. For Jacques, it is the ease of communication that he identifies as important. Jean talks to us about how being able to communicate his feelings and concerns is comforting and enables him to carry on with renewed hope for the future. *"Moi j'ai des problèmes. Je m'exprime à lui. Il m'écoute. Ça me fait du bien. Tu sais, c'est fini là. Bon parce que lui m'a apporté des conseils. Il m'a aidé sur différente choses. Et puis là bien je peux avancer. Tu sais, je peux trouver des solutions parce que là je me suis exprimé. Il m'a écouté. Il est capable de m'écouter. Et puis après ça, à la fin, il me donne des réponses pour savoir quoi faire! Fait que là le sourd lui, il est soulagé."*

Everybody at the centre signs so communication is rapid, direct and natural. *"The reason why I go to CCSMM is because communication happens here. I'm very comfortable communicating. We're dealing with one language. But that cannot be said for the other places. There aren't any interpretation services or communication services available elsewhere except for here."* Since everybody signs, there are also fewer misunderstandings and little necessity for intermediaries. When intermediaries are needed, interpreters are selected in accordance to the needs of people. Because most people there are deaf, there is a good understanding of each other's needs as most share similar experiences.

For Vivian, the fact that sign language is readily accessible means that she can let her guard down and relax for a moment. Here, she does not need

to concentrate on how to make communication happen in order to be understood nor does she have to work doubly hard to figure out what is going on around her as is the case as soon as she steps out of her home. Perhaps most importantly, she is accepted for who she is. Being deaf is "okay". She does not need to apologize for being deaf nor does she have to try to convince people that she is a normal human being and that her language is equal to speech. At the centre, the importance of signing is clear. It enables exploration, expression and interaction with others. It is part of one's identity. It is no mystery. It is a basic and logical reality. It is nature's way of accommodating for not hearing.

Among the services provided by the centre and which are especially valued by participants is the provision of interpreters for those who have particular needs. Because the centre is aware of the needs of deaf people as well as their signing abilities, they can request an interpreter suitable for particular cases. *"La première fois quand je suis venu ici il y a deux ans, ils m'ont dit: 'bon t'as besoin d'un interprète.' Bien là je continue à venir ici. Fait que là je vais venir ici jusqu'à ma mort. J'irai plus ailleurs. Je vais toujours venir ici. J'aime cette place ici."* (Jacques) *"Avec le Sivet, c'est long à avoir un interprète. Il faut que tu réserves une semaine d'avance tout le temps. Depuis ce temps-là, je viens ici. J'ai payé ma cotisation et là je suis content. J'aime venir ici."* (Thomas) Georges who has limited signing ability and complete illiteracy, recounts. *"Ici, interprète LSQ/ASL. C'est ensemble. Ça veut dire que c'est des bons services de communication. C'est bien mieux ici."*

The Deaf Community Centre also provides information regarding various issues. As well, it links people to appropriate resources. For Charlotte, the centre has been a major source of support over the years. *"Et puis, si t'as des problèmes avec la police ou les hôpitaux, à savoir ce qui se passe à la court. Tu sais, plein de services comme ça."* Vivian uses the centre to access health information as well as various other resources. *"I get my information at the CCSMM because they have a health project and so whenever I need to know information, they'll help me through it. ...They can tell me what services are available out there, where services are provided for deaf people. That will make things easier. If I need an interpreter or if I need something to do with technology*

or whatever my needs are, they would probably be able to be of some resource to me."

Others use the centre as a meeting place, a place to socialize as many recreational activities are organized by the centre. *"Ca fait quatre ans que je viens ici parce qu'il y a le club de l'Abbé de l'Epée."* (Thomas)

Members of the Centre can have a pivotal role in helping people cope with the constraints brought forward in the narratives: *"If you're talking about a deaf person who needs help, I will always be supportive to them... It might be a problem having to do with a doctor's appointment or a problem with using the TTY because they are not literate... It might have something to do with calling the Bell Relay service. I mean the Bell relay service is a place where misunderstandings happen all the time. We need some kind of direct communication. Not going through a third party. Something as simple as making an appointment. So it can be difficult because the person can make the appointment but I have to look for the interpreter and make sure that all the information has been given such as time and place. And often, I will call the hospital and tell them that there needs to be an ASL interpreter... So I act in a supporting role because I don't like to see other deaf people being oppressed."*

Although the centre is a place where one can access information and find support, the lack of resources limits the available support. The fact that the provision of interpreting services is unknown to many deaf people is partly due to the fact that this service is not externally promoted because of limited financial resources. The centre has a restricted budget as it is funded solely by a non-profit organization, Centraide. Although its members are pleased with the interpretation services provided, it must be selective as for whom it provides these services. Presently, it tends to restrict the services to those who are illiterate as they usually cannot get through the health system without an interpreter.

At the present time, only one deaf person is employed to do the administrative work as well as to provide psychosocial support to the deaf community. According to Jean, the demands far outweigh the resource. *"Moi je regarde ça, lui il est tout seul. Il vit comme un fou. C'est un employé permanent*

et puis les secrétaires elles changent. Et puis lui c'est impossible de rencontrer toutes les personnes. C'est impossible! Là il peut pas tout faire. Moi je le regarde aller. Il aurait besoin de 3-4 employés avec lui." Other people comment: *"It's not enough to have one person do the work for the whole community. There's not accessible service where we can get information if someone needs it."* (Ann) *"They need more than they have. They provide us with some pamphlets but I don't bother picking them up because I don't understand the language, the vocabulary. It's not accessible and I don't find the information very clear."* (Vivian)

In the last few years, a 'health project' has been underway. The project aims at making health services more accessible to the Deaf. The one person hired to implement the project has been unable to keep up with the needs and demands of the community. Although fluent in one sign language, there are often demands for assistance in both sign languages.

Above all, the centre is a unique place which fights against the fragmentation of services that is particularly painful for the Deaf, who do not possess the necessary abilities to circulate between the different systems. In their lives, the problems encountered progress to the level of a generalized anxiety, with the numerous traces found in the narratives. From the narratives, we have the impression that the mere fact of disposing of a 'unique ghetto' contributes to giving them a sense of coherence in their lives.

Separate Worlds revisited

In the narratives, deaf persons spoke of being different from hearing persons and of wanting to be recognized for their differences. On the one hand, they do not want to be considered as totally different, as objects of curiosity. Jean talks to us about feeling singled out. *"Aussi, parfois les professionnels sont curieux à savoir des affaires personnelle comme notre premier contact avec les personnes sourdes. Ils veulent savoir comment faire pour apprendre les signes. Est-ce qu'on peut communiquer par signe? Est-ce qu'il y a beaucoup de mots? Ah c'est incroyable! Tu sais, j'aime pas ça me faire poser toutes ces questions-là. Ça c'est des à côtés. Moi je suis venu ici par affaire. Si tu as envie de me poser ces questions là, tu me les poseras à l'extérieur. Bien*

là au CLSC, pourquoi ils font affaire avec les sourds? Tu sais, moi j'aimerais ça que ca soit simple."

On the other hand, deaf persons insist that they live in a different world, that they do not have the same needs and the same expectations as those who hear. This requires professionals to understand and adapt to their needs. Health professionals are ill informed about deafness and the realities of deaf people and attach misleading tags to deaf persons. *"Hearing professionals work with deaf people and make assumptions about deaf people."* Ann's narrative indicates that in health care situations, there is likelihood that professionals use categorizations that do not fit. Labeling can only serve to alienate and stigmatize deaf persons as it has no positive content.

The recourse to the notion of culture offers deaf people a way to have their difference recognized and to transform this difference into positive features. It transforms personal suffering in a collective phenomenon which is a matter for sociopolitical discourse. The notion of culture enables deaf persons to situate themselves in a position of equality and negotiation similar to other cultural communities.

The claim of a distinct and valued identity is a common thread throughout the narratives. Ann talks to us about being deaf and the importance of understanding the 'deaf perspective'. *"Doctors just don't know anything about the issues that I face as a deaf person. They don't understand us. ...Most doctors tend to focus on the ear and maybe think about cochlear implants--they think that they have to make a deaf child hear.* Ann gives the example of a deaf couple who consulted with a physician regarding their deaf infant. *"Of course, the doctor said, Oh my god! You have a deaf child. We're going to have to test him. We're going to have to give him speech lessons. This is so horrible. This is of course, through an interpreter. And the parents said, 'Well, we're pretty happy that this child is deaf. We don't want him to have speech lessons or anything. The doctor said, 'oh, no, no. You have to have the child aided. You have to have the child take speech lessons.' And the parents said, 'were very very happy that the child is deaf like us. This is great. There's always two sides to the story. Doctors tend to focus on the negative, the bad. Doctors are often misinformed about what to do. Many times parents will come to them when they have a deaf*

child and doctors refer them to a psychologist. And the psychologists won't know what to do and will refer them to specialist. Sometimes it makes perfect sense to refer the parents to the deaf community to find out what to do and what it's like to be deaf." Vivian also comments about the the biased orientation of the health system. *"...The doctor or the health care professional always informs the parents that oralism is the way to go, that the child should learn to speak. But never do they promote sign language. Whether the child becomes an oral deaf person or not, that child will never be hearing. It's not beneficial for the deaf child to be brought up oral. I have spoken to some mothers of deaf children and one of the mothers told me that when it was found out that her child was deaf, right away she was told that she should go to the oral method, the oral school. Sign language was never promoted. Obviously, there is a lack of information. That is a very precise example. So I would like doctors and health professionals to be more aware of deaf culture and that would make the process a much smoother one. The cultural aspect of deafness is missing. So we need to give them a slew of information."* In no way does Vivian perceive her deafness as something that needs to be healed or cured. It is her way of being. The first step to promoting the health of deaf persons appears to be the acknowledgement of their difference.

Ann also recalls of a situation where a hearing counsellor made a number of incorrect assumptions regarding a deaf client. These errors were attributed to the fact that the cultural aspect of deafness was ignored. She expands: *"...historically, hearing professionals tend to focus on the 'ear'. It doesn't work and that's their perspective of deafness. But there's two sides to the story. There's the medical view but there's also the cultural perspective. We are people. You know, our situation is different. We need to have information given to us in a different format. Doctors always think deaf people are crazy, have psychological problems, but they don't. I'm just like you! I'm a human being. I may not have the full story and not have been given the opportunity of learning everything but I'm still a person and I'm not crazy just because I'm deaf."*

In the narratives, this claim of a separate world manifests itself in a particular way, through the privilege granted to sign language instead of an oral

language. The latter will always be inferior to the way hearing persons use it. The insistence on speech and the lack of recognition of the importance of sign language is perceived as a rejection of deafness and its specificity.

Alexandre stresses the importance of mastering a language that is their own, a language with which they can go towards other languages such as French. It enables access to other knowledge because of the possession of a strong base on the level of comprehension. It serves as the building block for a strong identity. The nucleus of the person is solid, the person can then move forward, towards the world. By contrast, he points to important problems with the present educational system that by insisting on oralism does not give children the necessary base to integrate with the world. *"A la base, on devrait avoir la LSQ et par la suite, avoir des langues orales. Parce que c'est de construire une confiance en nous. C'est que nous c'est visuel. Il faut avoir une compréhension visuelle et pouvoir s'exprimer de façon naturelle. Là on est limité parce qu'on ne va pas en profondeur des choses. Il faut savoir ce qui est notre identité. C'est un outil. La LSQ, après ça, elle va nous amener du progrès en français. ...On est des bilingues. Là actuellement, dans les écoles, le système, les sourds sont faible en français. 85% sont analphabète. A cause de quoi? Parce qu'ils ont pas le bilinguisme. Ils ont pas la LSQ. Ils les integrent. C'est dommage. A Gallaudet, il a des sourds avec des doctorats et puis ils reussissent bien parce qu'ils ont une base solide. Ils comprennent bien leurs langues et puis après ça, ils peuvent comprendre l'anglais. Ils écrivent. Et puis après ça, pour la parole, l'oralisation au travail, ils s'integrent. Ils ont pas de problème parcequ'ils ont une base solide. C'est comme quand tu construis une maison. Tu construis ta fondation et après ça, tu construis tes murs. Si tu construis tes murs sans fondation, ta maison sera pas très solide, ah. Bon bien c'est la même chose."* He adds: *"Le maître, c'est le système d'éducation. Si ils ont des bons programmes, des bons professeurs, après ça, les enfants vont grandir, ils vont être capable de lire. Ils vont avoir de la philosophie, plein de choses. Ils vont aller dans les cegeps. Ils peuvent devenir des avocats, des professionnels car ils ont des leaders qui vont s'en prendre."*

At another level, and coming full circle, the present educational orientation is perceived as having its roots in the health care system. *"Là,*

aujourd'hui, il a 90% d'oraliste, c'est fort. Ça c'est à cause des hôpitaux. Quand les enfants viennent au monde, bien là ils ont des prothèses. Ils vont voir les audiologistes. Ils favorisent beaucoup l'oralisation. Et puis c'est normal parce que les parents se demandent quoi faire avec leurs enfants. Fait que là ils sont soulagés. Ils ont pas les conseils à savoir qu'il y a une communauté sourde. Et puis lorsqu'ils atteindent l'âge de 18 ans, la majorité se détache de leurs familles, quand ils se retrouvent dans le monde finalement, bien ils viennent dans la communauté sourde. C'est toujours comme ça que ça se passe. He adds that the present educational orientation is also a reflection of the difficulty that parents have in accepting their child's deafness, to cope with a deaf child. Therefore, they tend to integrate the child into their world. *"Ça c'est à cause des parents. Tu sais, on a les oralistes, ceux qui font de la communication complète, on est tous séparés. Et puis là c'est le gouvernement qui est influencé par l'Association québécoise de parents avec enfants à problème auditif (AQUEPA), les centres de réadaptation, les professionnels, l'implant cochleaire. On est tous divisé. Fait qu'on est faibles. On a pas de défense. La seule defense c'èst le centre communautaire".* He expands: *"Les parents entendants quand l'enfant grandit, ils s'en prennent toujours à l'enfant parce que c'est les parents qui ont la parole. L'oraliste, s'il est pas d'accord, bien les parents vont dire, "Toi écoute" et puis eux parlent. Et puis là l'enfant se laisse toujours abattre. Il accepte , accepte, accepte. Et puis là il grandit comme ça. Il a prit l'habitude d'accepter et puis d'accepter. Il a pas d'identité. C'est ça son problème."*

From that perspective, the notion of separate worlds takes on a very different meaning, the focus being on difference, more specifically, on language and on different ways of being and not on deficiency in the oral way. Through the acknowledgement of sign language, the notion of a separate world could become more akin to the notion of a different world, a world that would be inclusive instead of exclusive, a world where people could hold on to their true sense of self and to their dignity, a world where they can realize their true potential. In this light, Vivian longs for sign language to be integrated in schools for the hearing as it is in the United States. She states: *"I think that if the educational system, I'm talking about the public educational system, I think that ASL courses should be part of the curriculum along with English and French.*

Children can learn how to read and write English, French, as well as ASL and LSQ. That way, kids would graduate from school and they would understand sign language. They'd be able to communicate Instead of waiting until their in their 20's or later, to start learning. They could have access to that knowledge very early on." Because it is easier for hearing persons to learn to sign than it is for deaf persons to learn to speak, making sign language available to children early in life would open new doors not only for deaf persons but for hearing persons alike.

The narratives point to the fact that many deaf persons claim their differences through the form of culture. It is a way to give a positive outlook on their situation. It enables them to circumvent their difficulties and situate themselves as a group, on an equal level with other groups of human beings who also belong to a culture. It is a strategy that enables them to overcome the sentiment of isolation and of deprecation by giving the problem a collective dimension, a recourse which parallels other oppressed minorities. "*...Faudrait qu'ils comprennent que les sourds ont leur culture. C'est quoi leur culture? Bon c'est quoi leurs modes de communication. Comment comprendre, comment ça s'est classé dans l'esprit, l'adapter pour les sourds. C'est comme si on était pareil. On a pas l'information. Ils ont pas d'information sur les sourds. Ils ont rien. Là c'est pire qu'avant. En plus, c'est des plus et des plus. On peut pas aller direct au but.* (Jean) Ann echos: "*It's important that professionals and interpreters know about the cultural issues of the deaf community. When you have social, emotional problems, maybe there are cultural issues involved. Also, how do you deal with deaf persons as a counsellor. How does the health professional provide help while being culturally sensitive? Or else a problem may come up, I may not necessarily have the tools to deal with it and so by having access to communication and by learning the ways of dealing with certain issues that come up in my life, I'll be able to resolve alot of issues outside when I'm in the community.*"

Alexandre also associates his culture, his deafness, with a different way of being and of seeing things. "*Et la mentalité est différente des entendants, hein. Je vais te donner une exemple. Si je rencontre un entendant, on jase, on raconte des histoires comiques. L'entendant trouve ça plate. Il ne rira pas mais*

nous autres les sourds, on va rire, on la trouve comique. On va rire. S'il me raconte une histoire d'entendants, lui il va rire mais moi je la trouve bien plate. C'est à cause que notre mentalité et notre culture est différente. La mentalité chez le sourd, on est direct nous. Par exemple, on va dire, 'hey, je ne suis pas d'accord avec toi.' Les entendants font pas ça. Ils vont contourner. Ils vont avertir plus doucement. Ils vont prendre une façon plus habile comme moi je te propose, je te conseille que tu es mieux de pas faire ça. Mais le but est le même. On va arriver au même but mais la façon d'y arriver est différente. Je te donne une autre exemple. La mortalité. On va dire, cette personne est morte. On indique le mot direct. Eux, ils vont peut-être le remplacer par un mot plus dilué. En anglais, c'est 'pass away'. Tandis que le sourd, il y va plus direct. C'est la mortalité. C'est la mort."

When Alexandre, an authority with the deaf community, speaks of his culture he inherently speaks of a deaf identity. *" L' identité sourde, ça veut dire que je me regarde comme personne sourde. C'est mon identité. C'est comme quand j'applaudis, je lève les mains et je pivote. L'implant cochléaire, c'est pas me respecter. C'est comme on met de côté la culture sourde ce qui fait que je n'ai plus d'identité. L'identité sourde, ça veut dire que j'ai ma culture, j'ai mon mode de vie, j'ai mon monde. L'entendant a son monde."* From that perspective, education in oral programs restricts the development of a sense of identity: *"Les sourds disent: on nous démoralise car il y a les entendants. Bien non, il faut être fier d'être une personne sourde. On est pas des handicapé. Tous les sourds entre nous, on se sent pas qu'on est des handicapé. Quand on se retrouve avec les entendants, là on se sent comme des handicapé. On se sent regardé parce qu'on est des sourds Quand je parle d'identité, c'est ça, c'est quoi? Je suis qui moi? C'est ça l'identité. Il y en a des sourds qui ne le savent pas qu'une personne sourde à sa culture. Ils disent, ah, la personne sourde va cogner sur le bureau pour attirer de l'attention. Mais en fait, c'est ça la culture sourde. C'est parce qu'il manque d'information. Le tapage, ça fait partie de la culture sourde. Mais l'oraliste, il n'a pas de monde. Il n'a pas d'identité. Il sait pas à quel monde il appartient. Bon, les entendants sont des personnes oralistes, c'est certain qu'ils arrivent à communiquer entre eux mais dans un groupe, ils ne peuvent pas arriver à suivre, à avoir le fil des idées. Aussi par*

exemple, les oralistes savent pas signer alors quand ils arrivent dans la communauté sourde, bon, qu'est-ce qu'ils font? Ils sont entre les deux." Ambivalence of many deaf persons towards their deafness is traced to the educational orientation, to the deficit model orientation of education and teacher training programs and to the dearth of qualified deaf professionals and educators in all such programs. *"En fait, tu sais, à l'école, c'est parce qu'on lui a pas enseigné , on a pas expliqué l'identité, la culture sourde. Si un professeur lui parle, lui il connait pas la culture sourde donc il manque d'information. Moi quand j'allais à l'école, l'Institut des Sourds, on se regroupait entre Sourds. On connaissait notre identité. On avait des grandes personnes qui étaient sourdes alors on avait notre identité. Mais quand c'est un entendant, on arrêtait de signer pour cette personne là. Il fallait oraliser. Mais en fait, on avait le droit de continuer à signer. C'était ça notre différence. C'est ça qu'on devait apprendre. C'est ça notre identité mais avec l'intégration, ils n'ont pas de modèle. C'est ça le problème qui vivent présentement. Moi çe que j'ai remarqué le plus, quand on signe ensemble, là ça va bien. Ça c'est une identité à la culture sourde."*

Sign language is perceived as intimately associated with deaf culture and a feeling of belonging to deaf culture. *"S'il n'y a pas la LSQ, il n'y a pas la culture. C'est tout. S'il a la LSQ, il a la culture sourde parce que c'est deux differents modes de communication. C'est deux mondes. Alors c'est quoi la différence? C'est la LSQ. Alors dans la culture sourde, on a l'aspect visuel. Tout est visuel. Tandis que dans le monde des entendants, tout est auditif. Notre culture, c'est mon identité, mes valeurs. Dans notre culture, c'est les signes. On est une famille la communauté."* (Alexandre) The attraction to other deaf persons in social situations appears to be automatic and mediated by a common language which enables the sharing of knowledge and experience. *"...Ensuite, quand on est mélangé dans la société en général, quand on communique entre nous, les sourds se regroupent et les entendants se regroupent. Ça se fait d'une façon automatique. Ils se retrouvent entre eux. Pourquoi? Parce qu'on est plus confortable de communiquer entre nous. Quand c'est un entendant et un sourd ensemble, c'est pas facile là hein! 'Ah, il fait beau dehors. Ah il fait beau.' Après ça là, tu sais, la philosophie, la vie sociale, la politique, ces choses là, on est limité. On est pas capable*

d'échanger. Mais là, entre sourds, on est capable. Si on va voir une pièce de théatre, les entendants frappent des mains nous on lève les mains. On pivote des mains. Ça veut dire qu'on félicite. Ça c'est la culture sourde. Les entendants frappent les mains. C'est différent. Mais moi frapper les mains, j'entends pas le bruit que ça fait. Mais quand je vois les mains qui pivotent dans l'air, c'est visuel, alors pour moi c'est attrayant ça." (Alexandre)

Reference to deaf culture delineates a feeling of belonging which transcends particularities and creates a sense of solidarity. *"En plus, dans la communauté sourde, à la base, on a les mêmes idées. Par exemple, moi si je rencontre un sourd de Québec, que j'ai jamais rencontré. Il a sa vie et j'ai la mienne. On fait un rapport sur l'intégration dans les écoles. Alors j'écris un rapport. Quand on compare les rapports, on a la même chose. En plus, dans l'ouest canadien, une personne que j'ai jamais rencontrée, on compare les rapports, on a à peu près la même chose, les mêmes problèmes. Dans le monde entier, on compare des rapports, en fait, on se sent opprimé. Nous on se sent opprimé les personnes sourdes. On se sent pas respecté. On resent l'intégration, la discrimination dans le travail, partout dans les écoles. On sent qu'on a les mêmes choses. Pourquoi? Parce qu'on a la même communauté. On peut s'échanger. Tu sais, c'est comme les Haitiens, la communauté haitienne. Pourquoi ils se regroupent entre eux autres? Pourquoi ne se mélangent-t'ils pas avec les noirs et les blancs? Les noirs se retrouvent ensemble parce qu'ils ont la meme culture, le même respect, les mêmes droits. Ils ont les mêmes valeurs, le respect des mêmes valeurs. Tu sais, la clef importante, c'est la LSQ. S'il n'y a pas la LSQ, il n'y a pas la culture."*

Similarly, Ann compares the deaf community's situation with that of the black community. *"There's alot of parallels between the oppression of deaf people with the black community. Sometimes when you have the black community and the white community, sometimes the black community feel that they're in a minority situation dealing with an oppressive majority. It's the same thing with the deaf community. They don't have avenues to express themselves, the black community starts infighting, you know, basically getting on each other. And that's happening in the deaf community as well. There's no other avenues*

for us to express ourselves and so we need to have other avenues to do that. And to make our community healthy and to make ourselves healthy as well."

This general strategy that consists of considering their difference in terms of culture supports the voicing of collective inquiries towards the government. Among the persons interviewed, it implies an option for the development of separate, but equal quality services. *"I prefer that we be a separate entity and that way everything would go by much faster. The government doesn't recognize deaf people's rights. They're always lumped with the handicap. For example, when I go to a hospital, there's always a ramp for those who are mobility impaired. Then why not give some of that money to the deaf so that we can have services. The right services. Why aren't our rights recognized? We don't get anything. I mean we're asking for interpreters and they're giving us the bare minimum service. We need interpreters. We don't need to have bare minimum services. We need more than that. Equitable service."* (Vivian) *"There is no representation for the community in the government. And of course, they get left by the wayside. There is no voice and so they get overlooked. ...I guess the problem is that the government is looking for people who have degrees. If you have a degree, you have an education, fine, they will talk with you. But where are they? They don't exist in Quebec. Deaf people have to get better educated in order to be recognized by the government. So that's one of the problems. It's the lack of education in the deaf community."* (Ann)

One can conclude that deaf persons, living in a separate world, transform this separateness into something positive that gives them a framework within which they feel more actualized, respected and understood. Jean's narrative conveys that it is not easy to be deaf in a hearing world but acknowledgement of his being and his reality would come a long way in his journey towards personal acceptance and actualization. *"Il faut pas oublier qu'il y a à peu près 10,000 Sourds dans la province de Québec. A Montréal il y en a environ 3000 clients qui ont besoins. Il faut pas les tirer c'est 3000 Sourds là. Ils ont besoin de vivre. Alors, il faut les sauver. C'est une bonne population."* [2]

2. Note: Statistics on deaf Quebecers are difficult to find and no two organizations seem to agree on the numbers. Québec has a population of approximately 7 million people and the prevalence of deaf children in Canada is 1/1000.

Discussion

This study describes the experiences of deaf persons as they try to navigate the health care system and the strategies they try to put in place in order to meet their health care needs. The core theme of *separate worlds* captured the nature of the relationship between deaf persons and the health care system and, more generally, with the hearing world. This theme evolved in their descriptions of their experiences where it became clear that they perceived their world as distinct from the hearing world of health care services. The latter was characterized by a lack of understanding resulting from inadequate communication and lack of knowledge about the realities of the deaf community, as well as poor attitudes towards deaf persons leading to an overwhelming emotional response characterized by a feeling of alienation, stigmatization, rejection, exclusion and powerlessness. The narratives point to a paradoxical effect since what is supposed to be a source of help and support becomes a source of anxiety for deaf persons. In such a context, what was striking was the degree of courage showed by the people and the range of coping strategies they used. Nevertheless, individual strategies remain partial, fragmentary and entwined with difficulties. Deaf people rely on more collective kinds of coping strategies involving affiliation and involvement in groups of deaf people. The notion of culture helps to shape and strengthen the collective strategies elaborated by deaf people for confronting the hearing world and regaining a sense of valued identity.

An anthropological perspective was used in order to understand the world of meaning and health care experiences of deaf persons. In medical anthropology, the works of Corin, Bibeau, Martin and Laplante (1990), Good and Delvecchio-Good (1981) and Kleinman (1988), emphasize the role of meaning in health care experiences. These meanings and experiences are interwoven with what Corin and Lauzon (1992) call "relational threads" within a larger framework of cultural, social, and personal processes. The understanding of people's experiences compared with scientific knowledge can lead to new and more significant interpretations as well as more effective interventions. This being said, in this study, the cultural perspective brought into question the way

in which health professionals work with deafness. The health system focus on 'pathology' and 'normalization' is in contradiction with the way deaf persons perceive themselves. Deaf persons view their deafness as a meaningful human reality. The differing values have important implications for health professionals and the organization of health services. This study provides clues about deaf persons that may be of therapeutic relevance.

From a purely objective point of view, deaf persons and hearing persons live in separate worlds. While hearing persons depend on sound and speech to get through their daily lives, deaf persons rely on their vision and sign language to understand and communicate with the world. They surround themselves with visual elements such as light systems to counter the absence of sound and telephone devices adapted to their needs. Deaf persons also live in a separate world in a much more profound sense as well where separation becomes negatively loaded. Deaf persons perceive that the hearing world excludes deaf persons who depend on visual cues. Moreover, when deaf persons want to voice their opinion on issues that concern them, that affect their lives, they are often ignored. Their deafness makes it easy to push them to the periphery. Deaf people therefore "live within a world which is not of their own making but one which they must continually confront" (Higgins, 1980:22). This social condition leads to a desire to live a life designed by themselves rather than one imposed by others who they perceive neither understand nor accept them. Padden and Humphries (1988) are emphatic on this point. However, the notion of separateness is a complex matter. Within the deaf world, there also exists an inner tension where being different is also a source of anxiety. The stigmatization of sign language can lead to ambivalence as to where one belongs in the world.

In relation to health services and deaf persons, the notion of separate worlds comes out of a series of misunderstandings and awkward situations. Because deafness is invisible, interacting with a deaf person does not necessarily reveal the person's deafness. When the person's deafness is brought forth, it often elicits tension and confusion regarding how to proceed. In some cases, hearing health care workers react to deaf persons as if they were incompetent, and get angry and hostile. In other cases, it elicits curiosity. The

quick interactions and frequent referrals to other resources highlight the fact that deafness is confusing to health professionals. Higgins (1980) has drawn attention to the interaction between hearing and deaf persons and believes that deaf persons are 'victims of the assumption that everybody hears' and that these assumptions lead to awkward and unsatisfactory encounters. A recent study by Sawyer, Desmond and Joseph (1996) found that unlike hearing students, deaf students are intimidated by traditional clinical settings because of the limited possibility of effective communication and because of the high probability for embarrassment and frustration.

The lack of understanding of the needs of deaf persons leads to immense frustration and dissatisfaction with the services. It also engenders anxiety and fear which in some cases leads to catastrophizing and gets translated into an increase in physical symptoms as unresolved problems lead to chronic worrying. Kleinman and Good (1985) refer to the body as being the chief source of idiom and metaphor for the expression of distress, somatic complaints often expressing personal demoralization and social oppression. The lack of understanding also leads to marginalization, isolation and emotional suffering. To gain perspective on the deaf experience, Schein (1989) examined medical services and found that 'wrongs' were committed against deaf persons and contribute to the deaf community's sense of alienation.

To bridge the separate worlds, an interplay of communication strategies involving interpretation services and written communication are often used. However, the lack of understanding of profoundly deaf persons and their needs, combined with poor attitudes, has led to a myriad of other problems that, ironically, has served to further alienate profoundly deaf persons. A study by Hyde and Power (1996) showed that teachers' underestimate deaf students' communication in all communication modes, a situation they believe could engender self-fulfilling prophecies of poor performance.

In the case of interpreters, the lack of recognition of the need to efficiently access interpretation services during emergencies or at any other times, the lack of professionally qualified and skillful interpreters in both ASL and LSQ in the domain of health, the lack of sensitivity towards personal preferences, and the impersonal nature of the services and of the interpreters themselves has led

to tremendous frustration, anxiety, and an overwhelming feeling of injustice and dissatisfaction. Wright (1993) found that deaf people who use sign language are at a disadvantage when communicating with health care staff, including nurses. Similarly, Ebert and Heckerling (1995) found that although most physicians knew that signing should be the initial method of communicating with deaf patients who sign, only a minority used sign language interpreters in their practices. In a 1988 survey done by the National Association of the Deaf (NAD), over half of the persons surveyed said they could not get an interpreter whenever they wanted one and 70 percent were not satisfied with the services (as cited in Schein, 1989). A recent report, the Supreme Court of Canada (October 9, 1997) in The Eldridge Case, ruled unanimously that the failure to provide sign language interpreters for effective communication in the delivery of health care services, social services, education, training and employment violates the rights of deaf persons. The lack of professional interpreters seems to be a generalized problem. What our interviews also reveal is the importance of the intimate nature of the relationship between the interpreter and the deaf person. This points towards an interesting area of study in the future.

As an alternative to interpretation, reading and writing was often used to communicate health information despite the fact that many participants had difficulties with written communication, to the point of illiteracy. Ebert and Heckerling (1995) found that writing was the method used most frequently by physicians when communicating with deaf patients, even though they find writing a painfully slow process (Schein,1989). A recent study by Wilson and Hyde (1997) demonstrated that many deaf students have severe difficulty acquiring literacy and developing reading comprehension beyond an elementary school level. The difficulties were attributed to a combination of perceptual, communication, instructional, linguistic, and experiential deficits. The problems with deafness and literacy are well documented (Johnson, Liddell, & Erting, 1989; MacDougall, 1991;1998; Moores, 1987; Read, 1996).

The problem of reading and writing is an important issue; however, the difficulties associated with writing extend beyond literacy and touch deaf persons at the core of their being. Writing makes difficult the transmission of information that is emotional in nature as thoughts and feelings are interrupted

by the need to concentrate on vocabulary and sentence structure. Moreover, written communication is uncomfortable for most deaf persons as it makes deafness visible. It discredits them because the writing skills of deaf people may not measure up to the standards set by the majority who is hearing. Writing also accentuates deaf people's differences which brings unease for many. Even though they would like to be recognized as different, there is always the underlying fear of being evaluated on the basis of the hearing majority and thus categorized as 'handicapped' and 'inferior' to other human beings. The impatience of professionals in regard to writing only serves to further alienate deaf persons because poor attitudes are generally interpreted as rejection. Discomfort with writing constitutes the most tangible element of a general feeling of uneasiness with respect to the general population. Our findings indicate that deaf persons cannot communicate their true feelings and thoughts through writing, and having to try poses an additional emotional burden. Furthermore, writing stigmatizes deaf persons. These findings were not found in the literature; however, they deserve consideration.

Paradoxically, the very communication strategies, writing and reading, which evoked strong emotional reactions, are used by deaf persons themselves to overcome the constraints encountered. In spite of their inherent difficulties, deaf persons have to communicate and so they develop ways to use these communication strategies along with gestures. This finding is supported by Higgins' (1980) who found that deaf people often attempt to communicate with hearing people through writing or gestures. According to Higgins, while these strategies were generally practical, learned techniques developed over years of experience, they were deemed largely ineffective, because a strategy to combat one problem often increased the likelihood of another. Among other communication strategies used by deaf persons in this study is the use of family and friends as interpreters. Steinberg (1991) discussed the use of hearing friends or family members to interpret and stressed the need for clinicians to assess the extent to which the presence of these persons will inhibit full disclosure and create embarrassment or distortion of reported information. From the perspective of hearing children of deaf parents, Preston (1996), found that as interpreters, children are a cultural link between two often separate

worlds: the Deaf and the Hearing. Preston explored the social mechanisms and cultural values which determine the gender of the way we communicate with one another, and found that sign language and the practice of interpreting often touched upon a larger pattern of socialization and status difference between men and women. In our interviews, we found that having to appeal to children, close relatives or a friend as interpreter was the source of confusing roles and the muddling of barriers between the private and the public. Furthermore, participants did not wish to impose nor exploit. For others still, having to depend on family to interpret is inconceivable because of the fear of being perceived as dependent and weak, a stigma which many deaf persons continuously face.

For confronting the different health care situations, participants also mentioned individual coping strategies in an effort to maintain a sense of personal control and an atmosphere conducive to communication. Strategies such as: friendliness, hypervigilance, lip reading, positive thinking, patience, courage and perseverance were all efforts to maintain control. However, the strategies employed were often ineffective because of the sonorous orientation of the health care environment. Similarly, Higgins (1980) talked about strategies that 'help maintain the hearing's orientation that nothing unusual is happening'. The four techniques found by Higgins were: pretence, being alive to the situation, substitution of senses and collusion with 'wise' hearing people. Positive thinking, patience, courage and perseverance were not mentioned by Higgins. Nevertheless, regardless of the strategies used by deaf persons, a state of anxiety dominated. Furthermore, the inability to master the health care process was generally interpreted as rejection and was indicative of a real marginalization following a lack of socialization to the health care system. Lefcourt (1992) states that people who feel helpless, who do not believe that there is anything that they can do to affect those things that matter to them, are often found to be depressive or anxious. In contrast, persons who believe that they can be effective, who sense that their efforts are never entirely futile, will more often be found to be enthusiastic, resilient, and happy. In regard to health, feelings of control and effectiveness were found by Lefcourt, to be preferable to those of helplessness.

The narratives revealed that the difficulties encountered with the health care system are only an example of generalized feelings of exclusion and marginalization lived by deaf persons in their relationship with the hearing world. Participants signed of feeling alone and left out in the presence of their families, most of whom were hearing. They also spoke of being marginalized in the workplace and of being discredited because of their signing. Signing is unfamiliar to many hearing people and may lead to misunderstandings, negative evaluations and stigmatization. The communication difficulties encountered in the hearing world and the resulting sense of exclusion is well documented in the literature (Higgins, 1980:1987; Padden & Humphries, 1988; Schein, 1989). McKellin (1995) points to the lack of services available to parents of children with hearing losses. In his opinion, the lack of information concerning different communication methods and educational programs have significant effects on family relations and the family's understanding of hearing impairment and deafness. The problems are accentuated in rural areas of British Columbia, Canada where the range of programs are limited.

Goffman (1963) as well as other theorists have drawn attention to the stigma associated with deafness. Related terms are rejection, marginality, alienation and oppression. Higgins (1980) examined a number of issues with regard to the stigmatization of the deaf: discrediting the deaf, deafness as a master status, the issue of spread, scrutinization from the larger hearing world, and acceptance in everyday encounters. Because signing makes people stand out, it discredits them. Their stigmata becoming their master status, their individual capabilities and characteristics are often ignored in favour of negative attributions. These failings are assumed to spread to other areas such as employment. The central issue is the lack of acceptance and respect given to deaf persons. Schein (1989) preferred the term alienation to connote the active opposition that deaf people have often faced in history. Lane (1984,1992) has written extensively about the oppression of deaf persons and sign language. In the narratives, the stigma or the lack of acceptance of deaf persons and of their sign language, is a pervasive and deeply troubling moral theme.

In a positive way, the people interviewed in this study, countered the forces of alienation by affiliating with other deaf persons and developing their

own resources, thus giving meaning to their situation and to their lives. In fact, the use of a deaf social support network emerged as a common and effective way to overcome the constraints encountered with the health care system. One reason for this finding may be the sampling strategy, which comprised of deaf persons who frequented the Deaf Community Centre. Regardless, it appears that signing and deafness leads to a shared connectedness and traits similar to what may be seen in families or communities. This finding builds on previous research (Higgins, 1980; Higgins & Nash, 1987; Schein,1989; Padden & Humphries, 1988). According to Schein (1989), alienation is the motor that drives the deaf community and that the experience of rejection acts as a centrifugal force driving deaf people away from the general society. Affiliation, the tendency of people to seek each other out and to establish conditions that facilitate opportunities to intermingle, is seen as a counterforce to alienation. Steinberg, Sullivan and Loew (1998) investigated knowledge, attitudes and beliefs about mental illness and providers held by a group of deaf adults and found that deaf participants generally relied on members of the deaf community who were respected for their sensitivity, common sense, and life experience to provide informal counselling, moral support, and in some cases, shelter. Sawyer, Desmond and Joseph (1996) compared sexual knowledge, behaviour, and sources of health information between deaf and hearing university students and found that deaf students were more likely to obtain health information from alternative sources. While hearing students were more likely to consult their physician for health information, deaf students relied more on friends who sign, workshops designed for the deaf that included the services of an interpreter and computers. The authors concluded that it would be "presumptuous and possibly dysfunctional for educators to apply mainstream health education principles to diverse populations."

Although the deaf community can be an important source of support, not all deaf persons can access the deaf community. The opportunity to rely on friends and the deaf community for support, rests on the sharing of a similar means of communication. This means that deaf persons who do not share the language of Sign can feel marginalized with respect to the deaf community as they do with respect to the hearing world. There stems the difficulty for those

who have followed the oralists orientation and find themselves doubly marginalized. This finding is supported by a report written by l'Association des Droits et Intérets des Sourds du Québec (ADISQ), 1996.

One gathers that hearing persons with their present ideology have themselves organized the separate worlds as well as the different levels of reality of deaf persons. The normative orientation which has as an objective the integration of deaf persons to the services, ironically, accentuates their "separateness" as its approach from outside the person emphasizes deficiency. As it stands, deaf people are very critical of the present health care system and the solutions brought forward by hearing persons. Although some of these solutions may be appropriate for persons who are hard of hearing, they are not deemed effective for deaf persons. This ideology is at odds with the concrete reality of Deaf persons. From the point of view of deaf people themselves, deafness is much more complex and profound and is situated in a much larger framework of relationships and different ways of being. The insistence on defining deaf people's reality has created a great deal of tension between the world of the Deaf and that of the Hearing. The present ideology is the source of tremendous suffering and has led to the creation of a notion of separateness which deserves much attention.

Presently, the notion of deafness as deficit is transmitted to parents of deaf children who, in trying to cope with a diagnosis of deafness and the loss of an ideal child, are relieved when referred to pediatricians and audiologists. Rarely will parents be referred to the deaf community for another point of view, one based on life experience with deafness. Moreover, the focus on rehabilitation and oral education can be regarded as efforts to undo deafness. Although unspoken, the message is that the child's deafness is not acceptable, he or she is deficient, not different. Such a message is detrimental as it sets the stage for life to come as the deaf person will always fall short of what he ought to be.

The current problems in communication and academic achievement experienced by deaf children represent an orientation that places a higher educational value on speaking than the acquisition of knowledge, and fails to understand the particularities of deaf children. A recent report by l'ADISQ

(1996), indicates that the lack of a uniform system based on an accessible language is by and large responsible for the failure of deaf education. As a result of poor education, many deaf persons, as seen in this study, are illiterate and have great difficulty interacting with hearing persons, making it difficult to secure employment. According to La Fondation des Sourds du Québec, the number of deaf persons in Québec on unemployment or on social assistance is estimated at 91% (as cited in ADISQ). Furthermore, 85% of deaf persons under 30 years are functionally illiterate (Read, 1996). Moreover, unemployment, poverty and powerlessness are associated with higher rates for most mental disorders (Kleinman, 1988).

Many educators and other professionals believe that deaf children should be educated in their natural language, in sign language. This belief does not exclude the need to acquire other languages; however, sign language is seen as a stepping stone to the psychosocial and intellectual development of children and the foundation to other languages. In Québec, there is a growing feeling in the deaf community that deaf people form a culture with a distinct language, American Sign Language (ASL) and Langue des signes québécoise (LSQ), that must be recognized by all persons involved with the Deaf. Research has demonstrated that natural signed languages are 'real' languages, that ASL and LSQ are fully autonomous languages, and that natural signed languages have identical status in the brain as spoken languages (Petitto, 1993). In Canada, ASL has gained recognition in post-secondary programs and in adult training programs especially in the context of the Bilingual/Bicultural approach to education (MacDougall, 1998); however LSQ remains an unrecognized language in Québec (ADISQ, 1996).

The notion of culture, articulated by the deaf community in this study, provides a way for deaf persons to have their differences recognized, a way to situate themselves in a rapport of equality and negotiation like other cultural groups, to transform personal suffering into a collective phenomena marked by a sociopolitical discourse. Reference to the idea of culture enables deaf people to better articulate their claims towards the health care system and the government. I suggest that the critical insights given by deaf persons in their attempts to meet their health care needs be taken seriously. This would help

deaf people integrate into society and enable them to contribute in a significant way. The deaf community, I believe, is at the heart of the well-being of early deafened persons.

In Montreal, the existence of the Montreal Deaf Community Centre provides a safe place and refuge for many deaf persons. At the centre, communication is easy as everybody signs. Likewise, everyone is Deaf; therefore people have similar experiences and can identify and empathize with one other as well as provide viable solutions to problems. Signing and the sharing of deafness is conducive to the development of trusting relationships. Above all, the centre is a unique place which attempts to overcome the fragmentation of services. The latter is particularly painful for deaf people who do not possess the necessary ability to circulate between the different systems. From the narratives, we have the impression that the mere fact of having a unique place contributes to a sense of cohesion in their lives. Literature suggests that deaf communities are both a response to the negative experiences encountered by deaf people in the larger society and a positive means for deaf people to achieve a sense of wholeness and belonging (Higgins, 1987). According to Padden and Humphries (1988), when joining the deaf community, deaf people acquire a heritage, a language and a history that they can share and build upon. McLeod and Bently (1996) urge clinicians to look at deaf patients as people who belong to another culture and for whom English is a second language. They add that treating deaf clients as having a physical disability limits the clinician's understandings of the individual as a person.

The deaf community in Montreal appears to be evolving slowly as compared to deaf communities in some other provinces and states. For example, the deaf community in Winnipeg, Canada is strong and vibrant, speaking out on issues that affect deaf people and people who are hard of hearing (Daeninck, 1996). One could hypothesize that the attitude towards deafness is a major factor as is the present social structure. The conditions do not foster a strong community. The community obtains no governmental support for programs to promote the well-being of profoundly deaf persons. Furthermore, deaf persons are not encouraged to develop and retain their deaf

identity. Signing remains highly stigmatized. The present 'normative' orientation leads to tension within the deaf world itself, of being different but not wanting to be. This leads to isolation and powerlessness. In contrast, the deaf community in the United States is developing well. Schein (1989), who has developed a comprehensive model of the deaf community, attributes its development to the environment and to the fact that the deaf community is in the hands of the deaf community itself. There is no national social policy or agenda which dictates their development. Members of the deaf community are free to set the priorities of that community and to work to achieve them.

A Nursing Framework

The present 'normative' orientation towards deafness is ineffective in meeting the health care needs of early deafened persons. The focus on deafness as disability or deficiency in lieu of difference serves to alienate deaf persons and results in separateness and powerlessness. Such an outcome is contrary to what is intended. Perhaps the undue suffering is more a problem of misconceptions and misunderstandings than neglect. Then again, it may also have something to do with professional values and beliefs.

The McGill Model of Nursing provides a useful organizational framework for planning accessible health services for deaf people. In fact, the beginnings of the theoretical framework were first conceived in response to an identified gap in the Canadian health care system (Gottlieb & Rowat, 1987). The model focuses on the health potentials and health maintenance of groups of people. Inherent in the model is the belief that the strength of the health care system lies in its potential to contribute to the development of human resources: healthful living styles, healthy families and healthy communities. In an integrated health care sytem, the health and health maintenance functions of deaf persons have been totally neglected in the health care system.

Health is the central component of the model and the focus of nursing practice. It is a social process based on interpersonal attributes and learning phenomena. In the model, health is viewed as a way of being, living, and becoming and is related to potentials, strengths, and aspirations and not to inadequacies and limitations (Allen, 1979:1981). Coping and development are proposed as particularly important attributes of health. Coping is a function of

effective problem solving (Kravitz & Frey, 1989) whereas development is directed toward the achievement of life goals (Gottlieb & Rowat, 1987). In the model, environments are viewed as contexts for learning about health. Although the family is considered the prime context of learning, it is acknowledged that learning about health also occurs in other social settings such as school, work, clinics and community groups. A major role of nursing is to structure learning experiences that empower persons and enable them to define their concerns and thrive at approaches to meet their goals (Gottlieb & Feeley, 1995).

The McGill model guided this research from the beginning to the end. Since health in the model is related to potentials, strengths, and aspirations and not to inadequacies and limitations, the model made it very feasible to look at deafness from a different perspective. Coping is an important feature of the model, and having identified that deaf persons did not have access to health services, it followed to question how they coped with the gap in services. By focusing on coping, issues related to their development also unfolded.

The findings of the study overwhelmingly supported the premises of the model. For deaf people, deafness is related to health and is not an inadequacy but a different way of being and seeing the world.

The data not only supports the view that health is a social process but also supports the notion that learning and development are necessary parts of being a healthy deaf person. Although the narratives clearly showed that deaf persons attempt to set goals in order to develop, the present socio-political environment does not support them in their attempts to actualize themselves. The net effect leads to alienation and powerlessness rather than growth and development.

In the model, coping is seen as an important attribute of health. Deaf people invest enormous amounts of energy in order to meet their health care needs, such as trying every means of communication they can. Because of the current thinking regarding handicapped or marginalized populations and the present organization of services, the main, often invisible strategies elaborated by deaf people often become the source of additional problems. The most

effective coping strategy used by deaf persons for mobilizing themselves and for restoring a sense of identity is the reference to culture.

The excerpts also show that for many deaf persons, contrary to the current thinking, the family is not always considered the prime context for learning. However, the model allows for a broad definition of "family" and, in this situation, the data clearly showed that the biological family was not necessarily the supportive family. The most effective source of support was associated to the network of other deaf persons as well as deaf friends. It appears that deafness leads to a shared connectedness for healthful learning similar to what may be seen in families or communities.

The McGill model points to the importance of a collaborative relationship between the nurse and the family or individual in order to structure learning experiences that are empowering. This study was possible because of the quality of the links that were built with the deaf community. To overcome the general feelings of distrust evidenced in the excerpts and which the experiences of marginalization have been built on, a large place was given to the words of deaf people.

In light of the findings, the primary aim of nurses working with deaf persons should be to search with them to elaborate healthy ways of living given their unique culture and special communication needs. Since nurses work with issues that touch people's daily lives, it is important to surpass the categories of researchers and to enter those of the people, to use their words, in order to understand how they see their world. A second aim of nurses is to advocate for effective and responsible heath services so that deaf people can fully participate in decisions about their health.

Implications for Direct Care

The tension within many families indicates an urgent need for nurses to work with families where there is a deaf child. The data also suggests that the strategies used by nurses to communicate with deaf persons are not effectively meeting the needs of this population. In fact, the lack of understanding resulting from inadequate communication by nurses and other health professionals and the lack of knowledge regarding their language and culture, as well as poor attitudes towards deaf persons, creates anxiety and leads to feelings of

rejection and powerlessness. In spite of such a context, the courage displayed by the people and the range of coping strategies used revealed persons who were quite exceptional human beings. Some of these findings are supported in the nursing literature. For instance, Wright (1993) found that deaf persons are dissatisfied with the communication between themselves and health care staff. McLeod and Bently (1996) brought attention to nurses' lack of knowledge regarding the realities of deaf persons, namely the lack of awareness of their culture.

The results of the study imply that an approach centred on meanings and strategies developed by deaf persons would promote the development of meaningful nursing interventions. These would be based on an understanding of the personal stance taken by deaf persons in relation to the world and the problems encountered. The strategies and resources developed by deaf persons to meet their health care needs result from a combination of environmental, social, cultural and personal factors. Knowing the strategies deaf people use can be helpful for nurses as they can reinforce their positive coping strategies in difficult periods. A better understanding of the personal and collective strategies developed by deaf people could also be used to develop health education materials and programs tailored to the cultural and linguistic needs of deaf persons.

Support for the strategies elaborated by deaf persons may be regarded as an encouragement of marginalization. However, one cannot ignore the research findings which indicate that deaf persons seek health care as a very last resort. To the contrary, attention to the importance of sign language and the deaf community as well as the importance of interpreters serves to empower deaf persons and strengthen their creative solutions thus fostering their development. Attention to the culture of deaf persons is, I believe, the missing link with the health care system.

Cultural differences routinely interfere with communication. For any significant exchanges to take place with deaf persons an interpreter is usually required. It is necessary for nurses to understand the importance of a qualified interpreter and realize that one interpreter cannot be easily substituted for another. Consideration must also be given to gender, language of the user, and

personal preferences. Knowing how difficult it can be for a deaf person to schedule an interpreter, the nurse may have to be flexible in the scheduling of appointments. As well, when working with interpreters, the nurse should first discuss in detail with the interpreter what he or she is looking for. She should face the deaf person and not the interpreter. The interpreter should be requested to describe the whole content of the person's speech, not the interpreter's version, and to refrain from making judgmental comments. Following the above suggestions will indicate sensitivity towards deaf persons and their culture and can be the beginning of the development of a trusting relationship.

Implications for Health Service Policy

Given this study and the works of reputed theorists in the field of deafness, it is inappropriate to work towards 'rehabilitation' while disregarding the strategies and meanings that deaf patrons elaborate by themselves in order to reconstruct their experience. Nurses as well as other health professionals should support them in their efforts to reintroduce some internal sense of coherence and continuity within their lives.

In Sweden, it is policy to refer parents of deaf infants to the deaf community in order to understand the potential and possibilities that reside in their child (F. Boucher, personal communication, September 5, 1996). Given access to sign language from infancy, deaf children can develop in a way that parallels hearing children. Deaf people have developed a knowledge of deafness that can significantly contribute to parents' understanding of their deaf child, thereby reducing the tension that often develops within the family .

Given the extent of the problems related to health care services and deaf persons, it is my conviction that nurses need to take a moral stance against the lack of accessibility of health care services for deaf persons. Nurses must advocate for an environment that is visually and technically adapted so that deaf persons can navigate through the system with less anxiety. They must also champion the provision of professional interpreters and better adapted interpretation services as indicated by the recent Canadian supreme court decision. There is also a need to develop information materials in a form other than written. However, if changes to services are to be effective, they must

involve negotiations between the deaf community and professional perspectives. This study has clearly shown that efforts put into place by hearing persons to bridge the gaps between the world of the hearing and the world of the Deaf have failed to the point of jeopardizing the health of deaf persons and completely alienating them. It has also shown that the most effective solutions have come from deaf persons themselves.

There is no doubt that as long as there are deaf persons, they will gravitate towards one another and affiliate in some manner as the need to communicate and share is a profound human need. In Québec, being part of the deaf community sustains people's attempts to find a place within the world of hearing. This study points to the need for a health centre which would be in the hands of the deaf community. The centre would be a central reference centre and would employ both deaf and hearing professionals. Within the centre, among various services and health programs, would be a an interpretation service. The centre would be accessible to professionals and non professionals interested in learning about deaf people and their culture. The idea, I believe, would go a long way in promoting the health and well-being of profoundly deaf persons and in unlocking the present impasse with the health care system. It would imply an understanding of deafness beyond the 'normative' theory, one where clinicians would adjust their expectations about what it means to be deaf in a hearing society. It would also involve collaboration with the deaf community and a sharing of power and resources. In a similar line of thought, Steinberg (1998), recommended the use of existing information pathways such as the deaf community.

Implications for Professional Development and Training

Unless nurses are educated about what it means to be deaf, they will continue to be unable to contribute in any significant way to the health of the deaf population. Most nursing programs, reflecting the diversity of our society, are struggling to provide optimum experiences from among many options for their students. Most educators will agree that the current educational focus needs to be broadened in order to respond to social needs in the larger community. If nursing is committed to human rights, it must incorporate knowledge generated at the social margins in order to respond to the

multicultural and social challenges of our society. This will enhance the development of nursing knowledge as a science, and more importantly, the care of many of the more disadvantaged members of our society, including the Deaf.

Implications for Research

Although there is an increased awareness that deaf persons need to be viewed from a cultural perspective in the nursing literature, there is little knowledge regarding deaf persons themselves, of how, by giving meaning to things, they form a deaf culture. The lack of research related to this cultural group may be due to a lack of awareness regarding this population, as well as difficulties studying a people with a very different way of being. This research contributes to the actualization of the McGill Model of Nursing by providing a methodology that can be used to reach deaf persons and better describe, as compared to mainstream medical models, the reality of deaf people. A cultural perspective for eliciting others' points of view compared with our own categories can also help nurses become aware of their own biases and prejudices.

The significant gap in nursing knowledge in the field of deafness is indicative of some exciting research ahead. The fact that deaf culture is transmitted through deaf peers as opposed to the family can stimulate an interesting debate regarding the family as the main unit of socialization. Research questions that come to mind are: What is it like for deaf persons to go through the perinatal period? What is it like for the deaf elderly with multiple illnesses in long term care?

Future research has a role to play in informing hearing persons of deaf persons' point of view. It is necessary to understand the problems and strategies that they try to develop individually and collectively. According to the leader of the deaf community, the researcher is a gate keeper and bridge between the world of the Deaf and the world of the Hearing.

Research with the deaf community is not a simple process. Because of errors of the past, there is a great deal of mistrust of hearing researchers. Developing and maintaining trust when trying to understand deaf persons is crucial. Without developing the confidence of the participants and community

leaders, the information may be skewed or superficial. It is necessary to include deaf persons in all stages of the research process and to respect their way of being and contribution to the study. Unless the nurse is fluent in sign language, it will also involve working through a cultural broker. Collaboration with the deaf community can lead to increased sensitivity, knowledge, and insight with which the research was designed (Meadow-Orlans, 1990).

This research was only possible because deaf persons agreed to collaborate and accompany me through the research. This type of research is important for deaf persons as it brings forth their voice which may contribute to 'breaking cultural barriers to health care.' According to Meleis (1992a), one of the hallmarks for the future in nursing research related to cultural diversity, is the development and implementation of collaborative research projects. As more researchers from the clinical area and academic settings collaborate in research projects, questions and interpretations become more pertinent to clinical practice. Such collaboration can lead to the development and improvement of nursing models that effectively address diversity.

Limitations

A potential bias in the study was the inclusion of a majority of participants selected by people representing the Deaf Community Centre. However, the person representing the centre served as a cultural broker and helped in encouraging people to speak with me. Furthermore, inclusion of certain participants was essential because the objective of the research was that the data collection be rich and precise relative to a complex domain. Because of inherent communication difficulties, it was also necessary to have a majority of deaf people who had good capacities of reflection, pertinent experiences, and who were interested in reflecting on a line of questions. Such a sample was representative of deaf people's points of view.

The small sample size may be seen as a limitation but they have been compensated by the depth of information. The interviews demonstrated adequate saturation.

Interpreter fatigue was an issue with focus groups as he or she was constantly having to interpret. These situations may have affected the results; however, having a deaf cultural broker present in all but two interviews,

significantly reduced misunderstandings. Also, participants were all briefed as to how to use the interpreter prior to the beginning of the interviews. Nevertheless, out of consideration for the interpreter and for smooth running of the interviews, scheduling two interpreters for focus groups would be recommended. In another case, the participant had very basic signing skills making interpretation very difficult. The participant's limited language made it difficult for the interpreter to capture what he was saying. However, the deaf cultural broker knew the participant's signs and was able to clarify most of what was said.

Another limitation may be the fact that not all videotapes were validated by a second interpreter. The limited budget and the cost associated with interpreters necessitated that one interview be validated and the results generalized to the rest of the interviews. It is my opinion, that given the quality of the interpreters and having briefed them about the research and the questions prior to the interviews, the possibility of misunderstandings was reduced. Still, although I attempted to reduce the potential for misunderstanding, the possible existence of such a problem must be considered a limitation.

A critique of the research may be the fact that the analysis was not validated by the participants. Results will have to be given back to the community and be the object of inner debates (further validating and additional information).

Given that I am hearing, there is always a possibility of distortion. However, all of the interviews with the exception of two, took place with a well respected deaf cultural broker, thereby reducing the probability of distortion and increasing validity.

Conclusion

The notion of deaf culture has important implications for deaf persons and for health professionals as well, for it shows the tremendous ability of human beings to adapt and find meaning in their lives. At the heart of deaf culture, is the visual language of Sign. The value of the natural language of sign is well captured in an article written by Thomas H. Gallaudet in (1848: 1997), the founder of deaf education in the United States:

My object is to show the intrinsic value and, indeed, indispensable necessity of the use of natural signs in the education of the deaf and dumb. ...In attempting this, I wish I had time to go somewhat at length into the genius of this natural language of signs; to compare it with merely oral language, and to show, as I think I could, its decided superiority over the latter, so far as respects its peculiar adaptation to the mind of childhood and early youth. ...In what relates to the expression of passion and emotion, and of all the finer and stronger sentiments of the heart, this language is eminently appropriate and copious. ...So far as objects, motions,or actions addressed to the senses are concerned, this language, in its improved state, is superior in its accuracy and force of delineation to that in which words spelt on the fingers, spoken, written, or printer are employed (p.1-6).

Besides its role in education, sign language has perhaps its biggest impact on the well-being of deaf persons. Edward M. Gallaudet (1887:1997), the son of Thomas Gallaudet and the first president of the National Deaf-Mute College in Washington, presently known as Gallaudet University, the only liberal arts college for deaf students in the world, captures the importance of sign in the lives of deaf persons.

But the greatest value of the sign language to the deaf, when the whole periods of their lives is taken into account, is to be found in the facility it affords for free and unconstrained social intercourse. And in this, as in the matter of public addresses, nothing has been discovered that can fully take its place. It may even be asserted that so long as the deaf remain without hearing, nothing else can give them what speech affords their more favoured brethren. They may have much pleasant intercourse with others by the employment of writing-tablets; they may even enjoy conversation under many limitations with single individuals through articulation and lip-reading; with the aid of the manual alphabet they may have a still wider and more enjoyable range for the interchange of thought; but it is only by employing signs that they can gain the pleasure and profit that comes from conversation in the social circle, that they can enjoy such freedom of intercommunication as shall make it possible for them to forget they are deaf (p.29).

The findings in this study can be further summed up by the following: To be human is not to be like everybody else. People have different ways of being and in order to understand the essential character of various cultures and types

of individuals within each culture, within the society, details must be recognized and misleading tags as well as empty similarities dropped. The road to the general lies through a concern with the particular, a concern that considers and analyzes the various aspects of the whole person in relation to their environment. The road to the general lies through complexity and detail (Geertz, 1973).

Deaf people are visual people, with their own visual language, social organization, history, values, norms and behaviors, knowledge and expectations, in short, with their own way of being and becoming. In light of my research findings, when dealing with deaf persons, it seems important to focus on culture in lieu of rehabilitation. By giving a place to deaf people's narratives in regard to how they see their world, their deafness, as well as their place in the world, and by attending to the collective dimension in regard to the deaf community, nurses will contribute to empowering deaf persons. This, however, implies having to set aside values about "normalisation" or what it means to be integrated within our society, and accept the notion of separate worlds.

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APPENDICES

Appendix A
Guided Interview Probes
Section A - Health Services

To contribute to better health services to deaf persons, I'm going to ask you questions about your experiences with health services.

A Experience with the health care system
- past experiences?
- description of personal experiences
- commentaries regarding experiences of other deaf persons
- similarities between experiences of other deaf persons and their personal experience?
- what do they find most difficult in regards to health care professionals?
- difference of interaction between deaf and hearing?
- commentary concerning what stands out in regards to these experiences

A1. Difficulties and Constraints
- attitude of health care workers (expressions, behaviour)
- communication
- explanations (medical prescriptions? follow-up? other?)
- do deaf people speak amongst themselves about this subject matter?
- feelings?
- does the participant feel understood? respected?
- what are his hopes (in regards to health care services)

A2. Strategies
- how does the participant deal with the attitude of health care workers?
- what do they do when they feel frustrated? misunderstood? worried?
- does he/she speak about these feelings with other family members? other friends?, other deaf people?
- how does the participant obtain general information regarding health concerns (i.e. menopause, sexuality, nutrition, fatigue, childrens health)?
- who does he/she ask for advice?

- what does he/she do when an appointment must be made at the clinic or the hospital?
- does she use relais BELL, interpreters, family members?
- does he get himself to the clinic alone or is he accompanied? With whom?
- how do they make themselves understood at the clinic, hospital?
- what is the best way to obtain medical information?

A3. Written Communication

- does the participant use written communication to communicate with health care workers?
- what does the participant think of this method of communicating? efficiency? feelings?

A4. Interpreters

- does the participant call for an interpreter? when?
- what is the significance of the interpreter in regards to health care services? in other cases?
- does the participant feel understood with the interpreter?
- feelings? frustrations?
- hopes?

A5. Satisfaction

- what does the participant think of health care services? Is the service adequate?
- what does she like about the system? dislike?

A6. Commentary and Suggestions

- what changes would the participant like to see in the health care system?
- how would the participant improve the health care system?
- hopes?

Section B - Resources

- do you ever meet deaf people?

- in which situations have you met? in the arts? sports and leisure?

- do you ever speak about health care concerns? how to resolve health care problems? eg. child development?

- do you have a person or place where you can go for assistance, or can direct you to the appropriate place?

- who do you go to for advice? eg. deaf community centre, friends (hearing or deaf), family, neighbours

- in your situation, how beneficial could the Deaf Community Centre be?

- what would you think of a Health Care Centre for the deaf?

Section C - Conclusion

Okay. Thanks. Now, before we stop, I have just one more question.

Regarding deaf people and health care, are there any other questions that I should have asked you, or a last point which we have not talked about that would have been important to address?

Appendix A
Guide des Entrevues (French Version)
Section A - Services de Santé
Dans le but de contribuer a l'accès aux services de santé pour la population sourde, je serais heureuse de connaître vos experience en matière de santé .

A Experiences avec Services de Santé

- experience antérieur?

- descriptions des experiences personnel

- commentaires sur les experiences des autres sourds

- similarité entre experience des autres sourds et son experience personel?

- qu'est ce qu'il trouve le plus difficile avec les professionels de santé?

- différence d'interaction entre sourd et entendent?

- commentaires sur ce qui la marquer a propos de ces experiences?

A1. Difficultés et Contraintes

- communication

- explications (prescriptions médicales? suivies? autres?)

- attitude des professionels (expressions, comportement)

- Est-ce qu'on parle entre sourds de ce qu'on a parler?

- sentiments

- est-ce que le participant se sens compris? respecter?

- quel sont ses rêves (en relation aux services)?

- est-ce qu'il en parle entre sourd de ce qu'on c'est parler?

A2. Stratégies

- comment est-ce que le participant fait face aux attitudes des professionels?

- que fait-il lorsqu'il se sens frustrer? mal compris? anxieux?

- est-ce qu'il en parle a sa famille? ses amis, d'autre sourds?

- comment est-ce que le participant obtient sont information général en matière de santé? (eg. ménopause, sexualité, nutritrition, fatigue, santé des enfants)

- a qui demande t'il des conseils?

- comment fait-il lorsqu'il doit prendre rendez-vous a la clinique ou a l'hôpital?

- est-ce qu'il utilise relais bell, service d'interprète, ami, famille?
- est-ce qu'il se rend a la clinique/hôpital seul ou accompagner? avec qui?
- comment arrive t'il a se faire comprendre a la clinique, hôpital?
- quel est la meilleur manière d'obtenir de l'information sur la santé?

A3. Communication Écrite

- est-ce que le participant utilise la communication écrite pour communiquer aux professionels?
- que pense t-il de cette manière de communiquer ses besoins de santé? éfficaciter? sentiments?

A4. Interprètes

- est-ce que le participant fait appel a un interprète? Quand?
- signification de l'interprète quand aux services de santé? dans sa vie?
- est-ce qu'il se sens compris avec l'interprète?
- frustrations?
- rêves?

A5. Satisfaction

- que pense le participant des services de santé? service adéquats?
- ce qu'il aime? ce qu'il déteste?

A6. Commentaires et Suggestions

- quel changements est-ce que le participant aimerait voir aux services de santé
- comment aimerait-il améliorer les services de santé?
- rêves?

B. Ressources

- Est-ce que vous vous rencontrez entre sourds?
- Dans quel situation vous vous rencontrez? sports, arts, loisir?
- Est-ce que vous parler de question de santé? comment résoudre des problèmes de santé? dévelopement des enfants?

- Avez-vous une personne ou un endroit qui vous apporte de l'aide, afin de vous diriger sur les services de santé adéquats?
- Aupres de qui, prenez-vous contact pour des conseils? eg.Centre des Sourds, amis (entendants et/ou Sourds), famille, voisin.
- Quel importance donnez-vous aux personnes sourdes auprès de qui vous pouvez demander conseil?
- Pour vous, quelle importance peu avoir le Centre Communautaire des sourds?
- Que penseriez-vous d'un Centre de Santé pour les Sourds?

Section C - Conclusion

Tres bien. Merci. Mais avant que nous ne terminions cet entretien, j'aimerais encore vous poser une derniere question.

Y-a-t-il une question que vous auriez aime que je vous pose? ou un dernier point dont nous n'avons pas parlé, et qui d'après-vous apporterait une certaine lumière sur les relations entre les personnes sourdes et des services de santé?

Appendix B

McGill University School of Nursing

Written explanation

I will be conducting a research study regarding accessibility of health services to deaf people in the region of Montreal and Laval. To develop health programs that meet the concerns of deaf people, it is essential that deaf persons participate in the development and delivery of culturally appropriate health service programs. It is in this light that I would ask if you could select potential participants who are willing to share their experiences and who meet the following inclusion criteria:

1) use sign language as their main mode of communication

2) be at least 19 years of age

3) be able to reflect and provide detailed information about their experiences with the health care system

4) agree to a videotaped interview

Within the next few weeks, you will be contacted concerning potential participants. If you have any questions about the study, I can be reached at (514) 482-2222. Thank you for your collaboration.

Sincerely,

Nicole Parisé

Masters student

Appendix C
McGill University School of Nursing
Consent form

In signing this document, I am giving my consent to be interviewed by Nicole Parisé and _____.

I understand that I will be part of a research study that will focus on accessibility of health services to deaf individuals and their families in Montreal. This study, supported by a grant from the Ministry of Education, will provide information on how to make health services more available and accessible to deaf people.

I agree to be interviewed through an interpreter, at the Montreal Metropolitan Deaf Community Centre, at a time convenient to me. I will be asked some questions concerning my experiences with the health care system.

The interview will take about two to three hours to complete and will be videotaped.

This interview was granted freely. I have been informed that the interview is entirely voluntary, and that even after the interview begins I can refuse to answer any specific questions or decide to terminate the interview at any point. I have been told that my answers to questions will not be given to anyone else and no reports of this study will ever identify me in any way.

This study will help promote access to health care for deaf people. However, I will receive no direct benefit as a result of participation. As a token of appreciation and as a means of compensating for any inconveniences or monetary costs associated with participating in this study, I have received $40 for granting this interview.

I understand that a summary of the research report will be given to me if I ask for it and that I can contact the investigator if I have any questions about the study or about my rights as a study participant. The investigator can be reached at (514) 526-3187.

_____

Date

_____

Participant's Signature

_____

Interviewer's Signatures

Appendix C (French Version)
Université McGill
École des Sciences Infirmières
Consentement écrit

Par cette présente, j'autorise Nicole Parisé et _____ à m'interviewer, dans le cadre de ce qui suit:

Je suis conscient (e) de participer a une recherche subventionnée par le Ministère de l'Éducation, qui doit permettre une plus grande disponibilité et accessibilité des services de santé de Montréal et sa région, auprès des personnes sourdes et leurs famille.

J'accèpte d'être interviewé (e) par l'intermédiaire d'un l'interprete, au Centre Communautaire des Sourds de Montréal Métropolitain, a l'heure et au moment de mon choix.

A cet effet, il me sera posé (e) des questions quant a mes experiences personnelles avec les differents services de santé.

La durée de l'entretien s'etablira entre deux et trois heures et sera enregistrer sur magnetoscope.

Cette entrevue ne sera pas remunerée; toutefois, a titre de dédomagement, je recevrais $40 a la fin de l'entretien.

J'ai connaissance que cette interview est entièrement volontaire, et qu'il m'est possible de refuser de répondre a une, ou plusieurs questions qui me seront posées, sans avoir a en préciser les raisons; et ceci, a n'importe quel moment de l'entrevue. Je peux également décider de terminer cettre interview au moment de mon choix.

Il m'a été dit que toutes les réponses que je formulerais dans cet entretien, resteront confidentielles, et ne pourront en aucun cas permettrent de m'identifier de quelque manière que ce soit. Toutefois, dans un contexte de validité, un deuxième interprète pourrait être demander a visionner le video.

Le but de cette recherche, auquelle je participe, est de permettre de définir une disponibilité et une accessibilité plus éfficace des services de santé auprès des personnes sourdes.

Si je le désire, il me sera fourni le sommaire du présent rapport de recherche, ainsi que la possibilité de contacter Nicole Parisé: concernant cette présente étude, ou concernant mes droits en tant que participant.

Nicole Parisé peut être contacté au (514) 482-9822 par voix ou ATS.

_____
Date

_____
Signature du Participant

_____
Signature des Interviewers

Appendix D

Demographic Data

Code: _____   Date of interview: _____

Gender: _____

1. How old are you?

2. Are you married ( ), single ( ), separated ( ), divorced ( ), living maritally ( )?

3. Do you have any children? yes ( ), no ( )? If yes, how many?

4. What is your religion? Do you practice regularly?

5. What ethnic origin are you from?

6. When did you become deaf?

   Birth ( )   Birth-age 3 ( )

   age 4-18 ( )   age 19+ ( )

7. Why did you become deaf?

   From aging ( ) loud noise ( ) runs in the family ( )

   illness (meningitis or other) ( )   don't know ( )

8. Who else in the family is deaf?

   mother ( )   father ( )   brother (s) /sister (s) ( )

   grandparent (s),   aunt (s)/uncle (s)/cousin (s) ( )

9. Are you....working full-time ( )   retired ( )   full-time student ( )

   laid off ( )   a homemaker ( )   unemployed ( )   other ( )

10. What kind of work do you do?

11. Family income

    less then $10000 $10000-$20000

    $20000-$40000 $40000-$70000

    $70000+

12. Do you receive money from social security, disability insurance, pension, public assistance? yes ( )   no ( )

13. What level of education were you studying when you last attended school?

Appendix D (French Version)

Données Démographiques

Code:_____   Date de l'entretien_____

Sexe:_____

1. Quel age avez-vous?

2. Etes-vous: marié (e) ( ), célibataire ( ), sépare (e) ( ), divorcé (e) ( ),
   Vivez-vous maritalement? ( )

3. Avez-vous des enfants? oui ( ), non ( )   Si oui, combien? ( )

4. Avez-vous une religion? oui ( ), non ( )   Si oui, laquelle?
   La pratiquez-vous régulierement?

5. Quel est votre origine ethnique?

6. Quand êtes-vous devenu sourd?
   à la naissance ( )   avant l'âge de 3 ans ( )
   entre 4 et 18 ans ( )   au dessus de 19 ans ( )

7. Pourquoi êtes-vous devenu sourd?
   Est-ce a cause de l'âge? ( ), a cause du bruit ( ),
   maladie (méningite ou autres) ( ), ne sais pas ( )

8. Avez-vous d'autres membres de votre famille atteints de surditité?
   mère ( )   père ( )   frère (s)/ soeur (s) ( )
   grandparent (s) ( )   tante (s)/ oncle (s)/ cousin (e) ( )

9. Travaillez-vous a plein temps? ( )
   Êtes-vous: retraité (e) ( )   étudiant (e) a temps complet ( )   menagère ( )
   Avez-vous été licencie (e) ( )   sans emploie ( )   autre ( )

10. Quelle travaille faites-vous?

11. Revenu familial annuel
    moin de $10000 $10000-$20000
    $20000-40000 $40000-$70000
    $70000+

12. Touchez-vous de l'argent de l'assurance chômage, pension handicappé,
    pension, bien-etre social?   oui ( )   non ( )

13. Quel fut votre niveau d'éduation lors de votre dernière année de scolarité?

Appendix E

Table 1: General Information

Participant	Age Category	Civil Status	Level of Education Completed	Employment	Educational System
1	30-39	Single	Secondary	Unemployed	Institution and regular school
2	40-49	Single	Post-Secondary	Employed	Institution
3	40-49	Married-Wife Deaf	Primary	Employed	Institution
4	30-39	Single	Secondary	Unemployed	Institution and regular school
5	40-49	Married-Wife Deaf	Primary	Unemployed	Institution
6	50-59	Single	Primary	Unemployed	Institution
7	60-69	Single	Primary	Unemployed	Institution
8	40-49	Single	Post Secondary	Unemployed	Institution
9	30-39	Single	Secondary	Employed	Information not available
10	40-49	Single	Post Secondary	Unemployed	Institution

1. For reasons of confidentiality, all names of participants are not included.

2. The term "single" refers to all participants living alone and includes persons who are divorced or separated.

3. The term "unemployed" refers to persons on Employment Insurance, social assistance or pensioned.

Appendix E

Table 2: Characteristics of Participants

Participant	Mother and Father	Age of Onset of Deafness	Cause of Deafness	Siblings
1	Hearing	Birth	Illness	Sibling Hearing
2	Hearing	Birth	Unknown	Sibling Deaf
3	Hearing	Birth	Unknown	Sibling Hearing
4	Hearing	Birth	Unknown	Sibling Hearing
5	Hearing	Prior to age 3	Illness	Sibling Deaf
6	Hearing	Between 4-18 yrs	Illness	Sibling Deaf
7	Unknown	Between 4-18 yrs	Illness	Unknown
8	Mother Deaf Father Deaf	Birth	Genetic	Sibling Deaf
9	Hearing	Prior to age 3	Birthing complication	Sibling Hearing
10	Hearing	Birth	Unknown	Sibling Deaf