

# Rehabilitation for Deafened Adults:

A puzzle with missing pieces

By

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**THESIS**

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## **Abstract**

This study explored the psychological and social impact of adventitious deafness, and the rehabilitation services that were offered to individuals who acquired this condition in adulthood. Qualitative interviews were conducted with a sample of eight deafened adults, who were recruited from across Ontario. The results show that medical interventions (e.g., audiometric testing, hearing aid provision, and cochlear implantation) were relied on exclusively as a rehabilitation approach in providing care to deafened people. None of the study participants were offered individual, family, or group counselling by their hearing health service providers. This lack of attention to the socio-emotional needs of the participants occurred despite the obvious negative impact of deafness, including family problems and social isolation and neglect. This gap in service makes it apparent that the rehabilitation system for adventitious deafness needs the involvement of counsellors and social workers to reduce the negative impact on individuals and families.

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For my daughter, Ruby. May she follow her dreams without distraction.

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## 1. Introduction

This project began with my first hand experiences as a deafened adult. After the onset of hearing loss at the age of 14 years, I received little in the way of rehabilitative services. My personal rehabilitative process consisted of speechreading instruction and the provision of a hearing aid. Without additional support from others, my family and I were left to our own devices to cope with this condition. This approach to rehabilitation created a situation where support for my social adaptation was limited to a few individuals who were, unfortunately, also socially disadvantaged. Thus, my personal growth as an individual was suspended because I was preoccupied with the day-to-day coping with deafness.

After a time, I began to frequent the local deaf club in order to satisfy a need for social interaction. There I began to realize that my experiences were quite different from people who were born and raised as Deaf people. My background as a

hearing person made me feel more like a “half-breed” and I did not feel welcomed into the deaf community. The experience led me to wonder if my experiences were unique to me. Differences aside, my interaction with other deaf people sparked the desire for personal and academic fulfillment.

Years before becoming a social worker, I volunteered to be the leader of a self-help group for deafened adults. Listening to the collective stories of other deafened adults showed me that their experiences were similar to my own. Although many did not share the detrimental behaviors (e.g. substance and alcohol abuse) that I resorted to, many experienced the emotional distress and social isolation that I had felt. More interesting to me was the fact that most, if not all, deafened adults lamented on the deficiencies of the deafness rehabilitative system. They spoke of insensitive professionals and being offered services that did not facilitate coping.

This anecdotal evidence was a striking contrast to the rehabilitative services that were offered routinely to children who are born or become deafened pre-lingually. Thus, my time during my undergraduate and graduate studies was spent exploring the phenomena of adventitious deafness in adulthood. I discovered that acquired hearing loss is a well-studied subject in the medical and audiological professions, but such research has focused on restoring deafened individuals to pre-loss functioning through either medical or audiological intervention, or both. Although this is a worthy cause, documented anecdotal evidence from those who have

experienced profound hearing losses indicate that this focus does not address the significant psychosocial stressors that impact deafened persons (Aguayo & Avena, 1994; David & Trehub, 1989; Glass & Elliot, 1992).

The obvious fact that deafened people are at risk of higher levels of adverse emotional states than non-disabled people has been written about extensively. Although earlier studies tended to focus on the relationship between profound hearing loss and mental illnesses (Benderly, 1980; Giolas, 1982; Levine, 1981; Meadow-Orlans, 1985; Pegg, 1983), later studies have more clearly identified the communication dysfunction and social isolation that play strong roles in negative adjustment (David & Trehub, 1989; Glass & Elliot, 1992; Luey, 1980). Despite documenting deafened people's claims of being underserved by health care professionals, none of the researchers who have recorded this population's experiences have examined the rehabilitative care that they received. Further confounding this, some researchers have suggested that the criticism from deafened people may be due more to their emotional response to deafness than the quality of the rehabilitative services available to them (Glass & Elliot, 1992; Meadow-Orlan, 1985). These studies contend that fear and denial of hearing loss leads deafened people to delay their entry into rehabilitation, thus, increasing the impact of deafness on their lives.

The absence of facts on the nature and adequacy of rehabilitative care that deafened adults receive after the onset of profound hearing loss led to this project, which explored these issues through a qualitative approach. The personal experiences of a sample of deafened individuals in becoming deaf and receiving rehabilitative care were examined to determine whether deafened people are, in fact, being poorly served by health care professionals, or if their cries of “they don’t understand me” are simply due to distorted perceptions of the rehabilitative services offered to them.

This thesis reports on a study in which eight deafened adults were interviewed about the impact of their deafness and their experiences with rehabilitation. The pertinent literature, although scant, is reviewed in Chapter 2. The methodology for the study is reported in Chapter 3. The life stories of the participants are summarized and common themes with regard to the impact of deafness and rehabilitation experiences are presented in Chapter 4. In Chapter 5, these results are discussed in relation to the literature. Conclusions and recommendations for rehabilitation are presented in Chapter 6.

## **2. Literature Review**

The literature pertinent to acquired deafness, also called late-deafness, was reviewed by manually and electronically searching library holdings at the National Technical Institute for the Deaf (Rochester, New York), as well as the southern Ontario university libraries, The Canadian Hearing Society library, and the World Wide Web. This search yielded journals, proceedings, reference books and monographs in the fields of deafness and social work, and a web page for deafened adults.

## **2.1 Adventitious Deafness and Its Impact**

### **2.1.1 Prevalence of Adventitious Deafness**

The role of occurrence of the causes of both congenital and adventitious deafness have changed over the years (Heath, 1987). Although many illnesses that have previously caused death are now treated successfully due to advancements in medical technology, the quest to preserve life has left more individuals with a hearing loss (and/or other disabilities). A condition such as Neurofibromatosis Type-2 (genetically caused benign tumors on the central nervous system) can be treated before it causes death, but its treatment (surgery) usually results in deafness. Furthermore, people are at more risk of becoming deaf in adulthood than they were before. Environmental and industrial noise sources have increased within the last century and people are more at risk of traumatic head injuries (i.e., an automobile accident) which can cause deafness.

In the most recent survey of deaf people, the incidence of deafness in adults was 670/100,000 population, or about 1 in every 150 people (Schein & Delk, 1974). In the United States population of 258 million in 1993, this would project to 1,728,600 deafened adults. In Canada's population of 30 million, this proportion translates to 201,000 deafened adults, and in Ontario, to 76,380 deafened adults (Statistics Canada, 1998). Of the total population of deaf people, adventitiously

deafened people account for 75% of adults who are deaf at the age of 19 years (Schein & Delk, 1974).

### **2.1.2 Causes of Adventitious Deafness**

The causes of adventitious deafness were documented in a 1984 survey of over 100 deafened people, in the United Kingdom, who were members of the National Association of Deafened People (NADP). This study revealed that 13.4% were deafened from congenital causes, 57.7% from medical and surgical causes, 3.9% from accidents, and 25% were of “unknown” (idiopathic) causes (Heath, 1987). Furthermore, among 348 respondents in a survey of the membership of the Association of Late-Deafened Adults (ALDA) in the United States, 41.5% reported experiencing progressive losses; 40.5% had medical losses; 12.8% had surgical losses; and 5.2% became deaf as a result of traumatic injury (Boone & Scherich, 1995).

Progressive hearing losses sometimes result from presbycusis (hearing losses caused by the aging process) or from overexposure to excessive noise, but many are idiopathic in nature. The root cause of idiopathic deafness cannot be found with the existing medical technology. Some speculative reasons for idiopathic hearing losses include heredity and environmental pollution. All people who have progressive hearing losses initially detect a mild decline in the hearing ability (usually during adolescence) that slowly deteriorates to profound deafness by middle adulthood.

Medical hearing losses are those that are a result of chronic and acute illnesses such as Menière's syndrome (a disorder with symptoms that include hearing loss, vertigo, and elevated pressure in the inner ear), physical reactions to medications with a side-effect that induces auditory sensory dysfunction (ototoxicity), or a virus. Sometimes medical losses occur overnight, but some people with medically caused losses have become deaf gradually over a period of time.

Surgical hearing losses are those that are caused by the complete or partial removal of the auditory nerves to alleviate another condition, such as Neurofibromatosis Type-2 (NF-2) or bilateral Acoustic Neuroma (auditory tumors). People with surgical hearing losses experience a sudden transformation from being a hearing person, before undergoing the procedure, to becoming a deafened individual afterwards. For these individuals, severing the auditory nerve introduces absolute silence into their world.

Traumatic hearing losses are incurred in a wide variety of ways. Automobile accidents, sports injuries, occupational injuries or even near fatal drowning have been causes of deafness. Often, traumatic losses occur rapidly. In some cases, the recovery from the trauma may lead to a recovery in hearing.

### **2.1.3 Sociological Perspective of Adventitious Deafness**

Adventitious hearing loss is best understood from the sociological perspective (David & Trehub, 1989). A deafened person is someone who experiences a profound hearing loss, which is interpreted as a loss of at least 90 decibels (dB) averaged over three speech-range frequencies (500, 1000, and 2000 megahertz [Hz]) in the “better” (milder loss) ear (Deafened People Page, 1998). At this level of hearing loss, verbally spoken words are no longer comprehensible. The dynamics of being “deafened”, however, are not captured in the statistics of audiological dysfunction. Deafened people were not born deaf. It is not ingrained into their core identity, as it is for those who are congenitally or pre-lingually deafened. Their deafness is viewed as a deficit aspect in their lives, relative to a capacity they formerly had. Those who experience profound hearing loss after being socialized as a hearing person must face the task of learning a new way to cope with the world without dependence on the auditory sense.

This is easier said than done. Luey (1980) reported that deafened adults often feel as if they are stuck between the deaf and hearing societies. They no longer can effectively function among hearing people as they are accustomed. Speech reading is not an easily acquired skill. Only 30 percent of the English vocabulary is visible on the lips. The deafened person trying to cope with deafness must resort to guessing to fill the gaps of dialogue. As many deafened people have reported, social gaffes result from inappropriate responses to the comments and questions of others. This stress and

humiliation leads to withdrawal from social settings. This does not facilitate adaptation to hearing loss while remaining in the normal-hearing society.

On the other hand, it is difficult for a deafened person to become a member of the deaf community. They may not be familiar with the norms and values of those who were raised in Deaf Culture. Individuals who are socialized as Deaf people are accurately described as belonging to an ethnic affiliation rather than being people with a disability. It is mainly comprised of individuals who are pre-lingually deafened and have attended a residential school for deaf children. People of Deaf Culture tend to use and value American Sign Language (ASL) as their primary language (Wax, 1995). The deafened individual's sign language skills may be poor or nonexistent. This makes it difficult for them to build social networks among congenitally or early deafened people. In the worst cases, strong efforts by deafened people to join the deaf community have been thwarted by closed membership cliques among Deaf Culture people (Wax, 1995). In this gap, deafened people become socially isolated. The effects of this isolation are manifested in a variety of negative states and crises.

For deafened people, impediments to convenient conversation with people from their pre-morbid life often result in damage to those relationships—especially with family members (Kyle & Wood, 1987). Elliot and Glass (1981) reported that people who experience severe-to-profound hearing losses have reported higher divorce rates than the non-disabled population. (While profound refers to average

hearing loss of 90 dB, severe losses are those in excess of 70 dB in the three critical speech frequencies, in the better ear.) For those whose marriages have remained intact, the structure and quality of relationships in the family system is altered (Kyle & Wood, 1987; Meadow-Orlan, 1987). This is attributed to the added stress placed on the non-disabled spouses, who often take on additional responsibilities to compensate for their partner's disability (Goffman, 1963). In this case, interdependence may evolve to dependence if the spouse of the deafened person assumes the role of being a personal (untrained) interpreter, telephone message-taker, and so on. This increases the level of stress on the relationship. When such a relationship involves children, the parental authority of the deaf partner usually is undermined when the relationships with the offspring become stilted through the hearing partner. This often brings conflict between the parents (Kyle & Wood, 1987).

One might naturally assume that the deafness rehabilitation system would be well equipped to provide care to deafened adults, but several studies have shown dissatisfaction among the affected population with regards to the services that they received. The repetitive theme found in surveys (David & Trehub, 1989), in-person interviews (Glass & Elliot, 1992) and in focus groups (Aguayo & Avena, 1994) of deafened adults is that the services that they received did not help increase their ability to function. The respondents in these studies stated that the professionals that were involved in their care did not understand the complex repercussions of the

condition and offered services more appropriate for either congenitally deaf people or those with mild hearing losses. For example, a few deafened people reported that they were offered vocational rehabilitation services when counselling for post-traumatic stress might have been more appropriate (Aguayo & Avena, 1994). On the other hand, some researchers pointed out that deafened people experience intervals of denial and social withdrawal. This delays their entry into the rehabilitative system, and the negative effects of profound hearing loss accumulate to levels greater than necessary (Glass & Elliot, 1992; Meadow-Orlan, 1985). These studies suggest that the impact of profound hearing loss would be less severe if the deafened people sought help earlier.

## **2.2 Existing Deafness Rehabilitation System**

Santos (1995) comprehensively summarized the deafness rehabilitative process in the *Encyclopedia of Social Work* (19<sup>th</sup> edition). Citing a multitude of research on deafness, this process was described as a system that is better prepared to implement early intervention for young children than for those who are deafened at a point later in their lives. By focusing more on academic and vocational training than on social rehabilitation, deaf children are provided many resources so that they may realize self-sufficiency in adulthood. What social rehabilitation that is provided is usually limited to maximizing the functioning in the classroom because social

integration for deaf children occurs naturally in the deaf community. Although Santos mention adventitious deafness in a brief passage, it described a deafened adult as a person whom becomes deaf at an advanced age. People who are deafened in the span between adolescence and middle adulthood were not mentioned in the review, suggesting that this population remains overlooked by deafness rehabilitation professionals.

This gap in rehabilitation services offered to deafened people was noted by Luey in 1980 and again in 1994. Among her concerns about the affective and psychological impact of profound hearing loss was the observation that social workers refer deafened clients to physicians and audiologists, apparently unaware that these professions are not equipped to deal with the complexities of social interaction. She advocated that social workers themselves should address social rehabilitation for deafened people.

After the data collection on this project was completed, a major social service agency serving deaf, deafened, and hard-of-hearing people in Ontario, published an example of an ideal process for rehabilitation services for deafened adults. In the form of an anonymous case study, the agency outlined a process that included initial neglect from physicians and audiologists, family dysfunction, depression and substance abuse, and referral to a substance abuse program that lacked familiarity with deafness issues. After the substance abuse counsellor declined to accept the

referral, the agency reluctantly accepted the client and provided a counsellor who was not deaf or deafened, but was described as experienced with deafened clients. The counselling sessions used two-way typing for communication and consisted of helping the client to vent “her rage and grief” (Frayn, 1998, p. 19). The client defined the counselling goals as advocating on her behalf to achieve changes in her family, education about communication needs and technical devices, and intervention with her employer to accommodate continued employment. The counsellor facilitated sessions for the family. Existing agency programs were used to provide the communication and technical assistance, and to intervene in the workplace, although the latter was described as, “The struggle continues.” The substance abuse issues were reported to have been resolved on their own.

Although the literature pertaining to the rehabilitation needs of deafened adults is scant, this oversight supports the need for the present study. It seems imperative to examine the rehabilitation deafened adults do receive, how adequately it has met their needs, and what overlooked types of rehabilitation should be provided to them.

## **3. Method**

This chapter describes the collection and analysis of the data. The sample selection, interview method, and analysis of data are described as well.

### **3.1 *Qualitative Approach***

The qualitative approach is the ideal method to analyse the rehabilitation of deafened adults because the factors that constitute individual experience and satisfaction with services are often a mixture of subjective (how they feel) and objective (the actual services received) issues (Palys & Little, 1983). As seen in the literature, there is no foundation for specific hypotheses about rehabilitation for deafened adults: what it should include, how it should be delivered, who should give and receive it, and what outcomes it should achieve. Essentially, a qualitative approach is the approach of choice when one wants to explore an area that is largely unresearched.

## **3.2 Data Collection**

### **3.2.1 Sample Selection**

An information packet describing this study was sent to 25 deafened subscribers of a newsletter written for Ontarians with acquired profound hearing losses. This packet (included in Appendix 7.1) contained a letter that summarized the study's goal, a discussion of confidentiality issues, a consent form that authorized contact by the principal researcher, and a demographic survey to aid in selection of a diverse sample for interview. This survey covered demographic information about age, gender, onset and length of deafness, cause of deafness, and self-assessed communication skills through lipreading and sign language.

The response rate to the solicitation was 12 out of 25 (48%). Of this number, 10 respondents volunteered to be interviewed; two respondents sent regrets. A sample of eight individuals was selected and invited to an interview. It must be noted that the sample was not selected at random. The importance in obtaining a broad range of diversity among deafened people according to the nature of hearing loss led to the use of a purposive sampling method. This procedure is often used when certain characteristics are required to enhance the representation of a sample to the larger population (Erlandson, Harris, Skipper, & Allen, 1993). For this study, it was viewed as important to represent various type of deafness, age at onset, present age, occupation, marital status, and the number of members in their immediate family.

### 3.2.2 Study Participants

Table 1 shows the characteristics of the deafened individuals that were interviewed. The sample contained an even balance between females and males. The mean age of the sample at the onset of hearing loss is 32 (S.D.=14.4) with a range of 13 to 40 years. The average number of years of hearing loss in the sample is 17 (S.D.=12.5) with 2 years being the shortest period of time and 39 years as the longest. There were no respondents who reported traumatic hearing loss (i.e., head injury). This cause of hearing loss is thought to comprise roughly 10% of deafened adults (Deafened People Page, 1998), and a pool of 12 respondents is quite likely to include none of this type. The three other types of causes of deafness—medical, surgical, and progressive—were represented in this sample. Of eight respondents selected for interview, the cause of deafness for three was unknown and progressive; surgery was the cause in three cases; and diseases (medical cause) caused deafness for the other two. Overall, four respondents experienced gradual progression of hearing loss; one participant's hearing loss developed rapidly; while the remaining three experienced sudden deafness. All respondents were Caucasian; therefore no conclusions may be drawn about the generalizability of the results and conclusions to other ethnic groups and cultures. The absence of ethnic diversity in the sample and the mailing list from which it was drawn could reflect a better social support system in other ethnic

communities, or it could simply mean that the multi-ethnic outreach by established deafened adult networks is poor.

**Table 1: Sample Demographics**

	<b>Kristy</b>	<b>Chantal</b>	<b>Elvis</b>	<b>Victor</b>	<b>Lynn</b>	<b>Marie</b>	<b>Jeffrey</b>	<b>Luc<sup>1</sup></b>
Gender	Female	Female	Male	Male	Female	Female	Male	Male
Year of onset	1958	1961	1969	1985	1988	1988	1990	n/a
Age at onset	13	34	20	26	34	40	61	29
Years deaf	39	36	29	12	9	9	7	2
Cause	Disease	Unknown	Unknown	Surgical	Unknown	Surgical	Surgical	Disease
Progression	Gradual	Gradual	Gradual	Sudden	Gradual	Sudden	Sudden	Rapid

1. The respondent (Luc) is in the early stages of hearing loss, but is not yet deafened.

### **3.2.3 Interviews**

The interviews were conducted over a two week period in April and May 1998. Five respondents were interviewed in person at two different sites, using space provided by The Canadian Hearing Society. Computer Assisted Real-time Translation (CART) stenography was used to compensate for the various level of sign language skills possessed by the sample. CART reporters are trained court reporters with advanced qualifications in real-time transcription. The CART reporter listened to the interview from behind a screen (for confidentiality) and typed the dialogue into a steno machine connected to a computer which translated steno codes to English in real time. The conversation was then displayed on a computer monitor so the interviewee could understand the questions that were asked of him or her. The

interview transcripts were automatically captured in ASCII format for later analysis. The effectiveness of CART stenography as a communication and data capture tool was shown in a previous study which involved a deafened researcher and hearing interview participants (Woodcock, 1996). These interviews were approximately two hours in duration.

Alternate methods were used to conduct the three interviews not held in person. Of these, two were conducted through electronic mail (email); one was a telephone interview. Geographic distance was the reason to use an alternate method for two interviews. Both of these individuals lived in remote areas of the province. For the third of these interviews, the alternate method was used at the request of the respondent. That person has a visual disability that renders the use of CART stenography impractical. The interviews conducted through email consisted of ongoing exchanges of notes over a span of three weeks. The telephone interview was completed in one session that lasted three hours. Alternate administration of questions followed the same set of inquiries as the personal interview. Preliminary review of responses showed that there were no noteworthy differences in the depth and scope of comments related to the medium of acquisition.

### **3.2.4 Interview Guide**

The line of inquiry for all of the interviews followed a general chronological order related to becoming deaf and dealing with the deafness rehabilitation system.

Open-ended questions were presented across a range of topics related to these experiences. When appropriate, probes and requests for clarifications were used to extract insightful information and reflections related to the objectives of this study. A structured interview guide (see Appendix 7.2) was developed to start at the point before the onset of hearing loss and follow the respondent's life events afterwards, but the exact sequence of questioning varied between interviews, to build and maintain rapport and adapt to the order that seemed most meaningful to the individual.

Phenomenological interviews obtained descriptions of the lives of the participants in this study before and after hearing loss, with a focus on coping and experience with rehabilitation. The major topics explored in the interviews were:

- life before hearing loss
- personal crisis or trauma before hearing loss
- cause and process of hearing loss and reactions to it
- reaction of family and friends to deafness
- family or friends hindrance or help with coping
- changes in social life influenced by deafness
- prior exposure to deaf people
- initial or subsequent vocational or educational effects of deafness
- rehabilitation services offered or sought out, initially or subsequently
- types rehabilitation specialists/professionals consulted

- involvement of family and friends in rehabilitation
- satisfaction with rehabilitation services
- other factors that helped or hindered coping
- desired changes if given opportunity to do again
- any other comments or recommendations

Information about emotional impacts, such as anxiety and depression, was obtained from information volunteered in response to these questions and provided in response to follow-up probes.

### **3.3 *Analysis and Interpretation***

After all the interviews were concluded, the transcripts were reviewed until each respondent's experiences with deafness were understood with clarity. The data were then broken down into units, coded, and sorted into themes. The major themes were determined a priori, to a large extent, by the foci of the study (e.g., pre-morbid life, onset, impact, etc.). More specific sub-themes (e.g., negative social impact, rehabilitative processes, etc.) emerged from the analysis. Units that did not fit into a theme category were placed into a "miscellaneous" category, and some of these were used to clarify other items later in the analysis. This process was repeated until a consistency developed with regard to themes and sub-themes. A negative case analysis tested the validity of the categorization process by re-paraphrasing items to

see if they would fit into different categories in an attempt to refute the themes that emerged in the first stage. If the re-paraphrasing did not increase clarity of the item, it was returned to the original category that it was extracted from. The general process of qualitative analysis that was used in this study was adapted from Lincoln and Guba (1985). The use of negative case analysis was adapted from Erlandson, Harris, Skipper, and Allen (1993). The participants' life stories were summarized and organized according to the major themes that had been established a priori. Member checking was conducted with the two respondents who were interviewed over a number of e-mail exchanges. The life story for these respondents was developed by the researcher and was reviewed and verified as accurate by each. The final stage of the life story analysis involved summarizing the respondents' experiences into an interwoven pattern that reflected the reality of their lived experience.

### ***3.4 Personal Experience of Interviewing and Analyzing Data***

Being a deafened adult made collecting and analyzing the data a more challenging task for me than it would be for a more neutral researcher. During the interviews, the participants' life stories elicited emotional responses within me because of my ability to empathize with their experiences. I had first hand experience with some events that they described. I sometimes found myself walking a thin line between asking a question and leading the respondent's answers. In other cases, I

fought to suppress anger at the treatment that participants received from others, particularly when one participant expressed absolute hopelessness in his life as a deafened person. To protect the integrity of the data collection process, I sought refuge in the use of my prepared interview guide when my objectivity was threatened during the interviews. I used it to keep my line of questioning as neutral as possible while speaking with the interviewees.

My ability to empathize required me to pay extra attention to professional and personal boundaries during the data analysis stage. This is because it would have been easy to misrepresent the words of the participants by injecting emotion that existed in me, but not in the speaker. After the initial categorization process, the use of the re-categorization process (negative case analysis) in the final stages enabled me to challenge my interpretations of the data. This was done several times for each participant's story until I was confident that the emergent themes were an accurate representation of what respondents actually said.

## 4. Results

In the first section of this chapter, the life stories of the eight respondents are reported. To acknowledge the evolution in the medical and social environment, the stories are organized chronologically so that the earliest respondent to be deafened (Kristy) is reported first, and the most recent (Luc) is last. For confidentiality, the respondent names are pseudonyms, resembling the respondent's actual name only in gender. Many of the life stories refer to a major service agency serving deaf, deafened, and hard-of-hearing people. This will be referred to as the Agency, to avoid the suggestion that this particular agency has been singled out for criticism.

The second section of this chapter presents the themes noted in the eight life stories.

## **4.1 Life Stories**

### **4.1.1 Kristy**

#### **4.1.1.1 Identifying Information**

Respondent number one is a Caucasian female in her early fifties. Coping with hearing loss was a life long experience for Kristy. She acquired a mild hearing loss in her childhood that progressed to profound deafness by the time she entered early adolescence. Kristy's deafness is genetic. It is a hereditary trait that emerged in several members of her family tree. She has been deaf for 39 years.

Kristy rated her speechreading comprehension level as high, and her sign language comprehension as low. The respondent acquired her speechreading skills through daily interaction. She learned to use rudimentary sign language through sporadic contact with deaf people who speak in American Sign Language (ASL). As a preferred communication method, Kristy relies on her cochlear implant (CI) when speaking with others. (A *cochlear implant* consists of a bundle of electrodes surgically implanted in the inner ear. The device transmits signals received by an ear-level external microphone to an externally worn sound processor, which passes signals to the implanted electrodes via wires terminating in a transdermal magnet. Contemporary implants typically have multiple channels corresponding roughly to 22 discrete frequencies over the speech range, which are rapidly stimulated as directed by

the sound processor, to relay a synthesized version of the sound input that many CI users are able to learn to interpret as speech.)

Kristy avoids using speechreading because “*lip-reading inhibits CI use.*” She does not experience many difficulties understanding verbal communication. Kristy said that her cochlear implant provides a high level of comprehension of verbal speech. This includes one-on-one conversations, settings with multiple speakers, and disembodied voices (i.e., voices on the telephone). She claims that only a noisy environment reduces her ability to understand verbal dialogue.

Kristy has a bachelor’s degree in computer science, and worked in computer programming before exercising an early retirement option. Her previous employers include firms in the private sector, an academic institution, and the Agency. She now spends her time doing volunteer work for the Agency and writing.

The respondent lives in a densely populated city in southern Ontario. She married a hearing person many years after the onset of deafness, and has a grown child. Their family relationship is close and supportive. Kristy has regular contact with her sibling, but seldom sees extended family members. She reported socializing only among other cochlear implant recipients. This is because she “*found a bond with these people.*” She says that is because they share the experience of the cochlear implant candidacy evaluation process. She does not relate to people of Deaf Culture

or deafened people that do not use a cochlear implant because “*CI users want to live in the hearing milieu.*”

#### **4.1.1.2 Pre-morbid Life**

Before the onset of deafness, Kristy was raised in a small rural town in eastern Ontario by her immigrant parents. She and her friends participated in conventional childhood activities in the region. She attended school, went hiking with her dog, swam, skated, and socialized with her peers. When she entered adolescence, attending parties, dancing, and dating relationships became the norm. As in most small towns, her classmates advanced through the grade levels together; she was well-known among her peers.

As Kristy’s hearing loss is hereditary, she had extensive exposure to hearing loss before the onset of deafness. This includes her deaf father, and a few people in her extended family with varying degrees of hearing loss. Unlike many other families with genetic deafness, the respondent’s family does not use sign language. On the contrary, her hearing family members believed that the deaf member should hide hearing loss through the reliance on oral communication and social withdrawal. Her mother encouraged her to conceal mild hearing loss and deny her father’s deafness. She once described her father as being “*weak,*” because he “*seemed so dependent on others.*” She once, for example, expressed “*repulsion*” that her father paid people to

drive him to work because he believed that “*deaf people should not possess a driver’s license.*”

#### **4.1.1.3 Onset of Deafness**

The first symptom of hearing loss was Kristy’s reliance on visual cues to comprehend verbal speech. This occurred at approximately the age of three. Several family members noticed that the respondent did not respond to voices outside her line of sight. Kristy does not know whether this condition was congenital or acquired, but she had a mild loss of hearing. Her parents did not address the condition because it remained stable and mild until she reached 10 years of age. At this point, her hearing began to deteriorate, causing problems at school. Her hearing was tested and she was diagnosed with a moderate hearing loss. Three years later, her hearing underwent a sudden decline that left her with profound biaural deafness. Thus, although her first hearing loss was in the preschool years, her transition to deafness was within the same age range as many other deafened adults.

#### **4.1.1.4 Impact of Becoming Deaf**

Becoming deaf placed the respondent in an emotional limbo. She did not view herself as being “deaf,” but she did not relate to being a “hearing” person either. Compounding this confusion is that her mother’s instructions to conceal this hereditary trait. Her mother told her “[*not to*] *tell anyone your dad is deaf...don’t let them know.*” After Kristy became profoundly deaf, her mother instructed her to

conceal her own deafness as well. This increased the friction that existed between her father and herself. The respondent feared becoming like him, and the prospect of it made her feel ashamed, angry, and lonely. The extended family members were not supportive. Her mother was condemned for “*perpetuating the deaf gene.*” They believed that adoption ought to be the preferred method of building families in this situation. Thus, the respondent hid her hearing loss from others. Kristy reported bluffing comprehension during conversations, but that this tactic was often unsuccessful. When her lack of comprehension was exposed, she became embarrassed, but continued to deny her deafness. “*I kept my head down. Don’t make a fuss. I didn’t ask for help...I didn’t ask for concession,*” she stated.

Becoming deaf during adolescence limited Kristy’s social interaction. Although she was accustomed to using speechreading while speaking with others, she found that she could no longer use the telephone. Unlike her peers, the respondent avoided contacting her friends through telephone because she needed her mother to relay the call. This caused embarrassment and had a constricting effect on her social life. Her mother was able to decide who could contact Kristy, and who could not. Furthermore, the respondent’s peers believed that she was “*odd*” because she never spoke with them on the phone. Kristy’s peers stopped inviting her to social events, and she became socially withdrawn. Her social network was reduced to two

individuals. These were the only peers who understood the magnitude of Kristy's hearing loss.

Kristy's pattern of denial and avoidance continued into her adulthood. She did not ask for accommodations, and frequently bluffed comprehension in conversations with others. While her speechreading skills helped conceal hearing loss, her inability to understand verbal speech became obvious to others. Instead of being forthcoming about her disability, she continued to deny it. She would treat any *faux pas* as an insignificant event and distanced herself from the incident. Friendships in her adulthood were few. She frequently avoided people who knew she was deaf, and situations that required a lot of interaction.

#### **4.1.1.5 Rehabilitation Experiences**

Although Kristy's hearing loss was first noticed during her early childhood, it wasn't until she was 10 years of age before her first hearing test. This was done at the school's insistence because Kristy began struggling in school. Her parents took her for a hearing test, and she was diagnosed with a moderate hearing loss. As treatment, her physician recommended a tonsillectomy. He suspected that a throat infection caused the decline in hearing. The surgery, however, did not restore her hearing. The physician then referred her to a hearing aid dispenser, and she was fitted with hearing aids. The respondent received no other rehabilitation services during her pre-adult years.

In 1980, Kristy learned of the development of cochlear implants in an Agency-published magazine. The technology was still in its clinical trial period, but she applied to undergo the cochlear implant candidacy evaluation process. Several tests were conducted to determine if she was an appropriate candidate for the procedure. This included an audiogram, a CT scan, balance testing, and psychological screening. The respondent's application was rejected because "*the technology was too crude back then.*" She described the device as being "*primitive*" and inadequate to remedy her deafness. This rejection caused disappointment for her, but her expectations were low.

After she was rejected for cochlear implant candidacy, the respondent had an audiogram each year. During her visits, she asked the audiologist if there was "*anything new*" in the way of remedies for deafness. For 11 years, his answer was negative. By 1991, cochlear implants evolved from a single to a multi-channel device, and the government approved it for use in a wider range of deaf people. The respondent applied for cochlear implant candidacy a second time. After undergoing the identical evaluation process, she became eligible for implantation. In 1993, Kristy received the cochlear implant.

The respondent did not receive immediate benefits from the implant. The rehabilitation was slower than she expected. She said that the quality of the sound that the device initially produced was "*horrible*" and she became nauseated. It was

difficult for her to discern one sound from another. Furthermore, after 35 years of deafness, she was not used to hearing so many sounds at once. Another factor that slowed rehabilitation progress was her speechreading skill. She believes her reliance on speechreading led her to neglect listening to voice patterns during conversations. She often visited the cochlear implant centre to modify her auditory map (the frequency profile of response programmed into the implant's sound processor). After six months, she began to comprehend verbal speech.

#### **4.1.1.6 Coping Strategies**

The respondent entered a career that required little interaction. She worked in data processing and computer programming at a time before computers became household appliances. Her supervisor and co-workers knew about her deafness because she felt obliged to disclose it when seeking employment. A majority of the work involved autonomous assignments in which memos replaced verbal conversation.

Kristy once worked for the Agency. Although it served deaf and hard-of-hearing people, the respondent did not socialize with the clients. She avoided other deaf people, and resisted learning sign language. She stated she “*saw deaf people signing in the street. I wasn't like them...I was repelled by that.*” In the end, Kristy only learned a rudimentary level of sign language skill because it facilitated interaction with a few deaf co-workers.

The respondent's denial of deafness was reduced at her husband's request. He encouraged her to "*acknowledge it rather than hide it, and bluff, and ask for help, if I need it...Don't just sit there and smile.*" If, in conversation, Kristy did not assert her needs, her husband would moderate the dialogue by asking others to speak more slowly and clearly. The respondent believes that her husband was instrumental to her acknowledgement of deafness.

#### **4.1.1.7 Reflections and Recommendations**

The respondent also stated that she has come to terms with the oppression that she received from family member during her youth. She described her parents as "*products of the times,*" and believes they would be different if alive today. She declined to describe the quality of her relationship with extended family members.

Kristy expressed disappointment in rehabilitation services, but made it clear that she does not blame the professionals involved. She said their tools were inadequate to remedy her hearing loss. It was only with cochlear implant technology that they had something to offer her. She stated that "*they were probably as frustrated as I was at their inability to cure my deafness.*" The respondent is satisfied with the "*wonderful*" work of the cochlear implant team. She attributes adjusting to deafness to cochlear implant technology, and believes that other deafened people should seek help through cochlear implants. Kristy stated that deafened adults should be implanted "*immediately—to minimize the trauma*" of profound hearing loss.

## **4.1.2 Chantal**

### **4.1.2.1 Identifying Information**

Respondent number two is a Caucasian female in her mid-fifties. The cause of Chantal's hearing loss is unknown. It began as a mild loss during her early twenties, and slowly progressed into deafness at the age of 34. The decline of Chantal's hearing was not linear. Her ability to hear faded in a series of alternating declines and plateaus until she experienced a final rapid deterioration at the end. She has been deaf for 26 years.

Chantal assessed her speechreading comprehension level as high, and her sign language comprehension level as moderately high. She uses speechreading to supplement her cochlear impact when speaking with most normal-hearing people. She does not have difficulties understanding verbal dialogue conversing in most situations. The only exceptions are conversations among large groups or in noisy environments. She stated that the use of rudimentary sign language to support verbal speech increases her comprehension level. When speaking with people who use sign language, the respondent uses sign language.

Chantal has a graduate degree in behavioural sciences. She is employed at an elementary school for deaf children. Her previous employers were also agencies that provide services to deaf and hard-of-hearing people. At one time, Chantal was a counsellor with the Agency.

The respondent married a decade before the onset of deafness and divorced shortly after she became deaf. She raised her two children on her own while attending college. She is a native of a rural area of northern Ontario, but presently lives alone in a populated city in the southern part of the province. Her pastimes include visiting relatives and friends, reading books, and attending community-based events.

Chantal feels that she has accepted deafness as a part of her identity, but she does not feel limited by this condition. She has hearing friends as well as deaf friends. Most of her family learned to use rudimentary sign language while speaking with her. Some of her friends learned rudimentary sign language while others rely on oral communication. For some friends, ASL is a native language. Chantal believes that she enjoys the best of both the hearing and the deaf worlds.

#### **4.1.2.2 Pre-morbid Life**

The respondent was raised in an unconventional family structure. Her parents divorced while she was young, and she was cared for by a close relative. Her only sibling was raised apart with a different relative. She had a moderate level of contact with her sibling, infrequent contact with her mother, and no contact with her father. The reason for the marital breakup was never explained to her. Chantal suspects that alcohol abuse played a prominent role in the problems that led to her living arrangement. This made her feel different than her peers. She felt that she had to keep “*many secrets*” from her friends. This made it difficult for her to identify with peers.

They had families while she did not. Chantal confessed that she often took refuge in her friends' homes because *“I loved them...I wished they were mine.”*

Chantal married shortly before the first symptom of hearing loss appeared, and relocated from her home town to a large city. They moved to accommodate her husband's promotion. She stated that she felt lost in a big city and felt *“very, very lonely.”* Six months after settling down in her new home, the respondent noticed a ringing in her ear that marked the beginning of hearing loss.

Chantal's only prior contact with deafness was befriending a hearing person with a deaf spouse. She stated that, while she had no discomfort during brief exchanges with this individual, she *“did not learn anything about deafness”* from him.

#### **4.1.2.3 Onset of Deafness**

At the onset, the tinnitus was mild without an obvious reduction in Chantal's hearing ability. This, initially, led the respondent to believe that it was her imagination. She came to this conclusion after repeated complaints to medical professionals went unanswered or ignored. Chantal stated: *“[I] didn't connect it [tinnitus] to my hearing...I thought I was going crazy”*. As the ringing grew in intensity, the progression of hearing loss became apparent to all. The process took about ten years to progress to deafness.

#### **4.1.2.4 Impact of Becoming Deaf**

The onset of deafness led to deterioration in the quality of her marriage.

Although there was already friction in her marriage, hearing loss exacerbated these pre-existing marital problems. *“He liked me to be a perfect wife, and then I wasn’t. It really bothered him.”* As her hearing deteriorated further towards deafness, the frequency of disharmony grew. Chantal described, for example, that she was reluctant to inform others about her deafness. *“I didn’t admit it...I never thought of myself as deaf.”* She minimized its magnitude by telling others that she was hard of hearing. She was unable to share her feelings about this condition. She also feared attending social events that involved people who were critical to her husband’s career. She believed that her lack of participation in group discussions made her seem snobbish. Moreover, she feared the risk of embarrassing herself and her husband over a misunderstanding caused by her inability to hear. They quarreled if she stayed home, or if she went with him, he berated her for some communicative *faux pas* when they arrived home afterwards. These arguments were usually one-sided with him screaming at her. They were often filled with derogatory comments, and violence on a few occasions. *“You’re deaf. Why do I bother talking to you?!”* During these quarrels, she could only see his anger, but not grasp the reason for it. These incidents left her in a state of bewilderment and high anxiety.

The fear that deafness rendered her unemployable prevented her from ending the marriage. At the onset, Chantal was in the last year of her academic program, and unemployed. Group discussion comprised a large portion of the respondent's professional interaction. Her growing inability to function in these settings threatened her professional competence and sense of security. She pondered: "*If I couldn't do group work, what am I going to do? How will I raise my children?*" Furthermore, she blames hearing loss for a lost job opportunity because she responded to the interviewer's questions with vague answers. This may have made her appear unqualified or mentally slow. She explained that, during the employment interview, "*I was trying so hard to be sure of what they (interviewers) were asking me but I didn't want to admit it [hearing loss] to them, or myself.*" The respondent believed that she had no control over her life. She experienced episodes of depression and despair. She said that she "*felt so helpless!*".

Eventually, Chantal's marriage dissolved, and she found herself more isolated. She lived in a large city, a great distance from her family. Communication with her relatives was difficult. She depended on written correspondence or asked others to place telephone calls for her.

#### **4.1.2.5 Rehabilitation Experiences**

When the tinnitus began, Chantal was examined by a physician to determine its cause. The doctor tested her hearing by holding a vibrating tuning fork behind her

head. Because she heard the sound of the vibrating fork, the physician concluded that she did not have a hearing loss. For a thorough evaluation, the physician referred Chantal to an audiologist. Instead of performing full audiometry, the audiologist repeated the tuning fork test, with identical results. The audiologist found nothing wrong with the respondent's hearing. Chantal said that both the physician and the audiologist did not acknowledge her concerns. They ignored her questions about her ringing ears or dismissed its existence. *"They put the tuning fork behind my ear and said I was fine...they must have thought I was crazy."* For some time after the initial exams, Chantal returned to these individuals to complain about the growth in the intensity of the ringing. They told her each time *"that it [hearing] was fine; there was no problem."* She estimates that she complained to them about the tinnitus approximately 15 times in the period of five years, but *"they never gave me a real hearing test."*

Later, Chantal was examined by another physician (#2) for an unrelated illness. She mentioned her ringing ears, incidentally, to him. He suggested that she may have a hearing loss and recommended a hearing test. Upon her inquiry if the ringing was real or imaginary, Physician #2 informed her that tinnitus was physiological pathology. This was the first time that she learned that the ringing did not suggest mental illness. *"I felt relieved to have an answer for what was wrong."*

Physician #2 referred Chantal to an audiologist (#2). He conducted her first audiometric hearing test. The results confirmed that she had a mild to moderate hearing loss. She was fitted with hearing aids and instructed on strategies to enhance their use. Following this treatment, the respondent had an annual hearing test done. Audiologist #2 tracked the progression of her hearing loss from mild to profound. She needed to upgrade to more powerful hearing aids biannually. Chantal followed this process for eight years. After being refitted with several pairs of hearing aids, the benefits ceased, and she stopped using them. The respondent discontinued consultation with audiologist #2 after she became deafened.

In the early 1990s, Chantal applied to be evaluated for cochlear implant candidacy. She learned of cochlear implant technology from articles in magazines related to hearing loss. She elected this procedure because she wanted more options in life than were available to her. Chantal underwent and passed the screening process. In 1996, after 20 years of being deaf, she became a cochlear implant user.

#### **4.1.2.6 Coping Strategies**

Chantal was still in school when her hearing deteriorated to deafness. She applied for tuition support from the provincial vocational rehabilitation office. The rehabilitation counsellor approved her application and she was able to complete her program. Through the Agency, the vocational rehabilitation department also rented a few adaptive technology devices for her use. Such devices included a portable FM

loop system (a device that increases the audio reception of hearing aids that are located inside the “loop” transmission area) and a TTY (also known as a Telecommunication Device for the Deaf [TTD]; an instrument that allows deaf people to contact each other over the telephone by displaying dialogue in a visual format. Such conversations require with one TTY at each end to communicate over the telephone. Telephone conversations between hearing and deaf people are facilitated through an on-line translation service otherwise known as a dual party relay service).

Chantal elected to do volunteer work at the Agency. During her time at this organization, she began learning sign language and met other deaf people. She received support in coping with deafness from the Agency’s staff. Three years later, Chantal’s volunteerism with the Agency became a full-time job. The Agency hired her as a counsellor to deaf and hard-of-hearing people.

Because she was in a turbulent marriage, the respondent had already participated in several self-help groups. She attended Alanon meetings during her hard-of-hearing period. She also attended Self-Help for Hard of Hearing People (SHHH) meetings. She continued to participate in these groups for a time, but withdrew when she began to feel that she did not have a rapport with the other members. At one point, she became involved in a self-help group for deafened adults. She felt comfortable among the group members, but travelling distance prevented

regular attendance. Furthermore, most of the members lived a distance from the meeting site, and the group eventually disbanded.

#### **4.1.2.7 Reflections and Recommendations**

The respondent expressed that she is only moderately satisfied with the rehabilitation that she received. She stated that, save a few, the rehabilitation professionals were not sympathetic to her needs. She said that some of the medical professionals treated her better than others, but “*there wasn’t a lot of information available to them.*”

Chantal attributes beneficial coping to her membership in the various self-help groups that she encountered. She particularly believes that Alanon helped her the most—even more than the self-help group for deafened people. This is because pre-existing problems and deafness-related problems were entwined. She could not discern which was the main cause of her unhappiness. “*I had a lot of problems. Deafness complicated things.*” She elected to take a holistic approach to coping with her problems. “*I didn’t focus on my deafness, but on my life situation.*”

The respondent believes that a deafened counsellor would facilitate coping better than the hearing ones that she encountered. She said that “*a hearing counsellor might be good, but a deafened counsellor could be more aware, understand the real issues.*”

### **4.1.3 Elvis**

#### **4.1.3.1 Identifying Information**

Respondent number three is a Caucasian male in his mid-forties. Elvis became aware of his hearing loss during middle adolescence. He was not aware of it at first. It was others who noticed that he sometimes did not respond to voices or sounds that others could hear. The respondent's hearing loss was mild at first, but progressed to deafness in adulthood. Elvis has been deaf for approximately 28 years.

Elvis rated his speechreading comprehension level as high and his sign language comprehension level also as high. He acquired speechreading through day-to-day experience, and learned sign language in a course at a community college. He relies both on speechreading and sign language while speaking with others. Elvis experiences difficulty comprehending verbal speech only with people who do not use sign language. Although he communicates well in one-on-one conversations with non-signing speakers, his comprehension declines as the numbers of speakers grow. His ability to comprehend increases considerably when the others use at least rudimentary sign language or other visual cues. Among other deaf people, Elvis does not encounter communication barriers. He does not wear hearing aids.

Elvis has a graduate degree in behavioural sciences. He is employed by a non-profit employment agency for disabled people. His previous employers include other non-profit agencies and the provincial government. One of his past employers was the

Agency. He has held a variety of occupational roles that included counselling, community development, and administration.

The respondent is married and has children whose ages range from middle childhood to adolescence. Elvis did not elaborate on his present life. His pastimes are gardening, theater, and reading. He was once involved in activism, but no longer is, and prefers to keep a low profile.

#### **4.1.3.2 Pre-morbid Life**

When describing his pre-deafness life, Elvis reports that he was closer to his mother than he was to his father. Although he spent a lot of time working at the family store, he had little interaction with his father at home. *“My dad worked more than me, he didn’t have much time for us during my teen years.”* The respondent’s mother managed the day-to-day family issues, and was more involved in his upbringing. Despite this, Elvis believes that his pre-deafness life was *“normal by any standard of the day.”* He was, and still is, close to his two siblings. The respondent had no contact with deafness prior experiencing a profound hearing loss.

#### **4.1.3.3 Onset of Deafness**

At mid-adolescence, others began to notice a slight loss in Elvis’s hearing. He did not respond to others under certain circumstances such as being called from another room. He also needed the television audio turned up higher than the others in the same room could comfortably tolerate. When they turned the volume down to a

comfortable level, the respondent complained that it was too low. At school, Elvis did not seem to understand questions that the teacher called on him to answer. More noticeably, he was usually unaware of these discrepancies. After a parent-teacher conference, his parent took him for a hearing test. It revealed that he had a mild hearing loss of an unknown cause. It was mild at that point, but would not remain stable. Over the years, the respondent experienced a steady deterioration of hearing that lasted until shortly after entering college. Five years after its discovery, Elvis had profound biaural deafness.

#### **4.1.3.4 Impact of Becoming Deaf**

Elvis described his initial reaction to being diagnosed with a hearing loss as “*disbelief de riguer.*” While still in high school, he denied the loss and blamed his lack of comprehension on others. “*I felt the problems were not mine...I blamed the teacher who picked on me, or other people for talking loud so I could not hear.*” As his hearing declined further, the respondent’s frequencies of classroom misunderstanding grew. These gaffes caused embarrassment in front of his peers. Elvis stated that these episodes left him feeling incompetent and full of self-doubt despite receiving high marks in all courses but one. Failing a typing course forced the respondent to acknowledge his hearing loss. The instructor used audible cues instead of teaching from a text book. He could not hear the bells that marked the beginning and end of the exams. “*It was the only course that I failed...still pisses me off.*”

The response of the respondent's family compounded his self-doubt. His father told him that hearing loss would block the respondent's enrollment at university, and he should settle for a realistic career path. His father's words caused emotional distress. Elvis said that his heart disagreed with this prediction, but his head told him to trust his father's wisdom. His mother offered only perfunctory support. *"My mom used to say I could, but in her eyes, I could tell that she didn't really believe it."* Furthermore, hearing loss was a non-issue at home. *"It was not discussed."* Worse yet, his father minimized its magnitude by telling others that the respondent's hearing loss was *"a small problem."* This lack of support and guidance deflated the respondent's confidence. *"I got caught in a cycle of can'ts."*

The respondent's lack of comprehension extended to the social area. He described his high school years as lonely ones. His family moved into town shortly before the onset of hearing loss, and not being a native of the community had already delegated him to "second class status." He was not welcome among the "in crowd," and to compound his classroom embarrassment, he was harassed after school. At best, they avoided him; in the worst cases, a few individuals would shout *"read my lips"* before launching a string of profanities. His only friends were other individuals on the fringes of their class grade level. This led to periodic episodes of depression.

Elvis had few romantic relationships during high school. Hearing loss did not make him an attractive dating prospect. His occasional dates were with females

outside his peer group. They were either in another class level or attended a different school (or both). Hearing loss and self-doubt made it difficult for Elvis to make commitments as well. His relationships usually consisted of one date. This allowed him to conceal his hearing loss. He broke off relationships when his partner began to notice the extent of his hearing loss. This pattern left him feeling unfulfilled.

#### **4.1.3.5 Rehabilitation Experiences**

Upon noticing that Elvis was unresponsive to certain sounds, his parents took him to a physician to determine its cause. The physician conducted a hearing test with a tuning fork. The respondent's lack of response to portions of the exam confirmed that he had a mild hearing loss. The physician recommended a tonsillectomy to rule out a throat infection as its cause. Despite the absence of symptoms of an illness (e.g., fever and nausea), the physician removed Elvis's tonsils. When this procedure did not improve his hearing, the respondent was referred to an ENT (ear, nose, and throat specialist, or otorhinolaryngologist) for further evaluation. The specialist determined the extent of the respondent's hearing loss and referred him to an audiologist. The respondent's parents did not act on this referral because they planned to move to another province within a month.

A short time after moving, Elvis was examined by an ENT (#2) in the new province. The ENT #2 confirmed the original diagnosis, and referred him to a second audiologist. The respondent was fitted for a pair of hearing aids and received training

to enhance their use. Elvis used hearing aids to support speechreading for a period of four years.

The respondent elected to discontinue hearing aid use when they no longer provided comprehension of verbal communication. By 1975, his residual hearing deteriorated until he heard only environmental sounds with hearing aids. At this point, he entered graduate school with the accessibility support of the provincial vocational rehabilitation office. He functioned in the classroom with the use of sign language interpreters, notetakers, and academic support counselling. The vocational rehabilitation office also funded his tuition as well. The vocational rehabilitation office subcontracted the Agency to provide these accessibility features. This was a pre-established relationship that applied to all students with hearing loss or deafness.

#### **4.1.3.6 Coping Strategies**

To cope with deafness in daily life, Elvis purchased several adaptive technology devices through the Agency. He acquired a TTY, visual doorbell, and a vibrating alarm clock. (Closed caption decoders for displaying television text transcription did not exist at the time.) These devices allowed him to be less dependent on others.

Elvis became more reliant on visual cues when speaking with others. His speechreading ability had improved with experience and he attended courses in sign

language. Moreover, he enrolled in a speechreading course shortly after forgoing hearing aids to improve on his pre-existing skills.

The respondent developed a few practices to minimize obstacles to social interaction. He befriended non-judgmental people. He said that this drew him towards “*intellectual types*.” He also developed relationships with people who became social mentors. These mentors were usually his friends’ parents who offered support, advice, and guidance on social functioning and academic problems. Although this help did not extend to coping with hearing loss and deafness, these individuals filled the “void” in Elvis’s life. They provided positive role modeling that he lacked at home. He said that discussions with his “adopted” families gave him a forum to explore feeling and receive feedback on his ideas.

Elvis found that enrolling in independent study courses reduced accessibility barriers. This helped him avoid attending lectures that often held little benefit for him. He spent his time reading and conducting research instead. Reading courses also gave him more one-on-one exposure with his professors. Direct contact with Elvis also improved their understanding of his communicative needs. They spent more time with him and gave him tips on which of his classmates could offer more help academically. One supportive professor supervised a study in which the respondent examined the condition of adventitious deafness. This project helped Elvis understand how acquired deafness had affected himself, and became his “*catharsis*.”

Towards the end of his academic program, the respondent became an activist. Along with people of various disabilities, he lobbied for greater accessibility to the university. He sought for the creation of a special needs office that would catalogue and implement strategies that would allow disabled students to gain access to quality education. This would eliminate the distraction of arranging accessibility services for themselves. This activism taught Elvis how to make use of resources that were available to deaf people.

#### **4.1.3.7 Reflections and Recommendations**

Overall Elvis is satisfied with how well he coped with deafness.

Professionally, he excelled over the accomplishments of his former high school antagonists who inhibited his acceptance among classmates. *“The last that I heard, the ‘Mafia head’ is a bag boy at the IGA”*. Spiritually, he found peace in his marriage and his family.

The respondent does not attribute beneficial coping to the involvement of the rehabilitation professionals. Most of them did not understand the issues that he faced. *“The ENTs, audiologists, and rehabilitation counsellors were barely trained to handle adventitious deafness.”* Furthermore, he was not comfortable with his rehabilitation counsellors because *“most of them could barely fingerspell.”* Moreover, he stated that he knew more about acquired hearing loss than they did. The ENTs and

audiologists particularly disappointed Elvis. *“They [ENTs and audiologists] should have been the authorities on the condition, but they didn’t try...they didn’t care.”*

Instead of rehabilitation professionals, Elvis attributes his beneficial coping with deafness to research and writing about acquired deafness while in graduate school. He also said that the guidance of his social mentors taught him how to deal with life and bolster his self-worth.

Elvis recommended that rehabilitation for deafened adults should include intensive family therapy. He believes that the family unit should receive counselling in isolation. In a “think tank” environment, the family could learn about the deafened member’s needs without distraction. He said that after two weeks of this therapy, the hearing members would have a better understanding of the communicative needs of the deafened member. The respondent also advocated the use of sign language in the home.

#### **4.1.4 Victor**

##### **4.1.4.1 Identifying Information**

Respondent number four is a Caucasian male in his late thirties. The onset of Victor’s deafness began while he was in his late twenties. It was the consequence of surgery to alleviate the symptoms of Neurofibromatosis Type 2. The respondent experienced two episodes of tumours on his auditory nerves (Acoustic Neuroma) seven years apart. Between two surgeries, a neurosurgeon removed tumors on both his

auditory nerves. The first surgery left Victor with absolute deafness in one ear; the second surgery extinguished all sound. The respondent has been deaf for 12 years.

The respondent reported his speechreading comprehension level as moderately high and his sign language comprehension level as low. Victor has a moderate level of difficulty communicating with others. Neurofibromatosis also produces tumors on the optical nerve that can cause diminished vision. Removal of the tumors often causes blindness. An additional consequence of the surgeries was facial paralysis. The auditory and optic nerves are close to the trigeminal nerves, responsible for facial control. The removal of neuromas caused a dysfunction in Victor's ability to pronounce words. Despite these complications, he can understand verbal dialogue in one-on-one conversation provided that the speaker remains in his line of vision. In group settings, the respondent needs verbal dialogue displayed in a visual format (e.g., handwritten notes or CART reporting) to participate in the conversation.

Victor earned an engineering degree and is employed in a technical field. He began working for his employer after his first surgery, but before the onset of deafness. The respondent was hired as a full-time employee, but has worked on a part-time basis for the last 10 years. This change was made to accommodate Victor's multiple disabilities.

The respondent married his partner after the onset of deafness, and has several children. He states that he is close to his family "*all things considered.*" He also has a

large maternal family that he visits on a regular basis. He has maintained close ties with a few hearing friends that he knew in his hearing days. He attends an occasional hockey game with them. Unlike his companions, he talks little while the game is in play. *“I watch the game and talk longer during intermissions.”* Although he desires more involvement, Victor acknowledges that *“communicating with a deaf person put a strain on them [friends],”* and reasoned that it is *“something that not much can be done about.”*

#### **4.1.4.2 Pre-morbid Life**

The respondent was raised in a medium-size city in southern Ontario. He is one of six children. Victor was active in recreational sports throughout his childhood and adolescence. He played hockey, squash, and participated in long distance bicycling between towns. As he entered young adulthood, less active pastimes (e.g., traveling, spectator sports, and poker nights) replaced recreational sports. It was during his young adulthood that the first symptom of hearing loss emerged. When the first surgery resulted in hearing loss in one ear, it did not lead to a loss of social functioning. Victor continued to participate in his favored pastimes. He was hired by his employer right out of college and has worked for the firm ever since. Victor had no prior contact with deafness before the onset of deafness.

#### **4.1.4.3 Onset of Deafness**

The respondent's first symptom of hearing loss began as tinnitus in his left ear. He reported this to his doctor. The physician referred Victor to an ENT to determine the cause of the ringing. When he noticed a slight loss of hearing on the left side, he referred the respondent to a neurologist for further examination. The neurologist diagnosed the cause of the tinnitus and hearing loss as a spontaneous occurrence of Acoustic Neuroma. He recommended removal of the tumor, and the respondent underwent surgery. Although Victor was deafened in one ear, he was able to function as a hearing person, as there was no hearing loss in his right ear. The prognosis was positive, though a small risk of reoccurrence existed. This lasted for seven years until the emergence of tinnitus in the respondent's right ear, and his neural system was reassessed. The neurologist then determined that the Acoustic Neuroma was caused by inherited autosomal dominant NF-2. The respondent underwent translabyrinthine surgery to remove the entire right inner ear. This caused absolute binaural deafness.

Victor experienced complications related to NF-2. ("*NF-2 is a complex disease*".) In addition to causing Acoustic Neuroma, he required several surgeries to remove tumors in other sites. He has a loss of vision, facial paralysis, and disequilibrium that occasionally requires use of a wheelchair. He also has difficulty speaking orally.

It did not take Victor long to acknowledge deafness. As he gained consciousness in the post-surgery recovery room, the nurse told him that it was a long surgery. He swore that he *“could hear her, but the doctors later did hearing tests, and there was nothing.”*

#### **4.1.4.4 Impact of Becoming Deaf**

Waking to absolute silence had a profound impact on Victor. He went into a state of shock when he realized the magnitude of his situation. The respondent became terrified at the prospect of not hearing sounds, particularly his own voice. *“I think that I nearly died then.”* He felt betrayed by his doctors. The neurologist misdiagnosed his condition as a unique episode—not a chronic condition. Victor had believed that the risk of reoccurrence was remote, but becoming deaf after the second surgery intensified the impact it had on him. *“All I could do is wonder why that S.O.B. couldn’t have told me that [about the future risk of deafness] in 1979!”*

The complexity of NF-2 symptoms makes it difficult for Victor to discern which issues are unique to deafness and which are due to other factors. He said that the individual seldom responds to a single condition. He became less outgoing after the onset of deafness, but Victor realizes that his speech disorder and facial paralysis tend to make some people feel uncomfortable while speaking with him. This thought makes him reluctant to meet new people. He also attends sports or social events less often than before, but he points out that his wheelchair use may be the prime factor

for the reduction. Regardless, he occasionally feels isolated and frustrated over the influence that NF has on him.

Besides moderate social withdrawal, deafness and his other disabilities forced Victor to first change occupational roles. He went from a responsible professional position to a one with a more supportive role. When he became physically unable to work full-time, Victor reduced his hours to part-time. This reduced his contact with colleagues, as well as limited his exposure to new developments in his field. It also caused a reduction in his earnings.

Victor's condition had a negative impact on his parents. Victor's condition left them heart broken, and they blamed themselves for giving him the gene. Although there was no evidence of the NF gene, Victor's parents believe that they should have been aware of it. He said this still bothers them. "*They [parents] didn't cope very well.*"

#### **4.1.4.5 Rehabilitation Experiences**

When Victor sought help for tinnitus before the first surgery in 1979, the physician attributed the ringing to listening to loud music. Other than age, the doctor had no basis for this conclusion. After the respondent protested, the physician instructed him to return if the symptoms did not recede in a few days. The ringing remained for over a month, and then he was referred to an ENT for reexamination.

The ENT suspected Acoustic Neuroma on the auditory nerve when his hearing was deficient in only one ear.

Seven years later, the ENT again referred Victor to the neurologist when the tinnitus returned in his other ear. An examination confirmed that new tumors had grown on the respondent's remaining auditory nerve. The ENT explained to Victor that this tumor was not independent of the first. Further examination of the respondent's neural system revealed that the tumors were generated by NF-2 instead of being a spontaneous occurrence.

Victor required intensive rehabilitation after the second surgery, more so than the first. He received rehabilitation throughout his six week hospitalization. His head and neck muscles were rehabilitated by a physiotherapist for four weeks. An orthopedic therapist worked with Victor on a daily basis to help him re-learn how to walk. He also worked with the hospital speech therapist.

Upon discharge, the hospital speech therapist referred Victor to an another speech therapist (#2) employed at the Agency. He did not attend many therapy sessions with speech therapist #2. Transportation to and from the Agency was an obstacle. Furthermore, he stated that he was uncomfortable with speech therapist #2 during his few sessions with this individual. *"I sometimes felt that they were babysitting me."*

Victor began attending rehabilitation sessions with an occupational therapist upon his return to work. The occupational therapist was hired by his company to facilitate his return to work. The therapist had a high level of contact with the respondent. Victor spent four hours, twice a week, with the occupational therapist exploring accessibility obstacles and solutions that would enhance his job performance. This therapist had no experience working with a deaf person. *“I was the first deaf person that she ever met.”* To fill this gap, the occupational therapist reviewed the available literature on rehabilitation for deafness and labour market re-entry. From this research, the occupational therapist developed a rehabilitation plan that included strategies for reconstructing communication modes. She held group therapy sessions with the respondent and his co-workers. The occupational therapist extended this strategy outside the workplace. The occupational therapist visited the respondent at home, and held communication reconstruction sessions with the entire family. The rehabilitation plan also included assertiveness training and the use of adaptive technology devices. The occupational therapist secured funding from the employer to purchase a few conventional adaptive technology devices (i.e., TTY and warning lights) and notetakers when Victor attended meetings. The therapist also experimented with seldom-used accessibility features such as Automatic Speech Recognition (ASR) and CART stenography.

The sessions with the occupational therapist were gradually reduced to an ‘on call’ availability. Victor said that he occasionally contacted the occupational therapist for counselling for work-related problems. She provided an objective view of the options that were available to him. From this, he selected his course of action. The respondent attributes his choice of reducing his number of work hours to part-time, instead of resigning, to one of these ‘on call’ sessions. *“I found that it was getting too hard to work, and wanted to leave. I thought that this was something I’d better talk to someone about first. I went to see her (occupational therapist). She explained that I had no objective reason for quitting; my boss was happy with the job that I was doing. Also, this was the early 1990s, and she explained how hard it would be to find another job. So I went part-time rather than going on disability.”*

#### **4.1.4.6 Coping Strategies**

Victor replaced lost pastimes with new ones. Most of these are activities that require little interaction with others. He enjoys cooking and reading. The respondent also does volunteer work for Neurofibromatosis and Acoustic Neuroma support groups.

The respondent uses several adaptive technology devices at home. Most of these are designed to accommodate for physical disabilities that are not related to deafness. The respondent uses a TTY for communication through the telephone, but prefers Internet and e-mail instead. For environmental cues, the respondent uses

visual signaling devices on the doorbell and telephone. He also uses a vibrating alarm clock.

Victor enjoyed a lot of support from his family. Their involvement helped him cope with the multiple disabilities that he acquired. They quickly adapted to his communicative needs, and cared for him while he recovered. Extended family members made a point to visit him often. When he was again able to care for himself, a sibling helped him find an apartment to increase his independence. After he began living on his own, his siblings took turns visiting to see if he needed help. *“In a way, deafness draws you closer to your family and friends.”*

#### **4.1.4.7 Reflections and Recommendations**

The main factor that helped Victor cope was support from the occupational therapist. He said that for a person that had no experience with deaf people, her insight and advice were exceptional. *“I think that she [occupational therapist] did an excellent job.”* Although he thinks highly of her, Victor also attributes his recovery to the support from his family.

Victor is satisfied with his rehabilitation process, and he would recommend it to others in a similar situation. *“I learned to walk and talk again. They must have done a good job.”* He does find room for improvement though. A few rehabilitation professionals *“tell you what to do instead of helping you along.”* Victor believes that rehabilitation professionals should guide the process, and empower the patient. He

also said they should be more knowledgeable about deafness than they were. *“I would have thought that the doctors and the nurses would have known more about deafness than the occupational therapist. They did not!”*

For a more service-oriented recommendation, Victor believes that deafened people need information to cope. He specifically pointed to information related to adaptive technology, communication reconstruction, and an overview of how deafness brings about new changes and conflicts in life. He said that service providers should have a list of resources on hand to offer a newly deafened person.

#### **4.1.5 Lynn**

##### **4.1.5.1 Identifying Information**

Respondent number five is a Caucasian female in her mid-forties. She was in her late-twenties when her hearing began a progressive decline. By her mid-thirties, Lynn experienced a sudden and profound deterioration in her residual hearing. The respondent has been deaf for nine years.

Lynn reports her speechreading comprehension level as high and her sign language comprehension level as moderately low. The respondent relies on speechreading while speaking with others, and only uses hearing aids to hear environmental sounds. She learned to speechread through day-to-day experience. Lynn does not have regular contact with people who use sign language, despite completing two years of sign language courses at the Agency. She believes that she

can comprehend spoken communication in one-on-one settings, but has difficulties participating in conversations with multiple speakers.

Lynn has a bachelor's degree in a health care profession, and is employed at a hospital. She is a department manager, but also does some periodic work in the hospital clinic. Both roles require participation in large interdisciplinary teams. The respondent is also active in her church and participates in planning several clergy sponsored community events each year.

Lynn is married and with her husband, she has two children. She met her spouse during the period that her hearing loss was mild. Her relationship with her family is a supportive one. She said that their adaptation to deafness was excellent. The children use fingerspelling to support her speechreading skills but her husband has all but forgotten the signs that he learned. Although little sign language is used at home, Lynn says that she communicates well with her family. This reliance on oral communication has led to a deterioration in her own signing skills. She has insufficient contact with people who speak in sign language to maintain her own level of comprehension.

#### **4.1.5.2 Pre-morbid Life**

Lynn stated that her pre-hearing loss life was “*normal as can be.*” She was raised in a small town in a rural area of northern Ontario and participated in common pastimes of the community. She attended school and its extra-curricular activities,

such as dances. Her summer pastimes included hunting, fishing, and playing sports games with friends. In the winter most of her pastimes were church or school-sponsored activities. Shortly before the onset of hearing loss, Lynn graduated from secondary school. She planned a career in the military and enrolled in the academy. Despite being hard of hearing for 16 years, Lynn had no prior contact with deafness before its onset.

#### **4.1.5.3 Onset of Deafness**

The respondent's first warning sign of hearing loss was the comments of others. Several people asked her if she was hard of hearing. Although she believed this to be odd, Lynn did not suspect that she had a hearing loss. Soon, Lynn's ears began ringing constantly. This led her to undergo a hearing examination. The hearing test revealed that a mild hearing loss caused the tinnitus. The reason for the hearing loss is unknown. Lynn's hearing stabilized at this level, and she continued to function without difficulty for ten more years. By her mid-thirties, she developed a serious episode of sinus congestion from a common cold or allergy. Although it was normal for her to have a reduced hearing ability while ill, this time it did not return after the congestion cleared. She waited for two weeks before having her hearing examined. The ENT stated that she had irreversible profound biaural deafness. The cause for this second decline of hearing is unknown. Unlike her initial loss of hearing, Lynn found that deafness was undeniable. Her inability to hear her own voice, with or without

hearing aids, forced her to acknowledge that she was no longer hard of hearing. *“It was scary not hearing my own voice.”*

#### **4.1.5.4 Impact of Becoming Deaf**

The prospect of permanent deafness devastated Lynn. She experienced emotional distress and disbelief. On the drive home from the examination, she became overwhelmed and *“had to pull off the road and cry for half an hour.”* The respondent also experienced episodes of anger. She could not relate to the condition. She did not know any deaf people, nor understand how people could function without hearing. She did not know what her rights were as a deaf person, and feared that the province would revoke her driver’s license. *“All of a sudden, your whole life is up in the air.”*

Deafness led to changes in how she performed her duties at work. Lynn became frustrated at not being able to respond quickly to the needs of other medical staff. She could no longer use a cell phone or rely on the public address system. At meetings, she had difficulty following the agenda. She spent more time struggling to determine which topic was being discussed than making contributions. Furthermore, she often left important professional development seminars without new knowledge because she could not understand the speakers. Lynn began feeling anxious about her job performance. She no longer felt that she was part of the team. The respondent even feared that deafness would eventually lead to job loss. Although Lynn now

admits that her fear was unjustified, she requested re-assignment to a less interactive role even though it fell below her level of training. Her participation on interdisciplinary teams ceased; she worked on the periphery.

For a time, the respondent welcomed the new assignment, but soon became frustrated at not making contributions to her field. To regain her sense of self-actualization, Lynn applied for a non-medical position vacancy in management. She felt betrayed when a less qualified, less senior individual won the position. She confronted her superior about the discrimination, but he minimized her feeling. He said to her: *“I’m sorry you feel that way”* without addressing the issue of discrimination.

Lynn’s deafness caused her parents emotional distress. They became upset and blamed themselves for the hearing loss. Her parents engaged in counterfactual thought as they tried to understand the condition. They believed that their approach to parenting was inadequate to prevent the onset of Lynn’s deafness, and it would not have occurred if they would have monitored her health more carefully. *“They racked their brains to see if I might have taken any medication or something they might have done to cause my hearing loss.”* Most of all, her parents felt guilty that they were not the first to notice the decline in Lynn’s hearing. *“They were quite upset about it then; I think it still bothers them.”*

#### **4.1.5.5 Rehabilitation Experiences**

Lynn underwent a physical examination to qualify for a military scholarship.

A hearing test was part of the physical. After the hearing test was complete, the examiner asked Lynn if she was hard of hearing. Being unaware of a decline in her hearing, she said no. The examiner responded: *“I think the batteries in our equipment must be dead because you didn’t do very well.”* He then gave her a passing mark.

After she began at the academy, other recruits made comments related to her hearing. She soon became aware that it was difficult to function in some situations. It was hard for her to participate in classroom debate from the last row of the classroom and she could not comprehend speakers in darkened lecture halls. Lynn attributed this to freshman year anxiety, but began to suspect hearing loss when her ears began ringing. At first, the intensity of the ringing was low, but when it grew stronger, she went to the military hospital for an examination. The military physician ordered a second hearing test. This second audiogram showed conclusive evidence that she had a hearing loss. Moreover, the loss was at a level below military standards. This led to a reassessment of her first audiogram. The results of the first audiogram were only slightly better than the second one. Lynn’s hearing loss began shortly before entering service. Because the scholarship was awarded based on an erroneous medical assessment, the military allowed her to continue with her studies at the academy, but she was not permitted to report for active duty. The respondent was not referred to an

audiologist for a hearing aid assessment. The military physician said that her hearing loss was still at a mild level and *“he thought that I wouldn’t want one anyway.”*

After Lynn learned of her hearing loss, she had audiograms taken by a private audiologist (#2) on an annual basis. They tracked the progression of her hearing’s decline. For the first two years after its discovery, the respondent’s hearing loss went from mild to moderate. At this point, she was fitted with hearing aids. For the next five years, Lynn’s hearing remained stable at this level, and audiologist #2 recommended reducing the frequency of her visits. She then had her hearing tests biannually.

One day, after seven years of hearing aid use, Lynn experienced a sudden deterioration in her hearing level. A common cold evolved into severe congestion. When the sinus pressure reached its apex, she could not hear her voice anymore—even with hearing aids. Her physician prescribed an antibiotic to relieve the congestion. After the illness abated, Lynn’s hearing did not return. The physician referred her to an ENT. The respondent was examined and the ENT stated the loss was irreversible. He did not try to explain the cause and rebuffed her inquires. The ENT said to Lynn: *“We don’t answer ‘why’ questions here.”* He then minimized her concern by pointing out that she had experience coping with hearing loss. *“Don’t worry about it. Look at how well you’ve coped so far.”* The ENT’s only recommendation was to join one of the local clubs for deaf people.

#### **4.1.5.6 Coping Strategies**

Lynn reviewed all available information on deafness to help her cope with her new condition. She learned of the Agency through a publication on hearing loss. She contacted the Agency's hearing health department to ask for information on their services. Lynn received pamphlets and brochures that covered the range of services that the organization offers. Lynn elected to enroll in their speechreading course to improve her pre-existing skills. She participated in this course for seven months. During her attendance, she met deaf people who used sign language. She befriended a few of these individuals, and began learning some rudimentary signs to speak with them. Eventually, Lynn elected to enroll in a sign language course to improve her use and comprehension of this language. She attended sign language courses for two years. Her husband also enrolled in these courses.

Lynn was one of two deaf people enrolled in the sign language course. Most attendees were hearing. The other deaf person was also a deafened adult. This individual led a peer-run self-help group once a week. The group was comprised of deafened adults who were trying to cope with hearing loss. Aside from the leader's fundamental training at conducting self-help groups, there were no rehabilitation professionals involved in these meetings. Lynn began attending self-help sessions and continued until the group disbanded. Although the duration of attendance in self-help

was less than one year, Lynn said that she “*was very comfortable with them...it was always fun to go to self-help.*”

After the incident of discrimination at work, Lynn believed that deafness made her less forthcoming about her feelings. In response, she enrolled in assertiveness training sponsored by her employer. Afterwards, she felt less hesitant about asking for accommodations. Ironically, a discrimination charge made by another employee led to a restructuring of management roles. Another individual took over Lynn’s department. The new department head promoted the respondent into management. Lynn received support and guidance from her superior while adjusting to this new role. “*The new senior manager was very, very supportive...I don’t know if she had any reservations about putting me in a manager’s position, but she supported me in everything I did. Always!*”

Lynn also coped with deafness by networking with other disabled people. This network was comprised of people of a variety of disabilities and had a goal of gaining more accommodations from the employer. They discussed their individual needs and human rights issues. A few of the people in the network were also deafened adults. Lynn did not feel comfortable with these individuals because they “*seemed like they were still in denial.. They lip-read all the time...speaking with them was too exhausting.*”

#### **4.1.5.7 Reflections and Recommendations**

The respondent's post-deafness life is as active as it was before the onset. She does volunteer work for a non-profit agency and is an active member of her church. She also presents workshops on acquired deafness and communication strategies to firms in the public and private sectors.

Lynn becomes frustrated at being deaf sometimes, but not with any particular issue. An accumulation of small irritants makes her wish that she was still a hearing person. She would like to use a cell phone or spend a night out at the movies with her family without depending on others to translate the story line. Regardless, Lynn said her overall quality of life is good.

Lynn's primary route to coping with her deafness was teaching others about acquiring a hearing loss. Presenting workshops and otherwise talking about the phenomenon carried her beyond the denial stage. *"Talking about it...getting people to understand that deaf people are pretty normal helped."*

Another factor that helped facilitated coping was support from others. This includes her husband, parents, and colleagues. One individual that Lynn credits most of all is her senior manager at the hospital. The respondent speaks highly of this individual *"because of the amount of support that she gave me. I think that this was sort of a big thing in helping me cope professionally."*

Lynn did not offer gratitude to the rehabilitation professionals that she encountered. She said they *“didn’t do me much good. They had kind of an attitude...there was no empathy.”* In view of this deficiency, Lynn recommends establishing an information source for deafened people trying to cope with deafness. *“I think if perhaps there had been somebody to say ‘look, these are all the things available. There’s a self-help group; there’s speechreading classes; there’s sign language classes’, but there wasn’t. I had to find them myself.”*

#### **4.1.6 Marie**

##### **4.1.6.1 Identifying Information**

Respondent number six is a Caucasian female in her late forties. Marie became deaf during her late thirties due to surgery to alleviate the symptoms of severe Menière’s Disease. The cochlea and semi-circular canals of both ears were removed through translabyrinthine surgery. She has been deafened for nine years.

Marie reported her speechreading comprehension level as high and her sign language comprehension level as medium. In one-on-one settings, she can comprehend spoken speech without difficulties, but has problems when multiple speakers are present. In group settings, she is unable to understand verbal dialogue unless assisted by an oral interpreter. Marie’s deafness is absolute. She is unable to use a hearing aid and is not eligible for cochlear implantation due to the surgery.

The respondent is employed by a community-based organization. She specializes in advocacy for disabled persons, and has a high level of contact with the public in her role. She participates in public forums on accessibility and presents seminars about the needs of disabled people. Before entering this occupation, she was a manager for a local retail business. She spends her personal time volunteering at her local parish. Her highest level of education is a high school diploma.

Marie married two decades before becoming deaf, and has one grown child. She lives in the rural northern Ontario town where she was raised. She described her spouse and child as being close and supportive of her activities. She seldom sees her mother; her father is deceased. Other adult family members are not as close, and only marginally supportive. Regardless, she has regular contact with all family members, and states they “*are still the centre of the universe to me.*”

#### **4.1.6.2 Pre-morbid Life**

Marie was an amateur musician before becoming deaf. She played guitar, and was a member of a band for 15 years. When she was not performing, she frequented concerts and recitals. Her pre-deafness life was filled with volunteerism as well. She was a member of the local church auxiliary, the library board, the local legion, and the chair of the palliative board. “*I loved life, loved to be involved in the community.*” The respondent had no prior contact with deaf people before the onset of deafness.

#### **4.1.6.3 Onset of Deafness**

The respondent's hearing loss began with an episode of mild vertigo. Within a brief period of time, tinnitus followed. It was clear that Marie had acquired Menière's Disease. Because this condition is incurable, Marie's physician instructed her on vertigo management strategies. Three months later, the vertigo and tinnitus increased to physically debilitating levels. She also experienced a painful fullness of the cranial cavity, projectile vomiting, and rapid loss of weight. Her doctor prescribed an intense pharmaceutical regimen to lessen the impact of the symptoms. This treatment included consuming up to twenty pills each day and intravenously administered morphine to control pain. Eventually, the physician recommended surgery to end the respondent's suffering. Marie's condition was becoming life threatening.

The surgery caused other disabilities to accompany deafness. Because the procedure removed the respondent's semicircular canals, Marie was unable to walk or sit. She had severe disequilibrium, and needed a wheelchair for mobility. Marie also experienced facial deformity and speech disabilities as well. The surgery also caused blindness in one eye.

The depth of Marie's deafness crystallized as she woke from surgery. Although the ENT informed Marie, through her husband, about the procedure's consequences, she expected deafness to silence external sounds only. She did not realize that she would be unable to hear her own voice. *"I just assumed that I*

wouldn't hear anyone else...I thought, 'Oh God, they never told me that I wouldn't hear myself speak!'". Only after the surgery for Menière's symptoms did she realize the full consequences.

#### **4.1.6.4 Impact of Becoming Deaf**

The depth of the silence traumatized Marie. She became terrified at her inability to hear her own voice. She denied that it was a permanent condition. *"I told myself it'll come back tomorrow. Just go to sleep, and this day will be over with. All will be well again tomorrow."* Her hearing did not return the next morning. *"I burst into crying because no matter what, I wouldn't hear music again."*

The respondent spent the first two years of rehabilitation in emotional isolation. She was unable to leave the house, and was dependent on others. She could not speak or walk. The respondent even required others to spoon feed her at mealtimes. Her social life consisted of participation in physical therapy. She saw no other people besides medical staff and family members. In the home, she was constantly left out of conversations. A few tried to keep her involved in family discussions, but these attempts were short lived. The dialogue was too rapid for them to offer her meaningful participation. Furthermore, Marie could not share her feelings with anyone in the family. They only offered support to address Marie's physical disabilities and seemed unable to understand her emotional pain. *"They all seemed defensive about the hearing part, and yet, if I needed help to go to the bathroom, they*

*all jumped and panicked.*” Moreover, the respondent’s feelings were minimized when her mother bluntly told her that, *“deafness is your problem. We all can hear you just fine. You have to learn how to lip-read better.”* Marie felt she was not free to share feelings because her family seemed not to acknowledge the existence of deafness. Feeling rebuked made deafness more isolating and frightening. *“I felt so unimportant to them.”*

After she regained partial mobility using a walker, the respondent was struck by a vehicle on her first excursion out of doors. (The driver protested that he had sounded the horn.) A fear for personal safety led to seclusion at home. Furthermore, while recovering from this incident, Marie became fearful of meeting new people.

#### **4.1.6.5 Rehabilitation Experiences**

Marie’s rehabilitation included physiotherapy and orthopedic care. The physiotherapist rehabilitated the range of motion in Marie’s head and neck muscles, and the orthopedic therapist taught her how to walk again. The respondent received physiotherapy daily for two weeks and orthopedic rehabilitation for the eight weeks of her stay in the hospital. After being discharged, Marie attended orthopedic rehabilitation, as an outpatient, three times a week for six months. During this period, she underwent additional surgery to correct facial drooping around her blind eye. While Marie participated in this regimen, she asked the attending therapists about rehabilitation for hearing loss. They told her that hearing rehabilitation would be

impractical. *“There would be nothing at all. The ears were totally destroyed, and a big gaping hole is left where the inner ear is located. So, hearing aids or a cochlear implant would not restore my hearing.”*

#### **4.1.6.6 Coping Strategies**

With a sibling’s help, Marie called the Agency’s head office to inquire about their services. She learned of this organization by “word of mouth.” The person answering her call stated that they could not offer services to her because she lived outside their catchment area. When Marie asked for the contact information for their local branch office, the representative stated that there were no Agency offices near her home. The representative told her that *“there are no counsellors available for people who live outside Toronto.”* Marie’s call was not transferred to a hearing health counsellor. *“We never made it past the first desk!”* The respondent wrote to the executive director about her experience, but his response did not offer any resolutions. The letter apologized for not being able to help, but *“we do not have the resources to offer services to people outside our catchment area.”*

To gain independence, the respondent purchased a few adaptive items. This included a hearing guide dog, a TTY, a television closed caption decoder, and visual signaling devices. She also took an assertiveness training workshop offered at the local library. This helped her to become aware of her boundaries. She set limits on how much responsibility she assumed during conversations, and began encouraging

others to cooperate with her needs. Marie began carrying paper and pen to assist speaking with people that she found it difficult to understand.

At one point, a minister introduced Marie to a deaf couple that lived in a city nearby. This couple taught sign language to hearing people. To improve her communication skills, Marie lived with this deaf couple for a period of six weeks. During this time, she completed eight courses in sign language.

The respondent found that talking about deafness help reduce emotional pain. She began speaking about deafness in various community forums. Marie volunteered to sit on a municipal committee to examine local accessibility issues. She also was invited to classrooms to talk about deafness and hearing loss at the local schools.

*“Talking about it [deafness] is therapeutic.”*

#### **4.1.6.7 Reflections and Recommendations**

Although the cost of relief from severe Menière’s Disease was high, Marie believes that she made the right choice. She regained the active life that she lost to its debilitating symptoms, albeit with modifications. She attributes beneficial coping to deafness (and her other disabilities) to her optimism and will to live—her spirit. Without her will to live, Marie believes that she would not have survived becoming deaf.

The respondent did not express dissatisfaction with her rehabilitation other than that her family members were ill prepared to deal with hearing loss. *“The family*

*became so overwhelmed at times, that they forgot about my feelings.” She believes that the rehabilitation professionals “should have told them about how I would feel inside. Not only the physical part, but what’s inside the heart...I think they should have been told that I would cry.”*

Marie also believes that the deafness rehabilitative system ought to have deafened counsellors available to help newly deafened people cope. She says that a *“hearing counsellor might be great, but they have not been there and don’t know the pain we feel.”*

The respondent’s final recommendation to rehabilitation services is that a network of deafened adults should be maintained to provide support for new deafened adults. She says that a peer mentor group of deafened people can offer empathy to deafened people coping with the condition. She says that *“they have walked in your shoes, and can offer a morale boost.”* Marie believes that only other deafened people empathize and show a newly deafened person that *“friends and laughter are still there...they too will laugh again.”*

#### **4.1.7 Jeffrey**

##### **4.1.7.1 Identifying Information**

Respondent number seven is a Caucasian male who is a senior citizen. Jeffrey became deaf as a consequence of surgery to treat Acoustic Neuroma. Benign tumors grew on his auditory nerves and removal was necessary to prevent further growth. The

procedure caused extensive damage to his auditory and facial nerves. Jeffrey has been deaf for nine years.

Jeffrey assessed his speechreading comprehension level as medium and his sign language comprehension level as low. The respondent stated that he can understand very little spoken conversation. He relies exclusively on his spouse to translate for him and stated: *“wherever I go, she goes with me.”* Jeffrey carries a pen and paper to assist communication when his wife is unable to accompany him. Without either, verbal communication is all but impossible. A hearing aid is of no use to Jeffrey.

Before retiring, the respondent was employed for 36 years, as an inspector for a vehicle manufacturing company. This was his only employer. His highest level of education is a high school diploma.

Jeffrey is married and has one grown son. He is a life-long resident of a large city in southern Ontario. He described his life as one filled with loneliness. His social life is limited to attending speechreading training sessions and staying home with his spouse. He stated: *“that’s about it. I mean, there is no social life.”* He lamented that he is unable to engage in simple forms of conversations such as perfunctory greetings. *“You would like to greet people with ‘oh, hi!’ but I cannot even do that...I can’t!”*

The respondent’s days are basically spent surfing the Internet and communicating with his friends though email or in chat rooms. When he is off-line, Jeffrey occupies

himself by reading. Once a week, the respondent attends speech therapy at the Agency. He also exercises twice a week at a local gym. Jeffrey said that he seldom does anything else because deafness intrudes in every aspect of his life—even special events. On one occasion, Jeffrey and his wife attended a concert in which his son was a featured solo organist. He described attending his son’s illustrious moment as a painful experience for himself. He said that after his son had played, *“Everyone came up and shook his hand. I could not. I couldn’t hear him play...it broke my heart.”*

#### **4.1.7.2 Pre-morbid Life**

This respondent’s pre-deafness life was the opposite of his present one. He described himself as a social person. He was an amateur vocalist. He sang in operas, choirs and at parties. He also participated in casual team sports. Jeffrey was a veteran member of his bowling league. He socialized during workouts at his health club at least three times a week.

Jeffrey had prior contact with deaf people. This was with two co-workers. Instead of interacting with these individuals, he stated that he kept them at a distance. *“I would say ‘hi,’ but avoid them...I would do that.”*

#### **4.1.7.3 Onset of Deafness**

Tinnitus marked the beginning of Jeffrey’s hearing loss. When he was in his late forties, he noticed a constant ringing in his ears. After a neurological exam, the cause was diagnosed as a spontaneous occurrence of Acoustic Neuroma. Jeffrey’s

physician recommended surgery to remove the tumors, but Jeffrey postponed this procedure for thirteen years. He preferred to reach retirement age before undergoing a major surgery. Despite the delay, Jeffrey stated the tinnitus was manageable and he did not notice a reduction in hearing. Upon retiring, the respondent finally consented to the retrosigmoid surgery (partial removal of the vestibular nerve). The ENT recommended this approach because it does less damage than the translabyrinthine procedure, and the respondent's hearing might remain intact. With the tumors removed, however, Jeffrey became deaf.

Besides hearing loss, the respondent experienced other complications. He acquired a mild visual disability and some facial disfigurement. His visual problems consist of insufficient ocular moisture. Jeffrey must use an eye dropper to administer a saline solution regularly. The facial disfigurement causes a moderate difficulty in producing words. People tend to have difficulty understanding his speech.

#### **4.1.7.4 Impact of Becoming Deaf**

Jeffrey's deafness caused a loss of friends. He said that surgery forced him to retire earlier than he expected. His co-workers were the people that he socialized with during his off hours. The few friends who remained in contact began to avoid him when they realized that he could not hear. He said that trying to talk to a deaf person made them feel awkward during visits. The discomfort was mutual. He was not the

same person after the surgery and no longer had a rapport with these people. Thus, he withdrew from social interaction with his pre-deafened friends.

Jeffrey said that deafness changed his perspective of himself. *“The silence...made me a different person!”* He believes that he is a burden to his wife. The respondent relies on his wife to manage household business, handle his incoming and outgoing telephone calls, and act as his “interpreter” whenever they leave home. *“Instead of doing things on my own, I give her more work.”* Jeffrey finds that deafness is an intolerable condition. He said that deafness brings more suffering than capital punishment. *“Let me put it this way, take the criminal’s hearing away rather than put them to death, and you will see the prison they get.”* The respondent sees only an empty future. He stated: *“I know tomorrow I’ll be deaf. The day after, I’ll be deaf. So, there’s not much future.”*

#### **4.1.7.5 Rehabilitation Experiences**

When the tinnitus began in 1977, Jeffrey reported it to his family doctor. The physician referred him to an ENT for a hearing examination. The respondent did not show a hearing loss in his audiogram. As a precaution, the ENT referred the respondent to a neurologist to determine the cause of the ringing. The neurologist diagnosed it as a spontaneous occurrence of Acoustic Neuroma. He had a benign tumor on the auditory nerve that was one centimeter in diameter. The neurologist recommended its removal, but because it was not life threatening, Jeffrey declined

surgery. By 1990, the tinnitus grew in intensity and removal of the tumour was necessary. The respondent retired, and consented to the procedure.

Despite post-surgical therapy, Jeffrey did not receive rehabilitation for hearing loss. The ENT referred him to a physiotherapist for head and neck rehabilitation and to a speech therapist to help relearn how to speak. For hearing loss, the ENT took a “wait and see” approach. Jeffrey was told that his hearing might return after three to four months—if at all. The respondent was discharged from the hospital two weeks later, and attended physiotherapy as an outpatient. His hearing did not return and he received no further treatment from the ENT.

The respondent received a referral to the Agency for speech therapy from the hospital speech therapist. He has attended oral/speech therapy at the Agency once a week for the last six years.

#### **4.1.7.6 Coping Strategies**

Jeffrey does not use adaptive technology devices at home. He is seldom home alone and relies on others to interpret the environment. His wife handles all family business and acts as his interpreter. *“When I need to go to the doctor, she does all the talking, and when we get home, she writes everything down for me.”*

While he has attended speech therapy for six years, Jeffrey has not learned sign language. He said that he is *“surrounded by hearing people.”* He has not considered learning sign language because he does not meet with people that speak it.

*“I have no use for it...it’s useless to me.”* He said this despite confessing that his wife attended sign language courses for about a year.

Jeffrey’s wife also investigated other coping strategies as well. She contacted the Agency and learned of a self-help group for deafened adults. At her encouragement, Jeffrey attended a session, but withdrew from it. He felt discomfort being among other deafened people because they were much younger and they spoke in sign language during the sessions. After this experience, Jeffrey refused to attend any other functions involving deafened people. One of these events was a convention sponsored by the Association of Late-Deafened Adults (U.S.A.). *“They (ALDA) held a convention right here in the city. I didn’t go...I said ‘what for?’.”*

Jeffrey had more obstacles to cope with than just deafness and a speech impairment. He suffered a series of serious illnesses in the span of four years. Two years after the surgery, Jeffrey was diagnosed with cancer. (He did not disclose its nature.) He underwent chemotherapy and radiology until the cancer went into remission. While recovering from this disease, Jeffrey suffered a cardiac arrest. While he was in the hospital recovering from the heart attack, he contracted spinal meningitis. He spent two weeks in a coma before his prospect for recovery improved. Despite surviving several life-threatening illnesses, Jeffrey’s outlook remained unchanged. *“After I went through all this, meningitis, the heart attack, the cancer,*

*everything was not as bad as the deafness...it's the worst thing that I have ever faced."*

One coping strategy that Jeffrey uses is conversing with people through the Internet. He has a large network of friends on-line. He frequents the chat rooms of several Internet service providers. Most of the people that the respondent converses with are hearing, but he said that he has three deafened friends on-line. Their favorite topic of discussion is being a deafened senior citizen.

The respondent also attends meetings of an Acoustic Neuroma organization. At one meeting, Jeffrey met an ENT (#2) who performs cochlear implants. ENT #2 suggested that Jeffrey undergo the cochlear implant candidacy evaluation. The respondent has completed a few of the initial tests to determine if the procedure can offer help.

#### **4.1.7.7 Reflections and Recommendations**

Jeffrey still considers himself a hearing person. For him, deafness is too foreign to accept. *"It is very difficult to accept it; you have to be born deaf. I cannot."* He says that his age makes it hard for him to adapt to a new life style. *"I was 62 years old (at the onset of deafness). The older you get, the harder it is to adjust to something new."* Jeffrey believes that his future is bleak, and only a cochlear implant may help. *"In an [cochlear] implant, I have hope."*

The respondent is moderately satisfied with the rehabilitation services that he received. Jeffrey's only complaint is that his progress has not been faster. He finds that others still have a hard time understanding his speech and his speechreading skills are not adequate to permit more social interaction. The recommendation that Jeffrey offered was that ENTs, speech therapists, and audiologists ought to know all the community resources available and refer deafened people to the Agency after they are diagnosed with hearing loss.

#### **4.1.8 Luc**

##### **4.1.8.1 Identifying Information**

Respondent number eight is a Caucasian male in his early thirties. The onset of deafness has not yet occurred. Luc sustained a moderate, but rapid, loss of hearing while hospitalized for a severe case of influenza. His physician suspected that this illness may have weakened Luc's resistance to an opportunistic virus that attacked his auditory nerve. He was in his late twenties at the onset of hearing loss. Luc has been hard of hearing for two years.

Luc reported his speechreading comprehension level as medium. He has not learned sign language or considered attempting to acquire this skill. He uses a hearing aid to support speechreading, and considers his hearing loss almost unnoticeable during one-on-one conversations. In group settings, though, he experiences a high level of stress. Luc finds multiple speakers difficult to lip-read.

The respondent is presently employed as a marketing representative. He has a bachelor's degree in kinesiology, and has been employed as a marketing representative for the past two years. The respondent's job requires meeting new people each day to make sales, as well as nurturing his relationship with the existing clients. This taxes his speechreading skills such that, by the end of his work day, Luc is physically drained and mentally "*exhausted.*" Despite the obstacles, he finds his job challenging. The respondent wonders how long he can remain in this occupation. He relies exclusively on oral communication and future deafness is "*always in the back of my mind.*"

Luc is married and has two small children. He is a life-long resident of a medium size city in western Ontario. He stated that he is close to his family, and has many close friendships. The respondent communicates well with his wife under most circumstances. Only when the children are playing nearby does he find it difficult to understand her. Conversations at the dinner table are the most problematic. He finds he is unable to hold a conversation because the clatter of the children eating overwhelms his ability to hear. At dinner time, Luc's wife tends to speak more to the children than with him.

The respondent stated that his relationship with his children has "*all the good elements of a healthy one.*" Their relationship is more physical than conversational. He prefers to wrestle, play games, and read books to them because "*young lips are*

*often unreadable.*” He says that he tries to speak with one child at a time because “*it’s impossible to hold a conversation with both at once.*”

#### **4.1.8.2 Pre-morbid Life**

Prior to hearing loss, the respondent described himself as an athletic individual. He played in organized hockey and other team sports. Professionally, Luc was a self-employed business owner in the construction business. Construction, however, was not his primary career preference, and dissatisfaction with this led him to explore other career options just before the onset of hearing loss.

The respondent’s only prior contact with deafness is with an aged relative. This person’s hearing loss was due to presbycusis acquired at the age of 75 years. Luc confessed to feeling apprehensive while speaking with this relative, but recalls that he did not pity him.

#### **4.1.8.3 Onset of Deafness**

While Luc was confined to the hospital to receive treatment for the flu, his hearing took an unanticipated decline. He was able to hear one day, but not the next. Within five days, he recovered some hearing in one ear. This left him with a moderate hearing loss in the left ear and a profound monaural deafness on the right.

The attending physicians diagnosed the cause of the deterioration based on symptomatic evidence. Luc’s hearing did not experience a linear decline. It, instead, fluctuated on a daily basis. He reported his hearing alternated daily between “*hearing*

*one day, but not the next.*” Furthermore, the respondent experienced a loss of equilibrium and Motion Induced Ocular Vibrations (MIOV). The respondent found it difficult to balance himself while walking. He often lost his balance and fell. When he could remain upright, he was unable to hold a steady gaze in motion. His vision vibrated with each step. Although the vibrations were physically minute, they forced Luc to move slowly when he walked. This permitted his vision to focus on the direction of travel.

Even though the respondent is not yet deaf, he has only a limited range of hearing. He cannot comprehend people who speak outside his line of vision or farther than a few feet away. He is unable to communicate orally on the telephone with unassisted hearing.

#### **4.1.8.4 Impact of Becoming Deaf**

Luc has experienced anxiety and periodic sadness over his loss of hearing. As his hearing fluctuated between high and low hearing cycles, his emotional state followed suit. With each waking day, Luc did not know if he could hear that day or if it would be spent in silence. If he discovered that he could hear, his outlook was good. He was despondent on the days that he could not hear. This was a traumatic period for him. Furthermore, Luc found living with this auditory instability isolating. On his “good” days, it was difficult to converse with others; on his “bad” days, he withdrew from all interaction.

Hearing loss forced Luc to change careers. Home construction often requires walking in elevated places. Moreover, a construction site is active with moving machinery. Luc felt at risk of injury. He was afraid of falling off a scaffold because of his balance problems or being stuck from behind by a vehicle he couldn't hear. The respondent grew concerned for his future. He felt that his occupational and financial outlook were uncertain. He was reluctant to change employment, fearing that his residual hearing would take a sudden turn for the worse and cause job loss, but after a few months, he accepted a job offer with a marketing firm. Despite a salary that is three times more than he earned in construction, he has a lingering fear that deafness will cause financial ruin. *"I feel the need to tighten up the belt, save up enough money, as insurance against deafness."* Luc's financial concern causes occasional marital friction when his wife purchases anything but essential items.

Luc's family was also affected. He has difficulty communicating with his wife when the children are around. The noise that the children make while at play interferes with their conversations. His wife must repeat herself several times before he can understand her. It is not unusual for them to suspend discussions until the children are in bed. Luc stated that this inability to converse is frustrating and makes him feel isolated. The respondent is dependent on his wife to handle simple tasks. While vacationing, for example, the respondent lets his wife check them in at hotels.

He claims that it is easier for her to do it, and this reduces the risk of embarrassment should he encounter communication difficulties.

The respondent described large family gatherings as stressful events. He understands less than 60 percent of the dialogue that occurs. Background noise interferes with his hearing. Furthermore, the pace of discussion goes faster than he can follow with speechreading. Compounding this are rapid changes in the topic. This makes dialogue a confusing string of chatter. Being unable to understand makes him feel disconnected with the event. *“I sit there watching all these little conversations that I didn’t hear...I couldn’t focus...I couldn’t concentrate.”*

#### **4.1.8.5 Rehabilitation Experiences**

The respondent was examined by an ENT after he reported an inability to hear. He underwent a series of hearing tests to determine the nature of the loss. Audiograms were taken on a daily basis for a week. This verified the hearing level fluctuations, but did not reveal a cause. The ENT observed that the secondary symptoms (loss of equilibrium and MIOV) indicated that Luc’s hearing loss was due to viral infection, but this diagnosis was not based on conclusive evidence. The ENT chose not to do a biopsy because the harm outweighed the benefits. Instead, the respondent was placed on a pharmaceutical regime to control the fluctuations.

The respondent received these anabolic steroid injections in the ear twice a week. The treatment began one week before being discharged from the hospital and

continued for a period of one year as an outpatient. The ENT wanted to control, not restore, his hearing loss. After six months, Luc's hearing stabilized at a level that permitted him to comprehend others through oral communication. He still experiences minor fluctuations, but his hearing level remains consistent at monaural deafness. The ENT recommended a "wait and see" approach. Nine months into treatment, the amplitude of fluctuation was no longer reducing. One year after the onset of hearing loss, the injection treatments ended. The ENT offered no prediction on the stability of Luc's hearing. The respondent no longer receives care from this specialist.

Luc was referred to the hospital audiologist. He was fitted with hearing aids and received training in communication strategies to enhance their use. This audiologist, coincidentally, also had a hearing impairment. The respondent stated that they communicated well despite both using oral communication. The audiologist's ability to function "normally" impressed him.

Shortly before Luc was discharged from the hospital, a hearing health counsellor from the Agency came to visit him. She offered him training with several assistive technology devices and information on hearing loss and deafness resources. Among the adaptive equipment were a TTY, a vibratory alarm clock, and a few visual signal devices. This contact was initiated by the hospital. The respondent welcomed the training, but declined the offer of a trial loan of the devices. The Agency

representative gave the respondent brochures on hearing health care. A hearing health counsellor made one follow-up home visit approximately one year later, but none since. His only other contact with the Agency is through the organization's periodic newsletters.

Three months after the onset of hearing loss, Luc elected to seek a second opinion. He asked the hospital ENT for a referral to another otolaryngologist. ENT #1 obliged, and the respondent was examined by ENT #2. This specialist referred Luc to audiologist #2 for an assessment of his hearing level. The results showed no further decline. Luc purchased a second, less visible, set of hearing aids from Audiologist #2. Interestingly, like the first audiologist, the second also had a hearing loss, and he too relied on oral communication while speaking. Luc has infrequent contact with this service provider that basically involves hearing aid maintenance.

#### **4.1.8.6 Coping Strategies**

Luc has not enrolled in a sign language course. He does not believe that it is necessary for him to acquire this skill because he does not know other deaf people.

To enhance his oral communication skills, Luc practices environmental control. He positions himself in areas that offer him an unobstructed view of the speaker's lips. He often forewarns others of his communicative needs, and does not hesitate to assert those needs when not accommodated. *"I'm bold enough to say 'Hey I'm sitting here [in the front row], somebody else is going to sit in the back!'"*

Luc avoids all unnecessary social functions that involve large groups. This strategy reduces having to make many new acquaintances at once. When he cannot avoid large social functions, he relies on his wife to translate group conversation while positioning himself to engage in discussions on the side.

The respondent does not use a TTY. He can converse on the telephone “fairly well” with his hearing aid, but only with conventional telephone sets. He does not attempt placing calls from a public phone or on a cell phone. The former usually exist in environments with a high level of background noise. The latter involves technology that is incompatible with his hearing aid. Luc does not use adaptive equipment at home. He relies on the family pet (dog) to warn of visitors at the door. “*The dog is more effective and persistent than a flashing light.*” He also does not use closed-captioning while watching television programs. He usually sits close to the television set and adjusts his hearing aid’s volume to suit.

Luc sought to understand his hearing loss through unconventional explanations. He and his wife once believed that the fluctuations were linked to lunar cycles. They thought that atmospheric pressure caused his hearing level to rise and fall. “*It was difficult for me to hear on a full moon.*” So, they tried to plot the moon in conjunction to the crests and valleys of his hearing. No real pattern emerged from this.

Luc also tried meditation to stabilize his hearing. When the meditation did not improve his hearing, the respondent sought help from a homeopath practitioner. He

consumed sulfur tablets diluted in water. “*That was supposed to alter my chemistry slightly.*” Luc participated in the treatment for six months, and terminated it when he did not benefit from it.

#### **4.1.8.7 Reflections and Recommendations**

Overall, Luc is satisfied with his rehabilitation. He said that the rehabilitation professionals offered important information that helped him adjust to hearing loss.

Yet, he wishes that he was introduced to a deafened peer mentor. Such a person would be able to offer him tips on coping. He believes that “*talking with someone who walked in the same shoes before*” would have made his transition less traumatic. Luc said that it would be difficult to arrange this type of rehabilitation service because his type of hearing loss is “rare.” His not being offered such a service does not diminish his respect for the professionals that he did encounter.

In the event that his hearing deteriorates into deafness, Luc stated that he would not hesitate to apply for cochlear implant candidacy. Although he believes that becoming deaf will be traumatic, Luc is confident that all his family and friends will learn sign language to speak with him.

## **4.2 Common Themes**

The life stories of the people in the sample are unique, yet analysis reveals several common themes in their collective experience of profound hearing loss. These commonalities emerge in relation to the negative impact that deafness had on the

respondents and their social arena, the care that they received from the hearing loss rehabilitation professionals, and the strategies that they used to cope with deafness. A description of the themes follows, below.

#### **4.2.1 Negative Emotional Impact**

The respondents reported experiencing distinct negative affective states in response to the onset of and ongoing coping with profound hearing loss, which included anxiety, grief, fear, and anger. Anxiety and grief were the prevalent emotions that affected all in the sample. Each respondent had episodes of anxiety-provoking emotions such as periods of distress, inadequacy and self-doubt. Similarly, all respondents experienced sadness and grief related to the actual loss or an inability to function as a hearing person. Six respondents reported that becoming deaf caused fear for personal safety, bewilderment over the surrounding circumstances, or a perceived insecurity about the future. Many respondents also reported episodes of anger. Although only one respondent (Jeffrey) reported feeling direct anger at being deaf, four others described becoming angry at one point or another. This anger stemmed from incidents in which deafness was a central issue, such as being furious or irritated at an inability to function “normally.” Other affective states such as embarrassment and shame were also reported. Overall, the consistency in the reported negative impact make it apparent that becoming deaf is an emotionally stressing experience for those who are directly affected by it.

## **4.2.2 Negative Social Impact**

The participants discussed three basic issues with regard to how family members and other people in their social network responded negatively to their deafness. First, they talked about how their families adopted different approaches to acceptance of, and persistence with sign language. Secondly, they described different types of negative treatment that they were subjected to by significant others. Third, the participants talked about their responses to the negative treatment by others.

### **4.2.2.1 Lack of Sign Language Acquisition by Family Members**

Only two family units (Chantal & Elvis) learned and used sign language. Two family units (Lynn & Marie) learned and abandoned the use of sign language, and three family units (Kristy, Victor, & Luc) did not learn sign language. One family unit (Jeffrey) was split with the spouse learning sign language but abandoning its use because the deafened person chose not to learn. One respondent (Victor) was unable to learn sign language, due to a visual disability. Overall, five of seven families (family of origin and/or marital family) of the participants who were able to learn sign language, relied on oral communication to speak with their deafened relative. (Although Jeffrey & Luc elected themselves to reject learning a manual communication method.)

#### 4.2.2.2 Negative Treatment Received from Family or Others

Respondents’ descriptions of negative treatment from others can be classified under five distinct types of negative behaviours (see Table 2). Each had a detrimental impact on the respondents’ ability to function socially in their family units. Not all of these behaviours were present throughout the respondents’ adjustment periods. Some emerged at the onset of deafness while others occurred later in life. Also, it should be acknowledged that some respondents (Kristy, Elvis, Victor & Luc) were lucky enough to have supportive responses from some members of their social networks (see “Coping” for discussion on this).

**Table 2: Negative Social Treatments from Family/Friends**

<b>Behaviour</b>	<b>Description</b>
<b>Discrimination:</b>	Being denied opportunities and/or social participation by others because of hearing loss.
<b>Frustration/anger:</b>	An increase of friction in the respondent’s interpersonal relationships that are directly or indirectly attributable to hearing loss.
<b>Diminution:</b>	The magnitude of hearing loss or related feelings being minimized by the respondents’ families and/or others.
<b>Neglect/exclusion:</b>	The act of not addressing the communicative needs which inhibit the deafened person’s social interaction.
<b>Oppression:</b>	An intentional act of exerting control over the respondent by limiting his or her access to information or social functioning.

The most prevalent negative treatment was social neglect and exclusion by family members or others. All of the respondents reported that they had been excluded from social participation because their communication needs were neglected or ignored by family members. Diminution of the magnitude of deafness was felt by

five (Kristy, Chantal, Elvis, Lynn, & Marie) of eight respondents. Their family members either minimized the severity of hearing loss and/or the impact of deafness on the deafened person's emotional well-being. The same five respondents reported that they experienced overt discrimination by others. The efforts, by three of these individuals (Kristy, Chantal, & Marie) to develop optimal communication to compensate for hearing loss were circumvented by the actions of others. The other two respondents (Elvis & Lynn) were victims of prejudice and intentional exclusion from social interaction (i.e., shunning and harassment by classmates) and opportunities for professional growth (i.e., underemployment). Four (Kristy, Chantal, Marie & Luc) of eight respondents reported others responding to their hearing loss with frustration and anger. Two individuals (Chantal & Luc) stated that the frequency of quarrels with their spouses increased after the onset of hearing loss. For the other two respondents (Kristy & Marie), the squabbles were more frequent with members of the maternal family. Apparently, the majority of the sample had experienced negative social treatment from family members that may not have otherwise received as hearing people. This suggests that the families of the respondents experienced difficulties adapting to profound hearing loss.

#### **4.2.2.3 Participants' Responses to Negative Social Treatment**

The respondents described various ways in which they responded to the negative social treatment that they received from others. Table 3 describes the four

main negative behavioural responses and classifies them according to the goals of stress reduction or assimilation.

**Table 3: Participants’ Behavioural Responses to Negative Social**

**Treatment**

<b>Goal</b>	<b>Behavior</b>	<b>Description</b>
<b>Stress Reduction</b>	<b>Avoidance:</b>	Limiting contact with certain people or situations to minimize interaction with anxiety-provoking people or situations.
	<b>Withdrawal:</b>	Disengagement from social contact to avoid anxiety-provoking situations.
<b>Assimilation</b>	<b>Concealment:</b>	Hiding deafness from individuals, usually strangers, who are unaware of the respondent’s hearing loss.
	<b>Bluffing:</b>	Concealing an inability to understand dialogue from individuals who know of the respondent’s hearing loss.

All of the respondents reported avoiding uncomfortable social situations or limiting contact with specific people. For some (Victor, Marie, and Jeffrey), an outright seclusion from social contact occurred. Fewer participants (Kristy, Chantal, and Elvis) used the assimilation behaviours of concealment and bluffing. The consistent theme in the sample’s responses to negative social treatment was evasive action, which may be viewed as a defensive strategies. They chose to reduce the impact of unpleasant interaction with others by avoiding certain situations or people. For example, one respondent (Luc) avoided social gatherings while other respondents (Kristy, Elvis, Victor, and Lynn) avoided certain types of people.

## 4.2.3 Rehabilitation

### 4.2.3.1 The Role of Medicine and Stages of Treatment

As would be expected with any physical condition or illness, the respondents first sought medical attention when symptoms of a disorder first emerged. Table 4 shows the distribution of the respondents' contact with health care professionals. Altogether, the eight respondents consulted 36 health care providers. Of all the health care practitioners consulted, 33 (91%) were trained medical professionals while three (9%) had paraprofessional training. The health care professionals were comprised of 13 family physicians, 10 ENTs, 8 audiologists, 2 neurologists, and 2 paramedics. The three other professionals included a hearing aid dispenser without training in audiology, an occupational therapist, and a military hearing examiner who may have only received training to operate an audiometer for hearing screening.

**Table 4: Health Care Professionals by Role**

Respondent	Physician	ENT	Neurologist	Audiologist	Other	
Kristy	3	1		1	1	Note <sup>1</sup>
Chantal	3	3		3		
Elvis	2	2		1		
Victor	1	1	1		1	Note <sup>2</sup>
Lynn	1	1		1	1	Note <sup>3</sup>
Marie	1	1				
Jeffrey	1		1			
Luc	1	1		2		
Total	13	10	2	8	3	

Note 1. Hearing aid dispenser.

Note 2. Occupational therapist.

Note 3. Military examiner.

Table 5 describes the stages of interface with the health care professionals, their referrals to services, and the treatment that the respondents received for deafness rehabilitation. As we can see, linear patterns emerge in the care that was offered to the respondents. These patterns—referred to as rehabilitative processes—are related to the number of stages between interface and termination, the type of health care professionals seen, and the type of treatment that was provided, but not the quality or intensity of the service that the respondents received. The lowest number of rehabilitative processes for a respondent was one; most experienced three processes. Furthermore, each process occurred at different periods in the respondent's life. For example, the rehabilitative processes of the two who received cochlear implants occurred several years after the process that preceded it.

Stage one primarily consisted of initial intake, assessment of the condition, and referral to a second practitioner. All but one of the initial contacts involved being examined by a general practitioner. The single stage one health care provider who was not a physician was a military paramedic who was trained (at least) to operate an audiometer.

In the second stage, all but one of the respondents' consultations were assessments and referrals to health care professionals in the next stage. The breakdown of service providers in this stage included 13 ENT specialists, one

neurologist, and one hearing aid dispenser (who was not an audiologist). The sole non-referral (Lynn) represented a termination of the rehabilitation processes.

Stage three consisted of 18 contacts that consisted of 12 referrals to medical practitioners, five treatments and one termination. Of the referrals, one went unconsummated at the respondent's discretion. The remaining were distributed among eight audiologists, two neurologists, one ENT physician, and one hearing health counsellor. The five treatments that were provided included one hearing aids prescription, one cochlear implantation, two surgeries, and one pharmaceutical regime.

This was followed by a treatment-laden fourth stage. Here, the respondents received a total of nine treatments that included two surgeries (on one individual), one hearing aid prescription, one cochlear implantation, one recommendation for annual audiograms, and one provision of hearing loss resource information. The single referral (Luc) that was made in this stage was to an audiologist. Two rehabilitation processes (Kristy and Chantal) were terminated at this stage because no treatment could remedy the respondents' hearing loss.

Only one respondent's rehabilitative process continued to a fifth stage. This consisted of a single treatment plan, which was the confirmation of a previous audiologist's recommendations by conducting a second audiogram.

**Table 5: The Rehabilitative Processes**  
(Treatments are represented in shaded boxes.)

Informant	Stage one	Stage two	Stage three	Stage Four	Stage Five
<b>Kristy</b>	Physician	Hearing aid dispenser	<b>Hearing aids</b>		
	Physician	ENT	Audiologist	None <sup>1</sup>	
	Physician	ENT	<b>Cochlear Implant</b>	<b>Audiograms</b>	
<b>Chantal</b>	Physician	ENT	Audiologist	None <sup>2</sup>	
	Physician	ENT	Audiologist	<b>Hearing aids</b>	
	Physician	ENT	Audiologist	<b>Cochlear Implant</b>	
<b>Elvis</b>	Physician	ENT	Audiologist <sup>3</sup>		
	Physician	ENT	Audiologist	<b>Hearing aids</b>	
<b>Victor</b>	Physician	ENT	Neurologist	<b>Surgery</b>	
	Physician	ENT	Neurologist	<b>Surgery</b>	
<b>Lynn</b>	Military Examiner	None <sup>4</sup>			
	Physician	ENT	None <sup>5</sup>		
	Physician	ENT	Audiologist	<b>Hearing aids</b>	
<b>Marie</b>	Physician	ENT	<b>Surgery</b>		
<b>Jeffrey</b>	Physician	Neurologist	<b>Surgery</b>		
<b>Luc</b>	Physician	ENT	<b>Steroid treatment</b>		
			Audiologist	<b>Hearing aids</b>	
			Hearing Health Resource		
			Counsellor	Information	
			ENT	Audiologist	Second opinion

Note 1. Cochlear implant candidacy rejected

Note 2 Misdiagnosis.

Note 3. Referral not used by respondent.

Note 4. Faulty audiogram assessment.

Note 5. ENT assumed respondent would reject hearing aid use.

#### 4.2.3.2 The Agency’s Role

Seven of eight respondents had some form of contact with the Agency at one time or another. Of these individuals, the Agency provided information services to six respondents (Chantal, Elvis, Victor, Lynn, Jeffrey and Luc), device sales to four (Chantal, Elvis, Victor, and Lynn) sign language instruction to two (Chantal and Lynn), and speechreading instruction to two (Elvis and Lynn). One respondent (Luc) received hearing health counselling and one respondent (Jeffrey) received speech therapy. It is particularly noteworthy that no respondents received family or relationship systems counselling. One individual (Marie) requested help from the Agency but was refused due to geographic concerns. The Agency is considered to serve that area but advised the respondent that it could not do so. These services can be compared against the model program of deafened services that the Agency portrays as its standard of care (Frayn, 1998) (Table 6).

**Table 6: Agency Recommended Standard vs. Care Received**

Service standard	Kristy	Chantal	Elvis	Victor	Lynn	Marie	Jeffrey	Luc
Information provision		◆	◆	◆	◆		◆	◆
Device sales		◆	◆	◆	◆			
Sign language instruction		◆			◆			
Speech reading instruction			◆		◆			
Hearing health counselling								◆
Speech therapy							◆	
Family counselling								

#### **4.2.3.3 Satisfaction with Services**

Five (Kristy, Chantal, Elvis, Lynn and Marie) of eight respondents expressed dissatisfaction with the care that they received. Of the dissatisfied, one respondent (Kristy) expressed satisfaction only with the cochlear implantation team while other cited various other reasons for their displeasure. These reasons ranged from professional incompetence (Elvis and Lynn) to generalized inadequacy in the health care professionals' training (Chantal and Marie). Although two respondents (Victor and Jeffrey) reported that they were satisfied with the work of their professionals, only one (Jeffrey) stated that he was satisfied with the service that he received with the Agency. One respondent (Luc) expressed neither satisfaction or dissatisfaction with his single rehabilitative process. As a whole, the results suggest that the rehabilitation that was offered to the study participants was inadequate.

#### **4.2.4 Coping Strategies**

The respondents employed a wide range of coping strategies to help them adapt to profound hearing loss. The strategies can be classified as either person-centred or interaction-centred. Person-centred approaches include those that do not require collaboration from others to implement on a day-to-day basis. This includes attending speechreading and sign language classes, using adaptive technology devices, and reading or talking about deafness. Also included is the use of trained hearing guide dogs (which was not categorized under adaptive “devices,” to respect

the life and intelligence of the dogs). Interaction-centred approaches are those which help the individuals *and their significant others* to manage interpersonal relationships: learning how to cope with negative behaviors through membership in self-help groups, developing interpersonal boundaries by enrollment in assertiveness training, and negotiation of communication issues from participation in family or group counselling.

#### **4.2.4.1 Person-centred Coping Strategies**

Table 7 shows the distribution of person-centred coping strategies among the six strategies reported by the sample. Among approaches used by at least half of the sample, six of eight respondents enrolled in speechreading courses, five purchased adaptive technology equipment, four enrolled in sign language courses, and four reviewed literature on deafness. Two approaches were used by fewer than three respondents. These were talking about deafness with others (two respondents) and purchasing a hearing guide dog (one respondent). Two respondents did not report to using person-centred coping strategies at all. The person-centred strategies helped the respondents regain some measure of social functioning. For example, speechreading courses brought some initial help understanding verbally spoken dialogue. Purchasing adaptive technology devices provided the respondents visual (television closed caption decoder) or tactile cues (vibratory alarm clock) to replace the auditory cues that they lost. Although the study participants reported using person-centred coping

strategies, they did not point out any single approach that could facilitate coping with deafness independent of other approaches. The only exception is the one respondent (Elvis) who stated that studying and writing about deafness was his “*catharsis*.”

**Table 7: Person-centred Coping**

Approach	Kristy	Chantal	Elvis	Victor	Lynn	Marie	Jeffrey	Luc
Speech reading instruction		◆	◆	◆	◆	◆		◆
Uses adaptive devices		◆	◆	◆	◆	◆		
Reading about deafness		◆	◆		◆	◆		
Sign language instruction		◆	◆		◆	◆		
Talking about deafness					◆	◆		
Uses hearing guide dog						◆		

**4.2.4.2 Interaction-centred Coping Strategies**

The distribution of the interaction-centred approaches used by the sample is shown in Table 8. Of these approaches, four respondents used self-help, two individuals attended assertiveness training, while only one respondent participated in family/group counselling. Interaction-centred coping facilitated the respondents’ coping with deafness by helping these individuals learn how to negotiate relationships. Two (Chantal and Lynn) of the respondents who attended peer-run self-help groups made comments pertaining to feeling of “comfort” in attendance. The respondents (Lynn and Marie) who enrolled in assertiveness training reported increased self-confidence and boundary definition as a result. The single respondent (Victor) who received family/group counselling expressed a high level of satisfaction

with the support that he received from the occupational therapist and his family members.

**Table 8: Interaction-centred Coping**

Approach	Kristy	Chantal	Elvis	Victor	Lynn	Marie	Jeffrey	Luc
Self-help		◆	◆	◆	◆			
Assertiveness training					◆	◆		
Family/group counselling				◆				

## 5. Discussion

The reported impact of adventitious hearing loss and deafness on the emotional and psychological well-being of the respondents is consistent with the results of previous studies. Episodes of anxiety, fear, sadness, and anger were consistently reported. Although each affective state was felt in various intensities by different respondents, it is obvious that acquiring this type of disability significantly disrupts personal well-being. Also consistent with existing literature were the reported responses to social anxiety. All of the respondents experienced social withdrawal and selective social avoidance to minimize the frequency of anxiety provoking situations that they encountered. The lower incidence of denial and concealment of hearing loss (only three of the eight individuals in this sample reported that they had actively sought to hide deafness from others) was somewhat surprising. It may not be coincidence that three of the four individuals with progressive hearing losses used

denial and concealment. Progressive loss is harder to detect subjectively. These respondents also became deaf more than two decades ago. Thus, differential use of denial and concealment may be attributed to social acceptability and/or progressive versus sudden hearing losses.

As has been reported in prior studies (e.g., Medows-Orlans, 1985), communicative needs of the deafened adults were often neglected by family members. All eight experienced communication difficulties in the family. Five of the eight reported that this neglect was rooted in familial denial of the condition. The magnitude of hearing loss was minimized or ignored outright, as was the deafened individual's feelings toward it. This diminution inhibited the family unit from developing optimal communication between the hearing members and the deafened one. For five respondents, this situation was the result of simple inattention to the communicative needs. This neglect occurred whether or not the family members were aware of the deafened individual's need for their cooperation with communicative barriers. The deafened person's communication needs were simply forgotten by others.

Sign language was not a common solution. Attempts to include the deafened individuals in family conversations were ineffective even when sign language was introduced to a family. Interaction typically moved at a pace that made it difficult for a single person to translate. Despite a few genuine attempts to include the deafened

member in the family discussions by a signing family member, the assisting relative's personal interest in the conversation prevailed over the deafened member's communication needs. Regardless of the reason for breakdown, the deafened people became mere spectators, instead of participants, to family affairs.

To a lesser degree, family members sometimes took advantage of the deafened person's deafness to oppress them, and remove their choices about how to cope. In one example (Kristy), the deafened person's family encouraged her to conceal hearing loss while she took steps to eradicate the hereditary trait through adoption. This confirmed her acceptance of the subservient status in society accorded to her and her deaf relatives. In the second example (Marie), a hearing family stymied the deafened individual's attempt at familial accommodation of her communicative needs by stating "*it's your problem. We all can hear you just fine.*" This conveyed that the family would not accept any change in their roles or behaviours, oppressing the development of a deaf alternative way. In a third example (Chantal), the spouse of the deafened individual communicated only on his terms (usually shouting). Although it was ineffective communication, it also confused, frightened and encouraged a sense of helplessness that delayed the emancipation of the abused wife. In all three cases, this family behavior increased the isolation of the deafened individual and prevented or retarded beneficial coping with deafness. By refusing to communicate about communication, they predetermined that the deafened person would continue to

interact with them in the old way, on their terms. This is consistent with the traditional definition of oppression which describes that language control is one technique used by an oppressor, such as an occupying force, to control the oppressed population (Freire, 1972).

Adventitious deafness warrants therapeutic counselling for dysfunctional communication issues. Seven of eight respondents reported increased stress in their familial relationships. A deafened person can only use sign language in a family that also learns this communication method and does not abandon it. All eight respondents reported being excluded from interaction, five of eight reported diminution of their disability, five of eight experienced some form of discrimination, and four of eight reported that they experienced increased disharmony in the relationships as a consequence of interaction with others. This pattern suggests that communication choices were not made by the deafened family member.

The exception to this pattern was the single respondent (Victor) who reported that the family was a primary source of support that facilitated his coping with deafness. This individual was also the only person that received counselling (provided by the occupational therapist) that addressed relationship systems, and involved the other parties. Separate meetings with work colleagues and family members were convened to negotiate new communication modes and relationship frameworks. This respondent also reported higher satisfaction with his overall rehabilitation process—

particularly with the work of this occupational therapist. Significantly, this relationship systems counselling was fortuitous, not arranged by the traditional rehabilitative sector. Instead, this service was provided by an employer as part of a return-to-work strategy intended to address the challenges of the respondent's coexisting physical disabilities!

Although the other respondents did not receive relationship systems counselling with the families or colleagues, all seven made contact with the Agency—an organization that claims to serve deafened people. Six received an assortment of services (a request for service by the seventh was rejected outright) including speechreading classes, sign language classes, speech therapy, technical device sales, and hearing health counselling, but none received family counselling. The Agency's own publication (Frayn, 1998) included family counselling among the most important interventions provided to deafened people. Hearing health counselling and speechreading training often *instructs* the individual to request others to make changes during one-on-one conversations (i.e., make eye-to-eye contact), but it is left to the learner to negotiate their relationships to achieve these changes. As we have seen, the relationships reported by the respondents are unequal in power, and to the disadvantage of the deafened person. The likelihood of the effectiveness of renegotiation of relationships and communication is minimal if left to the traumatized, oppressed deafened person alone. The role of counselling in guiding this

process—as done so effectively by the occupational therapist for Victor—is to convince the family that the status quo is not an option and to support the otherwise diminished deafened person to equalize the power relationships in the renegotiation process.

The Agency had opportunity to offer family/relationship counselling to seven of the eight individuals of the sample. Six of these individuals initiated contact with this organization at one time or another, but the most common service consisted of providing information on Agency services (notably hearing health counselling). Most hearing health training programs fail to aid coping with deafness because these strategies are designed to enhance the use of residual hearing: use of hearing aid features and peripherals, reducing background noise, and so forth. Four respondents purchased technical devices from the Agency, three respondents attended oral communication training, and two attended sign language classes.

The common theme among all of the respondents who had contact with the Agency—even for the three who were employed by the organization—is that family/relationship systems counselling (which the Agency has recommended as a standard of care for deafened people) did not materialize. The medical, and vocational rehabilitation community is apparently unaware of this fact, since no viable competition for the Agency's services has emerged. Although the Agency does not in fact serve the area near Marie, the perception that it does is likely a factor in the lack

of alternatives in her community. The perception that the adjustment needs of the deafened population are being fulfilled through the Agency is possibly the greatest damage done, in that it inhibits development of the services needed.

Although the model deafened-care program published by the Agency is individual-centred, with the client articulating treatment goals that involve resolving the particular family's issues (Frayn, 1998), Victor was the only respondent who received any rehabilitation that was not program-centred, and he was also the only respondent who reported no contact with the Agency.

The omission of counselling services for deafened individuals seems very unusual. Reliance on medical/individual focussed rehabilitation occurred despite the fact that counselling in general has been utilized for many other conditions that are prevalent in society. Since the 1950s, society has witnessed the growth of family and group counselling for disorders in interpersonal relationships but deafened people do not receive counselling for their family/relationship systems. Even when they accessed relationship counselling for another problem (i.e., occupational, vocational, or marital problems), as in the case of all but one respondent, the therapy did not address the issue of deafness. It focussed on the problems most salient to the professional's own training without investigating the potential impact that deafness may have on the problem. To fill this void, some respondents participated in peer-run self help groups. Self-help benefits participants by enabling them to feel normal

among others in similar situations. The experience may diffuse anger, fear, and sadness, and perhaps build self-confidence or assertiveness; however, it is not appropriate for all individuals, such as those with severe problems and those with inadequate boundaries. People experiencing severe dysfunction in the home may need professional help to restore an equilibrium before being ready for self-help.

There is clearly a lack of understanding about adult onset deafness among service providers. Medical intervention, although a natural first step towards rehabilitative care, was continued beyond the point of where such strategies were likely to be effective. The reliance on hearing aid use, as demonstrated by the pathway of referrals, suggests medical professionals' misunderstanding of the prognosis and holistic needs of deafened people. For example, the common approach (not including the two cases that involved misdiagnoses) to medical treatment began with the physician, who referred the individual to an ENT, and then to an audiologist to receive hearing aids. In the cases where deafness was absolute, no referrals to deafness rehabilitation were made.

It is evident that program-centred interventions distract from social needs of deafened clients. The multiplicity of client focussed interventions consume energy and attention while distracting attention from family/relationship issues. Except for Victor and the support that he received from the occupational therapist, the locus of rehabilitation services was the individual. Treatments such as hearing aids/cochlear

implantation, speech therapy, speechreading/sign language classes, and technical device acquisition involve only the deafened person and the service/device provider. The chief advantage of these individual-centred therapies is that training can be essentially preprogrammed. This is also a disadvantage, because such individual-centred therapies may not meet the social needs of the individual. This script was consistent throughout the 15 rehabilitation processes—and 31 professionals—that these eight individuals pursued.

Deafened peoples' main unmet needs are for professional intervention to equalize the power imbalance that exists between the deafened person and hearing family members, and to mediate and assist in renegotiating communication and relationships in the family (or with other significant others). This is the essence of the ideal model described by the Agency (Frayn, 1998) and is borne out by Victor's experience.

What seems to be forgotten in the pursuit to provide a “cure” is that adventitious deafness is not only a medical condition, but also a social phenomenon. Social interventions are required when deafness and hearing loss are diagnosed—especially if the individual's hearing loss is irreversible, as was the case for all eight respondents. This seemed especially significant for the three respondents for whom surgeons controlled the exact month, date, and hour that the patient would become deaf. This oversight was reflected in the satisfaction levels of the sample. Five

respondents spoke critically of the treatment that they received by medical professionals. These individuals described their rehabilitation as inadequate with complaints ranging from lack of research (“*They didn’t have a lot of information*”) to ignorance of the holistic impact (“*they forgot about my feelings*”), and finally, to an outright lack of compassion (“*They should have been the authorities, but they didn’t try...they didn’t care*”).

## **6. Conclusion**

Within varying individual competencies, the professionals in each aspect of the respondents' rehabilitation performed as they were trained to do. In the medical arena, general practitioners made preliminary evaluations and referred the respondents to the appropriate specialist. These professionals, either an ENT or a neurologist, applied a treatment that seemed most appropriate for the service that they offered and passed the respondents to an audiologist and/or a rehabilitation professional. These service providers offered the type of therapy that was consistent with the value system of their practice. For audiologists, rehabilitation for aural communication was provided. For vocational rehabilitation counsellors, strategies for academic and occupational gain were the fundamental bases of the intervention. In the case of hearing health counselling, services more appropriate for a population with mild to moderate hearing losses were offered. Individually, each of these practitioners might

have provided an adequate level of service within their specialty. Unfortunately, addressing relationship dysfunction fell outside the limits of their practice. This became apparent when all six respondents who were dissatisfied with their rehabilitation stated that counselling, peer support groups, and comprehensive information should have been part of their rehabilitation processes.

These results support Luey's (1980, 1994) call for social workers to become involved in rehabilitation for adventitious deafness. Any type of acquired disability involves a multitude of difficult changes for the affected person and his or her family. The onset of deafness marks the beginning of a transition from being a hearing person to a deaf one. Such a change involves a fundamental shift in personal identity and this impacts all members of the immediate family. As we have seen in the life stories of the respondents in this study, adaptation to such changes is not smooth or painless. Social workers, as change agents, are trained to work within the relationship systems of families to support adaptation during transitions. In the case of adventitious deafness, social workers could fulfill many functions.

First, a social worker could offer grief counselling to the affected individual. Such counselling could help the deafened adult to work through emotional reactions to the loss and to develop coping strategies to gain a sense of control. Second, the social worker who works in the deafness rehabilitation field could link the deafened person to peer support to normalize the condition and reduce the social isolation that

can occur. Third, a social worker should attempt to engage the family of the deafened person in counselling to help them deal with the emotional and practical impacts and to prevent the familial neglect or oppression of the deafened person that was experienced by many of this study's participants. In acting as a mediator during family counselling sessions, the social worker could bring important issues, such as adapting to new communication and familial roles, into the open and help the family problem-solve around issues. Fourth, social workers should act as brokers to needed resources and information for the deafened individual and the family. This should also include mediating and advocating with professionals in the medical and audiological fields, and with the place of employment of the deafened individual.

The case of Victor in this study demonstrates the potential effectiveness of such an holistic approach to intervention. Ironically, this rehabilitation professional was an occupational therapist with no experience with deaf people. Nonetheless, she assembled an effective "social work" type of treatment plan. The approach also resembled what the Agency has described as their standard of care for deafened adults (although this was not provided by the Agency to any of the people in the sample).

Although social workers could fill existing gaps in the treatment of adventitious deafness, the involvement of medical professionals cannot be ignored. This is because medical attention is the usual first step towards receiving help for adventitious deafness. Medical health care professionals should help lead the

deafened individual towards appropriate rehabilitation by including referrals to social workers in their treatment plans. Toward this end, social workers should be included in interdisciplinary teams that diagnose and treat deafness.

Because there is little information on the impact of adventitious deafness on the individual and his or her family, further research on this topic is imperative.

Adventitious deafness must be examined from the ecological perspective in social work research. Specific questions that warrant attention are:

- a) How does adventitious deafness affect the members of the families of deafened individuals;
- b) How does the impact of deafness vary according to the various family life stages; and
- c) What types of shifting in power balances occurs among family relationships when one of the members becomes deaf, and how does it vary with the family role and gender of the deafened person?

These types of studies must be conducted so that the caring professions (i.e., physicians, ENTs, neurologists, audiologists, social workers, etc.) will be able to identify the missing pieces of the rehabilitation puzzle for deafened adults. Otherwise

they will continue to be at a loss for a consistent standard of care for this condition,  
and perpetuate social exclusion of deafened people.

## **7. Appendices**

### **7.1 Appendix 1: Mailed materials**

Letter: Request to participate

Survey consent form

Demographic questionnaire

Note. Documents have been reformatted for inclusion in the thesis, with respect to spacing and type size, and thus do not appear exactly as issued.

### **7.2 Appendix 2: Interview materials**

Proposed interview guide

Letter: Consent to interview

**Letter: Request to participate**

<Respondent's name>

<Address>

<City>, ON, <Postal code>

<Date>

Dear <Respondent's name>

I am a deafened researcher and Master of Social Work candidate in the Faculty of Social Work at Wilfrid Laurier University. I am conducting a study into the impact of hearing loss and the rehabilitation process of post-vocationally deafened people. The purpose of this study is to understand and document the experiences of people who become deaf.

I am looking for deafened people who are interested in participating in the study. I understand that you used to receive the *Blue Jay Bulletin* that was distributed to deafened people in the Province of Ontario; The former editor suggested that you might enjoy participating in this study. The selection of individuals selected for an interview will be based on the answers that they provide to demographic questions found in the attached survey. The main criteria for selecting individuals will be to achieve diversity within the study sample with regard to cause of deafness, gender, age, and so forth.

Participants will have the opportunity to meet with me to be interviewed about their experiences with deafness and the rehabilitative care that they received. Generally, the interviews will follow a chronological order of events beginning at the point of hearing loss and progressing to the present in order to acquire an understanding of the benefits and shortcomings of the deafness rehabilitation service for individuals who become deaf after childhood. Communication between the investigator and the interviewee will be assisted with the use of Computer Assisted Real-Time (CART) translations to minimize the need for a high level of sign language and/or lip reading skills.

If you wish to participate in this study, please complete and return the survey and the consent form in the self-addressed stamped envelope that is included with this letter. Returning the completed questionnaire does not guarantee that I will ask you for an interview, nor does it obligate you to participate should you receive an offer to be interviewed. Furthermore, a survey that is returned blank or partially completed will not eliminate you from the pool of interview candidates if you sign and return the consent form.

By participating in this project, you will help me produce valuable research in the area of rehabilitation for adventitious deafness. Furthermore, recommendations about the types of rehabilitation that you believe will be beneficial to deafened people will be solicited as well. Any information that you give is strictly confidential. I will

detach your name form all other responses that you give to me and report all the results anonymously. Participation or refusal to participate in this study will have no effect on any rehabilitation services that you are presently receiving.

Individuals who return a signed consent form will be contacted within 30 days and informed of whether or not they are invited to participate in the interview portion of this study. If you choose to return the questionnaire, I would appreciate your response by <date>, in order that I can contact you by the end of <month> to discuss an interview, if needed.

If you have any questions about this study, please feel free to call me or my research supervisor. Our numbers are listed below. We will return your call as soon as possible.

Thank you,

Miguel Aguayo

Researcher:

Miguel O. Aguayo

4-79 Westmount North

Waterloo, ON Canada N2L 5G5

(519) 746-4226 TTY/FAX

Research Supervisor:

Dr. Nick Coady

884-1970 ext. 2666

## **Survey consent form**

### **Consent for Interview Candidacy**

If you wish to participate in this study, please read, sign, and return this consent form.

Next, to assist interview participant selection, please complete the questionnaire and return it with the consent form. Completing the survey is voluntary. You are not required to offer this information as a condition for interview candidacy.

For your convenience, a self-addressed stamped envelope is enclosed in this packet.

I, \_\_\_\_\_, understand that I am being asked to participate in a research study which is being conducted by Miguel Aguayo, a Master of Social Work candidate in the Faculty of Social Work at Wilfrid Laurier University, under the supervision of his research advisor, Nick Coady.

The purpose of this study is to explore the impact of profound hearing loss and the adequacy of rehabilitative process that deafened people receive. The information that is collected will be used to better understand the experiences of people whom become post-lingually deafened.

My participation at this stage is limited to the collection of personal demographic data that will be used to select interview candidates. I understand that my contribution may result in an offer to be interviewed, but I am not obligated to

accept such an offer. I also understand that I am not obligated to provide this information to be eligible for an interview. The act of returning this signed consent form retains my candidacy to participate in the interview stage of this study.

The following are benefits that I may derive from this study, if selected to participate:

I can learn more about research in social work. I can gain an understanding of the effects of profound hearing loss as experienced by other deafened people, and the rehabilitative process that they received. I also will become familiar with alternate methods of visual display of interpersonal dialogue as a form of interpreting/translations tool. I may feel satisfaction by offering a beneficial contribution to improve deafness rehabilitation services.

*I understand that my participation is voluntary. I may refuse to participate in this study without penalty to me. I may also withdraw from the study at any time without penalty.*

I understand that my research record will be kept confidential and that I will not be identified in any publication or discussion by the investigator.

I understand that I have a right to have all questions about the study answered by the researcher or the research advisor in sufficient detail to clearly understand the answer.

*If I have any other questions about the research, the procedures employed, my rights or any other research-related questions, I may contact the investigator or research supervisor at the numbers that are listed below.*

Researcher:

Research Supervisor:

Miguel O. Aguayo

Dr. Nick Coady

(519) 746-4226 TTY/FAX

(519) 884-1970 ext. 2666

I understand that I will be contacted by telephone/TTY within 30 days and informed of whether or not I will be offered an opportunity to be interviewed for the study.

Name \_\_\_\_\_

Date \_\_\_\_\_

Phone \_\_\_\_\_

Please check:    Voice    TTY    FAX

Best time to call \_\_\_\_\_A.M. \_\_\_\_\_P.M.

### Demographic questionnaire

Voluntary Information: Answer some, none, or all of the following.

Refusal to answer any questions will not influence your interview candidacy.

Name: \_\_\_\_\_

Gender (M/F) \_\_\_\_\_

#### Cause of deafness:

Disease (e.g., spinal meningitis, virus, unknown)

Medical procedure (e.g., antibiotic reaction, acoustic neuromas, NF-2)

Traumatic (e.g., head injury)

Progressive (e.g., hereditary, noise, aging, unknown without illness)

Please list any specific circumstances related to your hearing loss:

\_\_\_\_\_

Date of birth: \_\_\_\_\_ Age at the onset of deafness: \_\_\_\_\_

#### Family situation (check one in each column):

##### Marital status:

Single

Married

Separated

Divorced

Re-married

##### Living situation:

Live alone

Live with other adult(s) only

Live with children

Live with children and adult(s)

Live with grown children

Any other relevant information about your family situation?:

**Occupation:**

If you are currently working, or in the past, what is your occupational field?

---

**Lip-reading and sign language use self-assessment:**

Please mark a point on the line that best indicates your skill level:

**Lip-reading skills:**

**Sign language skills:**

I-----I-----I

I-----I-----I

awful

fair

great

awful

fair

great

**Please list any special accommodations that you would need if chosen for an**

**interview:**

---

### **Proposed interview guide**

I'd like to begin by asking you about your life before your hearing loss.

I understand that you lost (or began to lose) your hearing when you were about \_\_\_\_ years old. Can you describe what your life was like before you lost your hearing?

Can you describe your family life, ... social life, ... work (or school life)?

How satisfied were you with your family, work (or school), and social life?

Can you describe your relationships with family members/friends/colleagues (e.g., number and quality of personal relationships, extent of social support)?

Can you describe some of the social and leisure activities that you derived enjoyment from?

Have you experienced a personal crisis or traumatic loss before your lost your hearing?

If yes:

Please describe this crisis?

When did it occur?

Please describe how it affected your life?

How did it affect your relationship with family members/friends/colleagues (e.g., number and quality of personal relationships, extent of social support)?

Do you feel that you have recovered from this crisis?

If no:

What was the most serious problem in your life before you lost your hearing?

Please describe how it affected your life?

How did it affect your relationship with family members/friends/colleagues (e.g., number and quality of personal relationships, extent of social support)?

Can you describe the cause and process of your hearing loss and your reactions to it?

How severe was the hearing loss at the beginning?

What were your first thoughts and feelings when you noticed deafness/hearing loss or the first time?

Would you characterize these thoughts and feelings as coming from the heart or the head? Can you explain this?

Can you describe any progression in the hearing loss and its impact on you?

How did your family/friends feel about and react to your deafness?

What were the actions that led you to believe that your deafness affected them this way?

Is this something that they said and/or did?

Can you recall their exact words or any specific incidents?

Can you describe what types of changes took place in your close relationships as a result of your deafness?

What was the impact of these changes on you?

What was the impact of these changes on the others?

How did your family and friends help or hinder your coping with the hearing loss?

If help was offered:

Please describe how they helped and the impact on you.

What did they do to help you adjust to it?

How often did they help?

Did the help remain consistent?

Did it diminish over a period time?

If help was not offered:

What was the impact of this on you?

How do you account for this lack of help?

If others hindered coping:

Please describe how their reactions hindered your coping?

How did this impact on you?

How do you understand such reactions?

Please describe how deafness influenced changes in your social life in general.

What types of changes took place (changes in activities, etc.)

How did you feel about these changes then? Now?

Were lost activities substituted by another activity? If so, please describe.

What facilitated your involvement in these activities?

How have these new activities been helpful?

Were there aspects of your social life (e.g., activities) that did not change as a result of the deafness?

Does this activity (activities) rely more on vision or hearing?

Has your participation diminished or remained the same?

Any problems in participating in this/these pastime(s) come to mind?

Describe what helped you to remain engaged in these activities.

Did you know any deaf people before you lost your hearing?

If yes:

How did you feel about them?

What lead you to feel this way?

Did knowing deaf people help or hinder your coping with deafness?

If no:

What were your thoughts about deaf people before you lost your hearing?

Has your thoughts towards deaf people changed since you lost your hearing?

If yes, describe the nature of this change.

Did you try to meet other deaf people?

If yes, describe your experiences (frequency of engagement; difficulty of interaction).

In what ways did your hearing loss affect your employment (or student) status--in the beginning and then later?

Please describe any changes in your functioning on the job (or at school).

Please describe the reactions of coworkers and/or supervisors, bosses (or teachers and fellow students).

Were any accommodations offered to you by your employer (or school)?

How did you feel about these accommodations (being offered/not being offered)?

What accommodations have been offered to you in subsequent employment (or education)?

How have felt about these accommodations (being offered/not being offered)?

10. Describe what types of rehabilitation services have been offered to you or that you have sought out over the course of your deafness?

Were any services offered to you when you first became aware of your deafness?

If so:

What type of services were these?

Who offered them?

Did you try these services?

When did you begin treatment?

How often did you utilize this/these service(s)?

Describe what occurred during the/these sessions.

How did you feel about this/these services?

How satisfied were you with this/these service(s)?

What leads you to say that they were helpful/harmful/neither?

Would you recommend this/these service(s) to others in a similar situation?

What leads to you recommend this/these service(s) to others?

What rehabilitative services have you been involved with since?

Were these services offered by someone (is so, who) or did you seek them out?

How often did you utilize this/these service(s)?

Describe what occurred during the/these sessions.

How did you feel about this/these services?

How satisfied were you with this/these service(s)?

What leads you to say that they were helpful/harmful/neither?

Would you recommend this/these service(s) to others in a similar situation?

What leads to you recommend this/these service(s) to others?

Describe the types of rehabilitation specialists/professionals that have been responsible for your care.

How helpful or unhelpful were each of these types of professionals and in what ways?

How confident and comfortable did you feel in the care of “X”? Why?

Please describe how involved your family/friends were in your rehabilitation?

How did you feel about their involvement or lack of involvement?

Describe what you feel was the most beneficial thing that they did to help.

Describe anything they said or did that may have inhibited your rehabilitation.

Overall, how satisfied are you with the rehabilitation services that you received.

What additional services could have been offered to improve the care that you received.

What services do you believe should be offered to improve rehabilitative care for deafened people?

What other factors helped or hindered your coping with deafness (individual strengths, social supports, societal attitudes)?

Have your thoughts and feelings about deafness changed over time?

If so, how are they different now than when the loss happened?

If different:

When and how did this change occur?

Did it help or hinder your coping with deafness?

Please describe the events/experiences that may have led to this change of attitude.

If the same:

Why do you believe that your feelings towards deafness have not changed?

Please describe how this helped or hindered your ability to cope with deafness?

Describe what you would change if you could (personal reactions and coping strategies, informal support from others, societal attitudes).

Is there anything else that you would like to add to help others understand the impact of hearing loss and the adequacy (or lack thereof) of rehabilitative services that you received?

Thank you very much for sharing your experience.

**Letter: Consent to interview**

I, \_\_\_\_\_, understand that I am being asked to participate in a research study which is being conducted by Miguel Aguayo, a Master of Social Work candidate in the Faculty of Social Work at Wilfrid Laurier University, under the supervision of his research advisor, Dr. Nick Coady.

The purpose of this study is to examine and record the impact of profound hearing loss and the adequacy of rehabilitative care that deafened people receive. The data collected will be used to better understand the experiences of people whom become post-lingually deafened. Data will be collected through individual interview sessions. General questions that will be posed during this interview will be related to the individuals experience of deafness, and the responses of family members, peers, and the deafness rehabilitation professionals. The interview will be approximately 90-120 minutes long.

The following are benefits that I may derive from this study:

I can learn more about research in social work. I can gain an understanding of the rehabilitative process as experienced by other deafened people. I will become familiar with alternate methods of visual display of interpersonal dialogue as a form of interpreting/translations tool. I may feel satisfaction by offering a beneficial contribution to the field of deafness rehabilitation.

*I understand that my participation is voluntary. I may refuse to participate in this study without penalty to me. I may also withdraw from the study at any time (before and during the interview) without penalty.*

I understand that my research record will be kept confidential and that I will not be identified in any publication or discussion by either the investigator or the CART stenographer.

I understand that I am free to contact the investigator at the telephone number listed below if I have any questions.

I understand that I have a right to have all questions about the study answered by the researcher or the research advisor in sufficient detail to clearly understand the answer.

I understand that I can receive feedback on the overall results of this study by requesting it from the researcher; this information will be made available at the conclusion of this study. I understand that a copy of the entire study will be available in the Wilfrid Laurier University library and at the main office of the Canadian Hearing Society.

*If I have any other questions about the research, the procedures employed, my rights or any other research-related questions, I may contact the investigator or research advisor.*

I acknowledge reading and understanding this consent form, and I agree to participate in the study.

Respondent \_\_\_\_\_ Date \_\_\_\_\_

Researcher \_\_\_\_\_ Date \_\_\_\_\_

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