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Using Phenomenology and Action Research to Assist Adults with Hearing Impairment to Achieve Positive Life Outcomes

PhD

James Cook University

March 8, 2006

Thesis submitted in fulfillment of the requirements

for the Degree of Doctor of Philosophy

at James Cook University

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Declaration of Ethics

The research presented and reported in this thesis was conducted within the guidelines for research ethics outlined in the National Statement on Ethics Conduct in Research Involving Human (1999), the Joint NHMRC/AVCC Statement and Guidelines on Research Practice (1997), the James Cook University Policy on Experimentation Ethics. Standard Practices and Guidelines (2001) and the James Cook University Statement and Guidelines on Research Practice (2001). The proposed research methodology received clearance from the James Cook University Experimentation Ethics Review Committee (approval number H1351).

March 8, 2006

Name **Date**

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Abstract

Progressive hearing impairment in adulthood is often accompanied by debilitating psychosocial problems including major disruptions to a person's ability to communicate orally. This research describes the story of how phenomenology and action research are employed in more visual ways with adults with degenerative hearing impairment in an attempt to enable them to accomplish more acceptable life outcomes. Descriptive analysis, in the form of dialogic, introspective and retrospective phenomenology, is used to capture a deep understanding of the pertinent life experiences of eight individuals who are hard of hearing. Individual action research case studies are then conducted with two members of the original sample. Information obtained from the descriptive analysis enables participants to identify a specific challenge to address in order to achieve a positive life outcome. The phenomenology-action research approach was found to be both suitable and effective for all individuals engaged in this study, particularly for those who completed the action research process. It is, therefore, recommended that further research and development be conducted into the collaborative use of this approach in which the rehabilitation professional works in close co-operation with the individual experiencing progressive hearing impairment to achieve more empowering and self-affirming life goals.

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CHAPTER 1. RESEARCH FOCUS

Introduction

Progressive hearing impairment in adulthood is now being recognised worldwide as a burgeoning issue which causes major psychosocial disruptions to an individual's ability to communicate orally (Stenross, 1999; Stone, 1987; Trychin, 1991; Trychin, 1997; 1997a; Trychin & Busacco, 1991). The literature highlights the concern that there is an alarming lack of awareness regarding these issues, both for the many individuals with progressive hearing impairment and for the professionals who work with them. Furthermore, the impact of hearing impairment is experienced not only by the individual affected by it, but also by family members, particularly spouses and children, as well as friends and co-workers. More concerning is the claim that the majority of professionals often have a limited understanding of the very needs of the people they are trying to help, those individuals with hearing impairment (Clelland, 1995; Hill & Nelson, 2000).

Chapter 1 begins with a definition of key terms relating to this study. This is followed by a description of the background of the study, which provides the reader with an idea of the magnitude of the issues relating to progressive hearing impairment in adulthood. Details of the research are then outlined in the research statement, research focus, purpose, importance, assumptions, and scope and limitations. The two methodologies to be used in this study are introduced to demonstrate the flow from the phenomenological investigation and gathering of data to the use of this information in the action research process for the purpose of assisting candidates to achieve personal goals. The skills which participants may learn during the action research phase will not be limited to application with the particular challenge they address. Instead, it is expected that

the value of this approach will expand and include applications in many other life challenges.

Definitions

Finding appropriate definitions to describe the terms “hearing impairment” and “hard of hearing” in this study has been complicated. Wood (1987) points out how the terms used in relation to hearing impairment become blurred in the literature. This suggests a need for further work to be carried out in order to broaden the understanding of the impact that hearing impairment can have on individuals and their relationships, especially in adulthood.

Hearing impairment “exists on a continuum of severity from mild (common) to profound (rare) . . . . The term ‘impairment’ indicates that the . . . difficulty is sufficient to require support” (Pagliano, 2005, p. 322), particularly in the area of communication. An individual’s hearing is thought to be limited if his or her minor difficulties with hearing can be corrected to enable that person to function as if he/she had normal hearing. The term “hearing impairment” is used to describe those who experience difficulties with their hearing to the extent that they require additional support. There are two types of hearing impairment: “hard of hearing” describes an individual with some functional hearing available for oral communication, and “deaf”, where the individual has insufficient functional hearing for oral communication and consequently the person must use alternative forms of communication such as sign language.

Hill and Nelson (2000) provide the following definition:

> Hard of Hearing: People who have a hearing loss but who have enough hearing to use a voice telephone and to understand spoken language by listening carefully in a quiet environment usually with a hearing aid or other assistive listening device. A

> Hard of Hearing individual might have a mild, moderate or severe hearing loss. (p. A4)

Further, Hill and Nelson (2000) describe hearing impairment as “a broad term used by many Hearing professionals to refer to all people who live with hearing loss” (p. A4). They explain that members of Deaf culture strongly object to the use of the term “hearing impaired” because persons who are culturally Deaf regard deafness as a difference, and not as a disability or impairment. For Hill and Nelson (2000) Deaf culture is, “A distinct culture whose members highly value Sign Language, Deafness, a visual world view, and congregation of Deaf people” (p. A3).

The task of finding a term which most aptly represents by definition and application the population being identified in this study, as well as providing descriptions of such factors as anatomical functioning and adjustment to life circumstance, while upholding respect for the individual without using disablist language or implying similar connotations, has been a challenging one. Numerous dialogues took place between my advisor and me as we endeavoured to find an appropriate term.

I have decided to restrict my use of the term “hearing loss” to quotations. This is because of the term’s ambiguity and the emotional overtones that accompany the idea of loss. While the term might be accurate to describe individuals who experience progressive hearing impairment in adulthood, it is less suitable when describing a congenital condition which is stable. In the case of the individual with congenital hearing impairment, there might be no actual loss of hearing because there has been no measurable change in hearing over time.

I have also decided to restrict my use of the term “hard of hearing” and whenever possible to use the term “hearing impairment”. The term, however, is not intended to include people who regard themselves as culturally Deaf. I chose the “term hearing impairment” because the participants in this study have

progressive conditions which may change over time. Therefore, while the term "hard of hearing" may be accurate in the short term, the more generic term "hearing impairment" provides a better long term fit. The term "hearing impairment" is often used in the literature. It will therefore be used in this study to represent people who are hard of hearing, particularly those with progressive conditions who are unlikely to regard themselves as Deaf because of their extensive prior experience as part of the hearing community.

Background

The incidence of hearing impairment is being reported worldwide in large and increasing numbers. Von der Lieth (2001) claims that 10% of the European population have hearing impairment. In Finland, 10-12% of the adult population are identified as hard of hearing (Poussu-Olli, 2001). Furthermore, the percentage of the population identified with hearing impairment increases with age. For example, in the USA the prevalence of hearing impairment rises from 10% (House, 1999; Myers, 2000; Wayner, 1998) at age 40 to more than 33% at age 65 (Sorkin, 2001; Stenross, 1999).

In Canada, the Canadian Hearing Society (2002) and the Canadian Hard of Hearing Society (2001) report that 10-12% of adults (up to age 65) have sufficient degree of hearing impairment to be considered hard of hearing. However, this percentage will need to be revised upward as the population ages. In the 2000-2001 annual report published by the Island Deaf and Hard of Hearing Centre on Vancouver Island, British Columbia, a local service provider for this area, it was stated that 31% more people required services during the fiscal year than over the previous 12 months. Services required included obtaining information, hearing aids, assistive listening devices, and counselling.

In my work as a rehabilitation consultant on Vancouver Island, I have become particularly aware of the increase in the number of adults seeking

assistance in dealing with their personal struggles related to hearing impairment. Problems experienced by these individuals revolve around a change in hearing ability and/or health status, a change in the workplace such as increased demands and responsibilities where their remaining hearing is no longer sufficient to meet the daily and increasing demands, and difficulty with communicating in family relationships and/or in social situations. These challenges not only affect the individual with the hearing impairment, but they also extend outward to include the individual's family, social network and co-workers (Myers, 2000; Ross, 1999; Stone, 1987; Trychin & Busacco, 1991; Wood, 1987).

There has been a change in the expectations both at the individual and work levels. The increased complexity of daily life and developments in technology and medicine have resulted in individuals being less willing to engage in passive appraisal. Overall, there is an increase in the number of people identified with hearing impairment among the adult population who are actively seeking some kind of support and assistance.

Research Statement

Mithaug (1996) describes how people with disabilities often experience patterns of failure that lead to a loss of hope and a growing sense of helplessness. This despair can erode an individual's self-respect. Those affected become locked in a cycle of personal, social, and economic deterioration. People with hearing impairment are particularly vulnerable because of their reduced access to communication.

The emergence of hearing impairment in adulthood in many cases may be characterised as a "gradual and progressive" (Trychin, 1997a, p. 18) process, changing over years or even decades (Orlands, 1987; Thomsett & Nickerson, 1993). It tends to begin as limited hearing with the individual still being able to function as if he or she had normal hearing. Eventually, however, the individual

crosses a threshold to become hard of hearing. The “highly insidious character” (Hétu & Getty, 1991a, p. 305) of declining auditory ability affects both the speaker and the listener. The condition is frequently ignored, taking between 5-7 years on average before adults attend to the diagnosis and treatment of their suspected hearing impairment.

> The desire to hide or deny hearing [impairment] is very strong in our society, perhaps with good reason. Even [today], people who are hearing-impaired are often viewed as incompetent, stupid and subject to ridicule. The costs to the individual, and to society, are high. (Stone, 1987, p. 115)

Thus, individuals may feel alienated by their own fear, shame, denial, and isolation as they struggle to maintain a place in the hearing world. When frequent communication breakdowns occur, hearing family members, friends and co-workers may decide to reduce and/or sever communication with the person with a hearing impairment. This may lead to additional psychosocial issues such as depression, anxiety, guilt, anger, and shame (Trychin, 1991). Other debilitating cognitive, behavioural (Stone, 1987), interpersonal, and physical changes may also be noted (Trychin, 1997a). Indeed, according to Trychin (1991), the ramifications associated with progressive hearing impairment for the individual, their family, friends, and co-workers are extensive. These individuals therefore require professional assistance to manage their lives more effectively.

Research Focus

The literature suggests there is a lack of professional awareness and understanding of the needs of individuals who are hard of hearing (Allen, 1998; Cowie, Watson, Kerr & Douglas-Cowie, 1995; Hill & Nelson, 2000; Ross, 2001; Trychin, 1997a; Wayner, 1998). The curative medical model, with its strong links to positivist research, Getty and Hétu (1987) argue, remains the operative model

for rehabilitation approaches with adults who are hard of hearing. Professionals who endorse this approach purport to understand the needs of the individuals being served and profess to have the solutions. This research will endeavour to assist professionals to "understand people's personal experience of hearing loss" (Cowie et al., 1995, p. 292) by using a dialogic approach and, therefore, giving them important information regarding the unique, individual needs of adults who are hard of hearing. It is hoped that coupling the use of phenomenology with action research will further provide professionals with much-needed tools to help place the onus of responsibility for advocacy back on the individual with hearing impairment.

The focus of this study, therefore, is to investigate the use of phenomenology with eight adults with hearing impairment and to use action research with two candidates in particular to help them achieve more positive outcomes in their lives.

Purpose of Study

The purpose of the research is to develop a prototype for rehabilitation professionals which they can implement when working with adults who are hard of hearing. The prototype will consist of the integrated use of phenomenology and action research. Dialogic and introspective phenomenology will initially be used by the rehabilitation counsellor to obtain a deep understanding of the personal life experiences of individual candidates. Such knowledge, which will be acquired through the first phase of the study, will help them identify issues to be used in the challenge identification process and to define individual action research case studies. Hence, the goal will be to help individuals in the study achieve an increased level of confidence with decision-making and to influence life outcomes.

Importance of Study

Hearing impairment in adulthood is likely to become increasingly more prevalent as the population ages. It may cause individuals to experience serious problems with expressive and receptive oral communication, which can have a negative impact on both the speaker and the listener. If the hearing impairment is progressive and it is left unattended, it can result in the individual becoming caught up in a pattern of failure in personal, social, and economic areas of his/her life. These cycles of failure can lead to a loss of hope and a growing sense of helplessness, isolation, and despair.

Hearing impairment is often accompanied by an oral communication disorder that is evident during dialogue with hearing individuals (Ross, 2001; Trychin & Busacco, 1991; von der Lieth, 2001; Wagner, 1998) and "affects every aspect of a person's life" (Universal Hearing Health, 2000, para. 3). The impact of hearing impairment can be felt by the individuals experiencing it as well as by every person who comes into contact with them (Hétu & Getty, 1991a). With an estimated 10% of people being affected directly by hearing impairment, "it is difficult to find someone who has never experienced the effects of hearing loss, either in themselves or talking to someone who has it" (Universal Hearing Health, 2000, para. 3). Stone (1987) describes the magnitude of the problems for some individuals:

> Hearing impairment strikes at the very essence of being human because it hinders communication with others. It restricts the ability to be productive; it limits social intercourse; it reduces constructive use of leisure time; it affects physical and mental health; it often leads to poor self-image, to isolation and to despair and ultimately, it can affect the will to live. (p. 116)

Traditional rehabilitation approaches, which follow the curative medical model wherein the professional is assumed to understand the client's needs,

have been criticised harshly in the literature (Getty & Hétu, 1994; Trychin & Busacco, 1991) because in most cases hearing impairment cannot be cured. In addition, professionals in various fields often have little understanding of the actual needs of the person with a hearing impairment (Clelland, 1995; Hill & Nelson, 2000). Wood (1987) explains how he envisions the relationship between society and persons with hearing impairment: “There will undoubtedly be an attempt by society to treat them [persons with hearing impairment] not as they are, but how they perceive the deafened should be, or what in terms of employment, they feel the deafened are capable of [accomplishing]” (p. 160). Focusing on service to individuals with hearing impairment, Wood continues: “Those of you who deal with the deafened in a counselling or rehabilitation role such as hearing therapists, psychologists or others, will undoubtedly find your work more difficult and demanding if the above analysis is absorbed” (p. 160).

This study is important because it reports on the use of an alternative, more life-affirming approach that focuses first on the rehabilitation professional gaining a deep understanding of the individual’s pertinent life experiences and then helping that individual to engage personally in planning to achieve his/her own positive life outcomes through the use of action research.

Conceptual or Substantive Assumptions

This study has been predicated on the following assumptions:

1. A number of psychosocial implications are associated with adults with hearing impairment (Ross, 2001; Trychin, 1991; Trychin & Busacco, 1991; Trychin, 1997a). These include, but are not restricted to: depression, anxiety, withdrawal, guilt, excessive worry, dependency, and lack of assertiveness (Trychin, 1991). The degree to which any of these issues manifest themselves in an individual's life will vary.

2. The degree of hearing impairment, i.e., mild to profound, will not be the sole determinant of the individual's ability to function independently in the community. "Two individuals with the same audiometric profile may function quite differently—one functioning very well and the other functioning poorly" (Trychin, 1997a, p. 5).
3. It is assumed that many professionals in the field of social services and mental health services lack understanding of the unique needs of persons with hearing impairment (Hill & Nelson, 2000) and the skills to serve them effectively. Therefore, one of the major barriers associated with helping people with hearing impairment resolve their problems, according to Trychin and Busacco (1991), is "the unavailability of professionals who are knowledgeable about the psychosocial effects of hearing loss" (p. 21).
4. It is assumed that many of the unseen constraints, personal assumptions, and habitual behaviours associated with hearing impairment will emerge from the analysis of the data gathered from the interviews with each participant. This may provide participants with an opportunity to identify and change old and outdated paradigms with new ones. Moustakas (1990) describes how the data analysis can be enhanced by returning to the research participants and "sharing with them the meanings and essences of the phenomenon as derived from reflection on and analysis of the verbatim transcribed interviews and other material, and seeking their assessment for comprehensiveness and accuracy" (pp. 33-34).

Scope of Study

This study will focus on eight adults, four males and four females between the ages of 18-65. All participants will have a hearing impairment that is reported by audiologic measurements as being between “moderate to severe” (40 decibels (dB) in the better ear with correction--90 dB). This means they will all fit under the definition of hard of hearing. Participants will be further selected by a hearing impairment beginning after linguistic development. Participants may be using or may be able to receive some benefit from assistive listening devices or hearing aids, but are not likely to know or use sign language and typically will not be expected to affiliate with the Deaf community or self-identify as Deaf.

Participants in the study will be selected from the combined rural and urban area of central Vancouver Island. Medical professionals, audiologists, and rehabilitation workers in the central Vancouver Island area will be advised of my proposed study. They will be asked to identify individuals who, in their opinion, may fit the criteria and benefit from participation in the study.

Limitations and Delimitations of Study

Investigating the experience of persons with a hearing impairment will require the participants to give in-depth descriptions of their lives. This study will be limited to dialogue with the individual participants and will not include other family members, colleagues in the workplace or friends.

This study is not intended to provide counselling to participants. Any ideas or insights arising from the interviewer and participant which may be of therapeutic value will develop from personal critical reflection and dialogue. Clearly, each individual will have a unique set of personal experiences that relate to his/her hearing impairment. In addition to recording these individual stories, the goal will be to deliberately select participants whose ethnic backgrounds, cognitive ability and employment history are as diverse as is practically possible

given the constraints of the study. The results of this study, therefore, are not intended to be generalised to the larger population of individuals with hearing impairments.

The phenomenological investigation reveals the history of activities, attitudes, and judgements which have led to the development of the participants' current self-image and personal beliefs as a result of their hearing impairment. The phenomenological process can also lead to a deeper understanding of historical and entrenched patterns of thinking and behaving. The action research prototype that will be used in this study was developed by Kuhne and Quigley (1997). It provides a framework for the individual to reconstruct new attitudes and behaviours through analysis and reflection.

Methodology

Selection of Participants

A written appeal will be made to audiologists, medical doctors, and rehabilitation workers in the greater Nanaimo and Duncan areas of Vancouver Island requesting their help in identifying potential participants for this study. The criteria for selection will be provided. These will include participants being between 18 and 65 years of age and being able to produce an audiological assessment to indicate a moderate to severe hearing impairment with no less than a 40 dB hearing loss in their better ear, with amplification. Potential participants will be contacted by mail to determine their interest in becoming part of this study. Those participants who meet the criteria will be invited to become part of the study. These may include a possible mix of individuals who are employed/unemployed, rural/urban, single/married, and differing ethnic backgrounds.

Qualitative Research

Creswell (1994) defines qualitative research as “an inquiry process of understanding a social or human problem, based on building a complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting” (pp. 1-2). The interview process associated with a qualitative design, according to Silverman (1993), offers “a ‘deeper’ picture than the variable-based correlations of quantitative studies” (p. 15).

> Qualitative research involves the studied use and a variety of empirical materials such as: case study; personal experience; introspection; life story; interview; observational, historical, interactional, and visual texts - that describe routine and problematic moments and meanings. (Denzin & Lincoln, 2000, p.3)

The purpose of applied qualitative research is to gain a better understanding of the subject matter under investigation. The form of qualitative research being used in this study is phenomenology.

Phenomenology

A phenomenological study, as defined by Creswell (1994), is one “in which human experiences are examined through the detailed descriptions of the people being studied” (p. 12). The aim of the phenomenological approach, according to Moustakas (1994), “is to determine what an experience means for the persons who have had the experience and are able to provide a comprehensive description of it” (p. 13). This approach involves studying a small number of participants in an “extensive and prolonged engagement to develop patterns and relationships of meaning” (Creswell, 1994, p. 12). One means of gaining an understanding of the life experiences of participants is through bracketing of the researcher’s own biases (Creswell, 1994, 1998; Moustakas, 1994; Nieswiadomy, 1993).

Intrinsic to the phenomenological approach for Moustakas (1994) is the concept of “heuristic inquiry” (p. 19). He defines heuristics as “a process of internal search through which one discovers the nature and meaning of experience and develops methods and procedures for further investigation and analysis” (p. 17). According to Moustakas, the “self of the researcher is present throughout the process and, while understanding the phenomenon with increasing depth, the researcher also experiences growing self-awareness and self knowledge” (p. 17). These “creative self-processes and self-discoveries” may, therefore, become part of the research experience for all of the persons engaged in the research activity. Moustakas uses the term “heuristic inquiry” to describe the exclusive and continuous focus for developing an understanding of human experience. This understanding is achieved by participants “telling their individual stories with increasing understanding and insight” (p. 19). This process of story telling is consistent with the description of quest narrative by Frank (1995). In Frank’s model, people with disabilities seek to tell their own story for the purpose of exploring alternative ways to achieve a state of wellness. In both instances, there is a search for a deeper understanding of the problems, the achievements and the opportunity to consciously fashion new and alternative ways of perceiving the self.

Drawing from his own earlier writing, Moustakas (1994) identifies the following six phases of heuristic research design which will be employed in this study. These characteristics are clearly represented in the phenomenology approach.

1. Initial engagement. This represents the beginning of interaction with the subject matter and the participants.
2. Immersion in the topic and question. This marks the start of the inductive process.

3. Incubation. This allows time for thinking and the bringing into awareness of nuances and meaning in the setting that is under study. This phase provides an opportunity for capturing intuitive insights and allows the participant and researcher to achieve a deeper understanding.
4. Illumination. An opportunity for expanded awareness is provided.
5. Explication phase. This includes description and explanation to capture the experience of those engaged in the study.
6. Creative synthesis is applied. In this stage the researcher is able to bring together the individual's story as a whole. This includes the "lived experience" (Creswell, 1994; Janesick, 2000) of the individual.

In heuristic investigations, verification is enhanced by returning to the participants and sharing with them the meanings and essences of the phenomenon as derived from critical reflection and analysis of the interview data and the observations. This is done to seek the participants' assessment of its comprehensiveness and accuracy.

Information gathered during the interviews will be transcribed and transferred to hard copy. It will then be coded and categorised into themes. This information is expected to elucidate the challenges that may become the focus of the action research component during the second phase of the project.

Research Design

My proposed research strategy, therefore, will use a phenomenological design. This represents my interest in investigating the "lived experiences" (van Manen, 1997, p. xiii) of the participants with hearing impairment. My further interest is in using individual case studies where information from the descriptive analysis will be applied to identify challenges and define individual projects

according to an action research prototype developed by Kuhne and Quigley (1997). The goal of the whole process is to increase the proactive decision-making ability of the participants.

In designing my research study, I refer to Morse (1994), who establishes the importance of selecting a qualitative research topic that is capable of maintaining the researcher's interest over time. If a gap in the literature is discovered, where information on the topic is scant or unavailable, this can be a valid indicator that the topic has the desired potential for a qualitative research study. Another important consideration in selecting a suitable research topic is identifying the researcher's reasoning and motivation for selecting a particular topic to investigate. Are there "personal or professional experiences related to the subject . . . or strong feelings stemming from these experiences" (Morse, 1994, p. 221) that stimulate the researcher's interest? Morse warns the prospective researcher to be aware of his or her motives and biases prior to undertaking such a study. Van Manen (1997) states that in the human sciences, "one does not pursue research for the sake of research. It is presumed that one comes to the human sciences with a prior interest of, for example, a teacher, a nurse or a psychologist" (p. 1).

I am a professional rehabilitation counsellor with 30 years experience working with adults with disabilities of a sensory, neurological, musculoskeletal, cognitive, and psychiatric nature. Throughout my years of experience, I became aware of the lack of services for persons with hearing impairment, particularly in the areas of counselling and support for vocational and personal issues. Upon completion of my graduate studies in 2000, I was impressed with the potential of the action research approach used in my thesis and felt it could become a valuable tool for working with persons with hearing impairment. These two factors led me to the research topic I have chosen for this study.

In my case, I have a dual interest for engaging in this study. I have had an interest in working with individuals with hearing impairment since the early 1970s when I worked intensively with a young man who was profoundly Deaf. I learned sign language in order to communicate with him. As a rehabilitation counsellor and an adult educator, my present interest is to develop a deeper understanding of the psychosocial issues of hearing impairment and to look for ways to assist adults with hearing impairment to become more empowered and to become agents of desired changes in their lives.

Critical Reflection

Cranton (1994, 1996) describes transformative learning as the process resulting from an individual reflecting on the assumptions or expectations about what will occur, and on finding these assumptions to be faulty, revising them.

> Critical reflection is the central process in transformative learning. Our natural human interest in emancipation drives us to reflect on the way we see ourselves, our history, our knowledge, and our social roles. If we see that we are constrained or oppressed by any of our perspectives, we may be challenged to revise them. (p. 75)

Cranton (1996) uses the term “social” (p. 142) in the context of interactions with others in their workplace, in their community, or in a larger sense, in the society where they live. Her target is an audience of adult educators to whom she assigns responsibility in their role as facilitators. She states: “Educators [or counsellors] may be agents of change, or alternatively, keepers of the status quo” (p. 141). Further, in their role as facilitators, educators, and other professionals, they have a responsibility to guide individuals through a process of greater understanding through critical reflection. However, the responsibility does not

just rest with the professional as it is shared with those being served in the helping relationship.

Cranton (1996) cites Held (1980) for the purpose of broadening the understanding of the emancipatory element of critical reflection:

> The process of emancipation, then, entails the transcendence of such systems of distorted communication. This process, in turn, requires engaging in critical reflection and criticism. It is only through reflection that domination, in its many forms, can be unmasked. (p. 142)

Further, Cranton suggests that such "domination" prevents change from taking place in the life of individuals, as they may not be able to understand beyond their own perspectives. Within this context, the process of unmasking is synonymous with O'Neil and Marsick's (1994) idea of bringing thoughts and ideas to the surface because, in each case, whatever assumption, belief, or attitude had been concealed can be exposed. This in turn can lead to change. She concludes:

> But it is not until people see themselves as having the power of questioning systems that social reform can occur. Individuals come to know themselves by becoming conscious of the sources of their perspectives. When this awareness exists, people are then able to negotiate social change. (Cranton, 1996, p. 141)

When critical reflection is taken into the arena of identification of challenges, it is "even more powerful because attention is directed to the root of the problem" (O'Neil & Marsick, 1994, p. 23). They continue: "Even more significant gains are realized when critical reflection is involved . . . individuals learn how to surface, examine, and question the beliefs and assumptions that influence their actions and decisions" (p. 28). O'Neil and Marsick refer to Schön's (1987) attaching importance to reflection immediately following action. "They

learn to value the power of reflection on action in order to learn and shape future actions" (p. 28).

The desired outcome of critical reflection, according to MacDonald (2000), is increased insight, personal empowerment, and renewed commitment to effect positive change. For Cranton (1996), change may be contemplated as a result of critical reflection, which then leads the individual to assume a transformed perspective. Individuals experience the transformation when they become aware of the forces that help to shape their current situation. Critical reflection, therefore, has an essential outcome, namely a review of the underlying reasons for acting, a clarification of the actions themselves and an altering of future activities based upon the information gained and the recognition that they, as individuals, have the power to do something about it. The entire process can lead to personal empowerment supporting the decision to affect change and this change being embraced by the individual.

Action Research

Critical reflection is a vital component of the action research approach. Noffke (1995) argues action research "assumes that understandings and action emerge in a constant cycle" (p. 4). The use of critical reflection differs from most other problem solving methods. Reflection on actions influences those actions previously engaged in, and in turn, these new actions are reflected upon. Thus, a tautology is established whereby a pattern of critical reflection on new actions is conducted and all future actions are subject to the same type of scrutiny to determine their effectiveness and utility.

Additional support is provided by Kemmis and McTaggart (2000), as they demonstrate a connection between critical reflection and action research:

> Participatory action research (not always by that name) frequently emerges in situations where people want to make changes

> thoughtfully—that is, after critical reflection. It emerges when people want to think 'realistically' about where they are now, how things came to be that way, and, from these starting points, how, in practice, they might be changed. (p. 573)

Lewin (1946) believed action research was a vehicle for change and would allow people to translate their dreams into the language of action and evaluation. Lewin, the father of action research (Carr & Kemmis, 1983; Kemmis & McTaggart, 1988) described it as a four-step process. The first step was to examine the problem being posed. According to O'Neil and Marsick,

> Problem posing involves raising questions that open up new dimensions of thinking about the situation, whereas in problem solving, a person often looks primarily at solutions without questioning whether or not the initial assessment of the situation is the only one, or the best one, that is possible. (1994, p. 22)

Wallerstein (1987) refers to the problem-posing process as a way of drawing upon the person's experience to create a sense of connectedness with the issue being addressed. She refers to the three phases of problem posing as "listening, dialogue and action" (p. 35). Listening and dialogue are clearly represented in the earlier descriptions of phenomenology and this project's methodology. The final component is represented in the action research phase of this study. In the context of this study, problem posing will be referred to as a challenge in order to avoid the negative associations linked to the word "problem" (Kemmis & McTaggart, 2000). In particular, I wanted to avoid using a deficit approach where people with disabilities are positioned in negative ways when being compared to non-disabled people. The idea of a challenge encourages the individual to build on his/her own strengths rather than focus on personal problems.

The second step, according to Lewin (1946), refers to the action or execution of a plan. This is followed by the third step, where the results are carefully evaluated to determine whether they are consistent with the anticipated outcomes. Finally, following a careful analysis of the results of the first cycle, the same sequence is then repeated.

The action research process relies on the insights and the ideas of the participants to facilitate the formulation of realistic goals and ways to address the problem or challenge. According to Lewin (1946), action research is conducted with the spirit of collaboration, co-operation, and trust between the participants and the researcher.

In addition to the processes themselves, the most important purpose of Lewin's action research approach was to increase independence, to enhance autonomy and to foster co-operation. These values are consistent with those of Kuhne and Quigley's (1997) action research prototype and have been adopted within this current research design (See Figure 1). Participants will be expected to become more self-determining, self-reliant, and personally empowered through their involvement in the research.

Figure 1. Cycles of Action Research.

Note. Adapted from Creating Practical Knowledge Through Action Research: Posing Problems, Solving Problems, and Improving Daily Practice, (p. 27), in B.A. Quigley & G. W. Kuhne, (Eds.). New Directions for Adult and Continuing Education, no. 73, San Francisco: Jossey-Bass.

Previous personal use of the action research prototype (MacDonald, 2000) seemed to result in participants achieving a level of increased empowerment and commitment. This was thought to be what led to a marked increase in the rate of clients who successfully attained employment. In the context of this study, an attempt will be made to assist participants to achieve personal empowerment through the application of this action research prototype with two individual participants.

Ethics

Ethics approval has been obtained from the Ethics Review Committee, James Cook University (see Appendix 1). Prior to signing the consent forms, participants will be provided with a comprehensive verbal description of the purpose, methods, and possible risks and inconveniences or discomforts they might encounter during the research project. The consent will include a signed agreement to allow interviews to be tape-recorded. The circumstances under which the signing of the consent forms takes place will also be recorded. The anticipated commitment of the time expected for participants to engage in this study will be explained. All participants will be advised of their right to withdraw their consent and leave the project at any time. Research materials will be kept in a locked filing cabinet in a secure office. Pseudonyms will be used throughout the transcripts and the final thesis.

Questions will be developed for the purpose of gaining a deeper understanding of participants' issues relating to their hearing impairment. Additional questions will be included, but will not be restricted to the discussion of factors leading to the participant's decision to seek medical or hearing specialist evaluation, or to discuss issues affecting family, friends, and activities in the community or in the workplace. The interviews will be semi-structured. Questions relating to the participants' understanding of functions of the ear and

the nature of their hearing impairment will also be included (Hétu & Getty, 1991b). Interviews will be conducted in a local complex where privacy is ensured. The facility will be wheelchair accessible and conveniently located.

Conclusion

Hearing impairment affects the ability to communicate effectively with others, both from the perspective of the people with the hearing impairment and of others dealing with them. The consequences for individuals affected by hearing impairment include, but are not limited to: lower self-image, reduced powers of self-determination, decision-making and assertiveness, increased isolation, and even despair.

Professionals have varying degrees of knowledge relating to issues of hearing impairment as well as limited skills and training for assisting persons with this sensory impairment. Therefore, this study proposes to provide information through a dialogic and introspective approach to gain a richer understanding of the issues associated with hearing impairment. This study also proposes to explore a prototype of intervention which can assist individuals with hearing impairment as well as the professionals working with them in purposeful life planning.

The impact and far-reaching effects of communication issues associated with hearing impairment have been discussed in this chapter. Such issues reach beyond the boundaries of the individual to include family, friends, and co-workers. Indeed, awareness of this burgeoning problem is being recognised worldwide. The phenomenological approach that will be applied to gather information about the individual's lived experience was operationally defined. The study was predicated on the following five goals:

1. To use phenomenology to achieve a deeper understanding of the needs of eight adults with progressive hearing impairment.

2. To use the information gained through phenomenology to inform professionals about the range of experiences these eight individuals have encountered. The intent is not to generalise the effects of hearing impairment to larger populations but rather to help professionals gain an increased awareness of the magnitude of issues associated with living with hearing impairment by being made aware of the particular life experiences of these eight participants.
3. To work with two participants to help them use action research to build on their own phenomenological stories to define an action research project which, upon completion, would help them achieve a positive life outcome.
4. To use a combination of phenomenology and action research to assist two research participants to achieve more positive life outcomes by becoming more self-determining and self-reliant.
5. To develop a phenomenology and action research prototype which could be used by professionals to inform their practice when working with adults with hearing impairment.

In Chapter 2, I will provide a review of relevant literature which serves to highlight some of the psychosocial issues relating to hearing impairment. Chapter 3 contains a description of the use of phenomenology as a research method. The analysis of the phenomenological data gathered from the eight participants is then presented in Chapter 4. Chapter 5 focuses on the description of the action research activity, with two particular participants, and Chapter 6, the final chapter, consists of the thesis summary, conclusions, and recommendations.

CHAPTER 2. REVIEW OF LITERATURE

Introduction

A marked shift has occurred in the literature over the past 30 years, from regarding hearing impairment principally as a medical problem towards viewing it within a much wider perspective where the whole person's ecology is also taken into account. This shift has provided new opportunities to introduce more psychosocial interventions in conjunction with the current technical and medical ones being employed.

The chapter begins with an exploration of key terms, particularly "hearing impairment", "hard of hearing", and "deafness". As language has a strong effect on the way we think, particular attention has been paid to choosing the most suitable terminology. The author uses the literature to help explain why he has chosen to use the term "hearing impairment" in preference to "hard of hearing" and "deaf". The increasing prevalence of hearing impairment worldwide and the distressing absence of information and training for professionals in the field of counselling are then highlighted to provide a strong argument for more research into how best to assist adults with progressive hearing impairment. If this research is to adequately inform practice, then it needs to be qualitative and provide a deep understanding of life experienced by individuals with hearing impairment.

In the past, professionals who used the medical model tended to regard themselves as the experts who not only knew their clients' problems but also believed they had the solutions to ameliorate them. This approach tended to focus on the clients' external handicaps. Disability, though, is also socially constructed and interpreted. Negative interpretations may lead the individual with the disability to view him/her self in debilitating ways. These internal handicapping conditions can be at least as incapacitating as the external

handicaps.

The ecological approach, on the other hand, emphasises the necessity for clients to define their own needs and treatments in collaboration with the professional. This multifaceted approach gives prominence to the idea of individualising the intervention while paying close attention to the person's psychosocial requirements. Although individuals may experience a similar reduction in their hearing levels, the impact and implications of such an impairment can be enormously diverse and are, therefore, unique to the individual, his or her family, and significant others.

When using the ecological model, the professional becomes a researcher. He/she must value empathy in professional practice. This brings the personal into the professional. It is his or her job to gain a deeper understanding of the challenges being faced by the client and to design interventions cooperatively with him/her. There are two distinctive aspects of progressive hearing impairment within the social and relational context:
1) hearing impairment is "invisible" and 2) it is "insidious". The practitioner must consequently be specifically trained to provide particular services to persons with hearing impairment. Critical reflection becomes an integral part of the professional relationship because it is through the reflective process that the client begins to establish new life destinations.

Narration is one useful form of therapeutic intervention which may help give people with hearing impairment a voice. Another way to assist an individual's growth and independence is through focusing on self-determination and empowerment. It is especially important to acknowledge the process of client transition from the relative security of being "able" to the uncertainty and insecurity of living with a "disability". The practitioner aims to help the client override the temptation to react in a passive way and to actively seize the opportunities offered by the impairment. Phenomenology and other associated

research approaches, including action research, offer the professional a valuable way to gain a deeper understanding of the life experiences of the person with hearing impairment and work with him/her to design new prospects for a more effective intervention.

Definitions

As mentioned above, finding adequate definitions in the literature to describe what the terms “hard of hearing”, “hearing impairment”, and “deaf” mean has been difficult. As Wood (1987) points out, the various terms can become blurred. The expression “hearing impairment” is a generic term. It includes hearing difficulties from mild to moderate, namely hard of hearing, and extends through severe to profound, which leads to deafness. The precise crossover from hard of hearing to deaf differs among individuals depending on a large number of variables, but particularly age of onset. In general, individuals who are hard of hearing are distinguished from those who are Deaf by their chosen method of communication (Clelland, 1995; Foster, Barefoot, & DeCaw, 1989; Harvey, 1989; Stone, 1985). The primary means of communication for individuals who are hard of hearing is “through vocal speech and hearing, whereas deaf persons mostly utilize sign language or written language” (Clelland, 1995, p. 14). As mentioned in the previous chapter, the term “deaf” refers to the level of hearing impairment, whereas the term “Deaf” with a capital D refers to a distinct group of people, their language, and culture. Those who use sign language become part of the Deaf culture. Those who use speech and hearing to communicate become part of the hearing culture.

The blurring occurs when adult individuals are not able to use or understand a particular medium, for example sign language, so they continue to associate with the hearing culture even though they may have started to experience a profound hearing impairment. Depending on their prior life

experiences, their emerging hearing limitations, their surroundings and opportunities, communication for them may be far more tentative. People who are hard of hearing, especially those with degenerative hearing impairment in adulthood, are therefore stuck between two worlds (Stone, 1985), the world of hearing and the world of deafness. They may have a lifetime of hearing experiences but very few experiences of Deaf culture.

In her study with adults who were reported to be hard of hearing, Clelland (1995) describes how individuals who are hard of hearing "feel more handicapped by their loss than persons who are deaf" (p. 14). The level of frustration, concurs Harvey (1998), is markedly increased for individuals who are hard of hearing. Agreeing with Harvey, Erdman, and Demorest (1998b) refer to Stephens and Hétu (1991), stating these researchers have "observed that past research in this area has been compromised by inconsistent usage of the terms disability and handicap among investigators." They continue: "All too often the terms have been used interchangeably. Additionally, many researchers have failed to provide their own working definitions of the terms and have used them indiscriminately" (p. 124). Basing her discussion on the World Health Organisation [WHO], (1980), definitions and references from American Speech and Hearing Association [ASHA], (1994), Weinstein (1996) discusses the variations in meaning for the terms "hearing impairment", "hearing disability", and "hearing handicap". Her descriptions are consistent with Stephens and Hétu (1991). According to Weinstein, "a hearing impairment is an abnormal function of the auditory system. A hearing impairment can exist but may not be perceived by the individual" (p. S37-S38). She continues, "In contrast, a hearing disability refers to the effect of an impairment on everyday hearing ability and communication performance" (p. S38). The severity of a hearing disability is usually described in terms of the impact these auditory difficulties may have on the experience of the listener in specific terms such as the effect they have on

lifestyle, social isolation, and employment. Examples include difficulty hearing in noisy environments or determining sound source and directionality. For Weinstein, “a hearing handicap refers to the disadvantages imposed by an impairment or disability that limits the individual’s psychosocial functioning” (p. S38). These disadvantages may be experienced by either or all of the following: the individual, his/her significant others or the community. The handicap may influence their physical independence, social integration and ability to sustain economic sufficiency as well as any other daily functions. These definitions are consistent with Stephens (1996).

A detailed rationale for using this term was provided in Chapter 1. Therefore, since the term “hearing impairment” is broadly used in the professional communities, and, since this study does not include any participants who are Deaf, the term “hearing impairment” is used in preference to “hard of hearing”. The generic term “hearing impairment” is thought to be a more accurate term to use with this population than “hard of hearing” or “deaf”, and it is for this reason I have adopted this term in this thesis.

Establishing the Need for the Study

According to House (1999), “Hearing loss is the most common malady affecting adults in the country” (p. 161) and the number of persons in the United States reported to have some degree of hearing impairment is 100 times greater than those reported to be Deaf. Providing statistics from the United Kingdom, Getty and Hétu (1994) advise one in six persons experiences hearing impairment that is sufficient to limit his/her activities. Only 20% of these seek professional intervention, according to these authors, and the level of willingness to seek help decreases with age (Erdman & Demorest, 1998b). Furthermore, Getty and Hétu estimate there might be a lapse of “10 years” (p. 268) between the first signs of hearing impairment and the first intervention. Epstein (1999), agreeing with an

earlier report from Health and Welfare Canada (1988), points out the magnitude of the problem of hearing impairment, reporting a marked increase in the incidence of hearing impairment at this time. "We are seeing more young people in their 20s and 30s, as well as older adults, with late onset sensorineural hearing loss, which we know is relating to longstanding noise and loud music exposure" (p. vi). The Universal Hearing Health Organization (2000) reports an increase of 24% in the prevalence of hearing loss of all ages since 1970-71 (Universal Hearing Health, 2000a, para. 7). Richter (2001) concludes: "One in ten Americans has hearing loss. Over the age 65, that figure goes up to one in three Americans" (p. 9).

Absence of Information for Hard of Hearing Individuals

There appears to be a serious absence of information relevant to issues for persons who are hard of hearing (Clelland 1995; Foster et al., 1989; Harvey, 1989; Knutson & Lansing, 1990; Stone, 1987, 1992) and a plethora of information for persons who have early onset deafness. "The bulk of rehabilitative research is focused on early onset deaf [sic] populations, which is not necessarily applicable to other groups of students and adults who are hearing impaired [sic]" (Stone, 1992, p. 60). Speaking from an agency service provider point of view, Richter (2001) states: "I have found over the years that many organizations still only deal with deafness, not acquired hearing loss. They fail to include literature, videos, websites and other printed materials for people who are hard of hearing" (p. 8). The Universal Hearing Health Organisation (2000) reports the remarkable increasing numbers of persons with hearing impairment and inattention to this issue. "Strangely enough, the population of people who are hard of hearing has been given very little attention, considering the magnitude of the problem and the effects of hearing loss on people's lives" (Universal Hearing Health, 2000, Demographics, para. 1).

Bienenstock and Vernon (1994) agree with Erdman and Demorest (1998a) and Steinberg (1991), claiming the literature often reports a variety of disabling conditions and that a "paucity" (p. 129) of research exists for persons who are hard of hearing. In this regard, Health and Welfare Canada (1988) and Schroedel (1992) concur, stating: "There are astonishing gaps in information about these individuals . . . part of this shortcoming is due to the lack of research studies on this target population" (p. 44). Kyle (1987) claims, "Acquired hearing loss is one of the grey areas of our health care provision; it is one of the least understood of our social difficulties and it is one of the most solitary of our personal changes" (Kyle, 1987, p. iii). He continues, "It tends to creep up rather than arrive with a bang and tends to be difficult to accept" (p. iii). Erdman and Demorest refer to the "inadequate appreciation of the effects of hearing impairment on the quality of life" (p. 107). Kyle continues to explain how there is little support for professionals, saying there is "little to go on in the way of research and very little tradition of rehabilitation" (p. iv).

Referring to the lack or absence of information dealing with issues for persons with hearing impairment, Schroedel (1992) maintains, "This lack of knowledge about persons who are hard of hearing stifles development of effective policies and programs to serve them" (p. 44). Kyle (1987) demonstrates early agreement and attributes the slow development of services, saying these efforts are "hampered by little evidence and a reluctance on the part of individuals to be identified as hearing-impaired [sic]" (p. iv). In regard to specialised services for persons who are hearing impaired and who have concomitant conditions, Steinberg (1991) remarks upon the need for specialised mental health services, indicating that "availability and accessibility of clinical services have lagged behind developments in research." She continues, "Given the paucity of resources accessible to hearing-impaired persons at this time, it is likely that

more than 90 percent of this population's mental health needs remain unserved" (p. 380).

Referring to the need for further research for persons with hearing impairment, Clelland (1995) reports that information regarding issues of adjustment from a non-clinical perspective is lacking. Most of the information regarding adjustments to hearing impairment is directed at instructing people how to optimize the use of their hearing aids (Cowie, Watson, Kerr, & Douglas-Cowie, 1995; Harvey, 1989; Kyle & Wood, 1984) rather than providing information regarding the psychological effects of the increased difficulty in communicating within all hard of hearing persons' relationships. Clelland (1995) concludes: "Research with hard of hearing persons has been sparse, however, due to the large number of hard of hearing persons in our population (Rodda et al., 1992), it is important to study this group" (p. 16).

In a British Columbian study, Hill and Nelson (2000) bring the issues of hearing impairment into the sector of mental heath. "Many Hard of Hearing and late Deafened individuals face significant mental health problems such as poor adjustment to hearing loss, communication anxiety, social isolation and failure at school and work" (p. 4). These researchers identify that: "There is also a need for shorter term counselling regarding issues specific to adjustment to developmental hearing impairment, progressive hearing loss, and Deaf/Hearing identity issues" (p. D13).

Need for Professionals to be Aware

In their study on post-lingual hearing loss and late deafness, Cowie et al. (1995) emphasise the importance for all professionals who are dealing with persons with hearing impairment to become aware of the immensity and seriousness of the problem. They state: "Its impact on many people is ruinous. Such an issue deserves to be tackled vigorously by all the relevant disciplines"

(p. 295). Wendt-Harris, Pollack, and Lassere (2001) further this notion of the absence of information. “Many professors in audiology education have been saying for a long time that there has not been enough emphasis on rehabilitation of the individual with hearing loss. Many programs seem to just emphasize hearing aid dispensing” (p. 27). Trychin (2001) discusses the lack of understanding in the medical and other professional disciplines. “Sometimes, a physician or other professional gives erroneous and harmful information, such as, ‘It’s only a mild hearing loss, don’t worry about it unless it becomes severe’” (p. 15-16). He gives an example: “‘My doctor told me it’s part of growing old, and I have to get used to it’” (p. 16).

According to Hill and Nelson (2000), several of the service providers involved in this Canadian study state that a considerable number of persons who are hard of hearing and late Deafened face mental health problems of a sizeable magnitude such as their adjustment to hearing impairment as well as communication anxiety. They conclude:

> Communication accommodations and hard of hearing issues are not well understood by mainstream counsellors and so these individuals also face barriers accessing appropriate counselling about their issues. More research is needed to clarify the mental health needs of hard of hearing, and late Deafened individuals and their families. (p. B6)

Recommendations for This Study

Clelland (1995) focuses on adjustment to hearing impairment and the implications for professional counsellors working with people who are hard of hearing and recommends that additional research is required, particularly with persons between the ages of 19 and 65 years. Although efforts are being directed toward understanding the experience of individuals with minimal hearing

loss at 40 dB or less, Newman, Jackson, Hug, and Sandridge (1997) testify that the amount of available information describing the impact hearing impairment has on daily living with this target group is minimal. Clelland (1995) suggests that in future studies "it would be valuable to include a qualitative component to any future research. More in-depth probing of questions like: 'How do you cope with your hearing loss?' and 'What kind of support from others do you find helpful?'" (p. 59). Such research would provide a broader picture of the types as well as magnitude of the difficulties experienced by persons with hearing impairment as they adjust psychologically. The importance of understanding people's personal experience of hearing impairment has been highlighted by Cowie et al., 1995; Harvey, 1998 and Trychin, 1991. Getty and Hétu (1994) contend that we can learn about the needs of persons with hearing impairment by "listening to how they talk about their experience" (p. 270). "Further research is needed," recommend Hill and Nelson (2000), "to review the mental health needs and access issues facing individuals who are Hard of Hearing or have acquired a hearing loss" (p. 4).

Toward a Phenomenological Study

Wood (1987), a researcher who experienced progressive hearing impairment during his search for an adequate theoretical framework to explain some of the psychosocial aspects of late or sudden onset of deafness, states: "The only system that confronts this crisis of meaning and authenticity has been that provided by the existential philosophers and writers" (pp. 159-160). According to Wood, a deep understanding of life experienced with hearing impairment can be achieved through phenomenological investigation. Wood concludes, saying, "Each quest for authenticity is therefore specific and personal rather than general" (p. 160). Therefore, through the application of a phenomenological approach with each participant in this study, I expect

participants will gain a deeper understanding of the meaning of their own hearing impairment.

Disability as a Social Construct

Disability is socially constructed (Mairs, 1996; Murphy, 1987). Once a diagnosis has been assigned to an individual, disability is then "defined by society and given meaning by culture" (Murphy, 1987, p. 4). According to Mairs (1996), people with little direct knowledge of the physical and mental limitations of disabilities frequently define them in terms of the consequences associated with the disabling condition. As a result, an individual becomes disabled "only from the point of view of another defined by common social values as 'able'" (p. 13).

A Professional Paradigm of Disability

Intervening professionals, suggest Getty and Hétu (1994), have their own culture that to some extent modulates their interventions. "One basic dimension of this culture is the medical (curative) model for professional help: "We, as experts, know the clients' problems, but the clients don't; we have the solutions to their problems'" (p. 270). Albrecht and Verbrugge (2000) concur with Getty and Hétu, stating that the western world's perception of disability continues to be interpreted through the medical model paradigm. The "medical, inside-the-individual model of disability is the paradigm still accepted by most governments" (p. 294) and gives the responsibility for deciding individuals' disability status to doctors. Stone (1997) agrees with Steinberg (1991) saying the "paternalistic behavior [sic] goes hand-in-hand with pity—again a very insidious thing to watch and eliminate. This behaviour is particularly present among the medical and mental-health professionals. People with disabilities encounter people in these professions frequently" (p. 11). Professional educators, counsellors in schools,

and professional social workers are also particularly prone to this way of thinking about persons with disabilities. Harvey (1998) cautions therapists to avoid becoming "unwittingly . . . paternalistic over our clients and strive to cure them of those problems" (p. 154). This paradigmatic framework, maintain Getty and Hétu (1994), tends to make professional interventions uniform across individuals and focuses on short-term effects. "There is a new model for disability," describes Sorkin (2004), "a paradigm that has been evolving for some years. The new thinking is that there is no pity or shame in having a disability" (p. 13). Sorkin explains how it is the stereotyping and the fears about disability as well as the discrimination levelled at persons with disabilities that affect individuals with hearing impairment. These occur, she contends, because of poor access to services, and therein lies the real problem. "We have moved away from taking pains to hide the fact that someone cannot hear or see. We encourage people to be open about their disabilities and instead focus on what they need [in order] to fully participate" (p. 13).

Defining Hearing Impairment as a Disability

With respect to specific disabling conditions such as hearing impairment, Lane (1984) agrees with Mairs (1996) and Murphy (1987) that society defines hearing impairment as a disabling condition. As a result of their hearing impairment, suggest Harvey (1998) and Lane, people will perceive themselves according to the way they believe society perceives them. In other words, an individual may describe him or herself as inadequate and even deficient because he/she believes these labels represent society's perception of them. "A person's psychological feelings of inferiority are, in fact, a social construction; these feelings mirror society's negative view that having a hearing deficit prevents one from living a full life" (Harvey, 1998, p. 8). Harvey makes the distinction between disability and handicap, saying, "A disability is an objectively measurable medical

condition" (p. 51). He refers to an external handicap as those obstacles experienced in the environment. Internal handicaps may begin as external but later may become internalised as emotional obstacles preventing the psychological development of a healthy self-esteem. Persons with disabilities, continues Harvey, do not always attempt to remove the external handicaps they face. In his experience, "persons with hearing loss too frequently accept a wide array of internal handicapping self-deprecatory beliefs as self-evident truths which are beyond scrutiny" (p. 53). Sometimes the external handicaps cannot be removed until their internal handicapping conditions (their beliefs) are dealt with. How family, friends, teachers, and professionals perceive hearing impairment will also influence the way in which individuals perceive themselves. Their growth and development will be subject to the parameters created by these internal and external definitions. "Thoughts cause feelings which cause behaviour" (Harvey, 1998, p. 57).

Hearing impairment has been defined in the context of the medical model. This reductionist approach has minimised the impact of the social and personal implications of hearing impairment not only for the person with a hearing impairment, but also for his/her significant others and society at large (Frank, 1995). Educating society on the implications and ramifications of this burgeoning social problem is, therefore, a daunting task to undertake. Objectives of this study include assisting persons with hearing impairment to understand their own needs and aiding professionals in their work to help empower individuals with hearing impairment to make their needs known.

Moving From a Medical Model to an Ecological Model: Challenging the Modernist Perspective

According to Frank (1995), we live in a post-modern era with respect to illness, disease, and disability. People of the pre-modern and modern era were

less aware of basic physiology and anatomy, body systems and their functions. People were expected to rely primarily on the medical practitioner to diagnose, treat, and alleviate their illness, disease or disability. Sacks (1984), a noted neurologist and writer, describes his own encounter with modernist medical professionals following a personal injury. Sacks refers to the roles each played, "he [surgeon] the role of All-knowing Specialist, I the role of Know-nothing Patient" (p. 81). Murphy (1987) describes the temporary suspension of the "ordinary role" in life during his own sickness and disabling condition. He comments on how he was expected to conform to the role of a sick person as conceptualised by the modernistic ideology of illness. The role of the individual as determined by the medical professionals, according to Murphy (1987) and Charmaz (2000), is primarily to get well. Speaking against the modernistic model, Murphy (1987) states: "In our doctor-ridden culture, this means that he [person with an illness] must seek medical advice; he must take his medicine and follow the doctor's orders. This expectation mandates the proper role of the sick as one of passivity" (p. 19). Similar expectations apply to persons with disabilities.

Without questioning the competency of medical professionals, Albrecht and Verbrugge (2000) argue, "a key problem is that evaluations in professional settings rarely tap critical details of real life" (p. 301). It is the individual life descriptions that can provide a different perception of what constitutes a disabling condition. The provision of psychosocial care to patients experiencing chronic illness, maintains Price (1996), begins with an appreciation of what it is like to live with a chronic condition. Charmaz (2000) agrees with Albrecht and Verbrugge (2000), stating that although health researchers, medical practitioners, and policy makers may claim to represent the concerns of patients, "they seldom obtain systematic 'in-depth' views of patients' experience of health care, much less of what it means to live with continued illness" (p. 277). Once again, the same can

be said for people with disabilities, particularly those with hearing impairment. It is also important to understand the phenomenological aspects of hearing impairment for particular individuals.

Phenomenology and Medicine

Charmaz (2000) stresses the importance of understanding the phenomenological aspects of illness for the individual. The experience of a chronic illness, as viewed by Charmaz, means more than just feeling the discomfort and stress; it entails acknowledging the existing symptoms or the need for care as well. Part of the process of gaining this understanding involves searching the metaphors for meaning and gaining a clearer understanding of the struggles and difficulties which the individual faces daily. "To understand the experience of chronic illness, we must study what ill people think, feel, and do in their natural settings" (p. 277).

Thorne and Paterson (1998) maintain that there is a shift from the prevailing paternalistic and positive approach (Getty & Hétu, 1994; Steinberg, 1991; Stone, 1997) as reported earlier. Thorne and Paterson (1998) conducted a mega-study of chronic illness research and a review of literature from 1980-1995. Researchers, they advise, "have shifted their focus from an almost exclusively outsider perspective (Schneider & Conrad, 1980; 1983) to a strategic and systematic inclusion of the insider perspective in what it means to live with a chronic illness" (p. 173). Speaking from a post-modern perspective on medical practice, Thorne and Paterson (1998) contend: "As this body of knowledge has evolved, the image of health care relationships in chronic illness has shifted from the model of client as patient to one of client as partner" (p. 173).

Thomas (2000) illustrates the importance and value of such a shift for the physician or the rehabilitation professional as well as for the patient or client relationship. In her phenomenological research study of chronic pain, Thomas

discusses the relationship of the participants with their doctor. Participants claimed that the most significant others in their lives, even more important than family members or friends, were their physicians. Despite repeated experiences with doctors who presented in an unkind, impersonal, or even cruel manner, participants of this study could not abandon a belief that there was a caring doctor somewhere who would provide relief from their unrelenting pain. Of the 13 participants in this study, only two persons reported having anyone with whom they could talk freely about their experience with chronic pain. It is also important to understand the phenomenological aspects of hearing impairment for particular individuals.

Postmodernist Challenge for Professionals

There is an underlying pressure for all rehabilitation and medical professionals to turn the focus away from the client's and patient's interpretation and move toward the professional's greater knowledge of the situation (Bolton, 2001; Sacks, 1984; Stone, 1997). The challenge for practitioners, therefore, is to listen to what the individual/patient/client indicates he/she needs rather than to be governed by their own belief in their superior knowledge and ability to know what a patient or client requires without asking. Getty and Hétu (1994) describe all professional interventions directed toward persons with hearing impairment as being uniform, with the focus on short-term effects. They claim that the tools used for assessment, diagnosis, and rehabilitation are the same regardless of age, gender, ethnicity, number of patients, or population. These researchers call for the individualisation of services by professionals in the field of rehabilitation and medicine.

Another challenge for those professionals working with persons with hearing impairment is to include the individuals they serve in the rehabilitative framework as primary players in the mapping of their own life plans and decision

making. In some instances, this may call for a radical shift in thinking for rehabilitation and medical professionals. There is an increasing awareness and need in the health sector, contend Dahl, Vesterager, Sibelle, and Boisen (1998), for this to occur, particularly in the field of audiology. They state: “Patients themselves should define actual needs, and that the treatment and rehabilitation should be adjusted accordingly” (p. 143).

The vehicle for crossing the divide from modernist to post-modernistic thinking, according to Murphy (1987), will be empathy. “The scope of modern medicine . . . does not help patients [clients] learn to think differently about their post-illness worlds and construct new relationships to those worlds” (Frank, 1995, p. 6); therefore, when professionals of all disciplines employ empathic responsiveness, it will help them help clients and patients reconstruct their world following recovery.

Hearing Impairment as an Individualised Phenomenon

Newman, Jackson, Hug, and Sandridge (1997) undertook a study to examine the impact of minimal hearing impairment on psychosocial functioning and communication ability of participants in their daily living situations. Their findings showed there was distinct variability in the degree of handicap reported by those participants with minimal hearing impairment. Using the Hearing Handicap Inventory for Adults (HHIA), a measure of self-perceived hearing handicap, some subjects reported “no handicap” while others reported “significant handicap”. The authors concluded, “By screening for both hearing impairment and hearing handicap, it would be possible to identify potential candidates for rehabilitative services who might have been missed by pure tone screening alone” (p. 213). Moreover, Newman et al. (1997) maintain that communication difficulties for persons with mild hearing impairments cannot always be predicted on the basis of their audiogram alone. This is consistent with the findings by

Noble (1996) and Erdman and Demorest (1998a, 1998b). The audiological assessment is not always adequate to determine the level of psychosocial impact of hearing impairment.

According to Harvey (1998), in some ways communication frustration seems greater for people who are hard of hearing than for individuals who are congenitally deaf or who are culturally Deaf. Harvey explains how individuals who are congenitally Deaf are often resigned to the limitations of spoken English since the task of learning it may appear to be insurmountable. Individuals who are hard of hearing, on the other hand, are often acutely aware that they are missing something. Therefore, tremendous effort is exerted in trying to understand what is being said and often, in the final analysis, individuals with hearing impairment simply resort to guesswork. Steinberg (1991) states, "Only about 40% of spoken language is comprehensible through lipreading [speech reading]" (p. 381); therefore, the remainder is left to context and guesswork. Wallhagen, Strawbridge, and Kaplan (1996) agree with Wood (1987) that sensory changes such as decreased hearing can alter an individual's ability to communicate with others and have a remarkably negative effect on interpersonal relationships. The actual levels of hearing impairment, argue Wallhagen et al. (1996), may be less important to functioning than the perceived impairment. These authors conclude that "hearing impairment has also been shown to be significantly associated with multiple negative outcomes, including depression, loneliness, altered self-esteem, and diminished functional status" (p. 11). This is consistent with earlier research studies by Cowie and Cowie-Douglas (1992). Varying degrees of adeptness in speech reading, understanding of non-verbal cues and ability to interpret contextual information will influence an individual's ability to function in activities requiring communication. Therefore, the implications for someone with hearing impairment can only be understood on an individual basis.

Hearing Impairment as a Trauma

Progressive hearing impairment, maintains Harvey (1998), may be considered a traumatic event. "Acquired hearing loss is traumatic to the extent that it disrupts the psychological integrity of an individual" (p. 187). Trauma can be defined as an event that (1) falls outside of the parameters of ordinary human experience, (2) is beyond the perceived potential and ability of the individual to cope with, and (3) is markedly disruptive of the individual's psychological functioning (McCann & Pearlman, 1990). Damage to psychological integrity can be defined as the loss of psychological protection or vulnerability (Herman, 1992), a collapse of reality as one knows it (Epstein, 1991), or a shattering or breaking apart of one's sense of self (Ulman & Brothers, 1988). People have varying degrees or hierarchies of needs, affirms Harvey (1998). Some needs are central to the maintenance of an individual's psychological equilibrium or integrity, whereas others are more peripheral. If an event disrupts the satisfaction or fulfilment of these central needs then trauma may result. If, however, the event threatens only the person's peripheral needs, then a less severe reaction can be anticipated. Therefore, the potentially traumatic effects of hearing impairment will depend on how the impairment is perceived and the degree to which the central needs are affected. The same degree of hearing impairment may affect individuals in extremely different ways (Trychin, 1991).

In reference to the impact of hearing impairment on the individual, Rockow (2001) reports:

> The sense of loss can be devastating. It is fully understandable that they go through a grieving process that may last many months, even years. The effect is probably greatest for those people who suffer a sudden hearing loss, but it also accompanies severe and profound progressive hearing loss. (para. 6)

Gaining a greater knowledge and awareness of life with a hearing impairment may provide helping professionals with an opportunity to reach a deeper understanding of the impact hearing impairment can have on an individual. This may also serve to invite the individual affected by hearing impairment to become an active participant in the process of treatment and adjustment.

A Psychosocial Approach to Dealing with Issues of Hearing Impairment

Noble (1996) presents criteria for an effective psychosocial approach for persons with hearing impairment that address three important aspects. The first aspect relates to the individual characteristics of the person experiencing a hearing impairment and the effect these may have on his/her ability to interact with rehabilitative alternatives. The second aspect relates to the individual circumstances that the person is faced with in matters relating to family, community, work, leisure activities, and vocational pursuits. According to Noble, the individual will experience the direct effects of his or her hearing impairment in all of the aforementioned areas. As well, there is the hope of maintaining or improving functional communication. Finally, a psychosocial approach will address the circumstances of others with whom the person with hearing impairment lives, works, or otherwise shares or spends time. An important aspect of the purpose of Noble's work is that the "psychosocial approach necessarily includes recognition of the potential for disadvantages experienced by others involved in the life of the person with impaired hearing" (p. 6).

Psychosocial Effects of Disability and Hearing Impairment on Self

Pollin (1994) identifies eight distinct fears that most people with long-term disability experience. These represent a useful framework to describe characteristics which are common to persons with hearing impairment. These

characteristics include: the fear of loss of control; the fear of loss of self-image; the fear of dependency; the fear of stigma; the fear of isolation; the fear of abandonment; the fear of expressed anger, and the fear of death. Additional themes have been added to this discussion. This list is not exhaustive but represents the multifaceted aspects of disability and hearing impairment. Reference will be made to disability in a broad context as well as more specifically with regard to hearing impairment.

Fear of Loss of Control

From a personal and family perspective, Murphy (1987), a social anthropologist, describes the insidious deterioration of relationships as a result of his disabling condition. In his autobiography, he elaborates on how his authority in the family diminished due to a progressive and degenerative neurological disease. Murphy remarks on his transformation from an able-bodied individual to a state of paraplegia and finally to quadriplegia, losing all voluntary motor function below the neck. "Disability, dependence, and unequal reciprocity have eroded my leadership role in the family. My waning authority was not, however, a sudden precipitous drop triggered by illness, but another step in a gradual process that long predated my disability" (p. 215).

Murphy (1987) focuses on his inner world, relating his personal history using a metaphor of slow but steady loss of meaning and function in his life. "This was particularly frightening for someone who had clawed his way up from poverty to a position of respect. I had become a person of substance and that substance was oozing away" (p. 85).

This paradigm of gradual loss of function is pertinent to my study because Murphy's description parallels the sense of unremitting deterioration of control for persons with progressive hearing impairment in as much as the process is insidious (Stone, 1997), gradually eroding away an individual's practical

functionality. Harvey (1998, 2001) provides numerous examples of persons in families who struggle to maintain some sense of autonomy in life, authority in relationships and decision-making as their hearing gradually deteriorates.

In their studies of occupationally related hearing impairment, Hétu, Lalonde and Getty (1987) and Hétu, Getty, and Waridel (1994) describe the fear workers have of being confronted with the prospects of loss of position, authority, and status due to their hearing impairment.

Fear of Loss of Self-Image

According to Murphy (1987), "of all the psychological syndromes associated with disability, the most pervasive and the most destructive is a radical loss of self-esteem" (p. 90). People who experience illness and crisis in their lives often experience decreased self-esteem, feelings of inadequacy, and a sense of not being heard (Hutchinson, Wilson, & Wilson, 1994; Wallhagen et al., 1996). Cowie et al. (1995) conclude from their study that persons with hearing impairment struggle with a reduction in their level of confidence. Internalisation of the perceived stigma associated with hearing impairment can lead to a sense of failure and diminishment as well as damage to self-image when an individual has to acknowledge the irreversibility of his/her hearing impairment (Hétu et al., 1994).

Fear of Dependency

Frank (1991) recounts the fear associated with the changes and the loss of control (Thomas, 2000) over his life: "Your relationships, your work, your sense of who you are and who you might become, your sense of what life is and ought to be—these all change, and the change is terrifying" (p. 6). In their study, Cowie et al. (1995) focus on the concerns persons with hearing impairment have with respect to becoming a burden on significant others. Thomsett and Nickerson

(1993) describe the trials of reciprocating demands first with one partner experiencing progressive hearing loss while the other struggles with different disabling conditions. And finally, Ashley (1985a) and Ashley (1985b) echo the experience of rallying to the demand of decreasing abilities and subsequent increase of dependency on the partner.

Commenting on the results of interviews and questionnaires with late-deafened individuals, Cowie et al. (1995) describe responses of participants expressing feelings of loss of confidence in their ability to uphold responsibilities, hence becoming a burden to others. The conclusions drawn from this study are not restricted to late-deafened individuals but also to adults with hearing impairment of varying degrees. Cowie et al. contend that "understanding . . . is crucial for an effective response, be it from the significant others who interact with deafened people, or from the professions which aim to support them" (p. 293).

This change of role in the family (Meadow-Orlans, 1985; Wood, 1987) and the fear of dependence on the spouse (Hétu & Getty, 1991b) are frequently noted in the literature. Hétu and Getty and Wood identify dissatisfaction and burden on the spouse as direct consequences of hearing impairment for the family.

Fear of Stigma

Referring to persons with epilepsy, Stone (1997) explains how many individuals admit that "it's not the condition that troubles them, but the way society responds to their neurological disorder" (p. 65). For precisely the same reason, explains Stone (1997), many people with epilepsy have a significant fear of having a seizure in public. Similarly, because of fear of rejection and stigma, individuals who have a hearing impairment are afraid of having their condition exposed (Hétu & Getty, 1991a, 1991b; Getty & Hétu, 1994; Meadow-Orlans, 1985). "People are vulnerable to ridicule at any age" (Trychin, 2001,

p. 19). Relating to the loss of hearing and the subsequent reduced ability to communicate, Ashley (1985b); Cowie et al. (1995); Hétu et al. (1987); Hétu, Getty, Beaudry et al. (1994); Hétu et al. (1994) and Wood (1987) describe how the changing attitudes toward persons with hearing impairment by some of the important and significant others—spouses, children, co-workers, bosses, and friends—can be the most difficult aspect in coping with this situation.

In a study on occupationally related hearing impairment, Hétu et al. (1994) cite a "lack of compassion on the part of others" (p. 322) in the workplace as being the single most compelling reason for workers not to disclose that they had a hearing impairment. This study also showed that workers were not familiar with many of the characteristics of hearing impairment among affected workers. As a result, workers were not inclined to express compassion or provide help in their everyday workplace encounters with persons with a hearing impairment. In this same study they reported how the strong fear of being stigmatised by others in the workplace led to a concealment of the problem and its possible ramifications on other areas of the individuals' lives.

In an earlier study of occupational hearing impairment, Hétu et al. (1987) revealed that there was a fear and/or unwillingness to admit to one's spouse that a hearing problem existed. This reticence "increases with the severity of the perceived hearing disability" (p. 148). In other words, only when hearing impairment becomes a serious enough problem is it addressed. It is important to note that in this study, approximately 20% of those who believed they had a severe hearing impairment never discussed this issue with their spouses. Finally, the spontaneous response of the family to the hearing disability and to the after effects of hearing impairment due to noise exposure only contribute to the psychosocial disadvantages experienced by the worker, therefore further reducing any advantage to the individual with the hearing impairment to disclose his or her condition.

Schroedel and Gyer (2000) and Harvey (2001) refer to the particular issues of youth and young adults with hearing impairment leaving the comfort and safety of school in search of freedom. These researchers determined that due to fear of stigma, graduates might not be able to join the expected social networks that will lead to their expected or anticipated expanded sense of self-sufficiency. Schroedel and Gyer's 15-year follow-up study with college students who were hard of hearing found they benefited from counselling (Stone, 1992; Rockow, 2001) to help them accept and disclose their hearing impairment and to demonstrate a willingness to seek help and self-advocate.

Fear of Isolation

Isolation is one of the factors persons with hearing impairment encounter (Clelland, 1995; Dahl, 1995; Meadow-Orlans, 1985; Rockow, 2001; Steinberg, 1991; Stone, 1997; Trychin, 1991; Trychin & Busacco, 1991; Wood, 1987). "One of the worst things about hearing loss is the sense of isolation" (Richter, 2001, p. 9). Cowie et al. (1995) report how participants in their study described experiences of feeling marginalised in everyday experiences of living. Experiences of both social isolation and reduced participation were identified by participants in the study by Hétu and Getty (1991a). These experiences are reinforced by Ashley (1985a) and Wood. Just as the person with the hearing impairment is excluded from others, so too may the significant other become serendipitously isolated.

Murphy (1987) describes his personal struggle with loss through the progressive decline of function that transcended the spiritual and functional components of his life. He describes how people acted differently toward him following his recovery. Even more concerning were the changes in how he perceived himself and the changes he experienced in his self-image. He reveals that he felt alone and isolated despite the strong support of family and friends.

Murphy includes withdrawal in the mix of emotions, stating: “it only compounds the disabled person’s subjective feelings of damage and lowered worth, sentiments that become manifest as shame and guilt” (p. 92). Disabilities can rob individuals of their authority in systems such as the family unit, which then may lead to social isolation (Frank, 1995; Mairs, 1996; Stone, 1997; Wood, 1987) from family and friends, segregate partners in their relationship, and generally affect all members of the family and social systems.

Fear of Abandonment

Speaking to the solidarity of the experience of the stroke survivor, Secrest (2000) explains how several participants noted, “‘others don’t understand’ or that ‘only those who have experienced it can understand,’ referring to both friends and family” (p. 97). She continues: “Thus, life begins to take on a new rhythm, and the change is experienced as the relationship is transformed” (p. 97). Stone (1997) uses the analogy of entering a foreign country to explain the experience of living with a disability. There are new customs to be learned and a new language to master. Stone writes about her personal experience with disability and making the most of the changes in her life. Although on the one hand there is no exiting this new country, Stone (1997) remarks: “This is where you learn a lot about yourself, other people, grace, and, should I dare say, the meaning of spirituality in your life” (p. 101).

Frank (1991), a medical sociologist and survivor of two life-threatening diseases, reveals the impact his disability had upon his relationship with others. The loss, states Frank, goes beyond the physical body. He describes the worst thing that could happen and explains how it did happen. Many of his friends abandoned Frank and his wife because they could not deal with the threats his disability might mean to their relationship. Resuming the relationships with those who did not stick by and acknowledge his illness became much less integral to

their lives. The experience of illness did not just happen to him, but to his wife as well.

Workers fear being relegated to the sidelines and losing their sense of belonging, according to Hétu et al. (1994), if they reveal the reality of their hearing impairment to others in the workplace. This is an important factor which may lead to passivity and withdrawal in the individual with hearing impairment.

Themes of fragility, vigilance, and loss of responsibility, as presented in Secrest's (2000) phenomenological study with individuals who have experienced a stroke, are also evidenced in the descriptions provided by Thomsett and Nickerson (1993). Ashley (1985a) and Ashley (1985b) describe how these figurative themes of fragility exist for persons and families when hearing impairment occurs with a rapid onset and families become vigilant as they rally to preserve the integrity of relationships. In each of these instances there is the serious threat of abandonment and the perceived risk of being outcast.

Fear of Expressed Emotion

In a clinical example of his work as a counselling therapist, Harvey (2001) emphasises how both partners in a marriage relationship experience overwhelming emotions of anger, isolation, and guilt. What is particularly interesting about Harvey's example is that each member within this relationship is expressing similar feelings. They appear to be entrapped in a "vicious cycle" (p. 107) and each partner appears to be lacking the tools and the ability on his/her own to articulate his/her feelings and experiences. Sanders (1993) explains how the fears experienced by each person in the relationship or family must first be "externalized" before they can be "reduced through [planned] action" (p. 476). Sanders describes how both the family and the individual with the hearing impairment have to deal with the problem. Therefore, all those who are close to the person with a hearing impairment can be deeply affected.

The poignant impact of progressive hearing impairment on a family is demonstrated by Harvey (2001) in the following example. Referring to one of his clients, Harvey describes another instance of the "vicious cycle" (p. 94) his client found himself in, with respect to interaction with his family. This circumstance was precipitated by his lack of acknowledgement of his own fears.

> [He] lectured more in order to spare himself the anxiety and perhaps humiliation of not understanding what was being said. But, at the same time, since he could not control his progressive hearing loss, it led to increasing anxiety; and in turn, he lectured more. (p. 94)

Fear of Loss

Fear of loss is not distinctively or exclusively associated with disability. In this section, "loss" refers to the absence of position or ability to function, or to the inability to perform a task or activity. Frank (1991) contends that in order to cope with the changes which people with disabilities have no control over (Stone, 1997) they must begin to grieve their loss. He describes his own grieving, saying: "I needed to mourn the end of what I had been. It was like saying goodbye to a place I had lived and loved" (p. 38). Further, Frank acknowledges how his lack of ability to make specific plans for the future marked the "beginning of the loss of becoming" (p. 36). Ashley (1985a) speaks of his loss of personal aspirations, loss of his sense of his former self, detachment, and feeling of being marginalised from experiences of daily living.

From a therapeutic perspective, Harvey (1989) and Steinberg (1991) agree that in order for the family to reorganise following the acknowledgement of a serious loss by one of its members, there must be a period of mourning in order to reincorporate this individual back into the family unit. This seems to be the case not only for individuals who experience sudden or adventitious deafness but

also for any family where hearing impairment may have led to individual misunderstandings and discord. Restoration can only come following admission and a decision to rebuild. Speaking of loss in terms of traumatic events is potentially of enormous value. Harvey (1998) points out how important it is for the individual to seek a better understanding of the implications his/her trauma has first, and then share those insights with supportive and caring others.

Other Psychosocial Problems Associated With Hearing Impairment

Depression as a Psychosocial Effect of Hearing Impairment

In their six-year longitudinal study of the psychosocial and psychological impact of hearing loss, Wallhagen et al. (1996) observed how "sensory changes, such as decreased hearing, can alter an individual's ability to communicate with others and significantly affect interpersonal relationships" (p. 11). Trychin (2001) explains how "hearing loss itself may play a causative role in the depression or anxiety" (p. 18). Results show a greater than threefold likelihood of depression coupled with feelings of being left out, and nearly two and one half times greater likelihood of inactivity. It was reported that the likelihood of individuals not enjoying their free time doubled for those acknowledging a hearing impairment. This group was compared with control groups of the same age, status, education, ethnicity, and number of chronic conditions. These findings are consistent with many of the psychosocial problems reported by Cowie and Douglas-Cowie (1992). In this study, clinical depression was identified in 5% of the general hearing population and it was noted that clinical depression was identified in 19% of those individuals with mild and moderate hearing impairment. Remaining fairly constant to 70 dB, the ratio increases sharply beyond this threshold when speech discrimination is reduced to less than 70% and the pure tone loss is over 70 dB with amplification. In these instances the rate of depression rose to 59%. Similar

findings were provided in a study by Meadow-Orlans (1985). In regard to mental health services, Steinberg (1991) states: “Given the paucity of resources to hearing-impaired persons at this time, it is likely that more than 90% of the population’s mental health needs remain unserved” (p. 380).

Uncertainty as a Psychosocial Effect of Hearing Impairment

The greatest psychosocial problems associated with loss of hearing, claims Sanders (1993), are the uncertainty and the absence of knowing what to expect. “What is not easy is the terror that the concept of deafness evokes. The client feels he [she] has seen the future and it is intolerable” (p. 474). Sanders provides a comprehensive account of the many psychosocial ramifications of hearing impairment. He contends that individuals with a progressive hearing impairment must look into the future with the knowledge that the advancement of their condition is inexorable. Ignoring the reality is temporary, and ultimately individuals must come face-to-face with it. The future for people with a progressive hearing impairment, declares Sanders, is frightening. He refers to the “progressive erosion of their relationship and of their family relationship and of their means of deriving pleasure in life through communication” (p. 475). Finally, issues of loss of income, potential loss of employment due to communication barriers and the loss of role and identity, personal self-confidence and self-respect are all jeopardised by the loss of hearing. The individual’s very existence may be perceived to be in jeopardy as a result of possible loss of financial income.

Steinberg (1991) adds to this list of psychosocial problems associated with hearing loss: anxiety, social withdrawal, and family dysfunction. Loss of meaning in life is included by Wood (1987) along with a sense of hopelessness, dependency on spouse or significant others, and diminished social life.

Demoralization Syndrome and Hearing Impairment

Kissane, Clarke, and Street (2001) discuss demoralization syndrome in the context of patients in palliative care. This description encapsulates many of the fears identified by Pollin and Golant (1994). Demoralization syndrome is associated with chronic medical illness and disability. It is characterised by "fear of loss of dignity, social isolation, and—where there is a subjective sense of incompetence—feelings of greater dependency on others or the perception of being a burden" (p. 12). These characteristics are widely represented in the literature on psychosocial aspects of hearing impairment; therefore, they deserve mention in the context of this study.

Kissane et al. (2001) describe the experience of loss through disability and illness from an existential perspective. Along with a disability, there is a sense of hopelessness, loss of meaning, and existential distress. These are core features of the demoralisation syndrome, and according to Kissanne et al. all these characteristics must be present in order to make this diagnosis. "This distress [is] so commonly ignored within the medical model" (p. 12). Kissane et al. conclude: "While the demoralization syndrome may be a harbinger of depression, it stops short of meeting formal diagnostic criteria for major depression, and thus escapes active intervention in today's medical world" (p. 13). Hopelessness and helplessness result from the feeling of being confined or trapped or from not knowing what to do. These often occur in the presence of alienation and/or social isolation. Existential distress is described within the context of this syndrome as "the despair and angst associated with a loss of purpose and meaning to life, including relationships and, in some profound way, a loss of any sense of who one is" (p. 13).

Luterman (1984) refers to "existential loneliness" (p. 38), stating that it arises from the anxiety and fear we associate with separation. Speaking from his work as an audiologist, Luterman claims, "the underlying terror of progressive

hearing loss experienced by the clients was the feeling of being cut off and isolated" (p. 40). Verbal communication, states Luterman, is the primary means people employ to alleviate interpersonal loneliness. Trychin (1991) and Trychin and Busacco (1991) describe hearing impairment as a communication problem. When this forum for communication is diminished, the result can become very disturbing.

Effects of Hearing Impairment on Family or Significant Others

Hearing impairment and the associated problems deriving from it may, according to Harvey (2001), activate others' feelings and their attachments to issues of personal loss or trauma. Referring to the "private terror" (p. 109) associated with hearing impairment, Harvey discusses the reaction of family members coping with their own fear of adjustment to their spouse's or other family member's loss. He suggests that sometimes they may feel as if they are being "consumed by a range of emotions and fears that [are] encoded with [their] own unique metaphors" (p. 109). Sometimes these feelings may be associated with some other issues of loss or abandonment in their lives or to feelings relating to the projection of anticipated outcomes of loss due to changes to relationship, or changes to family economics as a result of hearing impairment.

Previous Life Experience and Hearing Impairment

From a psychoanalytic perspective, Harvey (2001) describes how previous life experience or personal loss or trauma can have an impact on an individual's adjustment to hearing impairment. In a Canadian National Health and Welfare Task Force (1988) publication, (Harvey, 1998, 2001; Trychin, 1991), reference is made to the way in which previous life can play a role in the individual's adjustment to hearing impairment. Harvey elaborates by providing an example from his clinical practice. "I wonder if there are other experiences or

losses that you've had—that you've brought to the relationship—that somehow cause you to react with more fear, more loneliness, more anger than you otherwise would've" (p. 107). In each of these references there is a solid recognition of the shared responsibility of the individuals with hearing impairment, their families and the community to assist in the rehabilitation process. This description is consistent with Stone's (1997) example by a psychologist with whom she works, who states, "A person who is a healthy, able-bodied member of the team [family] can suffer from the disabling condition as much, if not more, than the individual with a disability." She adds: "These significant others often carry these burdens silently" (p. 99). Whether this is a projection (Sanders, 1993) or a "vicarious" (Harvey, 2001) loss, the impact upon the others in the relationship can be remarkable.

Family and Significant Others

Hearing impairment is disruptive not only in the way it affects the individual personally but also in the way it affects his/her relationships (Sanders, 1993; Trychin, 1991). Hearing impairment "creates confusion about identity and personal values, disrupts personal relationships, and creates a feeling of insecurity and apprehension about the future" (Sanders, p. 474).

Kleinman and Seeman (2000) suggest disability must be dealt with in a broader context. They state:

> The experience of illness is not bounded by the bodies or consciousness of those who are ill. It reaches out to encompass a household, a family, or a social network. It reaches deep into the inner worlds of the patients, yet it is decidedly transpersonal. (p. 231)

They describe a family in crisis in which one of the children has been diagnosed with muscular dystrophy (Kleinman, 1988). Kleinman and Seeman (2000)

contend: “the illness experience affects each of them, not in isolation, not always in the same way, but in relation to one another” (p. 231).

Stephens, France, and Lormore (1995), reporting on their investigation into the effects of hearing impairment on the individual’s family members and friends, note that psychosocial problems represented 24% of problems listed by both the significant others and by the patients on their behalf (Hétu et al., 1987). Having to repeat things during live conversation with the significant others was reported as the most frustrating problem.

Ashley (1985a) and Ashley (1985b) disclose the devastating changes associated with hearing impairment on marriage relationship. Ashley (1985a) describes his experience of sudden hearing loss. “The plunge from a normally hearing world into one of almost total silence meant the plummeting of my happiness, aspirations, and hopes for the future” (p. 60). Ashley (1985b) explains in detail the adaptations that were required for work as well as for home life in order to manage. She refers to the text of a deaf poet, David Wright (1969), stating his poems provide “an admirable opening for any discourse on deafness; they are particularly appropriate for one by a hearing wife” (p. 71). I believe Wright’s text below may, in a small way, illustrate the experience of the spouse of someone with a progressive hearing impairment.

> About deafness I know everything and nothing. Everything, if forty years’ first-hand experience is to count. Nothing, when I realize how little I have had to do with the converse aspects of deafness—the other half of the dialogue. Of that side my wife knows more than I. (p. 71)

Glass (1985) maintains there is a need for more research to investigate the varied changes that occur in a family when there is a member who experiences hearing impairment. Glass concludes, “Successful coping probably requires unsuspected adaptations which are costly to all family members” (p.

173). Therefore, in order to understand the psychosocial impact of hearing impairment on individuals, an important further step is to explore the influence on significant others.

Unique Aspects of Hearing Impairment

Invisibility of Individuals with Hearing Impairment

Harvey (1998) suggests that the dubious distinction of deafness being the most "invisible" (Ashley, 1985a; Clelland, 1995; Dahl, 1995; Getty & Hétu, 1994; Richter, 2001; Ross, 1997; Stone, 1992; Trychin & Busacco 1991; Weinstein, 1996) disability might well be shared with individuals who are hard of hearing because they may be more "invisible" (Dahl, 1997; Ross, 1997), since they often go unrecognised by the lay person. The barriers associated with being a person with hearing impairment make his/her experience in the hearing world tenuous and equally as fraught with barriers as those experienced by persons who are deaf. Ashley (1985a), former member of the British Parliament, refers to the "laudable endeavour" (p. 69) of hearing people attempting to communicate with someone who is deaf. These same misunderstandings by hearing individuals are also experienced by people who have hearing impairment and are not categorically deaf. Ashley remarks upon the ease associated with hearing people as they become patronising, tending to equate the hearing impairment with a loss of reason "perhaps because of the invisibility of the handicap or a result of difficulty in communicating. It is one of the heaviest burdens deaf people [and persons with hearing impairment] have to bear" (p. 69).

Sacks (1970) articulates a major problem associated with the struggle with an "invisible handicap" in his description of a patient with a profound proprioceptive deficit.

> The lack of social support and sympathy is an additional trial—disabled, but the nature of her disability not clear—she is not, after

> all, manifestly blind or paralysed, manifestly anything. This is what happens to those with disorders of the hidden senses. (p. 50)

The Insidious Nature of Hearing Impairment

Hétu, Getty, and Jones (1993) focus their investigation on the effects of progressive hearing impairment, citing this as more common and more devastating than sudden hearing loss because of its "insidious nature" (Hétu et al., 1993, p. 364). Another distinction is that persons experiencing sudden hearing loss are already aware of their loss, whereas persons with progressive hearing impairment are in the process of becoming aware. Trychin (2001) describes how readily people adapt to hearing impairment and miss the gradual erosion of this sense.

> There are a number of people who don't know they have a hearing loss. One reason for this may be the insidious nature of some types of hearing loss, that is, that their hearing loss had a gradual onset, and they adapted to each slight reduction in hearing ability. (p. 15)

Continuing with the distinction, Hétu et al. (1993) explain that many persons with sudden hearing loss experience mourning and grief as they work with their partners and families to "make sense of the impact of hearing loss on their lives" (p. 367). In contrast, for persons with progressive hearing impairment, their experience is not preceded in the typical manner as described. Denial, anger, depression, and finality of the loss occurs in less defined ways since these individuals "are tacitly involved in a process of coping with hearing difficulties while they are becoming aware of them" (p. 367). Describing further the impact of hearing impairment, Finn (2001) explains how "hearing loss, even with the best-fitting aids, impacts every interaction of our lives—relationships, work, education, and intimacy. It also impacts on our interaction with ourselves,

undermining self-confidence, self-esteem, and mental and physical well-being" (p. 31).

The Value of Empathy in Professional Practice

Empathy and Medical Practice

An integral part of adjustment, healing, and transformation for persons experiencing illness or disability, according to Dixon, Sweeney, and Gray (1999), is the empathic response of all medical and rehabilitation professionals and therapeutic counsellors. Levasseur and Vance (1993) describe the meaning of empathy in the context of the medical doctor-patient relationship.

> The human understanding that we wish to indicate with the word *empathy* is not so much a psychological transposition as a respect for, and openness to, the concerns of the patient whose benefit is the entire aim of the caregiver's profession. The idea of empathy that is truly crucial for clinical practice is that of genuine attention to the individual patient's concerns, and the acceptance of those concerns. (p. 81)

Dixon et al. (1999) examine the contravening views of physicians and patients. They report that in a consumer survey, respondents indicated the three most important priorities of patients were "to have a doctor who listens and explains clearly, who allows sufficient time for consultation, and with whom they are able to get an appointment" (p. 310). Thomas (2000) explained how, despite repeated experiences of doctors who presented in an unkind, impersonal, or even a cruel manner, participants of this study could not abandon a belief that there was a caring doctor who would provide relief from their unrelenting pain. Of the 13 participants in Thomas's study, only two persons reported there was anyone with whom they could talk freely about their experience of chronic pain. Patients interviewed by Miller, Yanoshik, Crabtree, and Reymond (1994) in a

study involving individuals who experience severe pain, all claimed that their physicians did not listen to them when they tried to describe their pain and its impact on their daily lives. When researchers interviewed the physicians, a different understanding of listening was discovered. To the physicians it meant hearing words in the context of diagnostic cues, rather than placing the words into the context of the patients' lifeworld. This communication gap between the physicians and patients was reported to be the strongest theme in the study by Miller et al. (1994).

Two of the top three priorities for physicians, according to Dixon et al. (1999), were to involve their patients in treatment decisions and to offer patients up-to-date treatment options. "It seems that GP's wanted to be expert practitioners of modern medicine, while their patients were looking for physician healers" (p. 310). These authors conclude that the ability to listen and to empathise are among the most important skills for physicians to have and use today. Not being listened to by doctors is a well-documented complaint of many types of patients, "but may be particularly galling to the pain patient" (p. 695).

Spiro (1993) takes the position that the physician's first and primary task is to decide what is going on with the patient and to determine what tests must be done, if any. "At the same time, doctors must listen to what the patient tells them, remaining open to be moved by the story even, for that will open the clear path to diagnosis" (p. 4). Speaking as a medical doctor, Spiro claims: "Listening goes straight to the heart and helps to create empathy. Empathy opens our eyes to let us see what the CT scan has missed. The ear is as important as the eye in medical practice" (p. 4). Taking empathy into a broader context of other helping professions, Spiro maintains: "Empathy, however, underlies the qualities of the humanistic physician and should frame the skills of all professionals who care for patients" (p. 7). Finally, according to Dixon et al. (1999), "the attitude of the doctor can make an appreciable difference to the psychological response of the

patient who feels the need to be understood and listened to empathetically" (p. 310).

Empathy and Professional Practice

"If the personal is brought into the professional," claims Bolton (2001), "then the empathy between the client and professional will be increased" (p. 5). Bringing the concept of empathy into the realm of persons with hearing impairment, Sanders (1993) discusses the factors that transcend the physiological or sensory changes, incorporating threats to relationship, employment and personal independence. Sanders goes on to describe the need for understanding and empathic relationships between people with a hearing impairment and professionals. "A hearing handicap aggravates other personal concerns and generally erodes self-confidence. These problems in turn create a need to share the burden with someone who is able to empathise and who has the ability to guide the client" (p. 474). The challenge for any professional is to bridge the gap of modernist thinking to postmodern expression and recognise the person's wholeness.

Bolton (2001) remarks, "One of the greatest benefits to . . . a client in any interaction with a practitioner, is the sense of their relatedness to the professional: that they [the professional] are interested, involved, and care" (p. 6). Thorne and Paterson (1998) maintain there is a need to negotiate partnership relationships between providers of care and patients. This perspective is important from the standpoint of my proposed study because it denotes an empowerment of the candidates and subsequently their active involvement in a program of rehabilitation. Thorne and Paterson (1998) also point out how people with chronic illness experience variations in their desire and ability to assume an active role in the management of their illness.

> Let us [providers of care] learn when our patients want to be treated as partners, but let us also learn when they want to be in control of our actions, and when they want us to assume complete control. Only then will we be able to offer the full range of support the chronically ill tell us that they need to live their lives as productively as possible within the limits of their illness. (p. 176).

In summary, empathy goes far beyond the parameters of medical or other professional diagnosis and treatment. Although hearing impairment is first a medical diagnosis, it encompasses many more professionals such as audiologists, audiological technicians, teachers, and vocational and rehabilitation professionals. All of these professionals are called to reach the same level of empathic understanding and willingness to listen in order to assist the individual in his/her adjustment and beyond.

Critical Reflection as a Means for Gaining a Deeper Understanding

Critical Reflection and Professional Practice

In order to make professional services both accessible and effective for persons with hearing impairment, professionals must critically question their practice, taking into consideration the diversity of individuals and life situations of the people being served (Getty & Hétu, 1994; Hétu & Getty, 1991; Stone, 1992). This requires professionals to demonstrate a willingness to learn from the individuals themselves by listening to them when they describe their experiences with their problems. Many professionals, contends Stone (1992), are in the profession of assessing others but find it difficult to monitor their own behaviour. Cranton (1996) emphasises the need for professionals to enter into the process of critical self-reflection. This, she maintains, will lead to professional

development that is both transformative and emancipatory. Cranton refers to this as a process whereby professionals become researchers of their own practice. Stone (1992) recognises the difficulty professionals have in monitoring their own behaviour but holds the position that the rewards for doing this can be significant. “Any person who has enough self-confidence to monitor his or her own behaviour and voluntarily seek peer feedback will have the edge and have a positive impact on the people they serve—whether through research or direct clinical practice” (Stone, 1992, p. 63).

Teachers and counsellors who are in search of ways to support this type of empathetic enquiry, for the purpose of gaining a deeper understanding of ethnic minorities or students, must “‘travel into our own worlds’ in order to ‘travel to those of others’ and gain empathic understanding” (Salvio, 1998, p. 11). This same approach, it can be argued, can be used for gaining a richer and broader understanding of persons with disabilities.

Therefore, reflective practice, according to Bolton (2001), “supports practitioners to see their relationship with their student, client, patient, or colleague within a range of possible roles. This is a way of rounding out practice, as well as a response to practice” (p. 11). Bolton refers to the ideal of “holistic practice: of seeing the whole patient or student or client rather than just a disease or teaching situation or problem” (p. 11). It is impossible, argues Bolton, for practitioners to leave their personalities, their sense of humour, their beliefs, and their fragilities outside the interview room. They need to be aware that they too assume different roles at different times.

Howard Stone (1992), a founding member of one of the world’s largest non-profit agencies serving persons with hearing impairment, Self Help for Hard of Hearing Persons Society in the United States, speaks in support of the need for critical reflection in the practice of professionals. “Any person who has enough self-confidence to monitor his or her behaviour and voluntarily seek peer

feedback will have the edge and have a positive impact on the people they serve—whether through research or direct clinical practice" (p. 63). These reflections can, therefore, be taken back into our individual practice situations and can improve and develop individual practice (Bolton, 2001; Kolb, 1984).

Rogers (1969) refers to the experience of effective practice as being a demonstrated willingness to have faith in one's own knowledge, skills, and experience and the trust in the process one is engaged in, relating to the client with respect and regard that is unconditional and positive. Rogers comments on the educated practitioner in the context of critical thinking. He contends that a practitioner can only be considered educated if he/she has come to realise that there is no knowledge that is secure.

Schön (1983) contends that it is important for the practitioner to reflect both during action and after action has been taken. Bolton (2001) borrows the term "reflection-in-action", using it metaphorically to describe the process as "the hawk in your mind constantly circling over your head watching and advising on your actions—while you are practising" (p. 15). Schön's reflection-on-action refers to the consideration of events after the fact for the purpose of enhancing practice. Schön's reflection-in-action is similar to Bolton's description of "reflexiveness" (p. 7). She states, "Being reflexive is focusing close attention upon one's own actions, thoughts and feelings and their effects; being reflective is looking at the whole scenario; other people, the situation and place, and so on" (p. 7). According to Schön (1983), reflection-on-action occurs when we consider the events after the fact for the purpose of enhancing our practice. The interactions, communications, and results or effects of decisions that are made and things that are done or said are all taken into account. Therefore, reflexiveness and reflectiveness can provide opportunities for insight. These processes have the potential to support personal and professional growth and development, whether this is in the midst of activities or following them.

Speaking to the dynamic aspects of reflective practice and the applications, Bolton states how reflective practice "can take its camera down to any aspect of practice with patients, [clients] . . . the interface of home and work, the impact of experiences in the past on present actions" (p. 7). According to Bolton, "nothing is too small or too big" (p. 7) for the lens of reflective practice to include in its view.

Critical Reflection with Clients

Charon (1993) and Cranton (1996) agree that reflective practice is achieved and understood by becoming immersed in it, as opposed to simply reading about it. Charon (2000) reports that through the process of sharing her own reflective writings about her patients, she has been able to broaden and clarify her understandings about them. Frank (1995) discusses one of the distinctive qualities of postmodernism: "Postmodern times are when the capacity for telling one's own story is reclaimed" (p. 7). Contrasting these two distinct eras, he explains how in the modern period the medical story had the distinguished "pride of place" (p. 7). Frank (1995) continues to explain how "the postmodern divide is crossed when people's own stories are no longer told as secondary but have their own primary importance" (p. 7). He concludes, "Postmodern illness is an experience of body, self, and the destination that life's map leads to" (p. 7). It is through this reflective and interactive process that the patient or client can begin to set new life destinations and directions for his/her life that may have been radically changed by illness or disability.

This process of educative practice, contends Bolton (2001), "can lead to greater agency, responsibility, self-understanding, and self- confidence" (p. 31). Therefore, critical reflection can be employed by practitioners in their own therapeutic relationship with clients or patients to establish new goals and directions or among professionals to increase awareness and skills.

Therapeutic Interventions

Client-Centred Interventions

Stone (1985) and Trychin (1991) both argue that counselling plays a vital part of any program to help individuals adjust to hearing impairment. Stone goes on to say how the adjustment to hearing impairment begins before the diagnosis is made; however, people tend to "get stuck somewhere in the process" (p. 114).

Noble (1996) emphasises the need for "psychosocial issues concerning disability and handicap to be firmly a part of the rehabilitation program" (p. 8-9) for persons with hearing impairment. Erdman (1994), Hyde and Riko (1994), and Noble (1996) all remark upon the need for a more client-centred approach to rehabilitation. They acknowledge the need for self-reporting methodology as part of the audiological appraisal and rehabilitation program development.

With respect to referring school-aged children, Goldberg and McCormick Richburg (2004) emphasise the need for the development of a collaborative approach among professionals, including "audiologists, psychologists, and educators to optimize the identification of children with MHL [minimal hearing loss]" (p. 152). Bader and Robbins (2001) agree with this united approach, saying, "The relationship between parents and hearing health professionals has a powerful impact on the efficacy of the (re)habilitation process" (p. 28). It is reported that of the 52 million school-aged children in the United States, 12% of these students are suspected of having MHI, according to Goldberg and McCormick Richburg and the impact this can have on learning, communication and other aspects of psychosocial development is remarkable. Whereas it is important to detect hearing impairment in children, and to have a collaborative approach between children, parents, and professionals, it is of equal importance to provide similar attention to the connection between professional sources for the purpose of detecting and servicing the requirements of adults with minimal hearing impairment.

According to Sanders (1993), Noble (1996), and Goldberg and McCormick Richburg (2004), there is a need for a more comprehensive assessment than just simply a technical evaluation of the issues arising from hearing loss. A multimodal approach to hearing impairment is necessary. "Attention to technical matters alone may miss the point as far as the individual's needs and social circumstances are concerned" (Noble, p. 9). Therefore, Noble's argument for the need to include personal experience in the assessment process is consistent and supportive of my efforts in this research project, i.e., to gain a deeper understanding of personal experience through a dialogic and introspective inquiry.

> Functional tests cannot tell the story of disabilities and handicaps, since these are to do with the person's actual experience in the world. Thus, that experience must be tapped, and the only way to do it is by asking people to make accounts of it. (Noble, p. 9)

Involving Significant Others in the Therapeutic Process

Noble's (1996) view is consistent with Hétu et al. (1993), stating that "others who undoubtedly do need to be significantly involved are the partners or other close family members, or close working or vocational colleagues, of the client" (p. 10). This strongly resonates throughout the literature (Harvey, 1998; Hétu & Getty, 1991b; Hétu et al., 1994; Hétu et al., 1987; Hétu et al., 1993; Steinberg, 1991; Stephens et al., 1995). Discussing the psychosocial framework of his professional activity with people who have hearing impairment, Harvey (1998) emphasises the importance of involving others in the therapeutic process. He states: "In addition, we are social creatures, products of overlapping social networks. The reactions of other people, significant others, parents, families, friends, neighbors [sic], teachers, bosses, professional helpers, remain important influences on our lives" (pp. 2-3).

Other Approaches and Interventions

Cognitive behavioural therapy can be used to counter negative thought patterns and assist in the effective promotion of healthy socialisation, according to Kissane et al. (2001). Furthermore, Kissane et al. and Trychin (1991) contend that to gain an accurate understanding of the person, knowledge of his/her past, contributions and celebrated accomplishments must be acquired. The negative thoughts can be reframed to eliminate the distortion of self and the promotion and restoration of personhood. Goal setting can be especially useful in overcoming problems of alienation and isolation.

Harvey (1998) describes his role as a therapist as one of helping an individual sort out the multi-layered psychological, social, and spiritual influences that often unknowingly shape his or her existence, and then to help that person live a more fulfilling life.

> By consciously exploring the 'dark' aspects of hearing loss—fear, anger, depression, and anxiety—one can achieve a level of psychological growth that transcends the 'acceptance' stage of the grieving process. This odyssey catalyzes a person to construct deeper layers of meanings in their life. (Harvey, p. 167)

In terms of learning to deal with the reality of how hearing impairment has changed one's life, Harvey (1998) reflects on the work of Victor Frankl and his book, *Man's Search for Meaning*, saying that the "search" is not a deliberate pursuit to derive pleasure or to avoid pain. Instead, it is aimed at finding meaning or purpose in our lives.

> We actively make decisions about what meaning(s) to attribute to certain events, whether to perceive them as good or bad, important or unimportant, half-empty or half-full, opportunity or calamity etc. Through our internal self-talk, [and] cognitive processes, we create or construct a meaning(s) for an event(s)

> which then determines how we feel and then what we do. (Harvey, p. 166)

This requires the individual to renounce the "role of victim, moving past the things we can't control or change and taking control of things we can control or change in our lives, moving from withdrawal to active participation" (Rockow, 2001, para.19). Stephens et al. (1995) and Stone (1992) agree that the approach of asking the individual with a hearing impairment to list problems he/she has experienced has proved useful in setting the direction for individualised rehabilitation programs.

Need for Trained Therapists

Stone (1992) reflects on his experience in his own life of sensory loss of both his vision and hearing and states that services offered by professionals are valuable but their skills and services frequently remain inaccessible to persons with a hearing impairment. Speaking about the shared responsibility in the rehabilitation process and the demoralization of individuals by professionals, Stone argues, "even in 1992, we are still regarded as a pair of ears to be treated rather than persons who have a role to play in the rehabilitation process" (p. 60). Clelland (1995), Trychin and Busacco (1991), and Hill and Nelson (2000) agree; there are few specialised counsellors trained in issues of hearing impairment with whom individuals can consult. Clelland (1995) and Stone (1992) report on the paucity of material with which to offer proper training to counsellors. "Those counsellors who are interested in working with hard of hearing clients", states Clelland (1995), "will unfortunately find little research and information which will assist them in understanding their hard of hearing clients and their experiences of psychological adjustment" (p. 3).

Hill and Nelson (2000) point out how mainstream service providers working with persons who are Deaf tend to focus on the pathology of Deafness at

the expense of the real issues. Therefore, service providers are “likely to minimize, or completely miss the real difficulties being presented” (p. 8). I believe this issue can be generalized to the much larger population of persons who are hard of hearing.

During their community consultation for the purpose of gathering data for the study, these researchers report hearing many concerns expressed by service providers. Some of the issues discussed included an “atmosphere of distrust, oppression, misunderstandings, in-fighting, and unresolved problems that exist in this field. In a community that is crying out for skilled professionals, burn-out of existing service providers is disturbingly high” (Hill & Nelson, 2000, p. 17).

Stone (1992) concludes by describing the value and the need for counsellors trained in dealing with issues of hearing impairment.

> An interactive relationship with professionals and others with similar problems can be far more rewarding and much less painful. Such a partnership poses a challenge to both professionals and consumers. The assumptions many professionals make are often narrow in focus. They simply do not take into consideration the unique environment, experience, and needs of people who are hard of hearing. Nor is it acknowledged that one of the best and most obvious ways of learning of the needs of people who are hard of hearing is by interfacing with them—talking with them and asking meaningful questions about their experience. (p. 63)

The goal of this research project and the goal of any therapeutic relationship is to assist each individual to become increasingly more responsible for his or her life. Describing the objective of phenomenological research, van Manen (1998) states it has “as its ultimate aim, the fulfilment of our human

nature; to become more fully who we are" (p. 12). Therefore, a phenomenological approach to the study of psychosocial issues of hearing impairment directed at enabling individuals to become more empowered in decision-making processes is a worthwhile objective.

Giving Voice through Narration:

A Therapeutic Intervention

Postmodernism exists, maintains Frank (1995), when people "tell their stories, in order to construct new maps and new perceptions of their relationship to the world" (p. 3). Storytelling and the expression of voice, he explains, "figure prominently on the landscape of postmodern times" (p. xiii). Frank contends that in order for there to be a shift from what he calls the "dominant cultural conception of illness [disability]" (p. xi), individuals who see themselves as victims of illness or disease must move away from being passive recipients of care to become "agenic" (Cochran & Laub, 1994, p. 3) persons. Contrasting the modernist perspective with postmodernism, Frank explains how up until now, ill people were simply expected to get well. In a postmodern society, however, people with illness or disability are called to take increasing responsibility for understanding what illness means in their lives. This may represent a major shift for individuals who are ill or who have a disability. Such a shift would mean people would be required to make a profound assumption in regard to taking personal responsibility in their lives. The scope of modern medicine, maintains Frank, has not included helping patients to "think differently" (p. 1) about post-illness life or to construct new relationships with health and wellness. According to Bolton (2001), sharing stories with each other is one of the best ways of exploring and understanding another individual's experiences. Hutchinson et al. remark that participants in qualitative studies can hear themselves speak about what an experience is for them. This, then, contend Hutchinson et al., makes it

different from simply thinking about it. They conclude, saying: “With increased self awareness, there may also be impetus for behavioural change”; therefore, “Telling one’s story and really feeling heard can be empowering for participants. Empowering involves movement and change” (p. 163).

Frank (1991), in his personal narrative, describes the difficulty he had in finding language to articulate his unique experience with his medical conditions. Sacks (1970, 1984, 1995) provides accounts of patients’ struggles as well as his own with articulating and explaining their individual neurological conditions. These authors were at a loss to find ways and means to reconstruct their own transformed lives as a result of injury and disabling conditions until they were able to write personal accounts of experiences and to tell their stories.

Bolton (2001) gives a description of storytelling from a teaching perspective, explaining how it can influence and inform the participant, the listener, and the researcher. She emphasises the importance of critical reflection on narratives as part of the process for the purpose of reaching a deeper understanding of the meaning behind the narrative account.

> A story is an attempt to create order out of a chaotic world. But for our experiences to develop us—socially, psychologically, spiritually—our world must be made to appear strange. We, and our students, [patients or clients] must be encouraged to examine our storymaking processes critically: to create and recreate fresh accounts of our lives from different perspectives, different points of view, and to elicit and listen to the responses of peers. Listening critically to the stories of those peers also enables learning from their experience. (Bolton, 2001, p. 2)

“As we put our feelings into words,” contends Rockow (2001), “they become more manageable” (p. 4). Harvey (2001) cites Brenner, Riemer, and Cutter (1993) as a means to help his clients reach a deeper understanding of the

principle of healing. "The pain of loss has a size and shape, a beginning and an end. It takes over only when not allowed its voice." He continues, "The more words we have for an experience, the more shape it has, the more it has a beginning and end. The less words, the less space, the more it takes over" (p. 65). The power of dialogue, the very act of telling one's own story to another human being who is prepared to listen and who even attempts to understand, will play an integral part in healing (Rockow).

Describing further the transformative potential of telling one's story, Harvey (2001) explains: "But a trauma story, no matter . . . the degree or context, must eventually relinquish its isolating grip and be told so that healing can begin." He adds: "There is a tremendous transformative power in dialogue" (p. 65). The value of storytelling is reinforced further by Frank (1995), who states: "The ill person who turns illness into story transforms fate into experience" (p. xi). Narration is described by Becker (1997) as "the practice of everyday life" (p. 26). She adds: "Narratives can provide us with important insights about people's experiences and their perspectives on them. Narrative is a means for giving voice to bodily experience, to embodied despair" (p. 26). Becker endeavours to demonstrate the existence of a deep connection between embodied experience—lived experience—and the enactment of this experience through narrative. She establishes a connection between narration and phenomenology and describes how in western culture, "narrative is our primary means of accessing the world of bodily experience and is essential to our understanding of that experience" (p. 26). "Narratives of disruption, especially those that unfold in repeated interviews over time, capture the temporal and phenomenological dimensions of disruption in the cultural life course" (p. 26). Therefore, the phenomenological interview, using a dialogic process to investigate the lived experience of an individual, can be a powerful means of reaching a broader understanding of his/her life experience.

Self-Determination

Murphy (1987) describes the human need to make choices for oneself in the face of progressive debilitating illness.

> The ability to survive on one's own and to maximize self-determination are essential ingredients of the basic drive to live. We try to shape the social life around us, rather than to become its pawns or victims, and this involves the use of power, however subtle and gentle. The disabled, as I have said, have few such resources. (p. 202)

Patient, Agent, and Locus of Control

Cochran and Laub (1994) discuss self-determination in terms of personal agency. They define an agenic person, saying, "An agent is one who makes things happen and a patient is one to whom things happen" (p. 1). Whereas an agent is active, the patient is passive or reactive. Frank (1995) offers assurance that storytelling may help overcome passivity with respect to one's disease. As a result, the person moves from being the recipient of treatment to the orchestrator of change. This locus of control Rotter (1966) shifts from externally directed forces (where the influencing factors are outside forces such as luck or chance) to internally directed forces that are contingent upon the efforts of the individual.

Cochran and Laub (1994) describe self-determination as the "sense of being the personal cause of one's action" (p. 4). This, they explain, "involves a totality of situated experience, more akin to felt judgement, that a person is acting out his or her own motives" (p. 4-5). In order to be self-determining, then, an aspect of introspection and self-reflection is required to gain a clear understanding of the goal or outcome one is striving to attain. It is also important to identify strengths and barriers which can enhance or encumber the fulfilment of these desired outcomes. DeCharms (1981) maintains that "a person's motives

are the reasons for thinking and acting and therefore explain or give meaning to an actor's behaviour" (p. 339). In 1984, deCharms expands his interpretation of the meaning of self-determination through terms denoting action. He contends that concepts such as choice, freedom, responsibility, and ownership of behaviour are all part of self-determination. "In a nutshell, originating one's own action implies choice; choice is experienced as freedom; choice imposes responsibility for choice-related actions and enhances the feeling that the action is 'mine'" (p. 279). In a later work, deCharms (1987) defines personal causation as "a deliberate action to produce intended change" (p. 8). Therefore, "the experience of being a personal cause is connected with having a meaningful motive, choosing, forming an intention, using knowledge and skill to produce changes (in short, planning), taking responsibility, ownership and freedom" (Cochran & Laub, p. 5). Self-determination is not a factor in isolation. There is a combination of elements that make up this sense of personal agency. "We understand a part through its place within a comprehensible whole" (Cochran & Laub, p. 4).

Gaining Agency through Collaboration

One major step in the developmental progression of independent management, as determined by Paterson and Sloan (1994), occurs when the individual is willing to abandon the perception that the health care professional has the sole authority. In their study, they report how participants identified the need to develop a "survivor mentality" (p. 14) in order to cope with the system that was designed to keep them healthy. "'Surviving' entails a willingness and ability to 'fight for one's rights.' This requires the individual to make a 'philosophical shift' from the passive role of patient to that of partner in the healthcare system" (p. 14).

According to Paterson and Sloan (1994), part of the process of assuming control for the participants in their study was the development of collaborative relationships. These relationships were formed when "each partner acknowledges the expertise of the other . . . neither the individual with diabetes nor the professional has all the answers" (p. 17). Participants in this study described authoritarian and highly directive professionals as the "antithesis of the collaborative partnership" (p. 17). Participants reported assuming control as a "developmental progression" (p. 19). This sometimes entailed risks and confrontations with health care professionals. "Other strategies to assume control," as reported by the authors, "included anticipating and dealing with threats to control, demanding and actively seeking collaborative relationships with healthcare providers, and fostering a personal support system" (p. 19).

Secrest and Thomas (1999) contrast the traditional role of the nurse, which they describe as one of "'doing for' others" (p. 245) with what they refer to as the current generalised role of rehabilitation, which is one of teaching and facilitating, or in other words, "'doing for' themselves" (p. 245). This is a particularly compelling observation from their phenomenological study because this shift in roles from "doing" to facilitating means the nurse or other rehabilitation professionals serve "an empathic presence in the stroke survivor's experience" (p. 245). This "empathic presence", contend Secrest and Thomas, may be as important as "doing" (p. 245) and could, according to these authors, facilitate a connection with more meaningful goal setting by the individual. This too is one of the primary objectives of this study: first to understand the lived experience of individuals with hearing impairment and second to assist them in meaningful life planning.

Empowerment

Most contemporary researchers state Thorne and Paterson (1998) are recommending models of professional-client relationships that are based on the concepts of partnership and empowerment "oriented to the needs of those with illness and not according to the expectations of the professionals" (p. 175). Thorne and Paterson conclude, through such a relationship, both medical and other professionals will be able to offer the fullest range of support that is possible. They will in return assist persons with chronic illnesses or disability to live their lives with autonomy and as productively and fully as they possibly can.

In a study by Derenowski Fleury (1991) designed to provide an "analysis of the psychological and social processes used by individuals to initiate and sustain cardiovascular health behaviour over time" (p. 286), the author describes empowerment potential as the "continuous process of growth and development that facilitates the emergence of new and positive health patterns" (p. 288). In other words, by being prepared and able to identify the readiness for these desired changes, carrying them out, integrating them into everyday life and maintaining such over time, the individual establishes a new pattern of behaviour that demonstrates a level of self-determination and personal empowerment. This study is important because it closely approximates the proposed action research methodology to be used in my study. Appraising readiness requires that the individual first construct a personal intention to change. Change was reported to have occurred when the behavioural intentions became personalised actions.

In the context of this study, integration of these planned changes occurred when such health-related changes were incorporated into the individual's life patterns. Further, the author explains how, throughout the process, there were two categories that occurred: imaging and social support systems. Imaging is referred to as the identification of desirable and undesirable states as well as the "formation of specific plans to realise or avoid these states" (p. 286). Imaging

was used as a means of constructing the implicit standards of behaviour as well as establishing and judging the desired performances and outcomes. Past experience was reported to be useful in identifying potential pitfalls and/or barriers to success. The processing of images of self provided a valuable framework for the interpretation of past behaviours. This also offered direction by having the individuals articulate their own expectations for performance and measurements for determining successful achievement of goals.

By assisting participants in the exploration of options, supportive others were seen as facilitators in the change process by examining life-change options together (Paterson & Sloan, 1994). Support systems, however, were occasionally seen as barriers, as they sometimes created and maintained boundaries even though their intent was to be supportive. Participants found that boundaries crafted by others often resulted in a decreased sense of personal autonomy and responsibility for sustaining desired lifestyle changes.

The individual's appraisal of his/her own readiness to initiate and sustain desired lifestyle change consisted of three categories: "1) re-evaluating, 2) identifying barriers, and 3) owning change" (Derenowski Fleury, 1991, p. 286). The first process required some level of self-reflection by examining the perceived worth of the behaviours they valued. Identification of barriers referred to the acknowledgement of the potential obstacles to change and the readiness and willingness to initiate and sustain planned lifestyle changes. In order to demonstrate ownership of change, participants had to accept responsibility for the changes and create intentions to act in ways that would result in the realisation of their desired and valued goals and outcomes.

Through change, participants acted upon plans and behaviours they constructed. In this study, change consisted of six categories. These included: "1) engaging, 2) strategies, 3) creating loopholes, 4) overcoming lapses, 5) self-monitoring and 6) affirming change" (Derenowski Fleury, 1991, p. 289).

Implementing strategies guided the creation of change and was based on expectations for performance as articulated by the individuals. Deciding upon goals allowed for a sense of enhanced personal efficacy and control over outcomes. Creating loopholes is defined as the flexibility by which participants could choose between alternative ways of behaving without experiencing a sense of failure. Lapsing refers to the re-emergence of previous habits while attempting to initiate new ones. Overcoming these lapses required the initiation of self-regulatory mechanisms that followed the violation of desired new standards of behaviour. Derenowski Fleury explains that eventually these were perceived as natural consequences of taking risks and attempts at trying to establish new, more desirable behaviours.

These lapses were reported by Derenowski Fleury (1991) as opportunities to learn and to re-evaluate the situation, to look at the circumstances that led to the lapse and to engage the process once again. As well, self-monitoring was used to determine whether there was an adherence to the performance criteria that would lead to the desired outcomes. Self-monitoring also brought issues of performance and approximation with desired outcomes to personal awareness levels that offered reinforcements of the potential for success. Affirming change refers to the expression of the value and worth of the chosen behaviours for the purpose of achieving a positive and desired outcome. Of the three categories that Derenowski Fleury identifies under integrating change—establishing rituals, achieving harmony, and transforming change—the latter is most important for purposes of comparison with my study. Transforming change refers to the construction of future goals in creating desired ways of being. "Transformation allows the realisation of individual potential through continued change and an enhanced sense of control over future health outcomes" (p. 290). This is a particularly important result for comparison with my proposed study, since it is

anticipated that through the action research process, participants will be able to make decisions regarding future planning.

Supportive others were regarded as facilitators who helped to articulate the valued ways of being as well as to create action statements based on those values. Identifying past experience through imagining figured into the model and influenced the development of methodologies to achieve the desired goals. Social support systems were perceived as potential barriers in directing life change through their role in the creation and maintenance of boundaries. Boundaries that were set by others were perceived as being the cause of a decrease in the sense of autonomy of the individual and, therefore, the sense of independence and responsibility for sustaining the changes.

Transition

A State of Becoming

In the case of a person with a disability, progressive or adventitious, there is a gradual or sudden change from life as the individual once knew it to a new and different way of life or living. Often there is an accompanying sense of personal loss. Social isolation, depression, and loneliness are some of the frequently used adjectives to describe this transition in instances of hearing impairment.

Becker (1997) discusses how people attempt to establish continuity in their lives following the onset of illness or disability. “The ongoing interpretation of events and experiences enable people to make sense of their personal worlds; and a knowable world provides a framework for understanding major events as well as everyday experiences” (p. 4). Therefore, any structure, something as simple as a routine that demonstrates a sense of continuity, can give some consistency and logic to an individual’s life. According to Becker, when the expectations about the course of one’s life are altered or not met, inner chaos

and disruption may result. This outcome, this chaotic state, may give rise to a sense of loss of future as discussed earlier by Sanders. "Restoring order to life necessitates reworking understandings of the self and the world, redefining the disruption and life itself" (Becker, p. 4).

The pain of loss, remarks Harvey (1998), does not need to be all consuming, nor does one have to simply "learn to live with it". Instead, he uses a metaphor with vision to describe how people may expand their experience of loss. He describes how the pain resulting from loss can be placed on the right side of our field of vision "where we can keep an eye on it while enjoying other sides, instead of in the centre of our visual field, where it would forever cast a pervasively ominous cloud" (p. 170).

Conversely, while empowerment of self is believed to be of benefit to the individual, it may also give rise to some degree of loss (Harvey, 1998). The individual may grieve the many opportunities that have been lost before making the choice to be assertive and decisive (Getty & Hétu, 1991). Grieving the loss of the familiar is, therefore, part of the transformative journey. A number of authors including Hutchison et al. (1994), Rockow (2001), Stone (1987), and Trychin (1991) all refer to the stages of adjustment to hearing impairment as closely approximating those presented by Kubler-Ross (1969) in the stages of death and dying. The reaction to loss, either through death or loss as in a disability, remarks Stone, differs in the "length of time and degree of reaction, not in its course" (p. 114), therefore emphasising the individuation of the experience of this transitional process. Stone concludes, "That is why counselling is such a vital part of any program aimed at assisting persons to adjust to hearing impairment" (p. 114).

In discussing the negative and often traumatic issues relating to disability and loss, Herman (1992) also explores the growth potential from these experiences. She states: "Helplessness and isolation are the core experiences of

psychological trauma; empowerment and re-connection are the core experiences of recovery" (p. 197). Harvey (1998) contends that hearing impairment, or any disabling condition (Stone, 1997) can offer an opportunity for individuals to create meaning in their lives.

Frank (1991) discusses the need "to seize the opportunities offered by illness" (p. 3). Illness, he contends, must be lived actively. "Through thinking, talking, and writing we can begin, as individuals and as a society, to accept illness fully" (p. 3). From his own experience of life-threatening illnesses, Frank goes on to discuss the transformative aspects of illness, stating life becomes different when one has lived through illness. Agreeing with Frank, Charmaz (2000) states: "Experiencing serious illness challenges prior meanings, ways of living that have been taken for granted, and ways of knowing self" (p. 277). "Illness can lead us to live differently," concludes Frank; "accepting it is neither easy nor self-evident. Seizing the opportunity means experiencing it fully, then letting go and moving on" (p. 3). But it takes time to change the old paradigms of living, especially if they have been pervasive in daily life for a period of time (Becker, 1997).

Harvey (2001) comments, "Coming to terms with the delicate balance—the dialectic—of both accepting and confronting unfairness is an essential developmental milestone for any disabled person or member of an oppressed minority" (p. 176). Charmaz (2000) refers to the uncertainty of life following the onset of disability and also the vulnerability. Continuing with this thought of vulnerability and uncertainty, the process of transition from a state of anatomical wellness to a state of sensory loss evokes fear of further deterioration or even complete sensory loss. Sacks (1995) describes a painter who loses all sense of colour. "He constantly feared that whatever had happened would happen again, this time depriving him of all his sight completely" (p. 12). Dialogue provides one

effective means of coming to a deeper understanding and acceptance of those things which can neither be changed nor reclaimed.

According to Harvey (2001), there is a “transformative power of relationship” (p. xvi) which may be experienced when those participants in a relationship with someone with a hearing impairment avoid the dangers and take advantage of the opportunities. Harvey defines psychological transformation as the “combining of discrete experiences to catalyze a higher level of being, of awareness, of integration” (p. 95). This can be accomplished he contends, when participants in these intimate relationships “listen, not only with their heads, but also with their hearts” (p. xvi) and attempt to empathise with the “lived experience” (van Manen, 1997) of the other.

Research with Adults with Disabilities

Using Phenomenological or Associated Approaches

It is important for the nursing professional, maintains Secrest (2000), to investigate the quality or nature of the life experienced by the primary support person of stroke survivors. By using an existential phenomenological approach, the nursing professional can gain deeper insight into what it means to live with a significant other who has survived a stroke. In turn, this will provide nurses with a fuller and deeper understanding of the primary support person’s world, and ultimately, the stroke survivor’s world too. In order to assist with the negotiation of goals, teaching and offering council, Secrest (2000) maintains that it is essential to first assess the nature of the relationship between the stroke survivor and the primary support person. This activity of establishing a baseline of understanding of the relationship is consistent with Derenowski Fleury’s (1991) empowerment model referred to earlier. Whereas Secrest’s (2000) model purports to leave the responsibility of planning in the hands of the professional nurse, my research project will rely upon the participants taking the responsibility

for planning (MacDonald, 2000) and the researcher taking the role of facilitator. Both approaches share self-reflection as part of the investigative tools of a phenomenological study.

According to Secrest, only 6% of the studies dealing with issues of stroke survivors were of a qualitative nature, and none of these were phenomenological studies. The importance of Secrest's existential-phenomenological approach is demonstrated in the way it "places primacy on the meaning from a first-person perspective" (p. 93). Thompson, Locander and Pollio (1989) report:

> This approach involves the analysis of in-depth phenomenological interviews. It blends the philosophy of existentialism with the methods of phenomenology. The result is a contextually based, holistic psychology that views human benefits in non-dualistic term and seeks to attain a first person description of the experience. (p. 133)

Pollio, Henley, and Thompson (1997) and Secrest (2000) point out how this type of investigation shows that larger sample size does not yield different themes. Rather, they illustrate increased numbers of experiences that highlight a similar number of different themes. Walton (2000) concludes from her study that nurses who were willing to understand the experiences and recognise the fears and aspirations of study participants diagnosed with psychiatric illness were able to make a real difference in the participants' lives. Walton reiterates: "Understanding and insight are possible, and it is my firm belief that through these, better helping relationships will be forged and healthier, happier lives enabled" (p. 82). The means to achieve this level of understanding and insight has been demonstrated throughout these phenomenological studies. Through phenomenological research, then, there can be an opportunity to gain a deeper understanding of the needs of persons with progressive hearing impairment.

As mentioned earlier by Thompson et al. (1989), the blending of the philosophy of existentialism with the methods of phenomenology, results in “a contextually based, holistic psychology that views human beings in non-dualistic terms and seeks to attain first person description of the experience” (p. 133). The existential philosophical approach of phenomenology as a research methodology, maintains Wood (1985), holds promise for gaining a deeper understanding of the unique aspects of hearing impairment.

In her opening chapter entitled “Mediating Disruption”, Becker (1997) describes how a woman escaping persecution in Hungary uses story to portray her efforts to reconstruct her life, the life before the flight from her country and the life following. There is a process of self-discovery that is depicted through metaphors of transformation and through the artwork created by this woman. In this description and story, the metaphor of death is used—death to one way of life and rebirth into another. Becker describes the tension that exists between the two lives, the life before the revolution and the one following in a new country. These images, Becker states, are not likely to dissipate, as they serve not only as a reminder but also as a reference point for the transitions that have occurred. A phenomenological approach appears to have merit for gaining a deeper understanding of the life experiences of persons with hearing impairment. Interventions can be based on the issues raised by individuals and the tools to restore life to a level of greater independence.

Summary

The potential impact that hearing impairment can have in adult life was explored and revealed in a way such that it does not recognise boundaries of age or circumstance in life, but affects all family members, friends, relationships in the workplace, and all aspects of daily living where communication is required. Furthermore, the literature evidenced that the magnitude of the problem of

hearing impairment is escalating. As well, the survey of the literature revealed that the effects of hearing impairment are far reaching and include but are not restricted to isolation, alienation, demoralisation, feelings of shame, depression, and loss of assertiveness and self-determination.

Hearing impairment has been defined in the context of the medical model and this has minimised its impact not only for the individual affected, but also for the person's significant others and society at large. Therefore, by defining hearing impairment in the context of a social disability, it may be feasible to deal more effectively with the widespread implications associated with it.

The literature indicates, as well, that the knowledge base available to professionals who deal with persons with hearing impairment is small relative to the growing need and that there are insufficient numbers of trained professionals available to provide services to the large and increasing numbers within this population. Therefore, a study designed to increase the level of information regarding the life issues for persons with hearing impairment as well as the exploration and development of alternative approaches for confronting such matters appears timely.

Narration is one means whereby participants can have an opportunity to become more actively involved in their own planning as they find a venue to tell their story. By using a phenomenological approach, participants may uncover those richly detailed "unreflected [prereflective] experiences" (Secrest & Thomas, 1999, p. 241) of their lives with hearing impairment. In so doing, they may have an opportunity to give voice to their experience. This may provide a further opportunity to move from a modernist to a postmodernist perspective and approach as individuals are invited to become increasingly participatory in the planning and execution of their future goals.

CHAPTER 3. METHODOLOGY

Introduction

As outlined in Chapter 1, two research methodologies will be applied in this research project, phenomenology and action research. These two methodologies will be discussed in two separate chapters: Phenomenology in Chapter 3 and Action Research in Chapter 5.

In the survey of literature chapter, supportive references were identified to illustrate how phenomenology could be used to provide information about the lived experience of individuals with hearing impairment. Through dialogue, critical reflection, and analysis of the data, life's challenges emerge for the individual candidates. This phenomenological data analysis will be presented in Chapter 4 and will be used as the source for the action research projects.

Chapter 3 provides an overview of phenomenology, including a brief description and outline of the goals of phenomenology. This chapter then outlines the process for gathering data, including a discussion of the criteria used for the selection of candidates, length and number of interviews, and description of research procedures. In addition, the use of bracketing interviews to reduce researcher bias will be discussed. A detailed description of the qualitative interview process will be included, along with a discussion of a hermeneutic design used in the analysis of data. The procedure for analysing the data will be the concluding section of this chapter.

Phenomenology is the study of human experience. Its goal is to seek an understanding of the meaning of lived experience as it becomes part of the individual's consciousness. Thus, phenomenology is not merely introspective, namely the action of looking within or under the surface of current experiences; it is also retrospective, the action of looking back over past experiences. This is

because phenomenology relies on retrospection or reflection on the lived experience as well as introspection.

What is Phenomenological Research?

Phenomenology is described by Solowski (2000) as "the study of human experience and the way things present themselves to us in and through such experience" (p. 2). In the same context, Husserl (1970), Schutz and Luckman (1973) and van Manen (1997) refer to this "experience" as the "lifeworld" of the individual—the world as it is immediately experienced. The phenomenological approach endeavours to seek and understand the meaning of lived experience as it is presented to the consciousness of the individual (Moustakas, 1994; Polkinghorne, 1989; van Manen, 1997). The "structure of meaning" (Moustakas, p. 16) establishes relationships among experiences, objects, and perceptions to provide deeper understanding to whatever is brought to the individual's awareness. "Phenomenology is concerned with the ways in which human beings gain knowledge of the world around them" (Willig, 2002, p. 50). Therefore, any objects of awareness brought to the level of human consciousness may be considered to be of potential interest in a phenomenological investigation and may include "not only the objects of perception but also those of memory, imagination and feeling" (Polkinghorne, p. 41). For Giorgi (1975), this understanding is gained pre-reflectively or prior to any attempts to conceptualize, categorize, or taxonomize individuals' experience. This would be accomplished through the analysis of the language they use to describe their life experiences.

To demonstrate the phenomenological approach, Polkinghorne (1989) uses the analogy of a triangle. Whether the triangle is presented as a series of sticks, a collection of metal pieces or lines drawn on a chalkboard, what remains constant is the "triangleness" (p. 42) of the object being experienced regardless of its factual variations. The experience with this triangle can be as varied and

different as the experiences of the person to whom it is being presented. Phenomenology, then, represents the different components, which in turn create meaning structures of the triangle for the individual. Likening this to the issue of hearing impairment, the experience of each candidate in the study will be unique to the individual yet he/she will share the overarching condition of hearing impairment.

The Goal of Phenomenological Research

According to van Manen (1997), "phenomenological research has, as its ultimate aim, the fulfillment of our human nature: to become more fully who we are" (p. 12). The objective of a phenomenological investigation is to gain an understanding of the experiences of individuals as they lived it through reflective dialogic interaction with a researcher and not by developing theoretical or abstract explanatory accounts of the experiences. Phenomenology, then, is not only introspective. It also relies on retrospection or reflection of the lived experience.

Van Manen (1997) remarks upon the educative or the pedagogic component of research, which provides more than understanding; it provides a source of information for teaching as well. "The method one chooses ought to maintain a certain harmony with the deep interest that makes one an educator (a parent or teacher) in the first place" (p. 2). Therefore, the integrity of the pedagogic approach will be seen throughout this research design.

Selecting a Phenomenological Approach

The selection of a qualitative research design was influenced by Smith and Dunworth (2003). Researchers using such a design generally engage in "exploring, describing and understanding the personal and social experiences of participants and trying to capture the meanings that particular phenomena hold

for them. In that sense the quintessential entity for the qualitative researcher is meaning" (p. 603). Furthermore, it is their belief that in qualitative research "an attempt is usually made to understand a small number of participants' lived experience or views of the world rather than trying to test a preconceived hypothesis on a large sample" (p. 603-604). This is also consistent with Creswell (1998). In particular, Smith and Dunworth (2003) argue, such an approach is useful when topics are "novel or under-researched and where there is a concern with understanding process rather than measuring outcomes" (p. 604).

Research Methods

Study Examples

Pollio, Henley, and Thompson (1997) provide three examples of a procedural method used in phenomenological studies. This procedure is similar to the one used in my study design. First, "in every interview, the co-participant was considered the expert, and the interviewer simply followed the course of the dialogue, asking questions primarily to clarify the meaning of what was said" (p. 58).

In the second procedural guideline described by Pollio et al. (1997), the primary researcher was asked to "highlight specific preunderstandings that might be evoked in dealing with subsequent interviews" (p. 58). In other words, the primary interviewer was asked about his or her specific interests relating to the topic under investigation. During the time when the transcribed texts were thematised, the primary researcher was asked by the group to point out specific references in the text used in arriving at a particular theme.

The third procedural approach used by these authors required the researcher to retain responsibility for thematising the remainder of the protocols. After all of the texts were thematised, initial summaries were prepared and shared with the co-participants. The interviewer called for a second interview to

listen to the participant's opinions regarding the summary and to determine whether it did justice to his/her experience of the phenomenon. If the participant was not satisfied, objections were taken into account, and upon completion these were presented to the co-participants again and the same question was asked: "Did this summary capture his/her experience?" In the examples described, "a third go-round" (Pollio et al., 1997, p. 59) was not required.

"In all dealings with participants, an air of equality was maintained; participants were quickly given to understand that their perspective was equal to that of the researcher and that they were considered co-investigators" (Pollio et al., 1997, p. 59). What also became obvious to these authors was the time and attention each co-investigator/co-participant spent on reviewing the dialogue between meetings, thereby giving thought to what had previously been discussed.

According to Pollio et al. (1997), a final description of the phenomena being investigated was initiated following the approval of each individual's summary by the co-investigators of the study. This description dealt with time, space, body, and relationships. These "provisional descriptions" (p. 59) arrived at by the primary researcher were presented to the committee to determine whether members of the group agreed that "the description was rigorously grounded in the text and illuminating of the phenomenon" (p. 59). Following this, a copy of the descriptions were then sent to participants and each was asked if "their own experiences related to the general structure developed from protocols provided by all participants" (p. 59). Co-participants were encouraged to report any objections to the primary researcher and their comments would be taken into consideration and used to clarify, or, if necessary, reshape the final thematic description. Only on rare occasions, according to the authors, did participants respond with comments even of a moderately critical nature.

It is not my intention to achieve this final level of analysis identified as the "four fundamental lifeworld themes [or] 'existentials' . . . lived space (spatiality), lived body (corporality), lived time (temporality) and lived human relation (relationality or communality)" (van Manen, 1997, p. 101) because it is outside the scope of this thesis and also, as I argue later, sufficient information for the purposes of this research can be attained through the process of analysis and thematisation of the data to provide the necessary foundation for the second phase of the study. I will deal with further recommendations in Chapter 6 with respect to this other level of analysis for future consideration.

Selection of Participants

A written request was made to audiologists, medical doctors, and rehabilitation workers in the greater Nanaimo and Duncan areas of Vancouver Island, BC, Canada requesting their help in identifying potential participants for this study. The criteria for selection were provided. Participants needed to be between the ages of 18 and 65, and able to produce an audiological assessment confirming a moderate to severe hearing impairment, i.e., hearing impairment greater than 40 dB in their better ear with amplification. Potential candidates were contacted by telephone to determine their interest in becoming part of this study. Following this, information describing the nature, purpose, and expectations of the candidates was forwarded to them. Those participants who met the criteria were invited to become part of the study.

The aim was to have eight participants, four male and four female between the ages of 18 and 65 with as wide a range of characteristics as possible. The potential mix of candidates could include but was not restricted to those who were employed/unemployed, living in rural/urban areas, single/married, or of differing ethnic background.

Length of Study

This study was divided into two phases. The first phase started in December, 2002 and required up to three one-to-one interviews with the researcher and the participant. The first interview was aimed at establishing a good rapport with the participants and provided an opportunity to explain what the participant could expect over the course of the interview(s). "The interviewer is responsible for creating a climate in which the research participant will feel comfortable and will respond honestly and comprehensively" (Moustakas, 1994, p. 114). Another focus of the interview(s) was to gather information relevant to the life of the participant, while keeping the interview simple and straightforward. Alternate methods would have been employed, i.e. writing, if there had been problems communicating orally. After the candidates had an opportunity to review the previous transcript, they were invited to write comments or to meet to discuss their interview transcription. When a second and third interview was required, the candidate and primary researcher engaged in the same process. These subsequent interviews were held only if the candidates wished to further their description of their life experience. Interviews were between 60-100 minutes in length. Interview length was of course dependent upon the individual and his/her ability to maintain concentration and willingness to further the discussion.

As many as four interviews were required in the second phase to complete the action research cycle. The action research phase of this study began in April 2003. The second and third interviews were not started until the candidate had the opportunity to read and discuss the previous transcript. This was the same procedure followed in phase one of this study. A more in-depth outline of the methodology for the second phase of this study will be provided in Chapter 5.

Individual follow-up interviews were conducted at three, six and nine months after the conclusion of the action research cycle. In total, the research project required up to 12 months to complete with each participant. The full length of the project was approximately 18 months.

Interviews for the initial portion of the study were scheduled to begin following approval from the James Cook University Ethics Committee. (See attached Appendix 1).

All interviews were audiotape recorded. These tapes were transcribed with care to capture the language of the candidates, the tone of emphasis they used during the delivery, and also pauses which might have represented contemplation, surprise or a momentary search for words. These descriptive elements were presented in the typewritten product. Interview transcripts were made available to candidates before their next interview.

Reduction/Epoche/Bracketing

Van Manen (2000) uncovers the onerous responsibility of the researcher, saying “the human science researcher is a scholar-author who must be able to maintain an almost unreasonable faith in the power of language to make intelligible and understandable what always seems to lie beyond language” (pp. xvii-xviii). This understanding is attained from the description of the personal experience of the individual under investigation. In order to understand the meaning given to the experiences of the participants, the researcher must free him/herself of any encumbrances, misconstructions or other impositions they might have with respect to the phenomenon under investigation. Therefore, as much as possible the investigative process must proceed without bias or prejudice on the part of the researcher.

Bracketing, or phenomenological reduction, as it is frequently referred to in the language of phenomenology, is a process whereby the researcher

suspends “theoretical beliefs, preconceptions, and presuppositions” (Pollio et al., 1997, p. 47). This is done to isolate the potential interferences which might otherwise distort the interpretive vision of the researcher. This does not involve an absolute absence of presuppositions (Giorgi, 1975; Kvale, 1996) but rather a careful critical analysis of the researcher’s own presuppositions. According to Merleau-Ponty (1945/1962 orig.), complete phenomenological reduction is an impossible task for the researcher to achieve. Therefore, to avoid conceptual inadequacy, Pollio et al. (1997) recommend a more positive application of the principle of bracketing. The bracketing process is not exhaustive; therefore, phenomenological reduction can become a procedure of continuous application. It can be likened to a downward spiral whereby an increasing intensity develops as the researcher engages with the candidates in the interview process as well as with the data during the analysis. These authors suggest the primary researcher use a more positive application of bracketing, “one that does not assume or require neutrality as ideal or even as an attainable perspective” (p. 47). Pollio et al. (1997) describe bracketing as “a way of seeing” (Pollio et al., 1997, p. 48). This is also consistent with Kvale (1983). In other words, rather than attempting to have the researcher suspend his or her “worldly knowledge, the interpreter applies a world view such that a phenomenological understanding may emerge” (Pollio et al., 1997, p. 48). This “world view” allows for a first-person description of the phenomenon to surface. There is no formal means for testing and subsequently proving with any certainty that the phenomenological understanding derived from an investigation is identical to the lived experience of the participant. Therefore, bracketing is an ongoing process aimed at attempting to “identify and correct interpretations in which the phenomenological perspective has been co-opted by incompatible suppositions” (p. 48). The role of bracketing is critical for accuracy and credibility of the phenomenological research process.

Pollio et al. (1997) advise that even the best efforts of properly attempted methods of bracketing can fail. These authors outline three procedures for overcoming the limitations of the bracketing process.

1. The interviewer should consider explicitly his or her motives and reasons for conducting research on the particular topic. One practice is to develop a personal statement describing the researcher's history and interest with the topic and any concerns specific to the phenomenon under investigation. A further step would be to conduct a bracketing interview. Here, the interviewer becomes the first to be interviewed on the topic under investigation. The primary researcher can provide a description of his/her current understanding of the phenomenon to become more attuned to his/her own presuppositions. This will enable him/her to become sensitised to the potential demands that will eventually be placed upon the participants during or following the interview, during the analysis and interpretations.
2. This second procedural recommendation is intended to help the researcher avoid imposing personal opinions onto the interpretation of the research data. This is accomplished in part by using terms and language consistent with the participants' language rather than using abstract terms arising from the researcher's discipline.
3. To arrange to have the interpretations of some of the interview texts with other members, such as in a group setting. Suppositions are more likely to escape the notice of an individual than they are to escape identification by a group. The group may offer a broader range of alternative perspectives, therefore offering in-depth analysis of the data and reducing the risk of describing

> the text in a stereotyped, biased or prejudicial manner. A group provides a public forum to test whether the interpretation is supported by the interview text. Members of the group may challenge the researcher by asking him/her to "show, where in the text, you got that interpretation" (Pollio et al., p. 49).

Frank (2000) also speaks to the human difficulty of this process of reduction, stating readers and critics need to examine their pre-understanding. She draws on the work of Moi (1985) to demonstrate the difficulties inherent in this activity. "Hermeneutical theory, for instance, has pointed out that we cannot fully grasp our own 'horizon of understanding': there will always be unstated blind spots, fundamental presuppositions and 'pre-understandings' of which we are unaware" (p. 84).

Therefore, as much as possible and as frequently as it was deemed necessary, bracketing interviews were conducted to identify and reveal thoughts, feelings and ideas which might have otherwise biased or prejudiced the investigation. In this study, four bracketing interviews were held. The initial interview was conducted prior to my meeting with the first candidate. Subsequent interviews were held during both phases of the study. This first bracketing interview was conducted for the purpose of sensitising me in my role as the primary researcher. First, I expected this process would help me examine more intensely any issues I might have relating to hearing impairment and also investigate further my reasons for choosing this target population for my research. Second, presumptions, biases associated with my early experience with persons with hearing impairment were expected to begin to surface through this initial bracketing interview. Third, I felt this would prepare me for subsequent bracketing interviews by sharpening my awareness and helping me to identify biases or preconceptions.

Rather than using a group to serve as the “public forum” for the purpose of testing my correct interpretation, I enlisted the support of a professional colleague as a technical consultant to assist me. She is a retired Registered Psychologist in the province of British Columbia. She also served as the transcriptionist for the interviews, and therefore she had a sound and objective grasp of the study. She and her husband (who is also a psychologist) became the sounding board for many of the impressions and feelings. It appeared to me that the best person(s) to discuss any issue of thesis writing would be someone who has had the experience directly.

The Interview

The interview process was influenced by Kvale (1996). All 12 aspects are referred to because each of these has been included in my interview process.

1. Life-world. “The topic of the qualitative interviews is the everyday lived world of the interviewee and his or her relation to it” (p. 30). The qualitative interview involves two people investigating themes that are of interest to both. Later the information gathered is analysed with respect to the life world as it is described by the person. In the context of this study, the interest is in the individual experiences rather than common structures in the experiences of candidates.
2. Meaning. “The interview seeks to interpret the meaning of central themes in the life world of the subject” (p. 30). The primary task in interviewing is to understand what the interviewee is saying. The role of the interviewer is to register and interpret what is said and how it is said. He/she must observe and be able to interpret vocalisations and nonverbal communications such as gestures or facial expressions. The role of the interviewer is to listen to the

explicit as well as the implicit message, “reading between the lines of the dialogue” and when necessary, formulating the message, sending it back to the interviewee for confirmation or disconfirmation of the interviewer’s interpretation of that message.

3. Normal Language. “The interview seeks qualitative knowledge expressed in normal language, it does not aim at quantification” (p. 30). In an earlier work, Kvale (1986) describes the importance of the qualitative element of the interview process, saying “the interview aims at obtaining as many nuanced descriptions from the different qualitative aspects of the interviewee’s life-world as possible” (p. 175). Therefore, the precision of the description and the adherence to strictness in the approach to meaning interpretation is fundamental to the qualitative research design.
4. Descriptive. “The interview attempts to obtain open nuanced descriptions of different aspects of the subjects’ life worlds” (p. 30). Van Manen (1997) refers to these descriptions, saying, “This is the world of the natural attitude of everyday life which Husserl described as the original, pre-reflective, pre-theoretical attitude” (p. 7). As precisely as possible, the interviewee’s experiences and feelings should be contained in the data. Interpretation is a separate process outside of the interview. “The question of why the subjects experience and act as they do is primarily a task for the researcher to evaluate” (Kvale, 1986, p. 32). Kvale likens the behaviour of the researcher to that of the doctor dealing with a patient. The primary task of both is to obtain descriptions in order to gain “relevant and precise information from which to draw interpretations” (p. 33).

5. Specificity. “Descriptions of specific situations and action sequences are elicited, not general opinions” (p. 30). Meaning can be extracted from the rich or “thick” Geertz (1973) descriptions given during the interview process.
6. Deliberate naïveté. “The interviewer exhibits an openness to new and unexpected phenomena, rather than having ready-made categories and schemes of interpretation” (p. 31). Descriptions of relevant themes should be as “rich and presuppositionless as possible” (p. 33). The interviewer should be curious and sensitive to both what is said and what is not said by the interviewee. Critical awareness by the interviewer of his/her own presuppositions is important. “Presuppositionlessness thus also implies a critical consciousness of the interviewer’s own presuppositions” (p. 33). The importance of this activity is further elucidated under the heading of “Reduction/Epoche/Bracketing” referred to earlier in this chapter.
7. Focused. “The interview is focused on particular themes; it is neither strictly structured with standardized questions, nor entirely ‘non-directive’” (p. 31). The task of the interviewer is to keep the topic as the focus of the interview within different perspectives or contexts. The interviewee then brings forward dimensions he/she considers to be important within the particular focus area. The interview may then lead the subject toward certain themes but not to specific opinions about the themes. The objective of the qualitative interview process is to gather information, not to reach conclusions.
8. Ambiguity. “Interviewee statements can sometimes be ambiguous, reflecting contradictions in the world the subject lives in” (p. 31). It

is the responsibility of the interviewer to determine whether the ambiguities or contradictions are due to a breakdown in communication in the interview process or a reflection of inconsistencies, ambivalences, or contradictions by the individual. What matters in the qualitative interview process is to identify and describe the possibility of ambiguity and/or contradictory meanings expressed by the study candidate. These contradictions represent the world in which they live.

9. Change. "The process of being interviewed may produce new insights and awareness, and the subject may in the course of the interview come to change his or her descriptions and meaning about a theme" (p. 31). Candidates may discover new aspects of the themes they have been describing. Previously unidentified components of these themes may emerge. The questioning or dialogue during the interview may instigate a reflective process where meanings of the themes described by the subject are no longer the same after the interview process.
10. Sensitivity. "Different interviewers can produce different statements on the same themes, depending on their sensitivity to and knowledge of the interview topic" (p. 31). There is a tension between sensitivity to the interview topic and previous knowledge of this topic of the interview as discussed in an earlier statement (point 6) in regard to "presuppositionlessness". Therefore, a deliberate and conscious naïveté may be required on the part of the interviewer to prevent any foreknowledge of the topic to be made known.
11. Interpersonal Situation. "The knowledge obtained is produced through the interpersonal interaction in the interview" (p. 31). The

interview may have very positive characteristics which are shared by both parties or it may be anxiety producing. In this later state, defence mechanisms may emerge for both the interviewee and the interviewer. Therefore, consciousness of the interpersonal dynamics should be taken into account both during the interview and following it, throughout the next stage, the analysis.

12. Positive Experience. "A well carried out research interview can be a rare and enriching experience for the interviewee, who may obtain new insights into his or her life situation" (p. 31). For the interviewees, finding someone with whom they can make a connection, someone who is willing to devote time and attention to them, to listen to them may result in their resistance to terminating the interview process (Kvale, 1996).

In keeping with this discussion of the interview process, Pollio et al. (1997) refer to Hagan's (1986) description of a non-mechanised interview format. First, it is not entirely possible nor is it necessarily desirable to achieve a "bias-free" position for the researcher. These authors continue, stating how it is not possible to expect only "neutral" or "value-free" questions to be asked. Understanding the participant's perspective is not simply a matter of finding a neutral phrase to use. Rather, it requires the interviewer to explore the meaning of the terms for the interviewee. Therefore, clarifying questions can and should be asked without attempting to determine the direction of the interview.

Second, if at all possible the interview should begin with non-threatening questions. However, as mentioned earlier, it may be impossible to identify questions of a non-intrusive and non-threatening nature for the participant because there may be cultural, personal or situational factors which are beyond the scope or awareness of the researcher.

Third, the interview process must be a flexible one. "At a minimum . . . a phenomenological interview cannot (and should not) be conceived as a rule-driven mechanical activity" (Pollio et al., 1997, p. 33). The interview is defined by these authors as a social experience and, therefore, it is subject to the same expectations of behaviour as other social encounters. To be restrictive or to be too informal may have consequences. "For the interview to be a path or way for understanding the life-world of a co-participant, it must be allowed to emerge freely rather than to be constrained by predetermined injunctions" (Pollio et al., 1997, p. 33). The purpose or objective of the interview questions, according to Moustakas (1994), is to evoke a comprehensive account of the individual's experiences of the phenomenon under investigation. These questions may be varied or altered or perhaps not even used if the participant provides a "full story of his or her experience" (p. 114).

In the interview process there were few pre-specified questions concerning the topic. Questions flowed from the dialogue as it unfolded rather than being prepared in advance. "In an open dialogue, such as typified by a phenomenological interview . . . the dialogue is grounded in participant experiences of both the interview and the phenomenon" (Pollio et al., 1997, p. 35). The reappearance of some of the issues which arose earlier in the interview was anticipated. Also, any questions asked by the interviewer were for the sole purpose of evoking description and not to confirm a theoretical hypothesis.

The Hermeneutic Circle

The hermeneutic circle is closely linked to phenomenological reduction in as much as the application of the cycle endeavours to safeguard against the inappropriate interpretation of the text. It is presented as an "interpretive procedure in which there is a continuous process of relating a part of the text to

the whole of the text" (Pollio et al., 1997, p. 49). Moustakas (1994) describes hermeneutics as "the art of reading a text so that the intention and meaning behind appearances are fully understood" (p. 9). Hermeneutic analysis, therefore, offers a realistic means for gaining a broader and richer understanding of the text.

To overcome what might appear to be a linear character arising from simply reading the data from start to finish, the researcher deliberately reads the text to understand earlier portions in relation to latter ones and conversely, latter portions to understand the relatedness to earlier ones. Thus, any particular portion of the text is given the opportunity to be understood in terms of the whole. Pollio et al. (1997) draw from Kvale (1983) and Register and Henley (1992), explaining how this prevents any passage being regarded as a "decontextualized thing-in-itself" (p. 50). These authors liken this hermeneutic process to the experience of reading, understanding, and describing a book. The closer determination of the meaning of these individual parts may eventually change the originally anticipated meaning of the whole, which again influences the meaning of the separate parts, and so on. In principle, therefore, this hermeneutic cycle can be an infinite process but in practice it ends once a sensible meaning has been reached, "a valid unitary meaning, free of inner contradictions" (Pollio et al., 1997, p. 47).

Between three and five transcripts, according to Pollio et al. (1997) are sufficient to begin to develop a sense of descriptive patterns and relations that characterise the different interviews. In my research design there were eight interview participants. There were sufficient numbers and variety to establish descriptive patterns and themes from the transcripts. The interpretive process was an open one. During the interpretive process, the researcher and the technical consultant met for the purpose of assessing how the developing thematic understanding fits each successive transcript. Thematic structures can

be modified when unique experiential elements emerge in a specific protocol. At this time the part-to-whole procedure, characteristic of the hermeneutic process, was applied for the purpose of yielding a more inclusive thematic structure. "A specific thematic structure, describing experiential patterns and interrelationships among themes, is the final product of an existential-phenomenological interpretation" (Pollio et al., 1997, p. 52).

In summary, the intended process of transformation, which leads from protocols to themes, "involves an insight-like process that comes from a complete immersion with both the original interview in the form of dialogue and its subsequent written form as protocol" (Pollio et al., 1997, p. 52). Formal or abstract principles are not the basis for developing thematic description. Instead, the researcher endeavours to capture what the experience was like for the participants. The meanings are captured in the language of the participants rather than in the formal language of a discipline or in abstract principles. The term "thematize" is borrowed from qualitative research according to Polkinghorne (1989) and refers to the process in phenomenological researcher where "it denotes that the search for essential structures involves identifying the constituents or themes that appear in the descriptions" (p. 51). Themes then are tied to the protocol. The task of the theme is to make the meaning of the protocol clear as to the way (or ways) in which the events described in the protocol were experienced and lived by the individual. Interpretations must always be supported by references to specific segments of the text. Thematic interpretation, therefore, is a continuous process. It involves going back and forth among the various parts of the interview text. Here, both earlier and later parts of the text are "continuously being rethematized in the light of new relations provided by an unfolding descriptive understanding of the text" (Pollio et al., p. 52).

> Thus, hermeneutic phenomenological method tries to "explicate" meanings that in some sense are implicit in our actions. We know things through our bodies, through our relations with others, and through interaction with the things of our world. Phenomenological research/writing succeeds when we can make these meanings recognizable. (van Manen, 1997, p. xiv)

Analysis of the Data

It is important to focus once again on the purpose of this study in order to understand the breadth of this investigative analytical procedure. There are two primary intended outcomes. The first is to gain an understanding of the lived experience of these eight candidates. Through the analysis of their stories, a more comprehensive understanding of their life experience with hearing impairment may be captured. The dialogue is expected to invite and to challenge individuals to recollect thoughts and experiences, perhaps for the first time ever. These are the "prereflections" Husserl (1964), van Manen (1997), and Giorgi (1975) discussed in the literature. This requires a great level of trust on the part of each candidate. They are to be admired for their generous gift of allowing the interviewer into their lives to the extent they did. There was no set pattern to the questioning; therefore, the direction of the interview was set by the candidate, which led to more searching and revealing questions by the interviewer. This again speaks of the gift each candidate made to this process. What is more, they gave the most valuable commodity in life, their time.

The second intended outcome from this research activity was to explore the utility of a model for rehabilitative professionals to use in their work with adults with hearing impairment. This was achieved first through application of descriptive analysis, in the form of dialogic and introspective phenomenology in order to capture a deep understanding of each adult's pertinent life experiences.

Candidates, therefore, were asked not only to tell their stories in detail, but also to allow the stories of their lived experience to be analysed in order for others to gain a glimpse and perspective of life with hearing impairment. Following this, in the second phase of this study, the broader understanding gained during the first phase was intended to identify a specific challenge. The objective was to construct individual action research case studies where the goal was to help individuals in the study achieve more positive life outcomes. Any one of these activities might be considered worthy of this level of research investigation all on its own. In order to accomplish the stated objectives, limitations did apply. For this reason, I used an adaptation of "data analysis spiral" (Creswell, 1998, p. 143).

Candidates going on to the second phase of the study accepted a new challenge of experiencing personal growth and development through the application of action research. In doing so, they were agreeing to have their life experiences analysed (possibly for the first time). In addition, they allowed their total experience in the project to become a tool for informing others within the helping professions to gain a broader understanding of hearing impairment as well as to become active participants in a process of planned change. These are remarkable contributions by these eight individuals.

According to Denzin (1989), identifying objective experiences in the lives of the study candidates provides a good starting point for the analysis of the data. Candidates were asked to give a chronology of life experiences including, but not restricted to: childhood, highlighting experiences through early, middle and high school education, marriage, and employment. Through this process, "epiphanies will emerge from the individual's . . . interviews" (Creswell, 1998, p. 146). The biographical texts were analysed and these yielded contextual experiences, providing meaningful descriptions. This approach became the general template for analysis.

Methodologies do not always maintain a fixed design. "Data analysis," Creswell (1998) explains, "is not off-the-shelf; rather, it is custom-built, revised" (p. 142). "It is important to be aware," Willig (2002) argues, "that phenomenology does not constitute a unified closed system of propositions and practices" (p. 50). According to Dey (1993), researchers "learn by doing" (p. 6) and in the process achieve a kinesthetic learning process shaped by unique circumstances of each particular study. As Creswell (1998) concludes: "Undeniably, qualitative researchers preserve the unusual and serendipitous, and writers craft each study differently, using analytic procedures that evolve in the field" (p. 142).

Creswell (1998) describes how data analysis can be represented in a spiralling image. "To analyze qualitative data, the researcher engages in the process of moving in analytic circles rather than using a fixed linear approach. One enters with data or text . . . and exits with an account or a narrative" (p. 142). Each action is intended to offer a different perspective, much like the illustration of a cube used by Solowsky (2000) where he describes how each turn of the suspended cube produces different sides, aspects, and profiles of the object or experience under phenomenological investigation.

Data management constitutes the first loop in the data analysis spiral for Creswell. Here the data are organised. In this study, both computer files and printed hard copies were used. As well as being organised, the files were converted to text units such as words, sentences, or stories told by the candidates. The volume of text derived from the interviews was enormous.

> The data gathered by qualitative methods are voluminous. I have found no way of preparing students for the sheer massive volumes of information with which they will find themselves confronted when data collection has ended. Sitting down to make sense out of pages of interviews and whole files or file notes can be overwhelming. (Patton, 1980, p. 297)

The next stage after data organisation is for the researcher to attempt to gather a sense of the whole. To achieve this, the transcripts must be read several times in their entirety. Once the data are organised, the next activity is to gather a sense of the whole (Creswell, 1994,1996; Tesch, 1990). During this process, the researcher attempts to immerse himself/herself in the details, thereby endeavouring to make sense of the interview as a whole initially, before it is broken into parts. At the same time, notes can be written in the margins of the text for future reference. Listening to the audiotapes of the interviews, reading the field notes, and reflecting upon the interaction will help to "'hear'" (Creswell, 1998, p. 144) what the candidate is saying. All of these procedures were applied in the analysis of the data.

Creswell's model then moves from the reading and "memoing" into what he refers to as the "heart of the qualitative data analysis" (1998, p. 144), the description, classification, and interpretation of the data. As the primary researcher, I described precisely what was seen or heard in order to develop themes or dimensions through classification systems or perspectives found in the literature. Details are provided within the context of language and circumstance as presented by the candidate. Consistent with Creswell (1998), van Manen (1997) explains how "phenomenological research finds its point of departure in the situation, which for [the] purpose of analysis, description, and interpretation functions as an exemplary nodal point of meanings that are embedded in this situation" (p. 18). The "situation" could mean the experience with another person(s), place(s), or event(s).

Classifying refers to searching for categories, themes, or dimensions in the data. In this study, I allowed the themes to emerge from the text of the transcripts. I made no effort to limit the numbers of themes or to achieve any standard for comparison between candidates. In this way, a rich, thick description emerged and helped to maintain the uniqueness of each candidate's

story and provided a valuable point of reference for the second phase of this study.

Creswell (1998) refers to interpretation as “making sense of the data” (p. 144) or as the lessons learned (Lincoln & Guba, 1985). This was done in an attempt to bring closure through the final chapter. I expected new interpretations to arise “based on hunches, insights, and intuition” (Creswell, 1998, p. 145) as the data were read through. This may also occur for the readers of this thesis as they engage with the data in Chapter 4. Finally, stepping away from the data provided me an opportunity to see more objectively what was happening through the entire research process. I was then able to articulate these events with my technical advisor and thesis supervisors.

Creswell (1998) discusses the final phase of the spiral as the packaging and presenting of the data by the researcher. In this study, results were reported in the form of each candidate’s personal critical reflections and ongoing qualitative data analysis. There was no attempt to formulate a hypothesis or to report frequency of language used or circumstances described. “Phenomenology does not allow for empirical generalizations, the production of law-like statements, or the establishment of functional relationships. The only generalization allowed by phenomenology is this: Never generalize!” (van Manen, 1997, p. 22). By concluding in this way, I believe the richness of the experience given by each candidate was allowed to be heard by the reader. I think this also demonstrated respect for the candidate’s description while at the same time informing others of his/her life with hearing impairment.

Summary

Solowski (2000) describes the phenomenological approach as “the study of human experience and the way things present themselves to us in and through such experience” (p. 2). The understanding of these experiences is gained,

according to Giorgi (1975), Husserl (1964), and van Manen (1997), prereflectively or before they are categorised or conceptualised by the individual. The phenomenological approach is intended to create a way and means for the participant to retrieve these experiences through purposeful dialogue with a researcher. For the purpose of my thesis, this information is then intended not only to inform the professionals working with people with hearing impairment but also to provide a deeper understanding for people with hearing impairment as a result of their dialogue and reflection on aspects of their experiences.

In the research methodology an ordered procedure and purposeful approach was presented, one which was intended to allow the participant to feel in control of the process. In this chapter, a comprehensive description of the procedural approaches used was presented. In this research design, the role of researcher was shared by the primary researcher and the study candidates. Following each of the interviews, the transcripts were shared with the candidates, first for verification and second for the purpose of reinforcing their own understanding of their experiences. Throughout the process of gathering, analysing, and sharing the information, it was vitally important for the participant to feel respected for their willingness to disclose, valued for their contributions and validated for their feelings. “In all dealings with participants, an air of equality was maintained” (Pollio et al., 1997, p. 59).

As information was reviewed, themes emerged. There were no attempts to compare frequency or similarity of themes because these represent the accounts of the individual, which in themselves have the power to inform the candidate and the researcher. Reviewing the data repeatedly provided a deeper and richer understanding of the life experiences of the candidates. In the chapter to follow, these experiences are presented with interpretation. The dialogue text is referenced frequently in order to demonstrate how the researcher arrived at his interpretations. The objective of the next chapter is to bring a broader

understanding of what life is like for persons with hearing impairment through the interpretation of their “unreflected experiences” (Sucrest & Thomas, 1999, p. 241) and for professionals working with individuals who have hearing impairment.

CHAPTER 4. ANALYSIS OF DATA

Introduction

Chapter 3 described how phenomenology would be used as a research method in this study. Phenomenology is a method of collecting information that facilitates understanding of an individual's life experiences.

Chapter 4 contains an analysis of the data obtained through the phenomenological process. This analysis allows the reader to attain a deeper understanding of the meaning associated with hearing impairment for each of the study candidates. Many of these experiences are pre-reflective, i.e., some candidates stated that they were providing particular comments and perspectives for the first time in their lives; no one had ever spoken to them about these issues before. Therefore, these individuals may be gaining new insights into their own experiences simply by the process of telling their own stories to someone else.

The research protocol as outlined in Chapter 3 was applied in this chapter for each individual participant. Following each interview, candidates had an opportunity to review the transcripts for their approval. The primary researcher read these transcripts several times during the analysis in order to gain a clear understanding of each individual's description of his/her life. Furthermore, in order to reduce bias and increase accuracy, bracketing interviews were conducted with the primary researcher and a hermeneutic cycle was implemented. This interpretive procedure allowed the individual to access in-depth personal knowledge and therefore provided information that was richer in content for the primary researcher as well. Data collection from each candidate was carefully thematised without attempting to reach conclusions or identify similarities among the individual research participants. Indeed there was an attempt to preserve the integrity of each candidate throughout the presentation and analysis of the narrative account, i.e., description of his/her experience.

Throughout Chapter 4 the salient themes are used as headings to describe the candidate's interviews. The numbers and titles of themes in the analysis for each candidate vary depending upon the diversity of their individual dialogue.

Introduction of Candidates

The analysis of data shall be for the most part presented in chronological order from the youngest to the oldest candidate. Two of the study participants continued on to become part of the second phase of this study, the action research phase. For the purpose of continuity, the data collected from these two individuals shall be presented in the latter part of this chapter. The analysis of their data will then feed into the report of the action research phase presented in Chapter 5.

Four men and four women were selected. Their age ranges, with one male and one female in each age category, were as follows: 18-28; 29-38; 39-48; and 49-65. In the following section I will introduce all eight participants. This introduction will then lead on to a much more in-depth presentation describing each individual participant.

Roxanne was 18 years of age at the time of this study. She was the youngest candidate. She was experiencing difficulties finding employment and therefore was only able to find work in areas which were incompatible with her hearing impairment. Roxanne reports adjustment difficulties during adolescence which were compounded because her hearing impairment was not identified until she was in her early teen years.

At the time this study was conducted, Aaron was 27 years of age. He was attending university in an undergraduate degree program. His career objective is to become a teacher. His hearing impairment was not identified until he was 12 years old. He recalled having multiple assessments as a child but his early

recollections surrounding identification of his hearing impairment were vague. He is deaf in one ear and relies on a hearing aid for amplification in the other.

Sherry was 32 years of age at the time of her interview. Most of her work life was spent in the area of clerical jobs. Adaptation devices were provided as a result of her own advocacy or in some cases from the benevolence of her employers. Her hearing impairment was not identified until she was in her early teen years.

There was a long history of hearing impairments in Rod's family of origin. His hearing was suddenly compromised as a result of an industrial accident in his twenties. In the years following, Rod pursued an academic program in order to avoid working in industry. Although his hearing impairment was evident to others, it was not until he was in his 40s when his search for appropriate interventions led him to acquire his first hearing aids. This intervention took place weeks before our first interview. Rod was 43 at the time of his involvement in this study.

Mindy was 46 at the time of her first interview. According to Mindy, her hearing impairment was minimised by her parents. Therefore, she did not become aware of the magnitude of the impact her hearing impairment had on her life until her late 30s when she was provided with her first digital hearing aids.

Nils's hearing impairment was due to occupational related noise according to the Worker's Compensation Board of British Columbia. His work on ships as a crewman and a cook exposed him to the drone of diesel engines 24 hours per day, 7 days per week. In his early career he was regularly exposed to noise from high-pitched machinery. Nils, at age 61, was the oldest of the candidates.

Sharon and Andre are the final candidates to be introduced; both engaged in the action research portion of the study. Sharon was 51 years old when she was first interviewed. She is a single mother with limited work

experience. Although her hearing impairment was identified in her early 20s, she did not seek interventions until much later.

Andre was 35 years of age when he was first interviewed. He was married and had two preschool children. His hearing impairment was identified when he was in primary school. Adequate interventions were not introduced until he was in his 30s. Andre had two careers, baking and underground hydro installation.

In this chapter, the transcripts from the interviews of each of the eight candidates will be analysed and summarised under headings or themes. These themes were extracted from the transcriptions and varied for each of the candidates. This analysis does not attempt to compare frequency of theme responses; rather, it aims to provide a clear picture of each candidate's life experience. Some themes will be repeated by other candidates.

Recording the Interviews

Each interview was recorded using two tape recording devices, each with its own boundary style microphone. While this type of microphone was not recommended by the technical experts for this particular type of application due to its power and sensitivity to surrounding sounds, it proved to be quite well suited for this purpose. Two tape recordings of each interview were made as a preventative measure against any malfunction or accidents. This also demonstrated respect for the candidate's time and contribution.

Transcribing the Interviews

Following each interview, the cassette tapes were played back to ensure each side had been recorded. One set of the tapes was then carefully wrapped and mailed to the transcriptionist. The other tape was stored safely in a locked office.

The transcriptionist is a retired psychologist who worked in her earlier years as a legal stenographer. Her attention to detail was meticulous. Tapes were transcribed onto computer using a high quality dictaphone machine. The material was then stored on computer disks. Following the transcription process, both the tape(s) and the disk were returned to me through the post.

Reviewing the Transcriptions

I listened to each tape and disk while at the same time reading the transcription on the computer screen. Corrections were made to the text as necessary. A second review of the tape was then carried out and the focus was to listen to conversational tone and nuances. A third and sometimes fourth review of the tape was completed in order to include emphasis from the dialogue and to indicate when the candidate paused in conversation or when emotion was being expressed. Inclusions of these verbal or physical demonstrations were deemed vital to the integrity of the communication and transcription because the candidates were expressing themselves sincerely. As well, this provided a greater “feel” for the data when the transcripts were analysed, as it allowed me to remember my own experience with the candidate from the cues written in the transcription. A final review of the transcript was done once all of the corrections were made, intonations were added to the transcript and emphasis was included. It was anticipated that a 90-minute interview tape required up to 16 hours of work for the transcriptionist and an equal amount of time for me to review one transcript.

The transcriptionist was available by telephone or in person to discuss how the transcripts should be formatted. Different formats were reviewed for the purpose of choosing one that would provide clarity and flow for the reader. Once this was completed, the remaining transcripts were formatted in a similar way to maintain consistency.

Length and Frequency of Interviews

The length of the interview varied, as did the number of interviews for each candidate. All candidates were provided with the option of having as many interviews as they wished to tell their story. For example, Nils was interviewed on two occasions and Andre (who will be presented in Chapter 5) and Mindy participated in three interviews. All of the interview lengths varied between 60 and 100 minutes.

Special Note

Each time I reviewed a transcript, whether this meant reviewing the material three, four, or five times, my intent was to remain detached in order to be able to complete the task at hand. I was able to accomplish this because the bracketing interviews gave me the opportunity to allow my feelings associated with hearing impairment to surface.

Legend

Emphasis will be noted in several ways. <u>Underlined words</u> will demonstrate a more emphatic tone than would normally be expressed by the candidate during the dialogue. **Bolded** text will be used to demonstrate increased emphasis and text that is bolded and **<u>underlined</u>** demonstrates extreme emphasis by the candidate.

Sometimes the candidate will provide his/her presentation using a very low tone of voice. These texts will be *italicised*. At such instances where emphasis is made by articulating the words quite sharply and emphatically (one word at a time), these will be shown in a <u>staccato</u> - <u>like</u> <u>text</u> with each word underlined separately to denote the candidates' desire to make their point clearly understood.

As mentioned earlier, some of the candidates engaged in three interviews. When the interviews were only conducted during one calendar year, the year will be noted following the candidate's pseudonym and preceding the identifying page number, e.g. (Andre, 2002, p. 9). Where more than one interview was conducted in the same year, the year will be distinguished by the letter "a" or "b" following the year, e.g. (Mindy, 2002a, p. 26). Therefore, the "a" will identify the reference to the first transcript in that year and "b" the second.

Notes from My Diary

I recorded in my diary how impressed I had been with the ease and comfort of the candidates. They all wanted to tell me their stories and almost all of them expressed their feelings of genuine surprise, even disbelief that someone would be remotely interested in their personal struggles. I thought of them as being brave. They were demonstrating such a generous trust, and a deep faith in both me as a researcher and the research process itself, especially considering how little they would have known about phenomenology when they first made the decision to become a participant. Over time, as I learned more about them, I developed a great personal respect for each of the participants. This process of acquaintance transcends the one, two, or three hours of interviewing. Learning about them became an ongoing process that stretched to encompass the entire period of data analysis. I felt particularly honoured to be a part of their lives and I wanted to treat their stories with as much respect and dignity as I possibly could.

I was advised to obtain help with the transcription and this freed me. It allowed me to focus on the actual research rather than being caught up in menial tasks. As I read the transcripts following their return from the transcriptionist, I would make corrections, add emphasis, and provide other clarification around voice tone. At that point I also became aware just how much I was distancing myself from the candidates and the data. When the final review of the transcript

was completed, the material frequently appeared “new” to me. I remembered feeling like a transcriptionist in the law courts, detached from the proceedings—until the final review of the material. This “detachment” kept me focused on the task and not on the meaning. To have engaged the meaning of the data early on would have taken my attention and kept me from focusing on the task at hand.

It became very difficult to envision the end of this process. From time to time, I lost sight of the end as I focused on the primary task, gathering the data. Although I had been well prepared regarding how the data would be organised and analysed, I could not comprehend how the next phase could be achieved, given the volume of data I was gathering. It appeared to me to be too daunting a task even to think about. As a result, almost serendipitously, this helped me to maintain my focus on the job at hand.

The interview process was a very exciting experience for me, my favourite time. The activity of conducting the interviews, transcribing, and then reviewing the tapes and transcripts, though, seemed to be an endless task which I had to revisit over and over again. I recalled my principal supervisor warning me not to “fall in love with the data to the extent that it would prevent me from being able to consider if from a range of different perspectives”. At first I was not clear as to the meaning of such a statement but as I engaged more closely with the data I began to gain a better understanding. It is easy to begin to think of the data as the most prized possession in the world—that it is flawless and pricelessly rich in quality. Initially I did find it extremely difficult to step back from the data and extricate myself from it, to disentangle my thoughts and feelings that were so closely and invisibly intertwined around it, to remove the judgements I had inadvertently made about their stories, judgements that harkened back to long-held unquestioned habits of thinking. At the start it was extremely difficult to accept any criticism whatsoever of my interpretations regarding the organisation or analysis of the data. Over time I frequently recalled my supervisor’s warning

statement and I found it helped me gain a more sophisticated perspective both on the process of gathering the data and in its analysis.

Roxanne

Identification of Hearing Impairment

Roxanne recalls first noticing changes in her hearing at age four or five. Following a cold or flu, she remembered having a serious earache which required emergency treatment at the hospital. To the best of her recollection, her hearing impairment was not investigated beyond this treatment in early childhood. Roxanne was not able to provide any further details regarding the point of onset of her hearing impairment.

The next noteworthy incident Roxanne recalled occurred approximately in grade eight when her teacher made a recommendation for a hearing test after noticing her classroom behaviours.

> It wasn't until high school that anyone discovered I had a hearing loss. I went through elementary school without hearing aids or anything. They noticed that I was a little hard of hearing because they'd call my name or something from the back of the room, and I wouldn't hear them, so that's when they realised and they gave me like a hearing test. (Roxanne, 2003, p. 2)

Roxanne recalled hearing the results from the audiogram report. She was advised her hearing impairment was not serious enough to warrant her being fitted with hearing aids immediately. The following year however, bilateral hearing aids were recommended. "It just progressed and it got lower and lower, basically. Yeah, like 20% over like two years or something" (Roxanne, 2003, p. 7). Tinnitus preceded what Roxanne described as a sudden degenerative hearing impairment during grade nine. Some time later, Roxanne noticed a marked reduction in her hearing following a head injury from a swimming pool

diving incident. "It made it worse, because I remember not being able to hear anything after that for a while" (Roxanne, 2003, p. 7).

External Locus of Control

Roxanne's teachers became her primary advocates during her school years because they were the first to acknowledge the possibility of a hearing impairment and recommend immediate action to be taken. There were enough indicators to alert the teachers to the existence of a problem, yet her hearing impairment went unnoticed at home. "My mom was pretty much always involved in her own little world . . . so it was mainly the teachers that noticed" (Roxanne, 2003, p. 3). Although Roxanne identified her hearing impairment at a young age, it would appear there was some resistance on her part to inform her parents or bring them in and be a part of the solution. "Yes, I was having issues with my mother as well, so I kind of felt alone and stuff like that" (chuckle) (Roxanne, 2003, p. 7).

Once her hearing impairment was identified and something was being done about it, Roxanne talks about her need for change.

> I was kind of like ashamed of it [her hearing impairment], because I did pretty good in school . . . and then it just made me like withdraw from everything almost and then I had to find a new place for doing things like starting from nothing. (Roxanne, 2003, p. 4)

This "new place" (Roxanne, 2003, p. 4), explains Roxanne, was a move to a new city. It was a fresh start for her, and new struggles emerged both in the academic and social realms. Roxanne did not think her family provided support to her during this transition.

Employment

During the past three years Roxanne has worked for two communication companies, each time as a telemarketer handling telephone inquiries. She described how this has been the only type of employment she has been able to find. At work Roxanne has to use a telephone headset which induces her (ITE-in the ear) hearing aids to emit the classic "screech" when she turns her head and the headset shifts. Roxanne relies heavily on speech reading during normal conversations; however, at work she cannot rely on this alternate method to pick up what was being said because she is engaging customers using the telephone. Roxanne relies on her hearing aids and her speech reading equally in order to gain the most from communication.

Her working conditions are quite unsuitable and stressful due to her hearing impairment. She explains, "My job is not a very good job for me" (Roxanne, 2003, p. 9). Roxanne relies on people's attitude and tone of voice over the telephone to alert her to what she might expect. For example, if the caller has an accent, Roxanne attempts to understand the context of what is being said, to listen carefully, and then to try to sort out the problems or issues. From there she attempts to provide solutions, and sometimes her efforts appear to her to be futile. Furthermore, she may have to ask repeatedly for clarification. As mentioned above, from a technical standpoint, there is the continuous risk of having the hearing aids screech because of the pressure of the headset on one or both hearing aids or a sudden loss of power due to battery failure. When problems such as the latter one arise, Roxanne has to decide whether she can rely on just one hearing aid or ask the caller to wait on the line while she changes hearing aid batteries. Thus, this type of work holds potentially stressful situations for Roxanne.

Adjustment to Hearing Impairment

In the workplace Roxanne may be required to inform a telephone customer of her hearing impairment and by doing so, she does bring attention to her situation. At present, Roxanne finds informing people about her hearing impairment to be much easier than it was in high school. She reiterated how prior to her reaching grade 12 it was very difficult to tell her teachers about her hearing impairment. She adds, however, that following graduation from high school and being in the workplace, she has attained a higher level of comfort in terms of advising people about her requirement for some degree of accommodation.

Roxanne explained she has been in a relationship with a young man for approximately nine months. They have common interests and she described herself as being very comfortable in this relationship. "He kind of understands where I am coming from" (Roxanne, 2003, p. 6), meaning he has a grasp of her needs regarding her hearing impairment because he too experienced problems with his hearing at an early age. Now that Roxanne is in a relationship and sharing things with someone, it appears her life experience has been enriched. The relationship, she states, "definitely makes me not feel lonely . . . I am doing stuff together with someone, like making decisions, household choices, that kind of stuff" (Roxanne, 2003, p. 28).

Compensatory Strategies

Roxanne's primary learning strategies in school included good retention of visually presented information through reading and speech reading the teachers. She put effort into remaining focused and she was able to gather sufficient information from her readings to achieve honour roll status in grade eight. When the teaching methods for high school became more interactive and liberal, it was more difficult for her to excel. The academic system became "more oral . . . not

just like from reading the books" (Roxanne, 2003, p. 3); therefore, learning in classrooms created a greater challenge for her. Roxanne recalls one point when the teachers were alerted to the problems she was facing. She explained how she felt her old learning strategies were no longer effective after grade eight.

Isolation

Following her being fitted with hearing aids, Roxanne reported, "I became sort of withdrawn from myself, like I felt it [her hearing impairment] was my fault! I felt ashamed of it almost" (Roxanne, 2003, p. 3). She remembers withdrawing from everything she found familiar. As well, she reported having problems with her mother and she described how this contributed even further to her feelings of isolation: "I kind of felt alone and stuff like that but I am all over that now" (Roxanne, 2003, p. 7). Roxanne places value on having the strength to manage life and change, and she appears to want to project an image of a strong and vital person with capabilities and personal power. During her latter high school years she sought new places to go for a fresh new start, "like start[ing] from nothing" (Roxanne, 2003, p. 4). It appears the combination of stress at home and at school, as well as issues pertaining to her hearing impairment, prompted Roxanne to move to another province. Roxanne explains, "Because I was just like stressed and so much had happened. I needed new experiences and things like that" (Roxanne, 2003, p. 5). The focus of the school program in this new province was more academic, wherein student participation was encouraged, rather than a mostly traditional lecture format. Therefore, school became a source of increased challenge for Roxanne.

From an early age Roxanne had a sense of aloneness in the world due to her hearing impairment. She stated until the time she met her present boyfriend she was not aware of anyone else with similar kinds of issues with hearing. Her first encounter with someone with a hearing impairment occurred in her later

teenage years. "When I was younger . . . I never knew anybody with a hearing loss. I was totally the only person" (Roxanne, 2003, p. 23). While Roxanne explained she is no longer the only person at work with hearing impairment, she failed to mention whether currently she has any close friends who have hearing impairment.

When she discusses her early feelings of loneliness and isolation, she states:

> Before it was like an agony. Like an anguish, like I was just really, I don't know, sad and deprived . . . like a lonely soul or something, but definitely I don't feel that anymore! I won't let myself feel like that anymore . . . I won't let myself go on that downward tunnel feeling. (Roxanne, 2003, p. 25)

Roxanne makes it clear that she feels less like an "alien" (Roxanne, 2003, p. 23) and more like a "human being, like a regular person" (Roxanne, 2003, p. 29). The path through the "downward tunnel" (Roxanne, 2003, p. 25) appears to have been a long and difficult one for Roxanne. Later during the interview, she stated she is now doing things to not feel lonely and so isolated, such as actively participating in positive activities outside her work. However, she concludes, "I am definitely sort of a lonely person" (Roxanne, 2003, p. 25).

It is reasonable to assume that Roxanne is struggling, and while she wishes to keep this private, her statements and actions bring it continually to the surface. In other words, the problems associated with her adjustment, in particular, feelings of loneliness and isolation appear to have intensified following her being fitted with hearing aids.

At this time, Roxanne is not quite as alone in the workplace, as one of her co-workers has bilateral hearing impairment. This marks her second encounter with another person with hearing impairment. As a result, she no longer feels "totally like an alien anymore; I kind of feel like other people are there too"

(Roxanne, 2003, p. 23). It is interesting how Roxanne did not become aware of other people having a hearing impairment until she was approximately in her later teen years. This is remarkable since an estimated 10% of the population of Canada in this age range have hearing impairment (Canadian Hearing Society, 2001; Canadian Hard of Hearing Society, 2001; Richter, 2001). In her closing comments, Roxanne and I discussed the term "alien" (Roxanne, 2003, p. 23). She describes herself as no longer feeling alienated and feeling "more like a human being, like a regular person" (Roxanne, 2003, p. 29). If one is to infer from such a comment that Roxanne had at one time not felt part of the human race, this indeed is an extreme description of alienation. It would appear, therefore, at some point in time, Roxanne experienced what can be described as a reunification with others, allowing her to feel she has something in common with people who do not have hearing impairment.

Self-Image/Self-Confidence

Troubled with thoughts regarding her hearing impairment and her need to wear hearing aids, Roxanne explains how she felt her hearing aids might lead her peers to think she was different or weird. "I wasn't comfortable enough with myself to accept it [the use of hearing aids] and didn't have basically enough support to, you know, work for the better" (Roxanne, 2003, p. 8). Roxanne describes her process of adjustment through the high school years.

> In grade 10, I was actually struggling with school, like with <u>myself</u> (chuckle), like a war going on and then I just decided that I can't fail! It was like, you know, a teenage thing I guess, like inner turmoil, I don't know. Just like you don't like yourself, you don't like your life, you don't like anything! Yeah, like you are going against your parents' ideas, other people's ideas. You have your own ideas. You basically start having <u>your own ideas!</u>

(Roxanne, 2003, p. 9)

Both of these comments, as well as one made earlier regarding her mother being preoccupied—"My mom was pretty much always involved in her own little world" (Roxanne, 2003, p. 3)—suggests an underlying theme of lack of support or understanding from at least one of her parents. Roxanne felt alone not only in terms of her hearing impairment but also with respect to her personal life struggles.

Through the process of talking about her early years, Roxanne revealed other aspects of her personality—rebelliousness and assertiveness. "Yeah, like you are against your parent's ideas, other people's ideas. You have your own ideas. You basically start having your own ideas" (Roxanne, 2003, p. 9).

When Roxanne talks about her work, a powerful theme of variability and upheaval emerges. She explains how at work she has "good days" when she can solve problems for many people with respect to their telecommunication accounts, cell phones, and electronic bundle service packages. Being able to help others appears to mask some of her internal worries and struggles. There are also some bad days at work wherein, "it may be stressful. I don't want to be there, I don't like anyone, I don't like myself" (laugh) (Roxanne, 2003, p. 9). Some of these feelings may arise from the frustration caused by the overwhelming auditory demands at work when she often has to listen to a variety of different customers' voices, i.e., accents, angry tones, and belligerent responses. In her private life she appears to experience constant distress. Roxanne's tone of voice while talking about her life during the interview suggested a deeper sense of sadness. Indeed, several times during the interview Roxanne became quite emotional, particularly when she referred to relationships with her parents. There appear to be some unresolved issues in this area of her life.

Roxanne indicated how nowadays, she has no difficulty informing people she has a hearing impairment and she is able to express her needs clearly and without reservation. However, in high school it was a different matter because she was reluctant to divulge that she wore hearing aids or required any special accommodations. She reiterated her early belief that she was responsible for her hearing impairment. "I felt like it was my fault, like I was, like it was my fault that I had the hearing loss" (Roxanne, 2003, p. 8). Roxanne refers to her hearing impairment as her "main weakness!" (Roxanne, 2003, p. 5).

Approximately two years ago when Roxanne was in grade 12, she was assaulted by a fellow student. The attacker was a girl Roxanne had befriended earlier in the year and with whom she once shared a locker. Roxanne maintained this assault occurred without provocation. She explained how the girl used her fist to strike her on the ear. This she states was not accidental but quite intentional. Her hearing aid was broken and it cut the outer area of the ear. Roxanne talked about being beset by a recurring fear of either losing or breaking her hearing aids and not being in a position to replace them. The attack had obviously left Roxanne feeling physically and psychologically vulnerable and this was reflected in her voice's tone of desperation as she described the episode and as she reflected on ongoing problems. "Before . . . I felt very, very vulnerable" (Roxanne, 2003, p. 14). When asked about her feelings of vulnerability, Roxanne stated she is working very hard at overcoming the residual fears in all areas of her life. "I am definitely feeling better. I am working on it right now basically and improving, trying to work on improvement in all the areas that I can!" (Roxanne, 2003, p. 14). The impression left with the interviewer is that Roxanne continues to internalise the episode and therefore feels responsible for the attack. She concluded, "I am trying to find people in my life that I can trust and you know so I don't have to feel like that. Finding the right type of people" (Roxanne, 2003, p. 14).

When Roxanne is complimented by someone, she undermines her own abilities and strengths by stating there are many more remarkable people who are in much worse situations than herself. She does not appear to be able to recognise her own achievements, accomplishments, and/or abilities as being noteworthy when these are pointed out by others.

Roxanne mentions how every day she endeavours to achieve changes in her attitude, and by doing so, she has been able to overcome her tendency to feel down as well as to effect changes in her adjustment to her hearing impairment.

> I have more confidence to stand up for what I believe and if I don't like something or what someone is saying or doing, I am not scared to say it and voice my opinion. If I don't understand I definitely ask a question . . . that's how you learn is by asking questions. (Roxanne, 2003, p. 24)

With respect to the positive aspects within relationships, Roxanne indicates that prior to her present positive relationship with her boyfriend she felt like the proverbial "chicken with its head cut off" (Roxanne 2003, p. 26). Thus, it would appear Roxanne's present frame of mind has changed: "Like I definitely want to be positive and advance and do good! Do the best I can do" (Roxanne, 2003, p. 26). She discusses further about the changes which have ensued. "I used to be really shy and inside and now I am almost a totally different person! I have come out of my shell, sort of, a bit. I don't know" (Roxanne, 2003, p. 12). Her statement lacks conviction and appears to depict mostly a wish or desire rather than an actual change or outcome. It would appear that for her, believing such changes have occurred is important, as she no longer wishes to maintain her previous state of mind.

Independence and Internal Locus of Control

Roxanne constantly makes efforts to increase her independence and life purpose. She explains how making her needs known is more than merely a means of standing up for herself. She is also "doing stuff for myself, not for everybody else" (Roxanne, 2003, p. 10). Indeed, "standing up" for what she believes is quite an important issue for Roxanne. Thus, striving for autonomy has become one of her aims in life.

She demonstrates a strong desire to become self-reliant and thus realise her own hopes, dreams, and aspirations.

> I have goals. I want to go back to school. I want to experience things that every other 19-20 year old wants to, like go travelling or go to the lake or, you know, anything. To enjoy life for once instead of being stressed out! (Roxanne, 2003, p. 11)

It appears Roxanne would have liked to partake in activities with friends her own age, which she has not been able to engage in before now.

In regard to gaining control over her life, she states, "It seems like more and more I am becoming more in control of everything, like the way I feel, the way I do things . . . the way my life is basically going, I have more control of my destiny" (Roxanne, 2003, p. 20). Roxanne appears to be harbouring an ongoing fear, the fear of losing her hearing altogether sometime in the future.

> I am scared of being totally deaf or something when I am older and I think it would be a good idea if I learned sign language maybe, and I definitely want to get a spare pair of hearing aids. (Roxanne, 2003, p. 22)

She continues to search for security in all areas of her life, including gaining an additional pair of hearing aids, retaining friend, and identifying a suitable occupation.

Stressors

Damage to or loss of her hearing aids or trying to function without them for any length of time is a major stressor for Roxanne. "Thinking about losing my hearing aids or not having them, that really stresses me out!" (Roxanne, 2003, p. 11). She relies heavily on her hearing aids for auditory input. "Without them I cannot hear anything . . . I'm deprived of a sense" (Roxanne, 2003, p. 8). Her aim is to attain financial security in order to be able to purchase another spare pair of hearing aids and therefore partially overcome her feeling of vulnerability. Furthermore, Roxanne extends her search for a stronger sense of security in her relationships. "I am trying to find people in my life that I can trust and you know, don't have to feel like that [vulnerable]. The right kind of people" (Roxanne, 2003, p. 14).

She likes to engage in adventurous activities; however, she fears she may damage her hearing aids by doing so. Indeed, she had such a negative encounter with a girl at school, and this has left her with residual fears. She indicated she is afraid people may take advantage of her physically and/or psychologically. "I am just also scared of people taking advantage of me because I wear hearing aids. You know, like in social situations . . . just being taken advantage of because I can't hear properly" (Roxanne, 2003, p. 13). Vulnerability seems to be a major issue for Roxanne because it affects trust. Indeed, she would like to feel more positive about trusting; however, she appears to question the efficacy of this desire. It is important to note that Roxanne has demonstrated a high level of trust and confidence by participating in this study.

Summary

Based on Roxanne's description of her family, it would appear she felt they did not provide her with the support she needed to understand or the help to deal with her hearing impairment during childhood or adolescence. Support for

identification of her hearing impairment and assistance with hearing aids came from outside sources. Roxanne grew up to become an independent-minded individual who relied mostly on her own talents and strengths to achieve her objectives. Sometimes this process of becoming independent and self-reliant may be costly, as it may require losing out on some of the typical age-related experiences of growing up. This may have indeed been the case for Roxanne. As the interviewer, I often had to remind myself of Roxanne's age. In spite of her youth she presented as someone with many more years of life experience.

Roxanne is a remarkable young woman. Among her noteworthy gifts is her tenacity, demonstrated through the nature of the jobs she has held. She has worked in areas which were highly incompatible with her hearing impairment; however, she was able to keep up and succeed against formidable odds.

Aaron

Identification of Hearing Impairment

Aaron's earliest recollections of his hearing problems preceded grade one. He remembers attending a preschool for children with disabilities, and in grade one he attended a school for children with hearing impairments. According to Aaron, he was referred to a Child Development Centre for an assessment prior to attending kindergarten. His parents were proactive regarding early interventions. "They [his parents] always have been supportive. They were always looking for the best training . . . if I needed someone to talk to, they were there. That was reassuring . . . I had a lot of advantages growing up . . ." (Aaron, 2003, p. 35).

Independence

Aaron grew up in a small community. At age six his parents allowed him to board a sea plane (harbour to harbour) and fly to Richmond, British Columbia

to attend a kindergarten program for children with hearing impairments. He would be picked up from the plane by an awaiting taxi and taken to school. After school he would walk home to his grandparents, where he stayed until the beginning of the weekend, and then he would fly back home. Aaron's maturity and trust were noted in his comments regarding his travel. "Nothing scared me. I was never really nervous" (Aaron, 2003, p. 4).

Schooling

Upon his return to school on Vancouver Island, Aaron was confronted with numerous challenges, both socially and academically. The focus of his preschool education in Richmond was speech therapy, learning to read and write the alphabet, and developing listening skills. When Aaron returned to attend school in his own community the following year, he skipped grade one, going directly from kindergarten to grade two. However, as he entered the public system, he was behind in Arithmetic and Science. Suddenly, Aaron was facing new challenges and he failed his first attempt at grade two. He attributed his failure to his teacher. "I think she failed me because of my attitude, not because of my grades, so I felt kind of angry that she held me back because they [referring to his parents] wanted me to go on academically" (Aaron, 2003, p. 6). Further, Aaron explained how his teacher's poor attitude toward the children in class was reflected in the failure of a number of other students in his class.

Isolation/Alienation

Aaron acknowledged the differences between himself as a young man with a hearing impairment and other students.

> I think I was too young to be able to understand the difference; I just think probably it is different but I don't think of it in a bad way

> or a good way. I don't know but the technology was worse then and it was more obvious that you were hearing impaired because you had to wear this big clunky AM/FM unit, I don't think it is the same now, I think it was lots more visible . . . with the big straps that came over your chest and the back, you looked like a half robot, you have wires hanging out of your ears. (Aaron, 2003, p. 6)

Aaron expressed his views regarding the importance of relationships during early childhood. "I think if you are struggling with socialising it distracts you from the academics too" (Aaron, 2003, p. 8). Aaron believes television plays a vital role in the socialisation process, as it provides children with common themes and interests to discuss. Aaron did not watch television; therefore, he was not aware of the newest toys on the market and he could not name baseball or football players or identify the latest movie playing in the theatres.

Referring again to the problems he associated with not having television to learn from in order to remain a part of the larger cultural and worldwide picture, Aaron spoke of how difficult it was for him to be without this source of information in his life. "I couldn't talk about fun things and that's hard, it's very hard to do that" (Aaron, 2003, p. 8).

Humour was something Aaron missed out on throughout his childhood. Cartoons were not captioned, and therefore, the "antics" of the characters offered little in the way of stimulating laughter. Aaron was aware of his limited access to information through the television. Therefore, his only sources for information were books and other written materials.

Imprisonment

Aaron describes metaphorically his experience of attempting to socialise with hearing impairment.

> I was looking through a glass that is muting the voices of everybody, that's what it felt like, you are looking into a room and you are looking at all these people talking but you don't know what they are talking about. (Aaron, 2003, p. 13-14)

Peer Relationships

During the interview, Aaron provided a graphic description of his early years in school; however, he phrased it in the present tense.

> Socialising in school is really difficult, because you are left out of all of that. But talking with little kids is hard too, you just cannot hear when you are in groups and all kids like to talk in groups . . . they all talk at once, so that was pretty hard as well (few seconds' pause) so there is two things going on there, one you don't know what they are talking about and two you can't hear half of what they are saying in the first place. (Aaron, 2003, p. 8)

Thus, it appears the social and interpersonal aspects of Aaron's life were severely restricted due to his hearing impairment, and one can only guess how extreme Aaron's loneliness was.

Aaron reiterates that socialising and academics are closely interrelated. Therefore, he believes he would have devoted more attention and time to academics if he had had more opportunities for socialising; i.e., his focus would have increased as distractions decreased. Further, Aaron is firmly convinced that his interest in school was undermined by his relentless search for belonging and being included by his peers "because you get so obsessed with trying to be part of a social group that you forget about the academics" (Aaron, 2003, p. 9).

Teasing and Bullying

The children in his school would literally "gang up" on an individual, according to Aaron.

> So it was pretty hard, it was hard to try and make friends and sometimes you were more likely to make enemies too, [it is] just that certain kids that are going to be making fun just because you have a hearing impairment, just like they pick on kids with glasses or who are overweight. If certain people don't like you then the rest won't like you. (Aaron, 2003, p. 9)

Indeed, he still has vivid recollections of being the target of constant attack. "I can still remember that feeling when you were a kid that happened, getting picked on and that I haven't forgotten . . ." (Aaron, 2003, p. 9).

Aaron's school comprised approximately 100 children from a small rural community. Each class had between 15-20 children and they all knew each other. There was a single clique and children were either in it or out of it. "So that's what I mean by when one kid gangs up on you then the others follow suit" (Aaron, 2003, p. 10). Aaron describes the experience of rejection from his peers being carried out by the class bully.

> I didn't do as bad as others I think but in my class I was the only one who got picked on for years until probably grade seven, I stopped being picked on, but I also grew a lot then too, I was always one of the smallest boys in class and I was antisocial, I mean I had a couple of good friends but for the most part I didn't have a lot of friends. (Aaron, 2003, p. 11)

The poignancy of his rejection is captured in his reference to the bullying and teasing by a group of perpetrators: ". . . they are the only kids that you know, it is like your second family . . ." (Aaron, 2003, p. 10). Aaron describes one incident when he was alienated, using the following scenario.

> There was a very big kid, he was really hard on me growing up all the way through school and I do remember one particular year because he got the whole class turned against me. He asked the whole class to raise their hands—this is how well known he was—to raise their hands if they didn't like me and I just remember that one class in particular, the whole class raised their hands when they were asked if nobody liked me . . . I think everyone was afraid of him . . . I didn't think of it as power but he could make you feel so powerless. (Aaron, 2003, p. 12)

His swift physical development and his interest in competitive sports seemed to influence the way his peers perceived him. According to Aaron, his rapid increase in height and weight commanded their respect. He reiterates how sports were the key ingredients for change. He was not able to access information from television or to develop bonds through interaction with groups; therefore, he earned his place on the basketball court. Perhaps he was overcompensating to make up for the years of unrelenting ridicule, but eventually he found favour with his peers. He discovered he was quite successful at expressing himself physically. Therefore, he gained confidence along with his growth in stature and girth.

Self-Image

Aaron was not able to access what was being presented on television during those early years, and he feels this affected him in a major way. He attaches a great deal of importance to television as a means for accessing information and social connection.

> What are you going to do if you can't really say anything, it is like you are going uneducated and you don't know what to say, they are not necessarily the most important things, but when you are a

> kid, I could not talk about fun things and that's hard, it's very hard to do that. But socialising in school is really difficult, because you are left out of all of that. (Aaron, 2003, p. 8)

The perception by others is frequently believed to be the worst possible. It is not until children are older that they can find ways to combat the feelings associated with being unique or different.

> When I was a kid I was probably self-conscious about girls seeing my hearing aid in my ear, but when you get older and out of high school you realise there's nothing you can do about it, so, just find someone who accepts you for who you really are . . ."
> (Aaron, p. 25, 2003)

Locus of Control

Currently, Aaron projects the image of someone who is mature beyond his very young age and at peace with himself. While being teased and picked on, he realised how in spite of his difficulties he had some strengths in areas of art and reading. "You don't necessarily have to have someone else know that you are good at something but just that I knew I was good at it was enough for me and that made me feel good" (Aaron, 2003, p. 19).

Upon reflection, Aaron acknowledged how change is beneficial, as he welcomed the opportunity to seek new work following graduation from high school. He describes the following situations as an example of an external locus of control.

> When you are stuck in the same place it is hard to rectify your mistakes because you are still in the same situation. It gets you in a certain way and you have to stick with it and it is almost impossible to get out of that stereotype, and that's why it was

> easier moving out of school [from elementary to high school in a different community]. (Aaron, 2003, p. 22)

Aaron discusses the shift from an external to an internal locus of control.

> When I went out of high school and out to [Terrace] I was a whole new person. There I made new friends and I was able to make new friends with people in circles and groups I wanted to be associated with. (Aaron, 2003, p 22)

It would appear that Aaron recognised his source of control at an early age: "Dating in groups was not very pleasant." One-on-one situations made it much easier to control the dialogue while on a date. This suggests that Aaron was able to manipulate situations to his advantage in order to maximise his enjoyment. The alternative, of course, would have been personally devastating. "I think relationships with girlfriends were more enjoyable for me than relationships with friends just because you weren't always in groups. It was nice just to have someone to talk to one-on-one" (Aaron, 2003, p. 26).

Compensatory Strategies

While Aaron was in grade four, he began to read high school level material. Prior to getting involved in sports, he acquired most of his information through reading, and he used art as a means of expressing himself. Both these skills set him apart in his uniqueness and talent from other classmates.

Sometime after he started high school, closed captioning on television was introduced.

> I was actually able to pick up humour off shows like *Cheers*. I watched a lot of adult shows and they helped change the way I talked and I could pick up things that they talked about . . . not just humorous things . . . I could actually <u>see</u> how people actually socialised. (Aaron, 2003, p. 13)

With the TV as his model, closed captioning became a resource for understanding social concepts and interaction, and he felt better equipped to interact with others in his life.

> So I know it is just TV but I knew there are differences between the real world and TV, but I needed a model so that I could get some sense of what people talked about and I knew that I was pretty far ahead of the other kids in school, I mean I could understand the social concepts pretty well. I knew what was going on even without any help. So mature wise I was really, really far ahead of my years and I don't know why that is, I think it helped me get through school. (Aaron, 2003, p. 14)

His introduction to organised sports came through a friend. None of his family members, he explained, were remotely interested in sports either as spectators or participants. Therefore, developing an interest in this area was a struggle for Aaron. Nevertheless, he found acceptance from others, and personal enjoyment and achievement. "I think that gave me some respect . . . in other ways and I got to the point where I really got into sports and I was just obsessed with basketball" (Aaron, 2003, p. 12).

A different kind of communication was required on the basketball court. He realised he did not need to engage in extended dialogue while participating in sports.

> I think that sports have a social atmosphere so you don't have to talk, so that was an advantage. You can communicate physically but that was an advantage to me because I was the same as everyone else that way and it is pretty easy to be social that way because you are not talking so much. It was just so much easier to do it physically than mentally because mentally I was disadvantaged that way. (Aaron, 2003, p. 16)

Compassion

Aaron's future plans are rooted in his early experiences. He recalls the time during his high school years when he was no longer subjected to constant teasing.

> I couldn't stand the way kids screwed with each other, so I stayed out of those groups and I think I was trying to be more helpful. I found myself trying to help more people who would find themselves struggling socially at school, so maybe some kids thought it was strange for me to be doing that, but it was the way I was, I was trying to help out others. (Aaron, 2003, p. 15)

Critical Reflection

Aaron has a clear memory of what happened to him and to others in their school. He recalls being amongst the last ones to be picked for a team sport by the captain during gym class or intramural school athletic events. As well, he remembers how adults perceived situations involving children incorrectly.

> I got so frustrated with teachers and adults who would say: 'Oh, don't worry about it, you know, it's just natural'. And I promised that when I grew up I would remember that, because I didn't want to be an adult who did not understand that, and I remember saying that to myself when I was a kid, not later on but as a kid I thought that. (Aaron, 2003, p. 20)

Thus, Aaron states when he becomes a teacher he will not support such a system of selection wherein someone will invariably lose out.

In the following comment, Aaron provides greater clarity to the meaning of isolation during his early life. As well, he makes powerful connections with his

own self-awareness, his compassion and his vocational goal to become a teacher for children with hearing impairment.

> Sometimes it helps for kids to be around other kids who are the same as them. That was impossible for me, I never met another person who was hearing impaired, unless they were over 60. I had not talked to anybody with hearing aids since I came back from Vancouver, so I had no social contacts with kids who were around my age and had hearing loss. (Aaron, 2003, p. 17)

Aaron continues, "I was just saying that I was by myself in that way and that's all I noticed" (Aaron, 2003, p. 18).

Summary

Despite the rejection and taunting during his early school years, Aaron emerged seemingly unscathed. He persevered in the midst of peer abuse and teasing and found his strength by relying on the support of his parents. Aaron never mentioned whether his parents intervened to stop the bullying and teasing. It is not clear whether his parents knew what was happening or whether they dismissed it as being "just natural" (Aaron, 2003, p. 20). Aaron reiterates how determined he is to not allow such behaviour to be perpetuated in the school where he will eventually work.

Aaron grew six inches taller throughout the summer of grade seven. This, he stated, changed the way in which others perceived him. He was no longer the underdog but rather the "tame Goliath". Aaron did not choose to seek revenge. Indeed, having lived the experience and knowing what it was like to be on both sides of the fence, he has opted to be on the side of the supporter and seek a future career in teaching. At present, Aaron states he has a trustworthy group of friends, a good job, and a supportive relationship with his girlfriend and with his family.

Sherry

Identification of Hearing Impairment

Sherry experienced hearing impairment from an early age, as did a number of her siblings. She described her father's hearing impairment as severe and remarked that four of the eight children in the family have hearing impairment. Proactive health, she added, did not appear to be a priority to her parents, and therefore her hearing was not tested until she was in her early adolescence.

Sherry's earliest recollection of her hearing impairment being noticed occurred in grade one when she was asked to go outside the classroom to have a discussion about her family. During a follow-up interview, Sherry explained how these adults asked her questions regarding her home life in order to gain some insight into her school behaviour. She explained she was unable to remember the details of the discussion or the reasons for such taking place, as she was a very young child at the time.

> I was six years old and very articulate, orally and written and I remember consciously telling them what they wanted to hear—what I thought they wanted to hear—that everything at home was 'peachy'. They commented that because I was the youngest of eight that I must be 'spoilt'. So . . . I agreed with these adults and smiled and showed my dimples **but inside** I knew I was fabricating something and manipulating them. (Sherry, personal communication, Monday, August 30, 2004, p. 1).

Sherry described how she felt. "I didn't feel spoiled. I felt timid, confused, very little, alone, teased, lost, nervous, [and] suspicious" (Sherry, personal communication, August 30, 2004). It would appear Sherry was attempting to explain that her hearing impairment was only one aspect of her childhood which affected her behaviour. It may be feasible that other issues within her home life

had an effect on her school behaviour as well. Sherry recalls how the discussion did not bring forth any type of action or formal hearing assessment until she was 15 years old. Goldberg and Richberg McCormick (2004) discuss the importance of having properly trained professionals engage in the hearing screening of children in schools. "In the case of hearing screening, relegating the assignment to someone who may be well-meaning but not sufficiently competent for the task may be a costly error" (p. 156). While the professionals to whom Sherry referred were not performing a hearing screening, it would appear that these professionals were either unaware of the indicators of hearing impairment or did not consider that there might have been other contributing factors for the behaviours that alerted them to difficulties in the first place.

Attention from adults and the opportunity to engage them in dialogue became the focus of Sherry's interests rather than interactions with peers. With better than average language development and good speech reading skills, she was able to relate to teachers and adults at an early age. Thus, Sherry believes that due to these factors as well as her overall high level of maturity, her hearing impairment went undetected during her childhood.

Teasing

The youngest of eight children, Sherry recalls being teased a great deal by her brothers and sisters. She remembers being a shy and reserved child but also being bullied both at school and at home. At school, "I was their target, a complete target" (Sherry, 2003, p. 2). During the early stages of the interview, Sherry explained how she believed the teasing was not due to her size or her hearing impairment, but rather because she was the "teacher's pet" (Sherry, 2003, p. 3). Other reasons for teasing included her "seriousness, not 'getting it', [and] over-attentiveness" (Sherry, personal communication, Monday, August 30, 2004, p. 2). Due to the stress in the family and the "constant yelling and arguing

(much was due I'm sure to my father's hearing but ultimately always to do with my father) . . . I automatically sought the friendship/safety of teachers" (Sherry, personal communication, Monday, August 30, 2004, p. 3). Indeed, she preferred the attention from people with whom she could communicate and hear, i.e., adults. It was not until later that her small size and her hearing impairment played prominently in the reasons for further taunting and teasing during high school.

Sherry's family moved from a prominent neighbourhood in a city in the BC interior to a rural island community. While her family was not wealthy, she believed they would have given the appearance of such when compared to other families who lived in the same area where unemployment was high. She described her home life on Vancouver Island as remarkably different from what she had previously known. She was not able to make new friends easily and stated, "Kids were really rough and they were mean, they were really mean to me. I got teased **a lot**" (Sherry, 2003, p. 3).

Being "concerned for the underdog in the school" (Sherry, 2003, p. 3) and focusing more on her concern for others and less for herself, Sherry believes these values made her different from the norm. Perhaps such attention to others led her to feel more like she was not alone. Her overt concern for others, her lack of participation in group activities, the perceived financial status of the family, her physical size and her hearing impairment may have all contributed to her alienation from her peers. At the same time, Sherry made the conscious choice to not involve herself with other children, hence further alienating herself from her peers. As discussed earlier, Sherry sought the comfort and safety of adults because they spoke clearly, had deeper and more audible voices, and had important things to say. Her affinity with adults was evidenced through Sherry's willingness and desire to work in the library during lunch hours where she could enjoy the comfort of trusted adults while finding refuge and safety from the

teasing and bullying. Furthermore, the additional rewards of accolades from the staff for her helpful efforts kept Sherry seeking the attention of adults.

Sherry described an experience wherein stones were hurled at her and bodily threats were made while she was on her way to school. Sherry's image of herself was one of a "little adult" (Sherry, 2003, p. 8) finding refuge in a serious world of adults whose company insulated her from the world of children she could not hear, understand, or relate to. In addition, she found refuge from the emotionally disruptive events she experienced at home.

At age 15 Sherry was fitted with a hearing aid. However, the torment of not being able to understand language continued. The hearing aids, she explained, did not help her in being able to discriminate which sounds should be amplified; thus, all sounds were increased.

Sherry related one final school experience she had after the acquisition of her hearing aid, wherein students at neighbouring desks would tap pencils on the desktops to prevent her from paying attention to the lessons.

> I think I was used to being kind of ostracised a little bit just because I was different, but I didn't prepare myself for the fact that people think that if you have a hearing aid then you must be intellectually challenged somehow. (Sherry, 2003, p. 26)

Schooling

"It was . . . a really loud classroom. There was a lot going on and most of the time I don't think I knew what was going on" (Sherry, 2003, p. 3). In terms of clarity and articulation of speech in the classroom, not all teachers were alike. When Sherry had to deal with a teacher who did not articulate clearly, i.e., a mumble, she would lapse into daydreaming out of sheer boredom, as she could not understand the content of the lessons. In addition, her absenteeism from school would increase under such circumstances.

In retrospect, it becomes obvious how key indicators of problems went unnoticed. During the interview, Sherry remarked upon how, despite her problems in those early first 10 years of schooling, her teachers remained unaware of the hearing difficulties she was experiencing while in the classroom. She emphasised how she felt her marked disparity in her performance from semester to semester should have been identified and investigated. For example, Sherry described how she would spell a new word based on sound unless she had seen it in written form before or while hearing it. She recalled an instance whereby she was asked to spell "bus depot" (Sherry, 2003, p. 32) and she wrote down "bus steeple" (Sherry, 2003, p. 32). She added that at the time she thought it was an odd combination of words, but she spelled them based on how they sounded. She reiterated how similar errors and indicators went unnoticed for years.

Hearing Aids

Sherry expressed how overwhelmed she felt when she received her first hearing aids. The sounds she heard were completely new to her. Learning what they were, associating and cataloguing them in her memory while adjusting to the hearing aids were described as exhausting experiences. "When I first got my hearing aid . . . it was just like the birds, the water dripping, I mean so many details, it was always exhausting but it was <u>amazing</u> (four-second pause), a whole new world, a whole new world" (Sherry, 2003, p. 30). This was her first experience with the myriad sounds she had been missing for many years.

Isolation

Taking her place at the front of the classroom in elementary school was probably due more to her small stature than her hearing impairment, according to Sherry. Academic exercises not requiring interactions were easy for her. On the

other hand, interactive activities such as sports were a different story. She recalled hiding inside the building during field days and group activities such as baseball because interactive field sports or gym activities required Sherry to rely on her weakest sense as the primary means of learning.

> I never knew how to play games . . . there's all these rules to these games, and they are never written rules, they are verbalised. But now I know that my hearing loss was huge, especially in a place like a **gymnasium** with **bouncing balls** and people are yelling—you might as well be in a different country, with a different language. I didn't hear a thing*, I didn't figure anything out*. (Sherry, 2003, p. 4)

While in high school Sherry volunteered to sit at the front of the classroom, which in retrospect, she believes, optimised her ability to hear more effectively. There was already a lack of interaction and participation between Sherry and her classmates; therefore, she was not missing anything.

Referring to her family, Sherry described her father's isolation due to his hearing impairment. "Because he could not hear people well he isolated himself and, you know, he would criticise everybody else for not speaking clearly enough" (Sherry, 2003, p. 36).

People who experience severe hearing impairment often request an explanation if someone tells a joke. Such requests may often be met with resistance by the person telling the joke, who will state that it would not be funny if it has to be repeated. Sherry's response to this premise is, "I don't need your humour if it's not funny enough to repeat it!" (Sherry, 2003, p. 13). Thus, being told a joke may be an alienating experience for individuals with a hearing impairment, as they cannot be part of the spontaneous fun, nor are they always able to understand it. Therefore, one-to-one relationships are more gratifying, according to Sherry.

A strong appreciation for music was instilled in Sherry from an early age. Sherry played clarinet in the school band; however, she did not participate in the band tours. She viewed her instrument as a means of expressing herself, rather than as her being a member of the band. As a clarinet player, she was able to sit in the front row where instructions were often focused on the individual and were given loudly and clearly by a teacher whom Sherry both liked and respected.

In terms of listening, Sherry stated in a contemplative and thoughtful tone her thoughts about it.

> *I think I listen to what I need to listen to and the rest of it I kind of let go, let pass over me*. (Spoken with a thoughtful and contemplative delivery). I probably didn't listen to the nattering away of other kids because it took so much effort to listen and hear. I probably knew it wasn't worth it. (Sherry, 2003, p. 5)

Thus, she believes she lost much of the information in class and still misses a great deal of conversation because concentration and listening continues to be hard work. This, she stated, was one of the factors which led to her isolation and eventual alienation by others who she believes could not understand how difficult it was for her to get involved with people, particularly her peers. It is important to note how Sherry was unable to understand what portion of conversations she was missing by not communicating with others. Wallhagen, Strawbridge, and Kaplan (1996) and Wood (1987) agree that hearing can alter an individual's ability to communicate with others and affect interpersonal relationships.

Sherry chose to disassociate herself from many childhood activities such as playing games, which of course required dialogue to explain rules and directions even when these games were initiated and played with members of the family, because she could not understand the rules clearly. "I never knew how to play games" (Sherry, 2003, p. 4). Watching cartoons on television was not an option because she could not read the lips of the cartoon characters or the

puppets in the children's shows. As an alternative, she recalls being able to entertain herself for hours sitting in a chair, doodling or daydreaming. "I'd be just staring up at the ceiling in my own little world. So that was a way of coping, I guess" (Sherry, 2003, p. 5). The backyard became the playground of choice because it was quiet and isolated with no distracting noises. In retrospect, Sherry states she believes perhaps her peers may have thought her to be snobbish, aloof, or even weird because she did not listen to conversations. For Sherry it was a matter of not being able to hear or to understand the content of a conversation.

Isolation and alienation did not stop with primary school or high school. "Even in university I felt like an outcast. I avoided social outings and joining groups" (Sherry, 2003, p. 8). Sherry opted to attend courses in the evening whenever possible, rather than during the day because evening classes were smaller and the noise was less strident. In addition, she explained, the evening classes were more adult oriented and, therefore, there were fewer distractions.

Family Issues

In her own family Sherry continues to seek the cherished gift of personal solitude where she can take solace in the quiet of her own company. She recalled one time asking her husband to take the children to a birthday party, leaving her alone in the house for two hours. This constituted a period of time where she could be alone without the expectation of interacting or having to work at listening to others.

"Now, when I have family, the hearing isn't just about me anymore. It's like, it affects everybody in the family and I am very selfish . . . I often don't wear my hearing aids [at home]" (Sherry, 2003, p. 9). Her digital hearing aids do not effectively filter the noises or variable tones such as those generated by small

children. In addition, having to constantly attend to family matters creates a heavy emotional and physical drain on her energy levels.

Sherry's youngest child is 10 months old. For her, discriminating whether she hears cries for food, changing of diapers, or attention are difficult tasks. Compounding this are the factors she refers to as her 'internal memories' of these sounds. Therefore, it is not always easy, nor is she always accurate in being able to differentiate real sounds from memories. "I can't trust anything!" (Sherry, 2003, p. 10) when it comes to matters of sound discrimination within the household.

Agitation can result from not being able to understand what is happening around her. This, she explains, can quickly lead to anger. When she gets involved in either conversation or activity inside or outside the house, she attempts to control the conversation and/or tries to be aware of its contents in order to keep pace with it. If she falls behind, she becomes distraught and angry. She described an attempt to move from these challenging situations where she found herself trying to control the environment by joining a 'mothers and their children' group through public health. One of the activities was a sing-a-long and this was geared for hearing parents and children. Handouts with lyrics were not provided. The leaders expected the mothers and children to learn the lyrics and actions by observing and listening. Unfortunately for Sherry, this was an exercise in futility. She described how she left the group frustrated and embarrassed, as she could not keep up with the oral instructions. Obviously, these activities were geared to a hearing world.

At home, music has previously been a source of pleasure and fulfillment for Sherry as well as for her husband. While she loves music, she is unable to understand the lyrics since the voices are often drowned-out by the background music. For Sherry, liking a song means appreciating "the person's voice, the intonation, the pitch, everything about hearing, except the words and/or the odd

word" (chuckle) (Sherry, 2003, p. 11) because she can only pick up certain words from songs. She explained how she creates her own lyrics to replace those she cannot hear herself. Unfortunately, music has now become more of an irritant which sometimes leads Sherry to feel exasperated and angry while trying to listen to it.

"In my family there's a lot of tension due to my hearing, for sure. There's a lot of me yelling, there shouldn't be yelling but there is! It is not always yelling in a harsh way, it is yelling to communicate" (Sherry, 2003, p. 12). In addition, her six-year-old daughter, who is full of energy, talks while she is constantly moving around and making noise in the process. Sherry is not able to "read" her speech and this contributes overall to the family experiencing difficulties communicating with her. She goes on to describe her family life and describes how her husband tends to lose clarity in his enunciation when he gets tired. Sherry does not always wear her hearing aids at home, and this adds to the already existing tensions. With respect to personal communication at home, she states,

> I am always walking to people, that's what is always happening, and they don't know that I am walking to them, so they're still talking. It's like I always hear everything twice, or three times. The first time is just to realise that they are talking to you; the second time is to get a bit of words and the third time is when you are right in front of them. By that time they are **mad** at you and they are tired of saying things three times. All that whole thing is exhausting because when you are walking, you have to stop whatever you are doing to go, it's not very good time management and you have to listen three times! It just takes everything out of life. It's not spontaneous! (Sherry, 2003, p. 13)

Occasionally, one of her sisters will invite the various siblings and their families over for a family gathering. These visits can become quite frustrating, as three of her brothers have a hearing impairment. Sherry tries to make their environment more conducive to communication by recognising their need for less distraction by turning the music down and raising the lighting. She explained how this irritates her sister because making these changes to the lighting and music destroys the ambiance. As a result, Sherry's level of frustration becomes so high under these circumstances that she finds it quite difficult to attend family functions. Issues pertaining to hearing impairment are not discussed or acknowledged by members of her family. The level of silence on these issues among family members is as pervasive today as it was when she was growing up.

Speaking about her father, Sherry referred to him as a very angry man. As mentioned earlier, he too had a severe hearing impairment. Sherry described him as a person who was constantly afraid his co-workers were conspiring against him in the workplace, to the point where he would blame them for not speaking clearly enough as well as accusing them of making comments about him. "It wasn't necessarily a good thing to grow up in a home where there was hearing loss (five- second pause) and it wasn't talked about . . . it might be talked around" (Sherry, 2003, p. 36), covered up or avoided. Further, Sherry described how her mother would say to the children, *"'Your father is in a bad mood so . . . keep your voices down'"* (Sherry, 2003, p. 36). Specific issues around her father's hearing impairment were never discussed or explained to the children; "it just wasn't ever communicated" (Sherry, 2003, p. 36).

Upon further reflection, Sherry came to the conclusion that her parents neglected the children in other matters of care, including hearing impairment. Her siblings sought help for their hearing assessments and/or hearing aids after they left home. Assistance was not offered by the family. She believes her

family experience with neglect during her childhood made her extremely sensitive to the needs of her own children, to the extent that she has felt devastated at the thought of their becoming ill or experiencing any kind of debilitating condition. During the interview Sherry revealed how recently a friend pointed out that she may be overcompensating as a parent in order to protect her own children from neglect and suffering. Upon reflection, Sherry stated, "I never thought that my hearing would . . . become such an issue in my own . . . new family" (Sherry, 2003, p. 7).

University/Education

"University was a **disaster!**" (Sherry, 2003, p. 7). During class she experienced the "most **difficult** time, (deep sigh) it was so hard, it was **so hard**" (Sherry, 2003, p. 8). Sherry sat at the front of the class when attending lectures in order to speech-read the instructor. When students asked questions, she would quickly turn to the speaker; however, by the time she identified him/her and attempted to speech-read the individual, it was too late. At this point, an answer was being given to the student and she would then turn quickly to the instructor. These few seconds would result in her missing not only the response, but the essence of the discussion. Indeed, she missed a great deal of the "in class" dialogues. This was described as a chaotic and frustrating time in Sherry's life.

While attending university, Sherry began to study French. Students were required to spend a great deal of time in labs where they used audio equipment with headphones. Sherry's first language was English. When attempting to listen to someone in everyday communication, she was able to at least have an idea of context in order to understand what was being taught. However, this was not the case with French, as the audiotapes were often of inferior quality and/or badly worn and used constantly. This, she explained, became a source of frustration and eventually she felt demoralised. She attempted to overcome the challenge

by registering in several other French courses, but to no avail. Eventually Sherry came to grips with her own reality in terms of learning a new language. "I realised at that point that it was my hearing and it wasn't that I was stupid . . . I think my self-esteem has been pretty battered up by the whole thing too" (Sherry, 2003, p. 25).

Employment

Sherry worked in many different jobs including working as a receptionist and transcriptionist. Using the telephone at work was always a matter of discomfort for her. "The phone is a scary place for a hearing impaired person because there's **nothing else** to rely on!" (Sherry, 2003, p. 13).

Sherry aspired to complete a degree in education and to teach for a living. She explained how the staff at the local university-college encouraged her to strive to achieve her goals; however, "nobody has ever really acknowledged my theory that it would be too difficult for me [to return to university] is a valid one [theory]" (Sherry, 2003, p. 14).

As a vocational and rehabilitation consultant, and prior to initiating this study, I had professional contact with Sherry. Another agency's employment counsellor with a background in teaching worked with Sherry to help her get a job as a dictaphone transcriptionist. However, the counsellor neglected to ask the nature of Sherry's disability. She was both unaware of Sherry's hearing impairment and her desperate need for hearing aid replacements to be able to do the job, hence reinforcing the premise that professionals in various fields have little understanding of the actual needs of the person with a hearing impairment (Clelland, 1995; Hill & Nelson, 2000).

Prior to taking her maternity leave, Sherry mentioned that changes were made at her workplace. At the time of the interview, she expected to be returning to her job by the fall of 2003. She worked in a cubicle-like office without an

enclosed ceiling. The office was located in the basement amidst a barrage of computers and electronic equipment. In terms of special equipment, Sherry was provided with a volume control headset for the telephone. This device was not adequate to muffle the surrounding loud office sounds. "The worst thing is when I am on the phone and people start talking, that's the absolute worst!" (Sherry, 2003, p. 38). The frustration caused by problems with the telephone also applied to Sherry's home. "It happens at home too. I can't hear the person on the phone, I can't hear the person talking, I can't hear anything. I have to start **all** over again!" (Sherry, 2003, p. 38). Sherry describes her befuddled feelings arising from these situations.

> It's like someone might just slap me in the face or something because I just become completely stupid! I don't know what they just said to me and I lost complete concentration (grasping head) and context and I am like this (continuing to grasp her head and shake it—laughing) right! (Sherry, 2003, p. 39)

When Sherry cannot meet her own goals, she begins to question her cognitive ability. She reiterated how it can be quite awkward for her to try and explain to someone on the phone what is happening, as it involves not only her hearing impairment but also the attempt to focus while competing with the distractions of other noises. We discussed how difficult it is to make people understand the issues around hearing impairment. Sherry commented there were limited prospects for positive change in the future where others will gain a deeper understanding of the needs of persons with hearing impairment, concluding, "they never will understand!" (Sherry, 2003, p. 38).

While Sherry acknowledges the social nature of the workplace, her need for solitude is most important. Therefore, she declines invitations to sit in the cafeteria and have lunch. She adds it would be impossible for her to relax and/or have a conversation. "The cafeteria is a disaster for me. Waaaay too much

noise. So, here I am, basically I am doing the same thing I did when I was a kid, which was retreating to be alone" (Sherry, 2003, p. 39). Sherry will often go outside in order to escape the frustration and irritation of the noisy cafeteria environment.

Sherry admits to not being a team player, and therefore, she seeks autonomy at work. Earlier in this analysis, it was mentioned that Sherry likes to maintain control, or at least keep abreast of the topic of conversation. If she is unable to maintain control over a conversation, she quickly loses track and this leads to alienation, frustration, and eventually to anger. Fortunately, her job entails leading a number of meetings, which is quite comfortable for Sherry. This situation reminds her of her school days when she stood up in front of her class to present a paper or when she read from the pulpit at church. She explained how during the meetings she is able to direct the conversation as well as maintain effective and efficient control of the process. In such situations, control ensures survival in the workplace.

In her opinion, staff in the workplace should be provided with ongoing training with respect to specific needs of persons with hearing impairment. Describing her experience with members of the staff, she explains how quickly they forget her need for accommodations or even basic respect. She needs to remind them constantly of her needs for adequate support in order to do her work. During the meetings, Sherry positions herself strategically in order to enhance her ability to see mouths to read their speech and their nonverbal expressions, particularly those individuals with low voice tone.

Invisibility

Sherry believes that hearing impairment is not viewed in our society as a disability, as it is not obvious to the observer. This, she notes, is one reason why she avoids people and situations which she feels compromise her dignity by

having to repeatedly explain the implications of her hearing impairment. Sherry's perception of her hearing impairment as she grew up within a non-supportive family is illustrated in her concluding statement, "If I had a significant disability, like half a leg, then my parents would have given me half a leg" (Sherry, 2003, p. 14).

Sherry reiterates how hearing impairment is considered invisible. "Nobody talks about it. It's like you have a tumour or something" (Sherry, 2003, p. 15). It appears this dogma-like silence has now become entrenched among her siblings, who never openly discuss the issue of hearing impairment. Therefore, the silence is perpetuated. While Sherry is not averse to wearing her hearing aids knowing these can be seen by others, she is quite sensitive about telling people she has a hearing impairment. "It's like **opening up your soul** and saying: '*This is what's weak about me*'" (spoken in a emphatic yet quiet and defeated tone) (Sherry, 2003, p. 15). The issue of invisibility is perpetuated in her relationships with her brothers and sisters and has been carried in this way since the early years in the family home. She emphasises that the issue of invisibility has been pervasive and affected her relationships with her siblings as a child and as an adult. She recollects how even to this day she continues to be perceived as "the passive one" wherein she believes everyone talks but no one listens to her.

Sherry speaks about her desire to be a "whole, normal, strong person" (Sherry, 2003, p. 16) and not to become the focus of attention as a person with a disability. She described the following imaginary scenario: If she went to a job interview and explained to the employer about her hearing impairment, questions would arise regarding her coping abilities at the workplace. The focus, she fears, would not be on how she could perform her job but instead on how her disabilities would prevent her from doing so.

Even the act of simply going for a walk becomes complicated. She described the ongoing difficulties she experiences whenever she removes her hearing aids before she goes out. At such times, if she decides to stop at a store to pick up some groceries on her return home she might get in a line up and realise she does not have her hearing aids. What can follow is the embarrassment she experiences as she tries to explain to the cashier of her hearing impairment and the absence of her hearing aids. At such times she wishes she could remove herself from the scene to avoid feeling challenged and/or compromised by her hearing impairment.

Sherry recalled a recent pleasant and refreshing experience when she met a woman with hearing impairment—unilateral deafness. They met at a parent and teachers meeting and realised their children were in the same classroom. Sherry and her new friend spent an evening sharing their life experiences dealing with hearing impairment. Sherry draws connections between the themes of invisibility and isolation as she describes her feelings about the friendly encounter.

> It's just that like finding someone you have something in common with that's <u>so important</u>. It is not like someone that you play tennis with, it's who you are, right? It's like suddenly finding another human being, like with two arms and two legs just like you and you have not been on a desert island or something, you know, you have something <u>so important</u> in common. (Sherry, 2003, p. 18)

Sherry recounted the events surrounding the birth of her son in 2002 and the emotional drain associated with the event. She had to request special permission to wear her glasses and her hearing aids during the Caesarean. When staff attempted to remove her glasses she became frustrated because she had to explain to professionals (who she felt should have understood), moments before the operation what her requirements were. She would have been unable

to understand instructions without her glasses because she could not have read their speech. Furthermore, hours after the birth of her baby, her husband had to advocate on her behalf because Sherry was asked questions she could neither hear nor understand, as she was not wearing her glasses or her hearing aids. The staff questioned her repeatedly and her husband had to intervene and explain that she was not upset, as they presumed. Instead, she was simply not able to understand what they were asking of her.

Control

The issue of control is critical for Sherry in terms of being able to survive in a hearing world. As mentioned previously, it is vital for Sherry's sense of security, when dealing with two or more people, to be able to control the conversation by either leading it or by being aware of its direction and aim. "There are certain situations where I feel like a victim if I can't hear" (Sherry, 2003, p. 24). Underlying themes of vulnerability to the extent of feeling threatened exist for Sherry. In restaurants she prefers to position herself facing the door, or with her back to the wall while on the ferry. She relies exclusively on her vision, as she cannot rely on her hearing for her safety.

At various times during the interview, Sherry told me how important clarity of pronunciation and articulation are for her. Furthermore, she admitted she has no patience with people who do not speak clearly and under certain circumstances she has become agitated and even quite angry if people mumble or articulate poorly.

Individuals who are directly affected by hearing impairment may need to exercise assertiveness in order to gain control of their environments as well as to achieve more effective communication.

Summary

The difficulties Sherry described during her childhood were compounded by her hearing impairment. At age 15, her hearing impairment was first diagnosed. While her teachers were alerted to Sherry's difficulties by her behaviour in school, it would appear her hearing impairment continued to be underestimated until later. Some of Sherry's descriptions of her life experiences are consistent with the literature on hearing impairment. Clearly, the absence of information and detection are among these. During Sherry's childhood, a pervasive lack of understanding of the needs of individuals with hearing impairment prevailed among her classmates at school, her teachers, her family, and also at her workplace as an adult. Sherry has high expectations about her needs being understood at the workplace; however, she is reluctant to assist others to recognise and acknowledge these. It is interesting to note how some of Sherry's behaviours are similar to those of her father's, particularly since he too had a hearing impairment. Sherry has demonstrated her tenacity, as she plans to go forward by returning to university and train for a new career in teaching.

Rod

Identification of Hearing Impairment

Rod reports an extensive familial history of hearing impairment, beginning with his father. Rod's hearing was damaged in 1984 while he was working as a licensed welder for a manufacturing company responsible for making large concrete mixing bins for cement trucks and compactors for garbage trucks. The damage occurred when Rod was welding inside an extended cement truck mixing drum. He reports to have been wearing the standard stethoscope-like hearing protectors consisting of ear buds held in place by a curved wand made of hard plastic, when one of the plant pranksters played a practical joke by striking the drum with a sledge hammer. "Unbeknownst to <u>him</u>, within an inch of where

he hit, was where the radial band was touching" (Rod, 2003, p. 5). The hard plastic loop which held the ear buds in the ears was at that instant touching the inside wall of the drum. "The vibrational shock wave travelled through the metal into the band and blew my right ear drum up" (Rod, 2003, p. 5). Several days later an audiological assessment verified the extent of the damage. According to Rod, the audiologist explained that at the time the technology was not sufficiently advanced to provide him with the proper hearing aids, given the nature and extent of the damage to his hearing.

> He said: 'Progressively you are probably going to get a little worse, but you shouldn't ever have it to the point where a hearing aid would be a blessing, more than a curse'. It [a hearing aid] will just make things louder, not clearer. (Rod, 2003, p. 5)

Thus, Rod accepted the professional's opinion without seeking further consultation or additional help for his hearing impairment for a number of years.

Subsequently, Rod left the manual labour industry and returned to university. At one point during his undergraduate studies, he was asked to work with one of his professors as a teaching assistant. This professor approached Rod and asked him about his hearing impairment.

> 'Do you have a hearing loss?' I asked him why. He said 'Well, what I have noticed and the comments that I wrote down are quite similar to what got told to me when I was in university'. When he [his professor] was in university doing his undergraduate work it [his professor's hearing impairment] became pronounced because one of his professors came forward and said 'I think you have a hearing loss' and sent him to be tested. I said, 'Well, yes I have a moderate hearing loss due to . . . 'and I explained what happened and he said, 'I don't think it's moderate anymore'. (Rod, 2003, pp. 5-6)

In 1992 Rod was encouraged to seek a second audiological examination, which he did. According to Rod, on the basis of this assessment, his hearing impairment was reported to be more severe than the initial assessment had shown in 1984. Once again, he was told there was no technological knowledge or development available to assist him with his current level of hearing impairment.

Following the completion of his doctorate, Rod moved to British Columbia and established an alternative medical practice in 1998. Rod explained how he dealt with his hearing difficulties within what he defined as a new culture of professionals with different disciplines serving clients; he stated: "To begin with, it was fine because I had my own little room, the only person I really dealt with hugely at all was Marleen [the office manager] and my clients were always in this extremely quiet room" (Rod, 2003, p. 7). His office was set up away from the main area where he did not have to struggle with competing background noise. Therefore, he was able to listen to his patients and to understand what they were telling him. Apparently, he had experienced problems hearing in the common reception area due to the noise from the traffic and the voices of the patients and other practitioners.

Denial

Rod developed a serious relationship with the office manager of the clinic where he worked. His fiancée had first-hand experience with Rod's difficulties at the office and then later within the home-office setting. After having a series of heart attacks in his late 30's, Rod moved his practice to his home. It was then that his hearing impairment became more evident.

> That's when the problems started and it started causing arguments between my fiancée and I and her children, and herself and I, because you'd get a lot of: 'he said, she said, they said' and my

> interpretation of what was being said (three-second pause), in a lot of ways, in hindsight, were unjust because I would hear one thing, but process into something really different, just because I would miss pieces of words. (Rod, 2003, p. 7)

> I never realised that my voice was beginning to become louder, increasing both in volume and speed, and that's automatically perceived in North American society as either aggression or anger and our 16-year-old would always come back at her mom going: 'why was he yelling at me?' (Rod, 2003, p. 8)

Rod explained how in one of the earlier audiology assessments the audiologist stated "'Man! You must fill in on the blanks!'" (Rod, 2003, p. 9). Indeed, Rod would "fill in" as many as three of every four words spoken in conversation, but still he was unable to confront his hearing impairment.

> It was getting bad enough that just arbitrarily when I would hear my fiancée say something to me I just 'umhum' or 'yes dear'. I had no idea what she was saying but it was just simpler to agree automatically and how she caught me up on it . . . is three times in a row she asked me: 'Are you an idiot?' [He replied] 'Yes dear'. And she actually had someone there, I didn't realise that her daughter was standing there. And they asked me, 'What did we say?' [I replied] 'Are you going outside?' (Rod, 2003, p. 8)

The exercise was meant to point out to Rod just how much he was missing from conversations. He simply was not hearing what was being said. Rod reported feeling frustrated and betrayed by the exercise, as well as being made to feel foolish by the family.

> It wasn't so much embarrassing as it was beyond frustrating, because I felt as if who I was, was being assassinated by them

> because I felt they played a trick on me, but at the same time I knew I didn't hear what they said. (Rod, 2003, pp. 8-9)

He added, "It wasn't so much getting caught in a lie as I felt ensnared inside of a helpless situation" (Rod, 2003, p. 9). This experience brought back the painful recollection of the hopelessness he felt following his earlier discussions with the audiologists. At those times he agreed to seek advice and help only to find out there was nothing that could be done to ameliorate his condition. Rod relied on the up-to-date knowledge of the specialist, and, therefore, he held the belief that nothing could be done for him. This experience with the family, as described by Rod, made him confront the reality and the seriousness of his hearing impairment. As a result, Rod could only envision his future years as becoming more helpless and being forced to detach from his family, friends, and work. When it was suggested he seek yet another audiological assessment, he procrastinated. He used the excuse that each professional he had seen earlier advised him of the insufficiency of technology when it came to providing him with the services he needed to address his type and degree of hearing impairment. Rod admitted to "sabotaging" the appointments his fiancée had set up with the audiologist for a hearing test by booking appointments for his clients at the same time. Eventually, and following repeated urgings by his fiancée, Rod sought another assessment.

Pride

Rod further describes these experiences, saying, "financially it dented me, but as a professional it was kind of a slap on my ability" (Rod, 2003, p. 9). It would appear that Rod's pride and his unwillingness to explore the problems associated with his hearing impairment any further prevented him from understanding what his clients' issues were. In retrospect, he described his unwillingness to collaborate with them and/or to develop an appropriate plan for

treatment because it would have meant admitting publicly to his hearing impairment. Thus, it would appear Rod was risking his practice and reputation by not informing people of his hearing impairment and by not attempting to gain further knowledge or the latest technology in the area of amplification devices. Therefore, Rod was adopting a passive role by allowing himself to believe the professionals had all the answers for him.

Isolation, Loneliness, and Alienation

An additional factor preventing Rod from pursuing further investigation into the new advancements in hearing aid technology was his family history and attitude. Rod stated, "Growing up in an Irish household you get told *no* twice, you just kind of say: 'okay, nuts on it, that's it, they are just never going to help me'" (Rod, 2003, p. 6). Therefore, a slowly advancing technology and Rod's lack of willingness to pursue it further appear to have resulted in an increased sense of isolation for him.

The prospect of loss became even greater for Rod, and increasingly more devastating. He explained how in his imagination he began to see himself losing his business, his house, his relationship with his fiancée and her daughters, and being alone as a result of his hearing impairment.

> The biggest thing was when it came to the relationships with friends and family*, I felt hopeless* (spoken in a quieter defeated tone in the last three words) because it was instilled in my head that there was never, ever going to be any help, I would just end up being deaf. (Rod, 2003, p. 9)

He reflected on his past life experiences, including recovery from alcoholism over the previous 10 years, recovery from a serious motorcycle injury, and now the probability of facing yet another huge loss in his life. He visualised his future as bleak. Rod explained how he could rationalise the prospect of being

deaf at age 60 but “it was a frightening prospect to think that by the time I was 45 years old, I probably would be completely deaf” (Rod, 2003, p. 10). Speaking to the fear and trepidation he felt, Rod states, “It was frightening, like I felt literally helpless, even with all the disciplines that I carry, because there is nothing even in my disciplines that would help that [Referring to sensorineural hearing impairment]” (Rod, 2003, p. 10).

> One part of the hopelessness that really bothered me, because in conversations if there were more than two people talking, I wouldn’t hear any of it, so I would either kick up and take over the conversation or *walk away.* (Italicised words spoken in a quiet submissive tone) (Rod, 2003, p. 10)

In the context of this study, this example embodies a sense of isolation because Rod would sometimes walk away from the situation and consciously isolate himself from others. However, Rod also describes situations when others alienated him. After he was fitted with hearing aids, Rod explains how friends reported their feelings about him and his social interactions.

> And I know at times, our friends have told us, there were times they didn’t invite us to some of their parties and stuff that they put on, because they figured I would be either a wet blanket or a dominating pain-in-the-ass. (Rod, 2003, p. 10)

Rod explains how his hearing impairment affects relationships within the context of isolation and alienation. “The actual social stigma that’s attached with the disability of hearing loss, is you either turn into a social invalid or a social pain-in-the-ass” (Rod, 2003, p. 10).

As mentioned earlier, when Rod spoke about his family history, he stated his father and several of his brothers have severe hearing impairments. He explained how many of his relatives had lost family relationships, homes, and businesses due to an accumulation of various problems in addition to their

hearing impairment. Rod's personal expectations of future outcomes in his life's endeavours were predominantly based on his belief that there is no help available for his hearing impairment.

As a result of his recent acquisition of new hearing aids which provided him with positive results, Rod feels vindicated, because these hearing aids had only been available during the previous two years. Therefore, he felt there was a valid reason for his not having been fitted a decade earlier. "It has only been in the last two years that the digital components have come out, that are sensitive enough, that would actually make a difference for the type of hearing loss that I have" (Rod, 2003, p. 2).

Employment

Rod talked about losing his clients in his practice because in retrospect he believed he may have appeared to be unfriendly and even angry at times. Sometimes he would fail to communicate adequately, which would result in general misunderstandings. He attributed all these difficulties to his hearing impairment.

> From a medical standpoint . . . I felt a little bit inept, because there were times I knew I wasn't hearing the complete story from my clients, so I had to work completely on instincts, and sometimes they [instincts] would let me down and there have been a couple of cases that came in that I wasn't able to help. (Rod, 2003, p. 9)

Rod provided an example whereby he made an appointment for clients to come on Thursday, as this is the date he heard them say they were available. When they arrived on Tuesday, two days earlier than expected, Rod had great difficulty accommodating them. Alternate strategies were quickly put in place to minimise the chance of this problem reoccurring. He described other situations with telephone conversations wherein he took down incorrect information.

Names would be misspelled and wrong dates and times were recorded. Often clients would ask Rod questions during their treatments session and if he wasn't facing them, he couldn't respond, as he was not able to hear what they were saying. Once Rod started wearing his hearing aids and these were noticed by his patients, he was told by several of them how they had been under the impression Rod was angry with them or perhaps he could not be bothered with their mundane questions. Rod recalls one patient saying, "We never realised you were deaf; [seeing the ITE hearing aids] we were kind of wondering why at times you were a little angry, but now we realise you were just loud, because you didn't know any better" (Rod, 2003, p. 11).

Compensatory Strategies

When Rod was younger, he was a professional singer. He explained how he was able to learn to speech read early and used this as his primary compensatory strategy following the industrial accident which caused his hearing impairment. At times Rod would miss portions of words and arbitrarily fill in the blanks. "I would hear 'peculiar' instead of 'particular'. That's because I would hear the 'p' and the 'culiar' and just arbitrarily put that sequence into the centre, when that's not what was being said" (Rod, 2003, p. 7).

Music

Although it was it was not my intention to include significant others in the study, Rod's fiancée asked if she could also be interviewed. As the primary researcher I thought it would be interesting to explore perspectives of significant others of persons with hearing impairment. Such investigation was beyond the scope of this study however, because Marleen appeared genuinely interested in expressing her thoughts about Rod's hearing impairment I agreed to interview her. The following references are the only ones used during this interview.

Rod described himself as being very gifted with a wonderful singing voice. A few days after Rod was fitted with hearing aids, he and his fiancée were driving together when Rod began to sing. When he was finished singing, his fiancée noticed tears welling up in his eyes. She asked what the problem was and he replied, “I always wondered what I sounded like” (Marleen, 2003, p. 29). She explained how Rod had never really heard his own singing voice for many years. When asked how he was able to manage a five octave range he replied, “I don’t know, it just it’s just like I feel it inside, it’s not fussy and it’s on key” (Marleen, 2003, p. 9).

Family Issues

Rod’s fiancée reported he likes to take his hearing aids out following a workday. When he tries to do this, Marleen reminds him of the struggles the family endured with him when he did not have hearing aids. He complies and wears them until bedtime.

Changes After Being Fitted With Hearing Aids

In order to illustrate changes in his behaviour after being fitted with the hearing aids, Rod described a number of scenarios with his clients. For example, while he was giving a treatment to an elderly person, as he had done many times before and prior to wearing his hearing aids, the woman’s professional caregiver was observing the treatment and she said,

> Your whole approach—it isn’t so much that it is <u>different</u>, it’s like it has <u>evolved</u>, it’s like you have become the mature practitioner after doing this for 25 years, instead of the rookie <u>always</u> <u>trying</u> <u>to</u> <u>prove</u> <u>a</u> <u>point</u>. (Rod, 2003, p. 11)

Now when he describes his treatment to a client, Rod explained how he does so in a more gentle and quieter manner as well as engaging in more

dialogue and offering more detailed explanations than before. As well, Rod asks his clients questions regarding their symptoms to understand them clearly, rather than automatically relying on his observations alone to determine the diagnosis and treatment strategies.

One of Rod's long-term clients provided him with the following description of their interactions following his obtaining the hearing aids.

> It's the difference from going to see a doctor at the hospital in emergency under that kind of a setting, versus now it is like going to your old family doctor who has a country practice and you are sitting down and you are having a chat, versus give me the details, shut up, I am going to fix you so you can go home! (Rod, 2003, p. 11)

Perhaps the most enlightening experience with respect to the "before and after" with his hearing aids occurred when his fiancée's daughter came to him, gave him a hug and said, "'It's nice to be able to talk to you.' I asked what she meant and she goes: 'It's nice that you are talking to me and not speaking at me!'" (Rod, 2003, pp. 11-12).

Regrets over Lost Time and Experiences

Alluding to the positive encounter with his fiancée's daughter, Rod states:

> If I would have known that three and a half years ago when we first got together, that something as simple as a couple of hearing aids would have stopped all the arguments and things for the last two and a half years (three-second pause) I would have gone back and done it all over again. (Rod, 2003, p. 12)

Furthermore, Rod now understands how his unwillingness to discuss issues pertaining to his hearing impairment had become a source of a great deal of strife and contention in his own family with parents and siblings. Ironically, by

avoiding the problems within his own family, he was perpetuating the silence as well as the misunderstandings and carrying these issues into another generation.

Insights

Rod recalls an incident involving his family which resulted in some unintended comic relief. He took a hand full of corn nuts, popped them into his mouth and bit down. He was described by the family members as "having gone bug-eyed" (Rod, 2003, p. 19). This was Rod's way of explaining how he realised for the first time the volume of inside noise when he was wearing his hearing aids—the noise he had not heard for years—was exponentially louder than he could have ever imagined. "I thought that I was going to blow my head apart!" (Rod, 2003, p. 12). This experience was in some ways not unlike Rod hearing himself sing for the first time in years following the purchase of his hearing aids. He was introduced to a new world of sounds.

Rod explained how his hearing impairment affects him.

> *I see hearing loss* (spoken very slowly and methodically for emphasis) as an actual crippling impairment, because it doesn't downplay what's going on, there is no other way to circumvent it. With my knee, I put my brace on and I can do a few things. If I wear appropriate footwear and my brace I can do a few more things; if I want to go rock climbing, instead of going up the side of the cliff in an hour it will take me three and a half hours. I can still get there from here—it just slows me down. The hearing literally put barricades up! It wasn't that there was a way around it; it literally locked me into a room, playing a pantomime of '*In a Glass Box'*. (Rod, 2003, pp. 12- 13)

His analogy of "playing a pantomime of '*In a Glass Box'"* depicts a person watching from the outside in, without being able to interact with the character

inside, because no sound can get through the glass barrier. The hearing aids have helped Rod restore his ability to communicate effectively and interact by taking him out of the glass box and by bridging between the two worlds—the world of silence and the world of sound. As well, his hearing aids have given Rod a positive outlook on the future.

> I think in the long run my whole life is going to start going back upward, both professionally and personally, but my circle of influence, both directly and indirectly, is going to benefit from the simple fact that the hearing aids have lowered that cross bar, so that now what hearing loss I have is now a handicap, a handicap and a restriction that I now understand. (Rod, 2003, p. 13)

Rod reiterated that he believes there is a marked change in the way his clients perceive him and, therefore, he feels he has an "obligation" (Rod, 2003, p. 13) to them.

> I have an obligation to be the best that I can be. If that's relearning the limitations that are imposed upon me due to my auditory damage, it's almost as if it's a new tool that I have to learn how to use. (Rod, 2003, p. 13)

An element of his learning process is being able to say to his clients, "This is new to me, be patient" (Rod, 2003, p. 13). Thus, Rod believes he is entitled to have a hearing impairment. He states he does not have all of the answers in regard to this adjustment process but he does feel he has permission to request some things to be repeated.

> It's almost like I understood that I had a hearing loss before, but because I looked as if I didn't have one, I didn't have permission to make the mistakes, and/or make the acknowledgement that I couldn't hear. With the hearing aids it is almost as if it's because they are a prosthesis in some senses, it gives me permission, or it

> gives me the perceived permission in other peoples' eyes to be able to say: 'Look, I can't hear you' and it's kind of like flags going: 'this guy can't hear, make allowances'! It's humbling in some senses. (Rod, 2003, pp. 14-15)

Rod describes how his self-perception has changed as a result of acknowledging his hearing impairment and having hearing aids.

> It's humbling in some sense, especially relationship-wise because it's made me . . . (seven-second pause) I always felt like I had to bluster past because I am a very large Irishman and because of my doctorate and what I do for a living, the uniqueness of it made me feel as if I had to prove a point (spoken at a faster pace); even though I had an impairment I had to work as if I didn't have one for the simple fact you don't go to a doctor who is sick! Now, with the hearing aids in, it gives the perception to others: 'Oh! *He has a hearing loss,* instead of: 'You have hearing loss?' (spoken in a questioning tone). It is the social perceptions, both business and personal that, it is almost that the hearing aids are a two-ended crutch; one they are a physical prosthesis that actually helps my hearing, but, for others it gives the allowances, when I ask people to repeat themselves they notice the hearing aids and go: 'Oh. He has a hearing problem, that's OK then. He is not just being pushy.' It almost empowers me enough to step down off that podium a bit and say: 'Look, I really didn't catch what you said, I do have a hearing problem, would you mind repeating it?' (Rod, 2003, p. 15)

It appears Rod has become more accepting of his hearing impairment and is showing a deeper understanding of his limitations.

Bringing Hearing Impairment into Perspective

With respect to hearing impairment and the overall impact it has had in his life, Rod states, “I would have two more traumatic injuries to my body if it would give my hearing back, because I can take the limits that my leg gives me and circumvent them; *I cannot do that with my hearing loss*” (Rod, 2003, p. 30).

His fiancée’s father does not wear his hearing aids and leaves them in the dresser drawer. Similarly, although Rod’s father has hearing aids, he does not wear them. Rod explained how important it is for his family members to be perceived as “whole”, in other words, without a disability. Rod describes the life of one of his brothers who has hearing impairment as “captive”. He lives with his wife on an acreage/hobby farm and has only limited contact with friends and family. He reiterates how his family places a great deal of value on being healthy and how they cannot tolerate the thought of sickness or disability because these conditions, they believe, can make them less than whole. Rod’s life experience with both branches of his family has led him to make a conscious decision to rise above the attitudes, behaviours and views by accepting his hearing impairment. He concludes, “A prosthesis doesn’t mean you are crippled, it is just a new tool” (Rod, 2003, p. 18).

Summary

Rod continues to struggle with the views and definitions of disability held by his natural family. He believes he has to overcome physical limitations in order to protect and maintain the image he feels society demands of him as an alternative medical practitioner. Nevertheless, Rod has made huge gains with respect to his acceptance of his hearing impairment. Following years of denial, he has now been able to reframe his disability into a more positive and acceptable experience. Perhaps one additional challenge for Rod is to rise above the silence with issues of hearing impairment in the family.

Within his own family, Rod has made the issue of hearing impairment a matter which concerns everyone. Through his own experience he can see how hearing impairment affects the entire family unit.

Rod also raised an important point about justice and corporate responsibility. There are warnings on cigarette packages and warnings on various medication labels and consumer products, but there are no warnings on the use of recreational equipment, musical instruments, or electronics. Activities associated with these and other pieces of equipment are among the major contributors to hearing impairment in society. However, it would appear that no action has been taken on the part of the manufacturers to educate the population on the use and/or misuse and resulting ramifications of such equipment. Furthermore, the manufacturers have not been held accountable for failing to implement such an educational process. These issues are worthy of note for future advocacy.

Mindy

Identification of Hearing Impairment

Mindy's hearing impairment was identified in grade one when the public health nurse administered hearing assessments in the school. Her hearing impairment had gone undetected by her parents for approximately six years. Mindy assumes this was partly due to her mother being constantly busy caring for a large family. Her stepfather had a severe hearing impairment as well. She suspected her problem was "overlooked because of the subtleties—not really knowing how to pick [it] up" (Mindy, 2003b, p. 2) or what to look for.

Mindy believes her hearing impairment began before the age of two and she suspected frequent earaches as a child may have contributed to the reduction in her hearing. She reported her family did not have the means for

medical coverage and her frequent earaches were treated by home remedies rather than by a medical practitioner.

Her stepfather minimised the seriousness of her difficulties and this led her to believe that her hearing impairment was not as severe as his. "I think that he saw that I could hear more than he did and so that I was okay . . . and that I didn't have that much of a hearing loss to worry about . . . " (Mindy, 2002, p. 9). Furthermore, her stepfather strongly disagreed with a recommendation to send her to the provincial school for children who were Deaf and hard of hearing. "He didn't think that focusing on the hearing loss would be good for my development . . . my stepfather nixed that" (Mindy, 2002, p. 9). On reflection, Mindy recognises the decision to not send her to the provincial school was a good one.

> In retrospect I bless him, because I learned lots of ways to survive it [hearing impairment] . . . and having him as a . . . I wouldn't say a mentor but as an example of someone that could carry on in the world [referring to a person with a hearing impairment]. (Mindy, 2002, p. 9)

As a result, her belief that her hearing impairment was not severe became further entrenched.

Medical Professionals and Audiologists

Mindy had undergone four skin graft operations to the tympanic membranes. She recalled undergoing a broad range of treatments with ENT specialists. Despite the various surgical interventions, Mindy was not able to detect improvement in her hearing other than during a brief period when her hearing acuity seemed sharper. In terms of audiologists and audiology technicians, she felt she had "run the gamut" there as well. "I had spent 40 years having audiograms but had never been introduced to how to read them" (Mindy, 2003b, p. 6). Her most recent experience with an audiologist was more

rewarding because he took the time to explain how to read her audiogram, which provided her with a clearer idea as to where her optimum level was when she wore her hearing aids in relation to where she would be if she did not have hearing impairment. It appears she wished to participate in the process of treating her hearing impairment; however, she was confronted with a medical model which tended to exclude the patient. Dahl, Vesterager, Sibelle, and Boisen (1998) state, "Patients themselves should define actual needs and that the treatment and rehabilitation should be adjusted accordingly" (p. 198). Indeed, most of the information she had gathered up to that time was obtained through her own research efforts using the Internet rather than requesting information from appropriately trained professionals.

Compensatory Strategies

Mindy recalled her teen years when her friends would grow impatient with her frequent requests to repeat what they had said. As a result, "I learned just to be quiet and roll with it, and act like I could hear" (Mindy, 2003a, p. 20). She believed that being honest and open with her friends and revealing to them her hearing difficulties might lead to insults, demeaning remarks, and/or possibly physical attacks.

> There were a lot of times when people would look at me strangely and I knew that I was off. Usually I used humour to get myself excused from that, but I also think that people also though that I was a bit daft because I was off so often. (Mindy, 2002, p. 7)

As well, her fear of exposing her hearing impairment affected her relationship with her employers and she risked losing jobs because of her reticence to disclose her hearing difficulties.

When she attended social events, Mindy would identify "a friend that was more empathetic and would sort of, you know, make sure that I heard the

important things or what was perceived by her as the important things" (Mindy, 2003a, p. 20) during conversations. Thus, she was willing to confide in one person, but she could not allow herself to reveal her difficulties to the public at large.

Since her early years, Mindy believed voice tone and body language, in the absence of interpretable speech, could provide her with complete messages. Therefore, when she was among a group of people, she would listen to the speaker as closely as possible and observe the behaviours and responses from other group members to determine interest, agreement, disagreement, or other reactions to the topic.

> I watch whole group bodies, body reactions to a conversation, like if person 'a' was leading the conversation, I still would be watching 'b', 'c', 'd', and 'e', to see whatever body language they were having, while I was trying to focus on 'a' for everything I could get. It was . . . very complicated and exhausting. (Mindy, 2002, p. 7)

This technique provided her with what she thought were positive and accurate results: "It looked like I had a lot of great insight" (chuckle) (Mindy, 2003a, p. 4). Thus, for Mindy, learning to read body language became an important tool and she believes she was quite good at it.

Paraphrasing was a tool Mindy used extensively to ensure she understood what was being said. It was perhaps a more effective means of handling the conversation, ensuring her interpretation was correct. In addition, she used speech reading as another means of interpreting the nuances of conversation.

> I listened with everything that was in the room, with every person, with every movement, the lips, with every trick I could find so that I could keep up with a conversation. Paraphrasing, asking people to repeat themselves, getting up close. (Mindy 2002, p. 13)

When Mindy started her current job, she suddenly realised to what extent her hearing impairment was affecting her life. "I truly, truly discovered my hearing impairment when . . . my job changed and I was in a computer lab being a help desk person" (Mindy, 2003b, p. 14). She explained how previously she had been able to control her work environment by using various techniques, such as positioning people where she could read their speech and make optimal use of her residual hearing. The coping skills which had previously been useful for her were no longer compatible within this new environment or with her new job in the computer lab. She found herself confronting a new reality as a result of her hearing impairment. "I was moved to a front line help desk situation; I quickly discovered I couldn't hear people who were asking for help . . ." (Mindy, 2003b, p. 6).

Mindy described the work environment as having many distractions such as keyboards clicking and the sounds of people talking to one another. These sounds, which are taken for granted by people with normal hearing, can be quite disruptive for a person with hearing impairment.

> I could be nose to nose with them and not get enough words out of them . . . to figure out what they were asking me. And so I spent a lot of time going from my little office to their computer to find out what they [wanted, or] . . . to have them **show me** what their problem was because I couldn't **hear** what they were saying. (Mindy, 2003b, p. 6)

Under ideal conditions, Mindy believes these problems could have been resolved in a portion of the time she was taking to resolve them. She spoke about feeling inadequate to do a job for which she was well qualified. "I was also frustrated with myself that I just couldn't hear . . . I just felt like a constant failure because I couldn't get their words the first time, or the second time (chuckling) or the third time" (Mindy, 2002, p. 2).

Determining the origin of sound continues to be a problem for Mindy. When she thinks she hears her name being called amongst a group of people, she looks for cues. For instance, she searches the faces in the crowd to see if she can recognise anyone. Then she observes facial expressions to see if any attention is being directed toward her.

Thus, Mindy feared her constant request to have clients repeat their questions, comments, or messages would eventually lead to rejection. Therefore, rather than informing the client about her hearing impairment, she created a strategy whereby she physically manoeuvred people by persuading them to move or come closer to her while continuing to speak till they were close enough for her to hear them. Her frustration eventually led her to ask the client to show her what the problems were with the computer or the computer program. At times the client would not comply with her request and conclude it just was not worth the extra effort, saying, “it’s not important” (Mindy, 2003a, p. 3). Mindy stated how she felt about such a response. “**That** would frustrate me!” (Mindy, 2003a, p. 3).

When Mindy’s digital hearing aids were sent away for repair for a period of approximately eight weeks, she realised how much she had come to rely on them to maintain contact with the hearing world. Once again she had to rely on the old strategies. The speed of recovery from a day’s work was slower, as was her ability to interpret messages in the workplace. She indicated she felt “wiped” (Mindy, 2003b, p. 28) by the time she returned home at the end of her workday. She remembers requiring more sleep, feeling unfocused, disorganised, and scrambled. Once again she became aware of the tiredness and exhaustion resulting from her attempts to hear. Thus, not having her hearing aids reminded her quite vividly of her prior experiences. Her once familiar strategies were now grossly inadequate for the demands in the workplace.

Mindy explains her need to assess the various environmental scenarios she faces within the work situation as well as when she is socialising outside the workplace. "My first and primary purpose initially is to figure out where to put myself safely so that I can best interact" (Mindy, 2003b, p. 30). In some instances she feels it is "hopeless" (Mindy, 2003b, p. 30) with no place to sit and other times she states that her best plan is to simply "tune out" (Mindy, 2003b, p. 30). Often, after assessing a situation, she determines that the best route is not to pursue it at all; therefore, removing herself from it seems to become her best option.

Learning

Mindy could not rely on her auditory ability to process information effectively. Therefore, she explained how she learned to visualise problems abstractly and develop solutions that she could apply in a practical manner. Sometimes conversations appeared to Mindy to resemble a puzzle. She was relying on what she referred to as her artistic ability or abstract skills to pull all the pieces together.

Self-Image/Confidence

As mentioned before, prior to her acquiring digital hearing aids, Mindy would ask people to repeat what they said and/or move closer to them. "When I didn't have [hearing] aids it was that thing about being a whole person and a whole person does not constantly ask for everyone around them to accommodate them, to stand within two feet to talk with them" (Mindy, 2003a, p. 4). She believed in a circular logic premise where people who are normal are whole, complete and without impairment and those who are not whole are not normal. It would appear, then, in using this line of thinking, Mindy was describing herself as a person who is not normal.

Imprisonment/Escape

Following her move to a new job, Mindy felt trapped by her hearing impairment with no chance to escape. "Isolation is something that you do to yourself and alienation is something that someone does to you" (Mindy, 2003a, p. 6). Thus, her fear of being found out and her unwillingness to explain her situation became her trap.

Stigma–Ridicule and Teasing

As a child, Mindy's siblings teased her about her hearing impairment. They would be quick to point out errors when she pronounced words incorrectly or when they had to repeat things. She has very early memories of the stigma associated with hearing problems and the intolerance and loss of patience by others about how she expressed herself. At a later time during the interview, Mindy referred to her siblings as being "horrible at times" (Mindy, 2002, p. 18). Mindy's sisters would refer to her as the "deaf wonder" (Mindy, 2002, p. 18), while whispering comments into her ears knowing she could not understand anything being said to her. These experiences of lack of indulgence and impatience were described as being extremely difficult in later years when people "didn't give grace to the fact that some of what I do is because of my hearing loss" (Mindy, 2002, p. 18). Such behaviour clearly showed a lack of lenience and forbearance of people towards her difficulties, particularly if she misunderstood what was said or if she took longer than expected to process and give a response.

Mindy's reluctance to speak and her frequent incorrect responses in the earlier years were attributed mistakenly to her having below average cognitive ability. When she meets old friends now, they frequently remark upon how much smarter she appears now than she presented during high school. Mindy considers these comments to be both warming and reassuring because they

indicate to her that people are not remembering her as Mindy, a person with hearing impairment. Nevertheless, these are blatantly unfair and cruel assumptions held by others towards Mindy's cognitive ability. In addition, there is an underlying discriminatory tone about such comments. She maintains she would much rather have been perceived as a person who was intellectually challenged—and then have the opportunity to demonstrate otherwise—than to be known as a person with hearing impairment. Indeed, a serious misconception about Mindy's intellectual ability has been allowed to remain unchallenged for thirty years.

Minimising of Hearing Impairment

Upon reflection, Mindy realises her stepfather emphasised the seriousness of his own hearing impairment and minimised hers. "I thought that I was below normal, but not greatly below normal" (Mindy, 2002, p. 12). There were no points of reference available to Mindy to make any sort of comparisons in terms of her hearing impairment other than her stepfather's opinion. At some point in time, Mindy asked the ear, nose, and throat (ENT) specialist's opinion whether it would be beneficial for her to use hearing aids, and his response was less than definitive. "Yeah, it would probably help'" (Mindy, 2002, p. 12). When a patient requests an opinion from a medical professional, there is a great deal of reliance on their medical knowledge to provide a clear and decisive assessment and/or recommendation. However, this is not what Mindy heard, and therefore, she not only concluded that hearing aids would not be particularly helpful, but it also reinforced her previously held assumption that her hearing impairment was not a matter of great importance. In addition, prior to being fitted with digital hearing aids, Mindy had not received any sort of reference point whereby she could compare her hearing levels of previous audiological functioning with current ones, nor did she have the forethought to ask. Trychin (2001) explains,

“Sometimes, a physician or other professional gives erroneous and harmful information, such as, “‘It’s only a mild hearing loss, don’t worry about it unless it becomes severe’” (pp. 15-16).

Earlier in the year (2003), Mindy requested a note from her doctor for the purpose of gaining workplace accommodations. She requested her doctor to write “moderate” hearing impairment, as this was in keeping with her understanding of the degree of hearing impairment. Her physician pointed out, referencing her most recent audiogram, that at some frequencies her hearing impairment registered in the “severe” range. She questioned Mindy’s request to minimise the degree of her hearing impairment. At that point Mindy realised what she had been doing for so many years. “Oh God, this is what I have done all my life. I have minimised my hearing loss!” (Mindy, 2003a, p. 2). Up to that point, Mindy perceived her hearing impairment just as her stepfather framed it for her years before. “My stepfather never said I didn’t have a hearing loss, he just put it off as not a big deal” (Mindy, 2003b, p. 15). Perhaps for the first time in Mindy’s life, the reality of her hearing impairment became evident to her and she realised how it had become a much larger issue than she allowed herself to believe or to accept. Harvey (1998) presents a scenario of Sue, a woman with acquired hearing impairment since early childhood due to meningitis. Sue describes her relationship and interaction with her mother, who minimised the impact of her hearing impairment on her life.

> And when I wanted to talk about my hearing loss, my Mom would dismiss me with “You do know dear, you have a hearing loss which means you need to try harder but you are just like everyone else so don’t worry about it and now please finish your peas and then help me clean up”. (p. 15)

Family Relations

Dialogue with Mindy's brothers and sisters is much more fluid now and it is not necessary for either her siblings or their spouses to repeat information quite as often. Her digital hearing aids allow her to participate more in conversations. She believes her family appreciates this change.

Mindy made an important decision to discuss the issues of hearing impairment with her family, particularly her own sons. When she asked her children what they thought about the improvement in communication with the help of her hearing aids, one son indicated there were no differences, whereas the other gave an emphatic "yes", adding that now he does not have to work so hard to talk with her.

Adjustments to Digital Hearing Aids

Mindy reported that the technician did not provide clear information on the use of her new hearing aids. As well, instructions regarding when and how to raise the level of amplification of the hearing aids from one to three were generic and did not emphasise caution or moving slowly from level to level. She was told she would know when she was ready for the next level. It appeared the technician assumed Mindy knew how to regulate and adjust her new hearing aids, and therefore, he did not provide any individualised training or guidance throughout this adjustment period. Getty and Hétu (1994) describe all professional interventions directed toward persons with hearing impairment as being uniform. They claim that the tools used for assessment, diagnosis, and rehabilitation are the same regardless of age, gender, or ethnicity. Therefore, there is a need for individualised practice in serving persons with hearing impairment, just as there would be for persons experiencing any nature of medical or psychological problem.

When Mindy was still at the second level of amplification, she required a three-month leave of absence from work to deal with the stress. The barrage of auditory stimulation became overwhelming. Thus, Mindy was dealing with two equally important and demanding adjustments, the new hearing aids and a new job. In addition, the new service desk where she was assigned in the workplace was poorly equipped to handle the unexpected demands and unprecedented numbers of requests for help.

Mindy's adjustment to the use of her new hearing aids was an adaptive process whereby she made a transition from the old ways of managing communication through reading non-verbal body language and facial expression to relying increasingly on her hearing aids. Eventually, reliance on the familiar "old ways" became less necessary, suggesting Mindy was making an adjustment to the use of the digital hearing aids. Later, the old skills were called upon once again when her hearing aids needed repairs. What was once familiar, she noted, was no longer the case. Her attempts to return to the sole use of old skills were no longer effective and the process was slow and inefficient.

Counselling

In addition to aforementioned adjustments, Mindy encountered a number of other psychosocial issues, prompting her to seek counselling. Harvey (1998) refers again to his patient, Sue, as having been "catapulted backward in time" (p. 14). As individuals rejoin the hearing world by being fitted with digital hearing aids, this may also become a psychological trigger which makes them aware of some of the losses experienced in their lives. Mindy found herself in a reflective state during counselling when she began to "piece together" (p. 14) some of the things she missed in the early years in her personal and family life. Just as there can be a cascade of new sounds with the dawning of hearing, so too can there be one of recollections and associations of experiences that appeared to have

been lost. Thus, counselling helped Mindy to engage in critical reflection and to challenge assumptions and misconceptions.

Through counselling she was able to redefine the meaning of skills and talents. Skills were described as an adeptness she can develop through practice. Abilities were described as "something you have and you work with as best that you can" (Mindy, 2003b, p. 36). Mindy can now recognise more clearly her limits in terms of how much time she can tolerate being on the help desk giving direct computer support. Prior to counselling, she would have berated herself for not being able to improve or to meet what she believed were her responsibilities in the workplace.

Advantages to Hearing Impairment

Mindy's first experience with the range and intensity of children's vocalisations occurred at the laundromat and she wondered what other experiences she had missed in the early years, such as sweet whispers of children and the sensitive words from a partner. At the same time, Mindy recognises how she has the best of both worlds. Whereas some people meditate to relax, Mindy removes her hearing aids.

Positive Aspects of Hearing Impairment and the Use of Hearing Aids

In an attempt not to "over attribute her difficulties to her hearing loss" (Harvey, 1998, p. 14), Mindy discusses the attributes of hearing impairment.

> <u>Relaxation</u>
>
> "It's like landing a plane. It is so good to land" (Mindy, 2002, p. 21). Flying is an extremely intense feeling for some people. Knowing that the plane is on the ground and that one is safe is a

very quelling experience. Mindy is able to relax once she removes her hearing aids.

Concentration

Freedom from distractions. When she is not wearing her hearing aids, auditory distractions are eliminated. This enables Mindy to increase her ability to concentrate.

Abstract-visual

Mindy looks for the non-verbal gestures to pick up
and attempts different means of communicating rather than relying solely on the verbal communications.

Streetwise

Mindy believes she has developed the ability to read behaviours, actions, and non-verbal expressions.

Development

"The bonus is that I got to be a good listener" (Mindy, 2002, p. 27).

In terms of the advantages there are for a person with hearing impairment, Mindy states, "There are probably way more [benefits] because I spent a lifetime telling people 'hard of hearing isn't that bad' in the sense of, you know, you can compensate in some ways" (Mindy, 2002, p. 26).

Relationship Issues

Mindy explained how her hearing impairment may have affected her marriage.

> I know there were times he got tired of talking to me, because . . . if I was tired at night and he had to repeat himself he would just give up and go to bed . . . sometimes it was a time when we needed to have dialogue and I just couldn't keep up. (Mindy, 2003b, p. 26)

Acceptance of Hearing Impairment and Accommodations

Mindy believes her hearing impairment became easier to accept after she started wearing her digital hearing aids because these enabled her to realise for the first time in her life what she had actually been missing. Prior to this, she had experienced a lifetime of not knowing what it meant to be a person with hearing impairment as compared to a person without it. The realisation was not sudden. Rather, it came over a period of months. "So that perspective has also changed, I think, [it] has changed the spirit of asking for things [accommodations]" (Mindy, 2002, p. 12). This represents a major shift from her passive acceptance of her stepfather's interpretation of the impact and degree of hearing impairment, to developing one of her own. In a sense, it is as though Mindy was granted the permission to be a person with hearing impairment, which she is now acknowledging.

> Yes, I have this big hearing loss and <u>yes</u>, I am going to have to ask for a little bit more than other people, which is not a thing that I was raised to do with my hearing loss; in fact, I would do quite the opposite and then, you know, get on with your life. (Mindy, 2002, p. 12)

Mindy's recognition of this difference in life before and after being fitted with hearing aids has had a major impact. Without such acknowledgement, Mindy might have simply continued to follow the lead of her stepfather.

Having gained an understanding of some of the challenges she faces in communication and how these relate to hearing impairment, Mindy has the courage to ask people to repeat what they say. However, she states, "I don't do it nearly as often [as she had to before she received hearing aids]" (Mindy, 2003a, p. 4). Mindy's attitude in terms of meeting her needs has changed dramatically. For most of her life, Mindy had not been aware of the connection between her behaviours and her hearing impairment. When she finally understood this relationship, this changed markedly the dynamics of her interactions with others. Her broader understanding and increased acceptance is illustrated in the following comment: "I think some of that also comes from facing my hearing loss and my challenges" (Mindy, 2003a, p. 4). It appears that her acknowledgment is now interpreted as having the freedom to act.

Mindy acquired a great deal of theoretical information about hearing impairment on her own. Her understanding of the difference between her hearing and that of others was provided by comparing her audiogram with those of individuals whose hearing was not impaired. Piecing the information together and formulating this into personal knowledge provided her with an understanding of what she experienced throughout many years. This new knowledge created an opportunity for Mindy to challenge the perspective she had formed regarding her attitude toward hearing impairment and the influence of her parents. Part of her resistance to accessing information and assessments, according to Mindy, was related to the "feeling that I was being disloyal to my stepfather, who to me was a good parent and with all good intentions [he] helped me with my hearing loss" (Mindy, 2002, p. 13).

Harvey (1998), in his ongoing dialogue with Sue, comments on the poisonous nature of silence. Sue recalls herself "standing in the dark barn looking out at the rectangle of light representing the outside world" (p. 18). Harvey captures the poignancy of the description and reinforces for the reader

the isolation factor inherent in Sue's silent memory. He asks, "Where were her mother and father in the rectangle of light?" (p. 19). The narrow rectangle of light shining through the window represents in metaphoric terms her relatively small connection with a pervasively dark and silent world. He talks about the lack of dialogue between Sue and her parents about her hearing impairment. "Sue and her parents had spared themselves the 'walk through grief's very core' (Rigsby, 1991) but at what expense? Their silence had made their grief poisonous" (pp. 18-19). If guilt was attached to the idea of Sue's speaking out and betraying her parents, giving voice to these feelings might have reduced the effects of what Harvey (1998) refers to as "the poisonous effects of [their] silence" (p. 19).

Referring to the challenges she has faced over the past four years in her work, Mindy states, "I have changed a lot of perspectives, a lot that were given to me by my parents that I never challenged before, and one of them is the acceptance that I do have a disability" (Mindy, 2003b, p. 34). This is an important paradigm shift for Mindy. The hearing aids help to "reduce the disability, doesn't make it go away; it gives me another set of challenges" (Mindy, 2003b, p. 34).

Exhaustion and Fatigue

"For the most part, I know that in hearing loss I struggle to hear and it is a challenge and it is an exhausting one at that" (Mindy, 2003a, p. 2). Armed with the knowledge that it is common for people with hearing impairment to be exhausted from the extra effort required to listen throughout the day, individuals find they have permission to be tired or fatigued. For Mindy, part of her exhaustion was the result of having to create immediate strategies to have people move around her and thus provide her with a chance to maintain a conversation with them. It was tiring to be perceptually alert to auditory and visual information and cues as well as listening for contextual information and observing reactions. "It is exhausting to think that part of communication is trying

to create the environment that is just right for communication that will work" (Mindy, 2003a, p. 3). In addition to the exhaustion there is the denial of there being a problem.

It was not unusual for her friends to become frustrated with her because she would nod off during conversations in the evening hours. "I had my fill of listening. That was all my body could do for that day" (Mindy, 2002, p. 13). It wasn't a matter of her being uninterested, but simply the result of her being completely exhausted and drained of energy due to her ongoing attempts to listen throughout the day. The hearing aids have enabled her to conserve the energy that would have otherwise been spent in her attempts to listen. Therefore, Mindy can now engage in social situations for longer periods of time. The fatigue is not eliminated; it is simply reduced. Therefore, it continues to impose limits on her ability and willingness to be social.

Misunderstanding by Society

Prior to her leave of absence from work, Mindy shared with her supervisor some of the adjustment difficulties she was experiencing. The response from her supervisor was, "Well, you didn't have this problem last year, why do you have it this year?" (Mindy, 2003b, p. 16). Mindy recalled reacting to the comment, saying, "It was like I had to defend myself suddenly for what I had [hearing impairment]" (Mindy, 2003b, p. 16).

Mindy had a gathering at her home with family at the same time as her hearing aids were being repaired. It was then she realised she was missing not only the punch lines of the jokes but also the story line as well. She alluded to feeling disempowered because without her hearing aids she was not able to determine whether the joke was actually humorous or not.

Critical Reflection

While sitting at the audiologist's office, Mindy found some magazines with articles on hearing impairment. After reading one of the articles she began to understand how close she was moving toward people in order to hear and understand them better. She became aware of how frequently she must be invading the personal space of other people by overstepping the imaginary lines.

When Mindy recollects her early experiences in school, she wonders what she missed in terms of social interaction with other students, such as building relationships and generally interacting with them when she sat at the front of the class. Even though hearing aids at the time were considerably less efficient and less powerful or functional than those on the market today, she wonders whether she would have been able to manage more effectively had she been fitted with them years before. The lost opportunities and experiences are incalculable. A person with a developmental hearing impairment is left to wonder about the question of "what if?" This might contribute largely to the psychosocial issues in the process of adjustment to hearing impairment.

Mindy's work on the help desk enabled her to change her perspective on how she sees herself in terms of her skills and abilities. Mindy has discovered she is a creative problem solver. Fortunately, Mindy has engaged a number of skilled professionals who have helped her attain a broader understanding of her strengths. As well, counselling allowed her to deal with some of those issues she might otherwise have kept "bumping on along into . . . in life because that's all I could do" (Mindy, 2003b, p. 42). She explains how the experience has provided her with alternative means to evaluate situations and that overall it has improved her life. She refers to these last years as "one of the biggest growth periods" (Mindy, 2003b, p. 42) in her life.

Invisibility of Hearing Impairment

Mindy talked about how the act of listening is frequently interpreted by others as actual hearing. For example, if a person hears the words, this does not mean he or she is able to process those words accurately or understand what is being said or even keep up with the pace of the conversation. Thus, hearing impairment is an "invisible handicap" (Ashely, 1985a; Clelland, 1995; Dahl, 1995; Getty & Hétu, 1994; Harvey, 1998; Richter, 2001; Ross, 1997; Stone, 1992; Trychin & Busacco, 1991; Weinstein, 1996) because others cannot determine what is being understood and what is not. Unlike the sensory loss of vision or the physical limitations such as amputations, which are quite obvious or definable, hearing impairment is not as categorically defined or readily understood by others because of the lack of visual indicators. Modern hearing aid technology has reduced the tendency to view hearing impairment as a disabling condition, as hearing aids are hidden away from view.

"The communications on the desk is what challenges me the most, <u>even still</u> in my job; and it is really hard to explain that to people because it is so invisible" (Mindy, 2003b, p. 37). At her workplace, Mindy experiences disorganised thinking, frustration and/or internal "short-circuiting" (Mindy, 2003b, p. 37) due to the pressures associated with the demands of hearing. She believes these reactions and behaviours are not readily noticeable by others; however, she experienced them deeply on a regular basis.

Mindy was invited to be a part of the help desk team because she demonstrated good listening skills. The strategies she used for survival skills in the workplace were perceived as effective skills for listening. The irony, therefore, is that these listening skills were borne out of necessity and a desire to succeed in the workplace, as Mindy was simply trying to do the best she could under difficult circumstances. For Mindy, communication demanded a great deal more effort than could have ever been anticipated by the person who invited

Mindy to take the position. Being hired to work at the help desk can be likened to an introvert being assigned the role of an extrovert, almost as if undergoing a metamorphosis.

Isolation/Alienation

As referred to earlier, Mindy attempts to illustrate further her feelings regarding the difference between isolation and alienation. She provides an example of someone responding to her request to have his/her statement or question repeated, saying, "it's not that important" (Mindy, 2003a, p. 3) as an example of alienation. In this illustration someone else is clearly making the decision about his or her willingness to communicate with another person.

Mindy remarked upon how hearing aids allow her to feel much less isolated and reduce the instances when she feels paranoid. In the past, she explains, she suspected others were talking about her because she could not be an active participant in the conversation. Hence, she recalls attempting to listen to conversations, as she believed she was not being fully informed and/or that people might be holding back. This lead to her questioning what was real and what was not.

> It is kind of like with the paranoia where I would think something was happening that wasn't. So it was kind of like I was never sure of where reality lay . . . I am never quite sure if I've got all the information without my hearing aids, and so therefore, I can't judge where reality lies for me completely or with great assurance. (Mindy, 2002, p. 19)

In an attempt to gather the necessary information for understanding, Mindy believes others may have formed misperceptions and misunderstandings. "People might have found me to be persistent or aggressive around that, but . . .

it wasn't my intention, it was more my intention that I know enough, so that I know how to go ahead with something" (Mindy, 2002, p. 19).

During her early years Mindy recalls being referred to as "shy", although she preferred to refer to herself as "reserved". Often she would be encouraged by others to express herself but she declined. This was partly due, she explains, to her not having sufficient time to formulate an opinion and also because she may not have all of the information. This may also require explaining to them about her hearing impairment. Mindy believed that people's impressions are based on what they can see.

> I didn't want them to hear what I wanted to say . . . and maybe that was one of my safe ways of being . . . by not participating too much I didn't have to listen as much, I didn't have to go off in left field as much and I didn't have to risk as much. (Mindy, 2003b, p. 20)

As well, being mistaken as a shy person was less risky, as there were fewer possibilities of falling into disfavour with others and/or revealing her hearing impairment. Indeed, for Mindy this may have been a safeguard against embarrassment.

Mindy wonders if her introversion is a facet of her personality, a learned response or related directly to her hearing impairment. She does not wish to over-represent hearing impairment as the greater issue in her life, particularly if there are other mitigating factors at work as well. At the same time, this may be perceived as an attempt to further minimise the issue of her hearing impairment.

Liberalism versus Autocracy in the Classroom

While in school, Mindy was able to benefit from the control imposed by an authoritarian teaching style where the teacher directed the conversation in the classroom. When this model shifted to a more participatory one, students were

encouraged to express themselves freely, and the teacher was no longer the primary source of information. Thus, Mindy was no longer able to identify the source of the comment, and the mental work required to keep up in this liberal environment was very exhausting for her.

Selective Hearing

In her early years, Mindy indicated she was told by her brothers and sisters she did not have a hearing problem; instead, she had selective hearing. She could hear “dessert” but not “dishes”. Whereas in her early years Mindy may have not been able to hear the difference between dessert and dishes, at present she has the power to select what she wants to hear and what she does not. For example, she finds small talk requires a lot more energy and provides much less benefit than formal conversation. During casual conversation, she states she must apply all of her listening strategies for relatively little return. She considers this a waste of her time and energy. She is now making choices, whereas before she would feel compelled to attempt to listen to what was being said or risk missing it all together. Mindy has found the freedom of selectivity in hearing with the help of her hearing aids.

Social Activities

Socialising continues to be limited for Mindy. “I don’t do a lot of social groups unless they are with people whose voices and voice tones I am comfortable with” (Mindy, 2003a, p. 6). Since listening is exhausting, people with hearing impairment make decisions with respect to ease of communication and the best use of energy. In the workplace, Mindy states she continually assesses the environment. For example, she positions herself with her best ear toward the weakest voices, and relies on her knowledge of the subject matter being discussed. The digital hearing aids reduce the time and energy required to make

these assessments, but some are still required. Mindy continues to utilise some of the old skills she used prior to the purchase of her hearing aids. In so doing, she increases the modalities for taking in information, though she does not need to rely on them solely.

Using Disability for Self-Serving Purposes

Mindy firmly maintains that environments need to be able to facilitate an individual's ability to hear enough of an ongoing conversation to be able to communicate. It is not that the person cannot "hear" the words that are being said, it is that they may not be able to make sense of them sufficiently well to understand their meaning. Using the term "disability" within the context of hearing impairment has some important implications for Mindy. Although she agrees she has a disability, she does not wish others to reach erroneous conclusions about what she us capable of achieving. Mindy referred to a recent experience in her workplace where she believes someone used a disability for self-serving purposes such as being excluded from doing certain less desirable tasks. Thus, she is quite sensitive to the use of this term and does not wish to be seen as someone who is using her hearing impairment as a means for personal gain.

Locus of Control

Mindy's mother made the decisions regarding her surgeries when she was a child. "The first couple of operations I think it was more for my mother than for me . . . the last two I'd say it was for hearing" (Mindy, 2003b, p. 5). During her childhood and later on as a young adult, she relinquished the control of her hearing impairment to her parents. Her mother determined what was best regarding surgery and her stepfather determined the severity of her hearing impairment. It was not until her later teens when she felt she had sufficient

information to make her own choices. Her new job forced her to face her hearing impairment and the associated issues. Mindy is taking important steps in establishing responsibility for her hearing impairment. She is being very consistent in her approach to gain control over her life.

Mindy is now able to assert herself in the process of decision-making and problem solving. For example, when her hearing aids were returned after being sent away for repair, she told the technician one was not working well. Rather than arguing with the technician, she demanded it be returned and repaired. Mindy explained how the technician reluctantly took it back. She demonstrated clearly her intention to not accept the suggestion by the technician that the hearing aid must be fine because it had just been repaired. Sometime later, Mindy recalled the event, explaining how in her mind she envisioned a triangular relationship had been created. There was the technician, there was Mindy and there was the counsellor acting in a supportive role promoting self-advocacy. For Mindy this was an acknowledgment of her own empowerment. She maintains that the counselling enhanced her ability to advocate for herself.

Future Plans

Mindy's interests do not necessarily include a change of career. Rather, a change may occur as a result of an avocational interest that she could pursue following her retirement. This pursuit, she states, would be to find something beyond work in the traditional sense of the word. It would also be something "empowering" (Mindy, 2002, p. 30) for her. It would appear from her search thus far that all the jobs require adequate hearing. Therefore, her hearing impairment repeatedly takes the form of a formidable barrier for Mindy. However, at the same time, Mindy feels the hearing aids have broadened her scope of possible future careers because she can handle new situations differently and more effectively. Hearing aids do not change the reality of her having hearing

impairment because it continues to exist long after the hearing aids are inserted and turned on. Her hearing aids enable her to work more effectively within challenging environments.

Summary

Mindy's passage from passive to active status occurred as a result of learning to understand and accept her hearing impairment. She has begun to grasp how much her hearing impairment has influenced her life. She has challenged many of the paradigms which had been maintained by her parents regarding her hearing impairment, and as a result, her attitude and perspective regarding the meaning of hearing impairment in her life has broadened.

Mindy continues to experience ongoing fatigue and exhaustion, and these are prevalent and problematic issues in all areas of her life. She has been able to be her own advocate at her workplace and she gained increased confidence in the process. Future plans may require further support and help from outside sources to assist with the structuring and layout of her options. Counselling and critical reflection have already assisted Mindy in her adjustment process.

Nils

Introduction

Nils's story is complicated by additional medical factors. For this reason, I am providing a brief overview of the complexities of his life circumstances. He presents with severe and unrelenting bilateral tinnitus. Over the past few years, his visual acuity has also declined dramatically. For ambulation Nils uses a cane. He has severe and chronic back pain from osteoarthritis and degenerative disc disease. Migraine headaches occur almost on a daily basis. The rapid onset prevents medications from taking effect and this leads to violent vomiting. He may also be confined to his bed for at least a day until the headache has

subsided. These symptoms are fairly recent, and have been preceded by the hearing impairment and tinnitus. The combination of these multiple conditions leaves Nils feeling quite incapacitated. For the purpose of this study, only the dual impairments relating to his hearing will be referred to in this chapter.

Identification of Hearing Impairment

According to Nils, he initially became aware that his hearing was deteriorating in 1989, though other people noticed it earlier. For example, Nils's early morning ritual of watching the television news with the volume turned quite high woke his wife up regularly and considerably earlier than she would have preferred. Nils's behaviour also alerted her to his ensuing hearing problems. His tinnitus started much earlier, around 1979, but it was not until 1990 that it also became a concern. By 1995 the hearing impairment combined with the tinnitus had become so severe that Nils had to take stress leave from work. At the time he contacted the Workers' Compensation Board for assistance to purchase bilateral digital hearing aids.

Stigma/Ridicule/Teasing/Discrimination

Nils described his job in the kitchen aboard a ship. One of his duties was to take meal orders from other crewmembers. It was extremely difficult for him to manage this basic task due to the constant background noise of the ship and his hearing problems. Twenty years ago, awareness and/or attention to the negative impact industrial noise could have on hearing was considerably less than it is today. Furthermore, wearing protective devices at the workplace or aboard ships was not mandatory, as it is now.

He was quite emphatic in stating his conviction that there is a stigma associated with persons with hearing impairment.

> The stigma surrounding . . . a hard of hearing person still exits and it exists in a strong way! My work mates, some of them at work in various capacities, lots of times, officers, which shouldn't happen kidded me and made fun of the fact, in various ways, of the fact that I was hard of hearing. (Nils, 2003a, p. 1)

Nils is convinced other people often associate hearing impairment with diminished intellectual ability: ". . . your intelligence is rated as lesser" (Nils, 2003a, p. 1). "When the person with hearing loss misunderstands or fails to understand, the other employees may come to view that person as being unfriendly, incompetent, slow-witted, weird" (Trychin, 2001, p. 17). Over the years, teasing and ridicule have been substantial. Furthermore, he maintains the stigma surrounding hearing impairment: "still exists, period, strongly!" (Nils, 2003a, p. 1). He described how the ship's crew humiliated and embarrassed him. He perceived such treatment to be physically and psychologically damaging.

Nils recounted instances where the ship's crew would approach him and yell directly into his ear. "Some of it was meant to be mean at my expense . . . Some of it was ignorance and some of it was just down right rude" (Nils, 2003a, p. 6). He was appalled by the discriminatory behaviour he was subjected to and dismayed by the thought of how it had been tolerated within a government work environment.

The problem of discrimination continues to occur in his personal life even now when he is not working. Although he does not interact with people to a great extent, he does come into contact with the public, for instance, when he goes shopping. He reiterates that discrimination against those with hearing impairment is a sad reality in all realms of society.

Even though his wife does not act in a discriminatory manner, on occasions some of her behaviours seem to upset him disproportionately because

they serve to remind him just how pervasive the isolation and alienation of having a hearing impairment coupled with tinnitus has become for him. "Even my wife, for heaven sakes, we have been married for 19 years, she forgets, she forgets, lots of times she still forgets that I have a hearing problem and she will yell at me, from another room . . ." (Nils, 2003a, p. 3). Empathy can be a difficult notion for individuals to grasp since it entails one's identification with emotions and feelings of another person. Thus, perhaps the best one can aspire to is to understand and sympathise.

The most common recommendation from others is to "turn your hearing aid up" (Nils, 2003a, p. 3). For him this typifies the general lack of real understanding from others for a person with hearing impairment. In Nil's case, if he increases the hearing aid capacity it amplifies all sounds, and this in turn intensifies his problem with tinnitus. Later on during the interview process, Nils remarked that quite frequently within a relationship one of the partners might forget and fail to consider the needs of the spouse with hearing impairment in association with tinnitus. When Nils and his wife watch television together, he maximises his hearing aid capacity while keeping the volume relatively low, presumably out of respect for her. However, she may at times not remember and will turn toward him to say something and her voice is amplified dramatically. "If she says something and she has a habit of doing that, leans over the couch or something and says something, I am 'Ohhhhh . . .'" (Nils, 2003a, p. 4) (demonstrating a pained facial expression and hands cupped over ears). He assumes most people, particularly someone who has been in a longstanding relationship with him, should be aware of his special needs.

Invisibility of Hearing Loss

For Nils, having an invisible disability such as hearing impairment makes his problems an easy target for ridicule. Regarding the invisibility of the

condition, he further observes how he is able to appear normal to people walking by him on the street. Yet under this façade of normalcy is a hidden burden he cannot share.

> I walk down the street with hearing aids and I look healthy, normal, relatively healthy, relatively normal, and yet, that's what's happening to me, I can't do this, I can't do that yadayadayada . . . and it goes on and on and on and it just invades your life (four-second pause) totally, total invasion of your every aspect of your life, your work, your social life, your physical well-being, your mental well-being, it gets everywhere, permeates like a cancer, goes right through you and yet it is not terminal (three-second pause) but it is lifetime. (Nils, 2003a, p. 14)

During the second interview, Nils commented how his friends have frequently said to him that they feel he has a "pretty good life" (Nils, 2003b, p. 2). He then summed up how he sees his life: "They have no idea about my life, I don't have a life, I do not have a life now! I don't! I just don't have a life!" (Nils, 2003b, p. 2). This illustrates an example of how people perceive life from their own perspective and may make judgements based on their own reality without consideration for individual differences. Nils reiterates how his friends are not able to understand him or his life within the context of his severe limitations, including his tinnitus and his hearing impairment. He describes his earlier life in terms of being a hard working, adventurous, and spirited entrepreneur, but his present condition prevents him from enjoying himself or even partaking in the kinds of activities he previously found pleasurable. Furthermore, in his youth he recalls looking forward and optimistically to engage in many of these activities during retirement. Now he no longer views these as viable options.

Tinnitus – A Catch-22

Nils's tinnitus makes it impossible for him to buffer the internal noise. At such times when the tinnitus is extreme, he has to turn his hearing aids off because he finds the amplification too unpleasant. A prosthetic device is only of value if it provides relief. Clearly, in these circumstances when the tinnitus is extreme, the hearing aids do not provide Nils with any sort of relief. Therefore, he finds himself in a Catch-22 situation where he has to turn off the hearing aids to cope with the tinnitus.

Nils describes his tinnitus as ranging from a roaring noise to a whistling wind and then back again to a roaring howl, then to other somewhat less intense noises. Even though the type and intensity of the sounds vary, there is never a time when he does not hear some noise. For the most part he describes the noise associated with his tinnitus as severe. Factors that appear to negatively influence his tinnitus are external noises, tiredness, and stresses.

When asked whether reduction in stress would impact positively on the level of the tinnitus sound, Nils stated that the difference would be in the nature of the sounds but not in the intensity.

> The hearing loss cuts out the clarity [of sound] and the tinnitus intensifies the noise, it is a double whammy, I mean just hearing loss alone I can probably handle a lot better, I mean they are pretty bad, but when combined with the tinnitus, it is the sensitivity [to the sounds and noise] that's terrible, terrible. (Nils, 2003a, p. 11)

Nils recalls that the tinnitus started around 1979 but its impact became serious by 1990 or later. Exposure to high levels of industrial noise over a regular 14-hour workday may have been a major contributor to the tinnitus as well as the hearing impairment. "It's hard to remember what good hearing is like . . . what reasonable hearing is like, not being able to hear things is unbelievable, unbelievable" (repetition for emphasis) (Nils, 2003a, p. 17).

Nils described his work on government ships and the problems with tinnitus, saying “lots of noise . . . so there is lots of noise, radio noise, engine noise, shaft noise, vibrations, and for a person with tinnitus, horrible tinnitus like I have, it is a nightmare, a nightmare” (Nils, 2003a, pp. 1-2). He recalled how one of the fleet’s captains took his own life because of his experience with tinnitus. Thus, the one person he knew who could understand his devastation is no longer able to provide him with support.

Working Environments

The working conditions aboard the ships were described as being awful, and Nils believes that his tinnitus and his hearing impairment were hastened by the noise aboard the ships.

> I had a hearing problem for quite some time and it just got worse of course on the government ships because some of them are so horribly noisy that it just quickened the pace of my hearing loss and the tinnitus, made it really bad. (February 17, 2003, p. 2)

Crews were flown in and out of northern coastal areas at the end of their sea duty. Nils flew regularly in non-pressurised aircraft and the trips became extremely painful for him. It frequently took several days after returning home before his hearing was restored. Nils believes the working environments and requirements of each of his different jobs exacerbated his hearing impairment and the tinnitus.

Employment

Throughout his working life, Nils made frequent career changes. He attended business school at 25, and at 47 he returned to college to complete a cooking program and was later hired to work on government ships. He planned

to start a new career at age 60; however, he was not able to fulfill his goal and employment change due to his hearing problems.

Medical/Psychological Ramifications

The pressures associated with work, his tinnitus, and hearing impairment became so severe that Nils experienced what he referred to as a nervous breakdown. He was unable to continue working after 1995, at which time he took stress leave. "It was strictly because of that that I lost my profession" (Nils, 2003a, p. 7). After a year or two on stress leave, he believed he could have returned to work had it not been for the hearing impairment and tinnitus. He left his employment for medical reasons which were precipitated by stress, anxiety, and depression.

Audiologists

On one occasion when Nils consulted an audiologist, he requested an adjustment to his hearing aids. The audiologist informed Nils he was not correctly adjusting the hearing aids to provide sufficiently high volume of amplification to match his hearing impairment. It appears the audiologist assumed that if Nils turned the volume up, this would rectify his hearing impairment. Nils was unable to communicate effectively to the audiologist the complexities of his problem, i.e., having a hearing impairment and experiencing severe tinnitus. Therefore, this may have led the audiologist to assume that his patient's problem was primarily the hearing impairment, and no additional symptoms were explored. Nils got the impression that the audiologist was making generalisations based on his hearing impairment, thereby not catering to his unique needs. On three separate occasions after he received the hearing aids, Nils tried to turn down the amplification power in the hope of creating a balance between managing the problems associated with the tinnitus and at the

same time maintain sufficient amplification to improve his hearing. On each occasion the audiologist informed him he was adjusting his hearing aids incorrectly. Understandably, it was disheartening for Nils to try to explain his efforts to the technician and yet not be able to receive the help he so desperately required.

Relationship Issues with Family

In Nils's opinion, when a family member has a hearing impairment there are serious adjustment issues for all of the members of the family to deal with. He provides examples of his own experience at home and how it affects his wife. Hearing impairment not only affects the person with the hearing problem, but the whole family. Nils believes that frustration is quite evident in his relationship with his wife, and he concludes, "If she had less patience, I am sure she would be gone before now" (Nils, 2003a, p. 14). Nils described his wife as someone who enjoys movies, live theatre, and concerts; however, she cannot attend these with him. Nils explains, "Her social life has been impacted in a major way too, just like mine" (Nils, 2003a, p. 15). Therefore, his wife's social life has been dramatically curtailed, partly by her own choice and possibly to an even greater degree by his hearing impairment. When they rent a movie, she watches it on her own unless she is willing to deal with his repeated interruptions to clarify what is happening through the movie. It appears spontaneity in their relationship has been greatly reduced.

Presently, Nils is planning and working on an underwater garden project. He can only work on it for an hour or so at a time due to his problems with arthritic knees. Nevertheless, this endeavour provides him with an outlet for his creativity. His wife, apparently, is not supportive of his projects, as she claims this takes too much time and money. Nils is somehow reminded of his father's lack of support and help for projects he wanted to carry out as a young child. The

similarity in experiences affects Nils quite dramatically, as he feels he is pushed further into isolation. He is unable to share his artistic ideas, and without his wife's support for even small projects, he feels alienated.

Isolation

With respect to family relationships, while Nils has no contact with his natural children, he keeps in touch with his wife's children from her first marriage, but his involvement is limited.

> It certainly inhibits the social interaction because when they are all talking, I cannot hear anything anybody is saying . . . I just cannot hear anything any anybody is saying (repetition for emphasis). You are sitting there and there's friends and family around and they are all having a wonderful time laughing and I am isolated, totally isolated, because I cannot hear a thing! (Nils, 2003a, p. 10)

Nils believes that integration into the group is not possible, as any attempts by his family group would lack spontaneity and freedom and would be seen as contrived. It is often impossible for someone who is wearing a hearing aid to differentiate and isolate a single voice amidst a group of people. Nils likens this to being in an isolation booth. "It isolates you, totally isolates you, you can't—it's impossible to integrate" (Nils, 2003a, p. 10). Hallberg (1996) describes "the invisible barrier" (p. 26) when discussing the problems associated with interaction with others when one person has hearing impairment.

Nils endeavours to fill the day with as many activities as possible but there is no real sense of fulfilment. "My life is just so bloody boring, you would not believe it!" (Nils, 2003a, p. 19).

Recalling a recent invitation to a 60th birthday party for a brother- in-law, Nils explained how he went early to help set up; however, as soon as the crowds came in, he left. He spoke of his feeling of isolation in the midst of a crowd.

> When you can't hear, if you love music for one thing and then you can't hear it—and you can't hear conversations, I mean, you just feel out there [demonstrating distance] you just feel like an idiot, an absolute idiot! I still do and I probably always will feel like an idiot alone sitting out on the patio and people are milling around inside doing whatever, and I can't partake of it. (Nils, 2003b, p. 4)

As Nils mentioned, the image he depicts resembles that of a person in a glass booth. That person is unable to hear what is happening or be a part of the activity. He/she can simply watch interactions and activities and remain oblivious to others. He reiterates that when there is more than one person engaged in conversation, he is unable to hear and understand. "If there's two people . . . I lose everything" (Nils, 2003b, p. 5). He is convinced that others cannot understand his feelings of desolation and aloneness.

Critical Reflection

Nils refers to his review of the transcript from the first interview and explains: "When you sit down and read it, and it's all there in front of you, the context, you know, it is quite dramatic, quite dramatic, very dramatic! It was very dramatic to me" (Nils, 2003b, p. 4). During this follow-up conversation, Nils told me how he experienced "a whole series of emotions" (Nils, 2003b, p. 6) while reading the transcript. For him the transcript portrayed a very difficult life experience. "I broke down in tears at one point because I read in one basic paragraph, I read my life going down the drain" (Nils, 2003b, p. 6). He was brought to tears as he read about the life of this man who experienced hearing impairment and tinnitus. It was difficult for Nils to come to grips with the reality of this story being his own story.

> It is sort of a biography (four-second pause) in a way. I can look at it, various parts of it . . . and go through a range of emotions. It's

> my life, sort of. I mean it's only part of my life, but I mean it is sort of skipping through as a biography. It's sad in a way. I am glad it [the interview] was done, I am very glad it was done. I am proud I was part of it [the study]. (Nils, 2003b, p. 11)

Indeed, for Nils this was the first time anyone had taken an interest in his life for the purpose of gaining a deeper and broader understanding of his experience as a person with hearing impairment. As well, this interview process gave him an opportunity to examine more thoroughly than ever before his thoughts and feelings about his life both in the past and at present.

The interview stimulated some reflections on his early life. When he was a teenager, his brother broke Nils's glasses and because his parents weren't willing to help him get them fixed, he was not able to replace them until he was 21 years old. He explained how his parents never provided him with support or encouragement for his activities and interests. At present, with his severe limitations preventing him from engaging in activities, he turns to his wife for support and encouragement. However, his interpretation of her lack of support and lack of encouragement for his creative ideas, as evidenced with the underwater garden in the yard, lead him to once again experience a lack of understanding and a sense of chilling isolation and even alienation. Nils seems to embed himself in his own loss, which likely leads to further feelings of bitterness and depression.

Plans Altered

Nils had planned to work until age 60, and then to take gun training and work with an armoured car service until age 65. "Without hearing you can't do that, can't listen to the radio, I mean if someone says 'this is a stick up', I can't hear, well, (chuckle) that's comical . . . so I couldn't do that either" (Nils, 2003a, p. 7). This scenario captures the sense of irony in his situation. The armoured car

service driver represents a bastion of protection and safety over individual and institutional valuables; however, Nils's hearing impairment would place all of these in jeopardy.

Further, many other jobs, including driving a taxi, were out of the question, as he would not have been able to listen to the radio or hear adequately when a passenger indicated a destination. "I mean it is pretty demeaning when you can't even get a job driving a taxi . . ." (Nils, 2003a, p. 7). The underlying theme of such a statement is one of deep demoralisation. This is represented by a person who realises that such a job, one which from his perspective requires very little training or skill, is now beyond his reach and capability. Nils believes the tinnitus and the hearing impairment represent huge obstacles preventing him from managing at least one final career change, and therefore, fulfillment of his plans.

Music

Nils described his appreciation and gift of music and singing was the greatest single activity he had in his life. He entertained at weddings and parties by playing guitar and singing. He has played for large groups of 100 people or more and this became a source of tremendous pride for him, as it provided him with personal fulfilment. He described music as the one aspect in his life, the one ability "that . . . sustained me through broken marriages, loneliness a lot of things" (Nils, 2003a, p. 8). Music was at one time the centre of Nils's social life.

One of Nils's favourite activities entailed sitting and listening to selected music on the stereo. His collection of CDs is now worthless to him, as he is unable to listen to the music and appreciate it—it is only noise. In terms of the role music plays in his life, Nils states,

> I personally cannot think of anything that destroys your life like hearing loss and tinnitus, it just **destroys** it, there is no life left,

> there is no life left, there really is no life left because you cannot do anything. (Nils, 2003a, p. 8)

Indeed, music was an intrinsic part of Nils's life, and when he was no longer able to play and sing, this was devastating to him and it severely limited not only his social life but his wife's as well. Nils's life restrictions due to his hearing impairment have been severe. For example, restaurants were too noisy and attending church was out of the question due to the singing and music, which have become strictly noise to Nils. Many other social activities have been curtailed primarily due to his inability to tolerate noise, as it leads to his feeling anxious and needing to leave to go to a quieter place. "I can't think of one aspect in my life that hasn't been affected by hearing loss" (Nils, 2003a, p. 8).

Summary

Nils is the oldest candidate in this study, and as such, he represents the other end of the spectrum. His hearing impairment occurred in mid life. He is now a man in his early sixties and he provides a very dramatic description of loss. Along with the sadness and desperation, he feels he has been robbed of the opportunities in life that he was longing to enjoy in later years. His discussion reveals bitterness and anger as he lives with no sense of purpose or fulfilment in his day-to-day life.

Nils experiences more than isolation. He is alienated by circumstance. The din of the voices alienates him because he has no choice in terms of remaining on site or even attempting to partake in the social activities with family or friends. His analogy of feeling like a person in a glass booth may represent an even greater loss, the loss of his freedom to choose.

Due to his hearing impairment, Nils may have been robbed of opportunities and enjoyment without a clear reason or explanation other than

perhaps “the luck of the draw” as well as the limited understanding of how severely an individual is affected by it.

To conclude, Nils reiterates that not only the individual with the hearing impairment is affected, but the spouse, the children, the family, and friends. Thus, all aspects of an individual’s life, i.e., social, intimate, and personal are touched by hearing impairment.

Andre

Frustration

When asked initially to describe his life and his experience as a person with hearing impairment, Andre’s first statement was “frustrating, very frustrating” (Andre, 2002, p. 1). Without hesitation, Andre describes his feelings during his early years. “It was very difficult for me to function. So I lived quite an isolated life” (Andre, 2002, p. 1). Throughout the interview process, Andre used this term to describe his life experience from early years to the present. He continues to experience frustration at the present time due to his hearing impairment.

Andre described what frustration meant to him by stating that he found it difficult to understand what was being said to him. He would attempt to pick out the words and try to determine the context in which the words were spoken. “When you don’t understand something, you are trying to pick out the words that you hear, like trying to figure out what they are saying” (Andre, 2002, p. 1). Picking out words to make sense of dialogue can leave a person feeling as though he/she is on the periphery—not belonging to the mainstream. This can be very hard and exhausting work as an individual strains constantly to hear what is being said. Andre did not understand why listening was such hard work. Referring to the level of fatigue that an individual experiences due to his/her hearing impairment, Pope (1997) states, “No one has told you that you may feel exhausted” (p. 37). Andre describes how fatigued he felt after returning home

from school: ". . . it is a lot of work, I put so much work and effort into the classroom setting but by the time I got home I was just exhausted" (Andre, 2002, pp. 5-6). Thus, a source of Andre's frustration was the result of his constant straining to hear and struggling to process and piece words together to attain meaning and context.

Being seen as "normal" (Andre, 2002, p. 2) is important for Andre and this desire is expressed several times during the initial interview and throughout the second and third interviews. Thus, further questions are raised in terms of Andre's perception of what "normal" meant to him as a child. Indeed, how would he, as a child, have explained what was wrong or what was different? It may be possible that differences are easy to discern; however, to understand what is meant by the term "difference" or what it would be like if differences did not exist are complex notions for a young child to grasp.

Andre moved from the unstructured and predictable home environment to a more challenging one in the classroom, wherein he was faced with major adjustments. Again, Andre uses the term "frustration" to describe how he felt when his teachers and professionals treated him differently to the other boys. There appear to be several layers of frustration for Andre. For example, he experienced frustration because his own perception of himself was not equal to that of others. As well, there is the frustration which goes along with being treated differently. "I never wanted to be special. I just wanted to be an average Joe" (Andre, 2002, p. 5). Thus, it is important to ask and determine how a young child interprets and understands such dissimilarities. "But I think I wanted to prove to the previous teacher that, "hey, *I'm not hearing handicapped.* I'm normal!" (Andre, 2002, p. 4).

Andre also uses the term "frustrating" to describe social activities while he was attending college. His frustration did not end with adolescence or his entry into adulthood. While he was in college, a great deal of socialising with friends

took place at bars and, while he believed girls were interested in him, he could not engage in conversation in these settings. When he attempted to do so, he would often miss what was being said to him and this would lead to feelings of embarrassment. "You really can't take me to the bars . . . it's too noisy. You can't really have a conversation with a hearing aid" (Andre, 2002, p. 6). Thus, the mere act of conversing with someone was troublesome, especially in places with background noise.

This ongoing theme of frustration also applies to areas of intimate and friendly dialogue within his relationships. Messages were not getting through. Thus, at a time in his life when relationships took on increased intensity and meaning, he described how he felt he missed the opportunity to engage and achieve contact primarily because the social environments were not suitable due to his hearing impairment. Therefore, he continued to meet these normal everyday opportunities with ongoing frustration. Quite frequently, friends, partners, and family members will forget what they can do to attain effective communication with individuals with hearing impairment. This appears to have been the case with Andre, as concessions were not being made to accommodate him.

Andre described his early years: "I spent most of my childhood not relating" (Andre, 2002, p.1). Thus he realised something was wrong or that his life experience was different from the norm, but he was not able to articulate it. Finally, interventions were initiated not by his parents, but by his teacher and the school nurse. He demonstrated his understanding of how important this intervention was by saying, "If it weren't for my grade one teacher noticing how isolated I was as an individual . . ." (Andre, 2002, p. 1).

When intervention was initiated, he was placed in a weekly speech therapy program over the course of several years. Andre describes his personal frustration during the primary grades when he was placed in the same speech

therapy program year after year. Not only did he not notice any change in his speech as a result of the programme, but he felt it was demeaning. These experiences with the speech pathologist simply reinforced his feelings of inadequacy: "The school made me take speech therapy and she would make me practice simple words like cat and bat and things like that . . . they were treating me like a child" (Andre, 2002, p. 2). At the same time, Andre may not have been clear on what the teacher or therapist was trying to achieve.

> Here I was in grade five, a ten-year-old student and this person is teaching me to do like three letter—one syllable, three letter words, treating me—to me it was treating me like a grade one. Over the years there was the same program every year, there was no advancement at all, just getting frustrated. Why do you keep teaching me how to say dog and cat . . . I'm in grade five! (Andre, 2002, p. 4)

There is an early lack of "agency" (Cochran & Laub, 1994, p. 1) in the description given by Andre. Cochran and Laub define an agent in basic terms as "one who makes things happen" (p. 1). The terms "agency" or "agenic person" are used in reference to a person who is prepared to take charge rather than simply allowing things to happen. Referring to his speech therapy, Andre recalls: "I just thought there must be a reason behind this. I thought this was part of the school program and I just left it there" (Andre, 2002, p. 4). He was never asked to be a part of the solution, and this theme of not being in control or even having any input is carried throughout the three interviews, which describe life experience beyond his early years.

Identification of Hearing Impairment

As mentioned earlier by Andre, he spent most of his childhood not relating to others. Presumably, he may have known at a very young age that he was

missing out on his childhood socialising experiences. He reiterates ". . . they [teachers and health nurse] just said something needs to be done here because I didn't hear properly" (Andre, 2002, p. 1). Andre uses the term "confusion" in those early years, saying, "confusing just because of misunderstandings of what you are hearing" (Andre, 2002, p. 1). It is not known what interventions the parents attempted but it might be assumed that the intervention at school was a sudden and markedly different approach from what he experienced previously with his mother and father. This may have also contributed further to Andre's confusion, as he was used to a comfortable environment at home where he was able to apply his interpretive strategies and probably understand conversations with greater confidence. Then, suddenly, he found himself in a classroom, which was a substantially different environment, and he had no idea what was happening. Hence, the situation changed very quickly from one which was presumed to have been quiet complacency with his parents' minimal regard for his hearing impairment to this sudden urgent need for intervention from outside sources. Based on what Andre indicated, his parents had not previously mentioned the seriousness or the potential impact of his hearing impairment. Then without any indication, recommendations were being made for intervention and the professionals provided dynamic and purposeful statements. "Something needs to be done!" (Andre, 2002, p. 1). These recommendations may not have been effectively explained to or been understood by Andre's parents, let alone himself. Therefore, the first ones to impact so immediately and powerfully regarding his hearing impairment were the professionals at school, i.e., the outside sources.

Alienation

"I had those hearing aids with the strings on them and so I was very visible and it was very difficult and frustrating for me to develop any friendships

with kids my age" (Andre, 2002, p. 1). At the time, the only type of available hearing aids were the chest pocket models with long external wires hanging from the earpiece. The first hearing aids Andre ever wore were a blatant source of alienation because they made his difference obvious—the "invisible handicap" (Dahl, 1997; Ross, 1997) was now visible. The hearing aids, Andre explains, distinguished him from other classmates and peers and made it difficult for him to develop friendships. "They thought I was some kind of alien . . . or something" (Andre, 2002, p. 1). How better to describe the experience of alienation than to describe oneself as an alien. Andre describes the first 11-12 years of life as being both isolating and difficult to function. The primary interaction with other students was with those "brave students" (Andre, 2002,
p. 1) who asked what the hearing aids were, and he would explain. Bravery intimates an exhibition of courage, a "stepping out" or "reaching out" by some of his classmates. There was a risk in the process. The intrepidness of youth is defined by a few who were willing to risk this potential rejection and alienation themselves in order to show compassion and to reach out in friendship. These acts of bravery are very honourable, but at the same time they may have further entrenched Andre's belief that he was different because the majority of boys and girls did not act this way.

Social isolation is one of the most critical factors faced by persons with hearing impairment (Clelland, 1995; Dahl, 1995; Meadow-Orlans, 1985; Rockow, 2001; Steinberg, 1991; Stone, 1997; Trychin, 1991; Trychin & Busacco, 1991; and Wood, 1987). Furthermore, Cowie, Watson, Kerr, and Douglas-Cowie (1985) report that the feeling of marginalisation from everyday experiences with hearing people is frequently identified in the research literature.

Andre recalls the impact his hearing aids had on him in the early years in terms of creating a stigma.

> During my elementary school days, it was very hard to develop friendships. I had no friends because my belief was they were scared of me or they just thought I was a little odd because I had the hearing aids that were totally exposed, the hearing aids with the box in the pocket and the strings. I just felt like an outcast and I was more or less treated like an outcast on a social basis during my elementary days. (Andre, 2003a, p. 3)

There were no vivid memories of early years reported by Andre, but he recalls isolating himself from teachers and students at school.

Harvey (2001) provides an excerpt from a brief dialogue during counselling with one of his male patients, a young man with an adventitious severe hearing impairment acquired at age four. As a child the young man would hide in the corner of the classroom, separating himself from the teacher and other students. Discussing the man's difficulty with not being recognised for his hearing impairment in school, Harvey states:

> You were in a lot of pain and didn't have a way to share it so you hid. You were troubled but not troubling. So they didn't notice you. Everyone including your teachers didn't get the meaning of your behaviour. (p. 55)

Andre described an early classroom memory wherein he questioned why he acted differently from the others and why he was the only one in class who was not at the drawing table. On reflection, he believes either he did not hear or did not understand the request of the teacher. He recalls asking himself, "What's wrong with you?" (Andre, 2002, p. 11). This provides an example of how Andre was missing information in school, and though he may have been aware that something was wrong, he was not able to associate this with his hearing impairment.

During elementary school, Andre shied away from students because he believed they shied away from him. Harvey (2001) continues to describe the previous scenario ". . . his peers and teachers avoided him; he felt more inadequate and hid even more; others avoided him more. How that vicious circle started is one of those 'chicken and egg' questions . . ." (p. 55). Harvey goes on to discuss culpability and likens the situation to a dance where responsibility is shared. This perspective is understood by his client, as he is given the opportunity to reflect on his own experience. For Andre, he may have felt a huge burden of responsibility. If Andre was taking cues from his fellow students and assumed they were correct, then responsibility becomes one-sided and he may have borne its onerous weight. He has already referred to himself as an "alien" (Andre, 2002, p. 1). The hearing aids made him appear different from everyone else. He states, "I spent most of my academic life and my personal life trying to fit in, trying to be normal again. (six-second pause) I always tried to be as, quote, *normal* as possible" (Andre, 2002, p. 2). This is a period that spans 12 of 18 years of life "trying to fit in, trying to be normal" Andre, 2002, p. 2) and an equal number of years taking on responsibility for the reactions of others. Andre believes it was the open-mindedness of high school students which finally led them to become more willing to socialise.

Andre likens his early school experience to the life of the cartoon character in the television version of the comic strip "Peanuts". He describes himself as Charlie Brown sitting at his desk listening to the teacher speaking. In the cartoon what the teacher says is simply expressed as, "Wawawawa" (Andre, 2002, p. 11). Andre recalls only hearing a similar meaningless noise coming from the teacher's mouth. He did not remember understanding the teacher's comments, what the lessons consisted of or what directions were given. Andre's comparison of his experience to that of the cartoon character Charlie Brown may also represent his low level of self-esteem as a child. In the cartoon series

Charlie Brown is depicted as the underdog, and perhaps unintentionally, Andre visualises himself in a similar manner as the “loser”.

Socialising for Andre did not begin until the age of 11-12. “Then in about grade six students became more accepting of me” (Andre, 2002, p. 1). Being accepted by particular groups occurred later in high school. “We all know that in high school the most important thing is your friends at that time. I started getting some friends. I started to get a group of friends [in high school]” (Andre, 2002, p. 6). As well, during high school there was a sense of acceptance and completeness. Becoming part of groups is important for young people, as it allows the individual to learn social skills, partly through group activities. In addition, one’s self image is developed to some degree through acceptance, involvement and interaction with others.

Andre equates humour with a positive element in his life, as it allowed him to relieve his feeling of isolation and dispel negative thoughts. He reiterated that if negatives are left unchecked, this might lead to feelings of isolation. He commented on having a good sense of humour that contributes to make his life more bearable and permits him to function. It would appear Andre sees negativity as something to be avoided or at least curtailed. Consequently, he uses humour as a coping mechanism.

The BTE (behind the ear) hearing aids were not introduced until Andre was in grade seven. “I think that boosted my confidence big time because I could hide it again; it [his hearing impairment] was invisible” (Andre, 2002, p. 7). The stigma of the hearing aids exerts a power over Andre which is pervasive and has permeated all levels of his life since childhood. According to Andre, it was not the hearing impairment itself, but the devices, the hearing aids which made him stand apart from everyone else. “I had those hearing aids with the strings on them and so I was very visible . . .” (Andre, 2002, p. 1). When they were replaced with smaller ones, it would appear his life had a new beginning.

Stigma

Andre described an experience which may have been his initial association with being different. One day his mother found him crying and so she asked why he was tearful. He said he wanted to be more like his brothers. "I don't compare to Byron and Jason . . . I want to do just as good as my brothers on these things!" (Andre, 2002, p. 3). He was referring to higher academic achievements. His mother's response suggests that Andre's hearing impairment made him different from his brothers and affected his ability to achieve higher academic objectives.

> Well, you have to accept that you have a hard of hearing problem and that's a disadvantage to you. You have to accept the fact that things are going to be challenging in your life. You are going to have to work three times harder than the average person to get a better grade in school. Just do the best you can! (Andre, 2002, p. 3)

Based on Andre's information, this discussion, which took place during grade six or seven, appears to be the first time his mother or father ever discussed with him his hearing impairment and the impact that it might have on his life. Harvey (2001) explains further how individuals learn to define their hearing impairment. In his discussion about Robert, he attempts to help him become more aware of how his thinking was influenced regarding who he was while attending school.

> It sounds like you were taught to view your hearing loss as a sort of package deal that comes with a massive cloud, with being out to lunch, not too bright, or reduced to nothing. You were taught to attach all that baggage to your disability. (p. 54)

Regarding other children in school, Andre stated, "They never treated me badly, I never got, you know, stuff like sticks and stones thrown at me, or

anything like that, I was just an (two-second pause) outcast" (Andre, 2003a, p. 3). Andre intimates that things could have been much worse for him at school. What is unjust is that he appears to have been made an outcast due to his hearing impairment. Andre may have assumed culpability, hence minimising his fellow students' actions or behaviours.

With respect to the issue of wearing his hearing aids, he states, "I was quite embarrassed wearing hearing aids with strings. I hated the idea of being exposed to the idea that I was hard of hearing and that's what those kinds of hearing aids did to me" (Andre, 2003a, pp. 3-4). This statement suggests Andre may have had a hate relationship with his hearing aids. He saw them as an indelible mark and the source of betrayal. Finally in grade seven, he was fitted with a pair of BTE hearing aids which he could hide behind longer hair, making them no longer visible. Thus, his hearing impairment returned to the invisible status. "As soon as I got the behind-the-ear hearing aids, it was an overnight confidence boost" (Andre, 2003a, p. 4). It seems Andre gained confidence from external sources.

Andre took a great deal of pride in being able to hide his hearing impairment from others during his later years in high school and college. He believes he became more accomplished at hiding his hearing impairment since the seventh grade and he talked about being able to deceive all of his classmates and friends. "I took a lot of pride in myself when people came up to me [and said] 'Wow, I didn't know you were hard of hearing!'" (Andre, 2003a, p. 4). He indicated that most people may have thought he spoke with an accent and as far as he was concerned, they did not consider the possibility of hearing impairment. "They always knew I had an enunciation problem but they just thought maybe I was just reading with an accent" (Andre, 2003a, p. 4). Indeed, being able to prevent his hearing status from being revealed was very important to Andre. The

importance attached to this attempted subterfuge was reinforced throughout our interviews. This may have been a social survival issue for Andre.

> But once they found out that I did indeed wear hearing aids they were like: '**Wow!**' That made me feel (five-second pause) confident, made me feel (10-second pause) made me feel proud, I guess an equal. I have always tried to (five- second pause) I have always been the type of person who doesn't want to be treated specially, so, that made me on an even keel, when they found out: 'Hey there's nothing special about him'. (Andre, 2003a, p. 4)

Since the beginning of the interview process, it was quite obvious that Andre wanted to be "equal" (Andre, 2003a, p. 4) to everyone else. He did not want to be special or unique in terms of his hearing impairment. Andre refers to "special" as it applies to "special needs". He also uses the term "normal" in such a way as to indicate that normal and equal mean the same. His interpretation of normal and equal reveals Andre's difficulty in accepting being set apart from others because of his hearing impairment.

Andre expressed his amusement at people's reactions when they were made aware of his hearing impairment. Apparently, these individuals would attempt to work hard at enunciating or even over-enunciating during a conversation with Andre, as they assumed this would create an environment of equality. However, in Andre's opinion this only accentuates the difference, as such attitudes bring the attention to his hearing impairment. At the same time, Andre recognises that his needs are different from the other men on the crew where he works, and he appreciates the extra effort of his foreman for walking over to him to speak to him closely rather than shouting across a large compound or attempting to be heard over the din of loud machinery and equipment on the worksite.

Self-Image/Self-Confidence

Andre has taken great pride in his ability to listen. Being able to give a compassionate ear to someone has given him a sense of value. He has also been appreciated for his willingness to share his weakest sense, his hearing. Others may believe this is an easy thing for Andre to do. "One of my friends told me in college, he says, 'For a guy who is hard of hearing, you sure are a great listener!' And I took a lot of pride in that statement!" (Andre, 2003a, p. 6). If the overall assumption by people is that listening is done at its best by those with good hearing ability, then this would be a great compliment to Andre. Therefore, in being complimented in this fashion, Andre's capabilities closely approximate those of people with normal hearing.

> So, I have great listening skills, I am very compassionate and so on. My confidence just goes up and down like a yo-yo! Throughout my whole life . . . I would have a couple of good months of high confidence and then, I might be having a couple of months of no confidence. It always frustrated me as an individual (four-second pause). I guess something would trigger it, maybe a bad mark in some course or something, whatever, something said to me in a negative way. I am a person who takes criticism very seriously and I take it to heart, and it beats me up a lot, I can't take criticism, constructive criticism, right, I have that problem and I always will. (Andre, 2003a, p. 6)

With respect to his confidence, it appears Andre sees his locus of control as external. He describes how his confidence can be very high for months and suddenly it plummets and remains at very low levels for an equal period of time. This may suggest depressive episodes. At such times he acknowledges how hard he can be on himself. Indeed, this has been identified as a lifelong pattern expressed throughout the interview. It is not just a single incident.

Andre explained how the Christopher Leadership Course in Effective Speaking has assisted him greatly to develop faith in himself, belief in his ability to function in a leadership capacity and to increase self-confidence. For Andre it provided a source of temporary respite from experiencing a larger world which he believes perceives him as different. In such an environment he is able to apply his newly learned active coping behaviours. Prior to the course, he described his confidence as being low. "Taking that course did wonders! It taught me a lot of things on confidence and confidence in myself, faith, and . . . some leadership skills as well" (Andre, 2003a, p. 6). Andre explained how "having a girlfriend" (Andre, 2003a, p. 6) would boost his confidence as much as reading the positive reviews in the local papers for his acting in high school plays.

Andre maintained a personal diary throughout his youth. This has proved to be a valuable tool as he reads about his accomplishments, particularly when he was not feeling confident. Reliving his achievements has enabled him to increase his level of personal confidence, even if such feelings are temporary. Andre recognised he is very hard on himself as he discussed the value of the diary. "I guess in a way you could say I become depressed and it helps me to say: [to myself] 'Hey, you are okay, Andre, you are not so bad after all', after I read these things in my diary" (Andre, 2003a, p. 7). These are more than self-reflections. They are acknowledgements from others that he is a person of worth and value. Again, the support and encouragement from outside sources helps him identify who he is and what is his worth and value as an individual.

Andre takes criticism very seriously. "I focus on it! Oh boy, do I ever! Whatever my mood is . . . if it is criticism, I focus on that thing" (Andre, 2003a, p. 8). Emotions such as anger are not discussed, and this may imply that Andre may not have disclosed his feelings to anyone regarding his hearing impairment to the extent that he had during these interviews. Rather, his emotions are kept inside, and as may be expected, there is a build-up of negative thoughts.

> The idea of holding it all in is a defence mechanism I learned myself and I learned it from my mother, because that's what she would do, she would take all the problems, and just take them inside and not talk about them and . . . just a learned trait, I guess. (Andre, 2003a, p. 14)

Andre reported that he experienced mood swings quite often and had to exert a great deal of effort to lift himself up from depression and turn his perspective around. "It takes a lot to dig myself out, I just keep saying to myself: 'You are not big, you are not that good a person yet'. I just focus on the negative of myself" (Andre, 2003a, p. 7). Speaking more affirmatively of his strengths and abilities, Andre states, "But nowadays I have been able to wake up the next day and say: 'it's a new day, time to start fresh'" (Andre, 2003a, p. 8).

Andre disclosed how during his early formative childhood years he was subjected to his father's verbal abuse whenever he made mistakes. He would then internalise the criticism as well as his own mistakes and engage in self-effacing talk for days. This pattern of behaviour still occurs at present.

> For example, if I am at my work and I make a minor error at the beginning of work, *it's there for the rest of the day* (chuckle). I can't—I just—think I make a mistake and I dwell on it. And I remember in the past if I had one bad day it would go on for three or four days. (Andre, 2003a, p. 8)

His current behaviour and attitudes in response to criticism seem to be rooted in these early family experiences. "Whenever I received a compliment I would always push it away and say 'Yeah, yeah, whatever' or it would be my mentality [to say] 'Why do you give me a compliment?' you know, 'what's the story behind it?'" (Andre, 2003a, p. 7). Andre explained how he grew up in a family environment where compliments were infrequent. Sarcasm and joking were the primary means of communication.

During one of the interviews, Andre stated that he was able to control his frustrations; however, he also explained how at times he would reach a level where he felt he could explode with anger. At these times he would be more likely to bring forward issues with his wife which had taken place weeks before. He expressed a wish to change the manner in which he deals with his anger by being able to think before reacting. As well, he would like to make a conscious shift from what he referred to as the "passive-aggressive" methods he has frequently demonstrated.

As discussed earlier under the heading of stigma, Andre recalled the early dialogue with his mother when she found him crying about his low achievement compared to his brothers. Her closing comment at the time was:

> God made you this way and you have to accept that. There is nothing you can do about your hearing loss, just deal with it, just do—just cope with what you have'. That was my turning point that made me accept that I was hard of hearing and there was nothing I could do about it. (Andre, 2002, p. 3)

Indeed, he may have found himself severely limited whenever he tried something new because he might have believed he would have to work harder than the next person in order to accomplish "average" (Andre, 2003a, p. 12) or "normal" (Andre, 2003a, p. 2) levels of achievement. "I would always have to work harder! I would always have to prove a point . . ." (Andre, 2003a, p. 12). Andre recollects his mother's statement as positive and accepting as well as reflecting sensitivity, wisdom, awareness and compassionate understanding. Harvey's (2001) dialogue with Robert provides an even more poignant picture in referring to the "massive cloud" (p. 54) and being "taught to view your hearing loss as a sort of package deal . . . You were taught to attach all that baggage to your disability" (p. 54). Thus, the explanation provided by Andre's mother may have reinforced for him the belief that he would never achieve the state of

normalcy to which he aspired. When this shift occurs and the source of power is externalised, Frank (1995) refers to this as “the loss of destination and map” (p. 1).

Andre was asked whether he would have behaved and/or felt differently if he did not have a hearing impairment. He responded saying, “I would definitely behave in the same way. It’s just that I would have more confidence, I think; confidence is the big one!” (Andre, 2003a, p. 21). It would appear Andre perceives his hearing impairment as the villain in his mind, the factor to blame for what he believes has caused losses in his life. With respect to relationships, he stated, “I would be saying to myself: ‘I don’t deserve this’, or I would always say to myself ‘she doesn’t deserve me’, and that kind of attitude. I think that would not be there. That would be eliminated” (Andre, 2003a, p. 21). Andre’s tendency to undermine himself and feel undeserving are both a reflection of his diminished self-concept and feelings of unworthiness to be the recipient of someone’s regard.

Andre recognises how he tends to dwell in negative thoughts and he acknowledges the impact such feelings have had on his life over the years.

> If I was a confident person all the time I probably would be doing a lot better career wise, I probably would do a lot better as a person. Like who wants to be around a person who is negative all the time. (Andre, 2003a, p. 10-11)

Such a negative attitude may be due to the constant wearing down of his self-image since childhood when he was unable to relate to other children in play or at school, having to relinquish control to adults at an early age, using hearing aids, his father’s verbal abuse, and his limited experience with friendships and relationships.

In situations involving work and job interviews, Andre believes he projects a positive image of himself. However, Andre acknowledges that while the façade

he presents to people is powerful, he is not happy, not satisfied with life. In the first interview Andre stated he did not wish to have special treatment. During the second interview he related how he uses his hearing impairment as an excuse. He provides an example: "I don't deserve a promotion because I am hard of hearing (eight- second pause). When it comes to special treatment, the same thing, I don't deserve special treatment!" (15-second pause) (Andre, 2003a, p. 12). These statements may imply that he wishes to be treated fairly, as he believes he requires help but has some difficulty in articulating precisely what kind of help he wants, needs, or will accept. Andre was asked whether anyone had previously taken this much interest in him with respect to his hearing impairment. He responded that no one had and added:

> I think it's going back to the attitude I have where I feel I am not that special. I feel privileged to be picked [for this study], but I am sitting there going, *there is probably better examples than I am, probably can help out with your studies better than I would, that's just how I feel*. (Andre, 2003a, pp. 14-15)

Once again, this statement reflects his ongoing belief in his unworthiness. Frank (1995) explains how "the body sets in motion the need for new stories" (p. 2). As Andre's old paradigms or beliefs about himself change, he will need to create new ones.

Employment/Advancement

Following his graduation from high school, Andre described himself as a "workaholic". "My first few years I worked as a kitchen manager—three different places. It required 60-80 hours of my time. That was my life—work" (Andre, 2002, p. 8). Andre's primary social activity involved bowling once a week and this was the one privilege that he allowed himself to have.

Andre applied for a promotion while working in the hospitality industry. He explained how he had credentials for the position while the other candidates did not. However, another applicant was hired for the job. He knew this was an unfair decision. He referred to it as his first "taste of reality" (Andre, 2003a, p. 12). He explains how he would have to work harder endeavouring to prove himself. "Yes, I am equal to this person, or yes, I am capable of doing the job" (Andre, 2003a, p. 12). Thus, it would appear Andre believes he does not have an advantage in the competitive world. Later, he explained how if he ever had to compete with another individual of equal qualifications to his own, he would most assuredly back away from the competition, saying:

> *He can have it. I don't deserve it* (spoken in a very subdued and conquered tone) because I would not want to be a nuisance, I guess you could say for the employer, I don't want to have the employer have to take extra steps to take care of me. (Andre, 2003a, p. 12)

After a few years in the hospitality industry, Andre moved to Vancouver Island on the recommendation of a friend. Here he was hired onto a semi-skilled labouring job where he has worked for the last 13 years. The demands of work were intense, requiring him to work between 10 and 13 hours per day—six days a week. Andre changed one line of work for another without stopping and questioning his motivation to keep such a pace or reflecting and asking himself why his focus was solely on work and not some of his personal issues.

Andre has been advised by his audiologist that his work environment is endangering his hearing, as he is at high risk of losing his residual hearing due to work-related noise involving heavy equipment, tractors, backhoes, and jackhammers. He has been trying to leave the job and return to school for formal education and a career change. He has approached funding sources as well as agencies to assist him with life issues such as career choices but these agencies

have not been receptive to his leaving employment to train in another area. In addition, Andre has been the primary wage earner since his marriage, and therefore there is a great deal at jeopardy if he leaves his job.

In terms of employment, Andre explains what he perceives to be a reality in the workplace for him. On several occasions during his career in construction, Andre believes he was overlooked for the foreman position. While he regards himself as a skilful worker, he has never been promoted. He attributes his lack of success to his hearing impairment.

> I have always been neglected whenever a foreman's job came up, or a promotion, and for example they would feel that somebody else would be a better person for the job. They won't tell me, but I know for a fact that they won't hire me as a foreman because they feel my hearing is a (six- second pause as he searches for a word) disadvantage, they feel that it would cause probably more problems than it should and so I have always been neglected in that way . . . I was hopeful for a while because I knew I was capable of doing the job . . . it was upsetting but it has come to a point where I come to realise that I have to accept it and that this is not going to happen. (Andre, 2003a, p. 11)

As Cochran and Laub (1994) argue, "a person becomes agentic through enacting an agentic orientation. Becoming an agent is a straightforward matter of effective or successful practice" (p. 31). The writers acknowledge this statement as an oversimplification of the process of taking responsibility for becoming self-determining. Cochran and Laub are simply acknowledging that the onus for such goals rests with the individual. Andre does not appear to be demonstrating the agentic trait to go out and ask the reason why he has not been promoted. In this particular case, he has assumed the role of patient status and has not demonstrated self-determination. As Andre explains, "I don't have the power or

whatever to take that step forward and say: 'Here I am, I deserve this!'" (Andre, 2003a, p. 13).

Placing himself in the position of the employer, Andre believes he would realise how activities such as using a telephone or one-on-one communications might create a serious "disadvantage" (Andre, 2003a, p. 11) and that it would "cause . . . more problems than it should" (Andre, 2003a, p. 11). Therefore, he believes he would not be the most appropriate candidate for the job of foreman. It would seem Andre has not researched the modern technology to find out whether there is anything that would assist him to overcome this "disadvantage". Once again he places himself in the role of the employer and indicates, "If I was an employer and I had two people with equal experience and qualifications, but one was a hearing disability and the other one wasn't, I would definitely go for the person who has no hearing disability" (Andre, 2003a, p. 11). Though recognising the unfairness of what he said, he concludes, "It's reality in my eyes" (Andre, 2003a, p. 11).

Children

Andre considers his children the centre of his world. In their eyes, he explains—although he does not feel like one himself—he is a hero. "'Who cares if my Dad is hard of hearing, he's <u>my Dad</u>'" (Andre, 2002, p. 10). For Andre, this translates into unconditional acceptance by his children. When Andre was asked about his relationship with them, he answered by describing it through their eyes. "My daughters have so much admiration for me that they asked me if they could wear hearing aids when they grow up" (Andre, 2002, p. 10). Andre explained how he feels his daughters give him a reason to live and concluded that he hoped they would never be embarrassed by his hearing impairment.

Relationships

Integration into social groups and male oriented activities came late during his final year of high school. "I felt social acceptance" (Andre, 2002, p. 6). Andre had been on the periphery during his childhood and through his youth; however, high school marked entry into a life where he became an equal. This was something he aspired to achieve for a very long time. This social acceptance did not apply to relationships with girls. "I felt that females would not be very interested in someone like me. It was very rough in high school because like I maybe had one girlfriend for about two or three months, that's all" (Andre, 2002, p. 6). Once again, Andre adheres to this belief of not being desirable due to his hearing impairment. As previously discussed, Andre had trouble hearing in bars, movies, and basically any place where there were competing noises. His comment regarding his short-term girlfriend relationship, "that's all" (Andre, 2002, p. 6) may have reinforced his belief that his hearing impairment is the primary reason for his limited experience with girls. It may also be a further reinforcement of his perceived unworthiness for being chosen or liked by girls. Andre uses the term "rough" several times throughout the interview in the context of the difficulties he experienced in opposite sex relationships.

Andre believed he was not acceptable as a partner in a male/female relationship. He raised questions which emphasised his feelings of inferiority such as, "What would she see in me, I would be just a *hassle*" (Andre, 2002, p. 6). "I would be a disadvantage to her . . . I would be a burden to her . . . I would feel like I would be a pain in the neck" (Andre, 2002, p. 8). The connotation of a "pain in the neck" is one of constant annoyance, limiting activities, being constantly reminded of the discomfort, and generally not very pleasant to endure. He reiterated how the loud din of talking, laughing, yelling, and music and the many distractions that are characteristic of the bar scene prevented him from participating and engaging in conversation. He emphasised how the bar scene is

not good for persons with hearing aids or persons who have hearing impairment because it is very hard to separate the important sounds and noises from those that are not. He continued to give further reasons why opposite sex relationships would be difficult. For instance, analogue hearing aids were particularly difficult to use in movie theatres because of the frequent variability of sound which is so prevalent in theatres; therefore, this eliminated the movies as an option for dating. Overall, he felt he would be perceived as more of a burden than an enjoyable person to be with. He concluded, saying, "I would feel that a female companion—she would not deserve a person like me—a hard of hearing" (Andre, 2002, p. 8). Andre continues to present himself as unwanted or damaged goods, someone whom no one would want or need to have in their lives. Andre uses depersonalisation on several occasions when he talks about himself. He does not describe himself as an individual with a hearing impairment or someone who is hard of hearing but as "a hard of hearing" (Andre, 2002, p. 8).

Denial/Avoidance

When Andre was a young child going off to school, he would sometimes remove the hearing aids before arriving at school and replace them before returning home. This, he explained, gave him a sense of being normal.

Andre was failing his academic year in grade three and his teacher recommended he attend a summer school for children with developmental handicaps. He was very successful with the summer session and returned to the mainstream program in the fall. Andre recalls making extra efforts during the summer school session to prove both to the teacher and the school that he was a student with "normal" (Andre, 2002, p. 2) ability. This constituted an exemplary effort on Andre's part, as he felt it was his responsibility, his duty and his right to prove he was normal. During the course of the interview, Andre stated that he would have failed the year because he could not hear what the teacher was

saying. Andre may not have been able to articulate what his needs were in order to help himself to become a successful learner in the classroom, and this may have further entrenched his role of a "pawn, one with little sense of agency" (Cochran & Laub, 1994, p. 5). He had to rely on his own interpretation of the events and follow his own instincts to guide him and understand why he was being sent to a special class for the summer; however, he did not share how he felt with anyone. Harvey (2001) provides further clarification of this scenario when he describes Robert behaving as an adult in terms of his therapeutic relationship, "Rather than passively accept and internalize his teachers' neglect in a self-depreciatory manner—being out to lunch, stupid, reduced to nothing etc.—he began to give some of the culpability back to them" (p. 53). It would be unlikely for Andre to be able to articulate such feelings during his childhood, but this comment demonstrates that it may have been quite feasible for him to experience them.

During the weeks between interviews, Andre recalled an early memory and he wished it to be included in the record. At approximately age 10, his mother observed him cleaning his ears vigorously with a Q-tip swab. He recalled telling her how he was attempting to burst the bubbles of water in his ears with the Q-tip. "I just thought, maybe there was some water way back in there, or something in there that I could get rid of and **perform a miracle**" (Andre, 2003a, p. 1). He was under the impression that there was pressure in his ears, much like the feeling one gets from swimming. He believed he could burst those "bubbles of water" and this would allow him to hear. During the interview, Andre did not provide many examples of times when he took matters into his own hands; therefore, this scenario may be an important one because it suggests he may not have been adequately informed about his hearing impairment. Indeed, his limited understanding and his experiences with swimming were the only

means of information and experience he had to try to alleviate his problem and restore his hearing.

Andre wished he could keep people from knowing about his hearing impairment. "I personally try to hide it [hearing impairment] from other people, from new people" (Andre, 2002, p. 2). He explained how people became aware of his attempts to fool them when he was asked a question such as "how was your day?" and he would respond with "yes", nodding his head and/or smiling. Often the response from the speaker would be a "funny look!" (Andre, 2002, p. 2). He would then feel embarrassed as he realised how his attempts to conceal his hearing impairment by resorting to the façade of a polite response to a misunderstood question had failed. Following this he would berate himself by saying, "Oh-oh, there I go again!" (Andre, 2002, p. 2). Andre explained how he avoids contact with people to spare them from becoming annoyed at his ongoing requests to repeat what they said, twice or even three times. Cowie et al. (1995) conclude that persons with hearing impairment struggle with a reduction in their level of confidence. Hétu et al. (1994 a & b) explain how internalisation of the perceived stigma associated with hearing impairment can lead to a sense of failure and damage to one's self-image, as it implies an acceptance of the irreversibility of such loss.

Being the "class clown" (Andre, 2003a, p. 4) in grades seven and eight allowed him to shift the focus of attention from his hearing impairment to his clowning behaviour. This was one of the few times during the interviews when Andre's described himself attempting to take control of situations. Furthermore, Andre became involved in Drama while attending high school. "I just flourished! It was nice to be able to be somebody else. [It] took me away from being myself" (Andre, 2003a, p. 5). He started with small roles and then moved on. "As I gained more and more confidence and the teacher gained more confidence in me, I just started getting not the big roles, but the harder parts to play" (Andre,

2003a, p. 5). Thus, becoming an actor provided Andre with a sense of normalcy by shifting the focus of attention from his hearing impairment. His positive feelings of success rewarded him internally as well as externally through compliments from his teacher, the audiences, and the theatre reviews in the local newspapers.

Keeping people from becoming aware of his hearing impairment is still a source of pride for Andre. Indeed, he endeavours to maintain good eye contact and he positions himself strategically to make sure he can see people's faces.

Fatigue

Individuals who have hearing impairment may exert a great deal of effort to establish and maintain communication. For Andre, listening attentively and concentrating during a conversation demands a great deal of work. "By the time I got home I was exhausted from listening in the classroom. It takes too much energy! It takes a lot of concentration" (Andre, 2002, p. 6).

Andre describes himself as a "lazy listener" (Andre, 2002, p. 5). Referring to the fatigue he experienced when he returned home from a long day at college, he stated, "I guess that's where the lazy listening skills come in" (Andre, 2002, p. 6). In his current lifestyle, Andre explains how he feels overworked and he has little interest in communicating.

> I have to do so much concentrating that I don't feel like listening *after a while* (chuckle), sometimes I just miss a lot of stuff. And that effort and concentration is required at all times for the person that is hard of hearing. (Andre, 2003b, p. 12)

External Locus of Control

As mentioned before, when Andre was in grade three his teacher suggested he would benefit from attending a special school for children with

disabilities. During this time, he had been failing school and it appeared to his teacher as though there were no other options available if he was to succeed at passing grade three. Andre's parents were advised of the recommendation and they complied. Following completion of the summer educational program, he was referred back to the mainstream. "They [the summer school teachers] thought that I was a *normal kid* just with a *hearing disability"* (Andre, 2002, p. 2). Andre's manner of description and his tone of voice suggest how this incident was a secret success in his life. He wanted to prove he was "normal" and he believed he was successful in this effort. Andre explained the three factors at play during grade three that led him to perform poorly. First, he was seated at the back of the room and he was unable to hear the teacher's voice. Second, according to Andre, the teacher did not articulate the words clearly at a time when Andre was relying on speech reading to interpret what was being said. Therefore, the cues provided by the teacher were insufficient and did not allow him to pick up any of the information he would have been able to under optimal conditions. Third, when the teacher spoke, she frequently faced the blackboard rather than facing the class, and Andre missed all of the non-verbal cues and he had no context within which to make sense of the little he was hearing. Thus, Andre was not provided with a suitable environment commensurate with his limitations or his compensatory strategies.

As mentioned earlier, Andre attended speech therapy classes from grade one through grade four. It would appear these classes did not offer variety and were delivered year after year. The frustration, the humiliation, and the lack of creativity in the method of instruction of the speech therapy sessions led Andre to feel there was no progress being made with respect to his speech. As well, it seems that since early childhood Andre had been conditioned to the status of the passive "patient" (Cochran & Laub, 1994, p. 1) and this continued on through his adolescence and adulthood.

Internal Locus of Control

Andre was determined to pay his own way through college, and to this end he held three part-time jobs after finishing high school. He attended school during the day and worked in the evenings and weekends. Thus, he made the choice to set aside normal school activities including getting together with friends, attending social events, dating, and building relationships in order to achieve what he had set out as his goal. This pattern did not change throughout the three years of his college program.

> I was a work-o-holic! Social life was out of the question. I worked all day and social life was non-existent. I had no contact with friends. It was *kind of a different situation*. Relationships were out of the question because I just didn't have time for them. (Andre, 2002, p. 7)

Andre established priorities for himself and worked to bring them to fruition. These choices suggest an internal locus of control.

Andre met his wife on the job site with the construction crew where she was a flag person. Traditional male/female roles were reversed when she asked him out on a first date, to a hockey game. Andre relates that at the time of his marriage he thought to himself,

> I married my wife because I felt that it was time for marriage for me and I also felt, this is what I am going to get, this is the best I can do (10-second pause). I'm still in that mentality that: 'this female does not deserve me in a relationship . . . and she is interested in marriage, so, this is what I get'. (Andre, 2003a, p. 24)

Andre's themes of low self-esteem, his poor understanding and lack of experience with women, as well as his belief that he was not the person in control of his life may have also been reflected in his experience of courtship and marriage.

Andre talks about events which contributed to the strengthening of his self-confidence.

> When I got those high reviews in my plays and my drama at school . . . it would boost my confidence up. Having a girlfriend on a regular basis would boost my confidence up in high school, but they were few and far between. (Andre, 2003a, p. 6)

Similarly, Andre found value in taking the Christopher Leadership Course in Effective Speaking. "After taking that course it just did wonders! It taught me a lot of things on confidence and confidence in yourself, faith, and just some leadership skills as well, and it really helped a lot taking that course" (Andre, 2003a, p. 6-7). Maintaining a diary provided him with a means to keep records and reminders of his successes as well as to lift him up from his periodic long bouts of depressed mood.

Andre described several instances when he felt in control. For example, he took an early stand with his mother when at age six he demonstrated his assertiveness by asking her not to walk him to school. "No. I want to walk by myself!" (Andre, 2003a, p. 2). She continued to watch him from the window but he only found that out later in life.

Within the family, Andre perceived himself as the black sheep. He associates this role with his being the first to accomplish certain landmarks such as being the first one to get a driver's licence, finish high school, and attend college. These were all important milestones for him during his developmental years.

When asked to provide his opinion about the interview process, he stated that he found it helpful for several reasons. On a cognitive level, Andre understands what is required in order for him to feel more functional and responsible. On an emotional level, he was required to take a great deal of risk. He acknowledges he would prefer that only very few people are aware of his

hearing impairment; nevertheless, he also realises it is his responsibility to inform them. He explains how he needs to be able to tell people when he cannot hear them and explain to them how they can help him to get the most out of the conversation. He adds:

> Having this interview helps me be more aware of that, be more conscious of other people, I *suppose I have to—it is my responsibility, it is my responsibility to make sure that I can understand and hear people, it's not theirs, if they don't know I should be informing them* (Spoken in a subdued tone*).* (Andre, 2003a, p. 15)

It would appear as if Andre struggles, as he knows what should be done but has difficulties implementing it. For example, during high school an awareness program was provided to teachers and parents. One exercise was described as the facilitator covering her mouth while speaking softly and asking people to repeat what was being said. These conditions were meant to provide the hearing audience with an example of what the everyday life experience is like for a person with hearing impairment. Andre said he enjoyed the exercise and thought it brought forth some interesting responses. For instance, one of the teachers who attended the workshop requested Andre to inform him of his needs and/or accommodations and to make a point of reminding him and other teachers should they not be aware or forget. Thus, as someone in authority advises others of the needs of a person with hearing impairment, Andre felt comfortable with others knowing about it. "All I found was humour out of it, at the time, and now when I reflect, it made me realise what we just talked about, that I should have taken responsibility and told the teachers" (Andre, 2003a, p. 16).

Acceptance

Earlier in this section, it was mentioned that Andre believed he was accepted by peers as a person with hearing impairment during grade six. "Then in about grade six students became more accepting of me" (Andre, 2002, p. 1). This was an important time, as he began to develop friendships.

Andre felt acceptance when his mother explained to him that he would always have challenges due to his hearing impairment. As well, in high school he was welcomed into activities with other male students from the same grade. Furthermore, Andre's children were not judgemental and accepted him unconditionally. In each of these situations, he feels his hearing impairment was not an issue.

Critical Reflection

Andre attributes many of his perceived losses to his hearing impairment, and when someone asks him what he believes life would have been without such loss, he states:

> Even if I stuck with my construction I would have been promoted, I would have . . . for sure. I would have had more success I would do better academically, I would, (three-second pause) Yeah, I'd probably be more sociable too! More outgoing, and probably, yeah, more, more confident! (14-second pause) I think some of my negative characteristics would still be there, that's just me. Stubbornness! For sure, stubbornness. I wouldn't have that attitude 'if it wasn't for my hard of hearing', I would not have that attitude of: 'I don't deserve this. I don't deserve that. Yes, I would be more outgoing. I just feel that I would be more confident. (Andre 2003a, pp. 20-21)

The transcripts from each interview were provided to each participant. For Andre, reading the transcripts became "quite emotional . . . especially all of the pitfalls that I had. In the long run it helps me to grow (five-second pause) and I think that's the most important" (Andre, 2003b, p. 9). He went on to say, "Whereas when it is written down like this . . . it's in your face. I cannot avoid it. Everything is there. I can't just pinpoint what I want to hear. It's **all** there! (Andre, 2003b, p. 11). In other words, many of the issues brought forward in the interview are those that he has avoided. At this point, for what appears to be the first time, they are obvious because he is confronting them directly. The areas which particularly touched him emotionally included discussions on marriage, his children, and being passed over for promotion. "It also made me realise that I shouldn't be embarrassed or trying to hide the fact that I am hard of hearing. I should be more comfortable with it" (Andre, 2003b, p. 9). As a result of Andre's reflections, many of the "what-ifs" have been brought to light.

Accepting his hearing impairment was a stepping stone for Andre, and he now wishes to take this further by not attempting to hide his hearing impairment. "When I read this [interview transcript] it made me realise that I am doing more harm by hiding it and I should help myself help others to help them realise that it is hard for the hard of hearing" (Andre, 2003b, p. 9). Reflecting on his past has allowed Andre to increase his awareness and understanding of his life as well as to assume more responsibility for it.

When asked whether the interview process was beneficial to him, he stated:

> [It] definitely helps a person like me, because I keep everything inside, it is really good, probably healing for me to express myself about my disability. . . [It] confirms to me that it shouldn't be an issue. I shouldn't be so hard on myself (13-second pause). Whenever you have a problem you should always discuss it, I

> know that, and this is probably a kind of an introduction for me to not be so concerned about trying to hide my disability rather than just, probably there is lots of people out there interested about life as a hard of hearing and that I should discuss myself more. (Andre, 2003a, p. 15)

Andre confirmed that no one had ever taken this level of interest in his experience as a person with hearing impairment prior to this interview process.

During the initial stages of the interview, Andre began to wrestle with the idea of telling people of his hearing impairment, and by the second interview his attitude became more positive toward doing so. Indeed, after reviewing his lifelong attitude of avoiding telling people about his hearing issues, he talks about taking more responsibility for making people aware of his hearing impairment.

> Make everyone I meet aware that yes, indeed I have a hearing problem, then if I don't understand you or if I can't hear you I should have the confidence to say I can't hear you, you have to enunciate better and I shouldn't be embarrassed to do that. I think having this interview helps me be more aware of that, be more conscious of other people. *I suppose I have . . . it is my responsibility, it is my responsibility to make sure that I can understand and hear people, it's not theirs, if they don't know I should be informing them* (spoken in a quite, subdued tone). (Andre, 2003a, p. 15)

It appears that possibly for the first time in his life and perhaps as a result of the interview process, Andre is reaching inside himself and searching for different ways of looking at his life experience.

Relationship, Marriage, and Communication

Much has been said already throughout this text about issues or relationships with women and also about marriage. Though some reference will be made to these topics, more focus will be given to communication issues and the connections they have for Andre within the context of marriage.

Referring to his family of origin, Andre recalls: "As a family we were never big on having serious conversations and stuff. . . sarcasm played a big role in our family affairs" (Andre, 2003a, p. 5). Andre referred earlier to his limited experience with opposite sex relationships and as a result, he has difficulty in engaging in intimate dialogue.

> When it comes to heart-to-heart conversation I avoid them. When it comes to (five-second pause) expressing myself emotionally it is extremely difficult. (10-second pause) I am a sensitive person but if I were to express myself sen-si-tive-ly it would be very difficult. (Andre, 2002, p. 9)

In terms of his marriage, if he were to do it all over again, Andre stated he would marry someone who was more patient and understanding about issues of hearing impairment. It became clear how absent this issue around hearing impairment was in his relationship with his wife. This raises the question of how much time was spent discussing issues relating to his hearing impairment during the early stages of courtship. How aware was his girlfriend and later his wife about his hearing impairment and the implications? How forthright was Andre about his hearing impairment with her? In a study by Hétu, Getty, and Waridel (1994), it was demonstrated that 20% of those individuals with a severe hearing impairment never broached the issue with their spouses. Andre explains how over the years of their marriage, there have been several heated discussions and the core of the arguments has been his hearing impairment. He describes his wife as a person who is easily frustrated and impatient. He uses an example of

his wife speaking to him when he was in a different room and as a result, there were problems because he could not hear her. Apparently, she assumed he heard and that he would comply with her request. When she found he had not, she was described as upset because her requests were not carried out. He indicates that when he does not hear what she is saying or what she expects him to hear, she becomes frustrated. Cowie, Watson, Kerr, and Douglas-Cowie (1995) conclude from their study with late deafened individuals that "understanding . . . is crucial for an effective response, be it from significant others who interact with the late deafened people, or from the professions which aim to support them" (p. 293). It follows, therefore, this same treatment of respect and understanding applies to individuals with hearing impairment.

According to Andre, his wife does not understand why he does not hear properly. "She'll say something and I take it as criticism and then I'm hard on myself, and the ball gets rolling!" (Andre, 2003a, p. 22). Misunderstandings are commonplace in relationships where one has hearing impairment. It may be that some of the difficulties in these relationships arise as a result of misinformation, anger issues or possibly a lack of willingness to understand.

Andre has identified a series of guidelines for effective communication with someone with hearing impairment.

1. The person attempting to communicate with an individual with a hearing impairment should be in the same room.
2. Both parties must maintain eye contact.
3. Both must maintain [an appropriate] from one another in order to be heard.
4. If the person with hearing impairment "blunders", the other individual should be prepared to say: "It's okay, it's okay" (spoken in a comforting manner).

5. Both parties must set time aside to communicate with each other (away from distractions of television, children, or other people).

Mistakes are frequently made by persons with hearing impairment, according to Andre, and this, he says, is due to communication breakdowns. It also becomes frustrating for both parties. For this reason, he feels traits such as understanding, consideration, and patience are primary requisites for marriage partners for persons with hearing impairment.

Andre admits he is not good with "I-statements" (Andre, 2003a, p. 22), nor is he very good at establishing or maintaining heart-to-heart conversations on sensitive issues. "I shy away from them. I avoid them at all cost!" (Andre, 2003a, p. 22). "Having a relationship I guess is new material for me" (Andre, 2003a, p. 23). He discusses his limited experience with women, saying he has a hard time understanding them. This, he feels, has added to the difficulty he experiences in his marriage. He emphasises how it is the "female mentality" (Andre, 2003b, p. 23) that he does not understand.

> Hard of hearing [an individual who is hard of hearing] relies on other senses and mine is facial expression. I can tell what emotions you are feeling by just looking at your facial expressions, your eyebrows, your attention, your mouth, and your body language. (Andre, 2003b, p. 24)

Andre relates these ideas of his wife, claiming often times she has the body language of someone who is angry or who has had a bad day at work. He then takes the interpretation to heart and internalises it, believing he is the one to blame. He wonders: "What did I do wrong this time?" (Andre, 2003b, p. 25). These perceptions appear to be internalised assumptions and they remain unsubstantiated.

Summary

Frustration and isolation describe Andre's early years. Although Andre's parents were caring and loving, from the information provided by Andre it appears that they demonstrated a passive ignorance of the impact that Andre's hearing impairment might have had on his life as well as not knowing what to do to alleviate some of the problems at an early age. As a result of his isolation during these formative years and through his teens, Andre's self-image was battered and he was unable to bond with boys and girls his own age.

Through my experience with Andre, I have found him to be a bright and industrious individual with depth, compassion, and sensitivity. His lack of assertiveness in relationships as well as the workplace affected his self-esteem and self-worth. Therefore, these are areas also that should be examined in order to work with Andre's self-development. As well, Andre has set his own personal objective—that of working on the direction of his marriage and identifying future career goals. In addition, Andre would like to work on ways of expressing his needs in terms of his hearing impairment as well as dealing more effectively with constructive criticism in daily life.

Andre demonstrates insight by saying, "Everything seems to revolve around being more assertive. I guess that would help guide me to become more directed to my goals—instead of avoiding them" (Andre, 2003b, p. 6). This awareness seems to have emerged during the later stages of the interview process and demonstrates how critical reflection can bring about further insights.

By the third interview, Andre had reviewed the transcripts from the previous interviews and he decided that the focus of his action research project should deal with increasing assertiveness.

> I think assertiveness is the main thing that I have to work on. I haven't been assertive enough with my life. I haven't been assertive enough with my marriage. Just everything with my life

> just kind of boils down to me being more assertive. (Andre, 2003b, p. 2)

Andre carries the focus of assertion to assuming responsibility for letting others know that he has low hearing by saying, "I have to be assertive with letting people know I have a hard of hearing problem. I have to make them aware!" (Andre, 2003b, p. 3). The next stage will be to identify the goals that can be addressed using this approach. There is a vast amount of material for an action research project and the onus will be on him to select the focus and begin the second stage of the project.

Sharon

Identification of Hearing Impairment

Early in the interview, Sharon described her experiences with regard to changes to her hearing.

> In my late twenties-early thirties I noticed there was some diminished hearing and I went to an audiologist and he said: 'Yes, you have it!' So I knew that I hadn't escaped the genetic fault and (eight-second pause—Sharon did not complete her statement). It stopped my having sound for a lot of years, it really did. (Sharon, 2003, p. 2)

Sharon goes on to explain how "all he [the specialist] basically told me was: 'You have the same hearing loss as your mother and your grandfather' and that the nerves would deteriorate" (Sharon, 2003, p. 5). According to Sharon, the doctor's report of her condition related strictly to the anatomical and/or physiological features of hearing impairment without including any of the psychosocial aspects of her condition. In her mind an entire history of hearing impairment and its effects were immediately unveiled. She expected her hearing impairment to progress in a similar and, therefore, predictable manner, just as it did for her

mother and grandfather. Thus, the verification of Sharon's condition by her doctor led her to believe yet another generation of her family would experience hearing impairment.

As a result of further investigation in the ensuing years, Sharon was able to establish both medically and experientially that she would continue to lose her hearing gradually. There was no preventing it. Sharon was aware of the consequences of hearing impairment because of her first-hand experience with her mother and grandfather. She remembered spending a great deal of time with her grandparents. These recollections became the foundation for her current beliefs and understanding regarding what she might expect.

Isolation

A second hearing specialist and later a research team at the university hospital substantiated the earlier prediction that the rate of deterioration in her hearing would increase under stress. Sharon describes her life during the years between 1991 and 2002.

> I ended up having <u>phenomenal</u> stress in my life, but, as long as I had one good ear, and I did until 1991, I had 80% hearing in one ear, I didn't care, I was fine with that, I worked. But in 1991, my hearing <u>crashed</u> due to a lot of really stressful things happening in '91 and I woke up one morning and it was gone! And I was going from about 80% down to about 60-55% in my good ear . . . . I felt not part of the world. (Sharon, 2003, p. 3)

For Sharon, the portent of the doctor became a reality. Luterman (1984) refers to "existential loneliness" (p. 38), describing it as the anxiety and fear associated with separation. Relating this to hearing impairment, Luterman continues, saying, "The underlying terror of progressive hearing loss experienced by the clients was the feeling of being cut off and isolated" (p. 40). For Sharon,

then, it is the interpretation, the meaning that she gives to this message which is important. "I felt isolated, I felt (three-second pause) over there" (gesturing away from herself, indicating a physical distancing) (Sharon, 2003, p. 3). Sharon described herself as not feeling as if she was part of the mainstream of society.

> I kind of dropped out in 1991. I didn't have any clue that there was any help for me, except for how my mother did it or how my grandfather did it, and that was just by sheer force and survival; nobody helped them. (Sharon, 2003, p. 16)

The dim prospect of not having help or friends to turn to, or other resources, further entrenched this isolation experience for Sharon. Ashley (1985a) describes his personal experience with sudden onset of hearing impairment and rapid degeneration, saying "the plunge from a normal hearing world into one of almost total silence meant the plummeting of my happiness, aspirations, and hopes for the future" (p. 60).

Sharon claimed she did not see evidence of anyone coming to help her or her son. As far as she was concerned, she did not have any other alternatives but "sheer force and survival" (Sharon, 2003, p. 16). Continuing to refer to this decade of isolation, Sharon explains her belief that this form of social isolation is self-induced.

> When I was isolated, when I isolated myself, I mean no one does these things to you, you make the ultimate choice yourself, but, when I chose that life in the 90s and I chose to live like that, my life was very small. (Sharon, 2003, p. 37)

Sharon chose a life of seclusion for her own safety and for the safety of her son. "The furthest out I ventured was Evan and I would come to the library, but life was very small, it was very contained. It was very safe, but very small . . . I would say I controlled it a lot" (Sharon, 2003, p. 37). Later Sharon describes a move to a local island community. Sharon was dissatisfied with the teaching

practices in the school; therefore, she chose to home school her son. Each decision was preceded by thoughtful analysis and dialogue with her son. To Sharon, her world appeared to have shrunk dramatically with the reduction of her hearing, yet she found ways and means to survive. Relying solely on her wit and her will, along with an inadequate hearing aid, Sharon began to make a life for herself and her son on an island community housing 400 other people.

Fear of Loss of Control

When asked about her reaction to the diagnosis from her specialist, she replied:

> Horrified! Horrified! I watched my grandfather. My grandfather seemed to cope well. I mean if he had problems, if there were things that bothered him about being deaf, he certainly didn't tell us, but he was a very stoic Russian man . . . he had been through much worse in Russia, so whatever else was happening, he never said anything. My mother, on the other hand, struggled something terrible. (Sharon, 2003, p. 6)

Her mother, a registered nurse, worked at the local hospital. After work she would tell Sharon and her sister of the events at work.

> She would be on the ward and she would have an awful time . . . I thought it was very ignorant of medical people to be like that . . . you are dealing with a medical condition and these are medical people. I thought it was very petty of them to be like that. She would tell us 'oh, so-and-so was teasing her today about this' . . . the doctor was mad at her and yelled at her because she didn't hear something right and she did something wrong and the doctor yelled at her . . . and [the doctor] said she shouldn't be there if she couldn't hear. (Sharon, 2003, p. 6-7)

Therefore, Sharon had experience with two divergent models in family members, each with a hearing impairment confronting daily problems in what appeared to be different ways.

Sharon's hearing specialist made her aware of the course of deterioration in her hearing and added that stress would accelerate the process. With the death of her brother and the break-up of her marriage in 1991, she experienced major stressors over a short period of time. At the time she was equipped with an analogue hearing aid. The hearing aid was grossly inadequate for her needs. It amplified all sounds and it was ineffective as well as inappropriate for the type and level of her hearing impairment. As a result, Sharon explained she temporarily lost faith in audiologists, as they had maintained that the hearing aid would help.

When asked about her feelings about the future, Sharon replied:

> Well, as a footnote, I think I have to say that I am probably—probably there is a part of me that is terrified, because I don't know where it's going to stop, and I don't know when and nobody can tell me that, because I don't think they know. (Sharon, 2003, p. 29)

Sharon placed her faith in medical professionals and technology and she was very disappointed when success was neither achieved nor sustained. "The story told by the physician becomes the one against which others are ultimately judged true or false, useful or not" (Frank, 1995, p. 5).

During the interview, Sharon reported how at the time when her hearing deteriorated markedly, she had to struggle to remain part of the hearing world. One of the forces against her was not having an adequate hearing aid. Rather than a self-imposed form of isolation, she felt that technology now kept her in isolation, alienating her from the hearing world. She expected technology to help her regain her position within the hearing world, but it let her down. Her

connection with the hearing world was literally and figuratively severed. She was locked out with limited means of communication.

The specialist informed Sharon that her hearing impairment was hereditary. This, she stated, was like "inheriting any other weakness in the body" (Sharon, 2003, p. 5). She compares it to a predisposition to arthritis and, in as much as she knew it was going to happen, she just did not know when. She explained that her life suddenly felt as though it was out of control. Her situation was further complicated by inferior and inadequate hearing aids, which resulted in a loss of faith in the medical profession to be able to provide answers. Sharon also felt certain that one day, stress could claim the remainder of her hearing and there was little she could do about it. She therefore chose to regain control over her life, seeking safety and protection for herself and her son, moving to a physical sanctuary—the island.

Denial

Sharon described life in her mid twenties.

> In my 20s I was good. (five-second pause) I knew it [referring to her progressive hearing impairment] was happening and I knew what was going to happen to me, but again . . . I was 20. I was going to university. I was partying. I was going to folk music things, it was the 70's. It was a happening time. I remember having one discussion about it [hearing impairment] with a friend of mine and her husband made a few comments and I thought: 'Fffffft (as if to dismiss it entirely) Well, I don't need to talk about this with anyone.' It was a non-issue! (Waving it off and away) I could hear the professors fine and this was not a problem! (Sharon, 2003, p. 11)

Sharon recognises how in those early years she lived in denial of her hearing impairment and this went on for a long time. "Oh, it is big denial! It's denial big time" (Sharon, 2003, p. 3). Although Sharon was aware of the changes to her hearing, just as it had been evidenced with her mother and verified by the specialist, she recalls a certain feeling of inevitability. Sometimes individuals may feel that as a result of their hearing impairment they are separated from the hearing world, and therefore they are no longer able to participate. Hétu, Getty, and Jones (1993) compare the adjustment for those with sudden hearing loss and those with degenerative hearing impairment. Sharon demonstrated attributes of both. Those with a sudden hearing impairment can "make sense of the impact of hearing loss on their lives" (p. 387), whereas individuals with a more insidious loss "are tacitly involved in a process of coping with hearing difficulties while they are becoming aware of them" (p. 367). It was reinforced through the review of literature how changes such as denial, increased anger, and depression are behaviours which can be experienced by individuals with progressive hearing impairment.

Sharon reflected upon the early years with her siblings when all of them experienced denial. "When we did talk amongst ourselves about hearing loss, her hearing loss [mother's], not ours . . . it was never going to happen to us, we were children and it was not a thing we ever conceived of" (Sharon, 2003, p. 7). There is an underlying theme of invincibility in her statement, expressing a belief that such a thing could never happen to them. This shield can be manifest in the form of denial, at least until such time as they are proven wrong, as it was with Sharon.

In her denial, Sharon turned to technology for help.

> Well, yes, okay, this is going to happen to me, but I will never be as deaf as my mother, or I will never be as deaf as my grandfather . . . that's not going to happen, and well, when it does happen,

> science will have found some marvellous thing . . . they'll install a chip or something. (Sharon, 2003, p. 3)

Technology did not provide her with the expected advancements and help, and therefore she became further entrenched in isolation, which led to alienation.

Stigma/Ridicule/Teasing

Sharon describes one of the tricks she and her siblings played on their mother. "We'd swear like kids do, and we would get away with it because our mother was deaf" (Sharon, 2003, p. 7-8). She excuses this teasing behaviour as simply "kid stuff" (Sharon, 2003, p. 7).

It is most uncomfortable for Sharon to have the issue of her hearing impairment brought up in conversation. "I don't like talking about it" [her hearing impairment] (Sharon, 2003, p. 21). She spoke of her resentment toward one of the women from a single women's group who is quick to make mention of Sharon's hearing impairment to newcomers.

In another scenario, Sharon spoke about an elderly woman, a newcomer to the island, who frequently tries to talk with Sharon about issues relating to her own severe hearing impairment.

> She sees me as a kindred spirit and she wants to hang on to me and it makes me uncomfortable because it is something I'd rather not focus on [hearing loss], and I just want to be part of the whole, not the exception anymore, and maybe that's got something to do with re-joining the world. (Sharon, 2003, p. 21)

When Sharon refers to the "whole" in this context, she is referring to the hearing community. Sharon is referring to her desire to be a part of the larger hearing community rather than being or feeling isolated as a result of her hearing impairment.

Sharon explained what happened in one of her jobs, working in a craft store. "What started to happen was that I couldn't hear the customers because . . . . there was a lot of noise" (Sharon, 2003, 11). While dealing with a female customer, Sharon asked the woman to repeat what she had been saying for the third time; the customer replied in frustration: "What's the matter, are you deaf?" (Sharon, 2003, p. 11) and Sharon responded, "Well, as a matter of fact, yes!" (Sharon, 2003, p. 11). Sharon described having feelings of shame for having embarrassed the woman. "The poor woman turned around and she walked out and, you know, she was embarrassed!" (Sharon, 2003, p.11). Sharon does not seem to consider that it was the woman who was offensive. This scenario also demonstrates Sharon's early experience and ability to stand up for herself when confronted by impatience and intolerance.

Sacks (1970) refers to the major problems associated with invisible handicaps. Though he speaks about a patient with a proprioceptive deficit, his description is poignant.

> The lack of social support and sympathy is an additional trial—disabled but the nature of her disability is not clear—she is not, after all manifestly blind or paralysed, manifestly anything. This is what happens to those disorders of the hidden senses. (p. 50)

When her hearing impairment is brought to the attention of others, Sharon describes how this "puts me there again [gesturing to denote that she is removed from what is happening, that she is outside of the arena of activity], and makes me feel like I am there, not part of it" (Sharon, 2003, p. 21). It appears Sharon feels immediately disempowered and even alienated under these circumstances. Sharon used similar gestures to describe her feelings of not being a part of the hearing world.

There is a statement of distinction, of difference expressed when her hearing impairment is brought to the foreground. "It makes me uncomfortable

because it is something I'd rather not focus on and I just want to be part of the whole, not the exception anymore, and maybe that's got something to do with rejoining the world" (Sharon, 2003, p. 21).

Compensatory Behaviours

Sharon explained how her mother often talks over people because she cannot hear what is being said. Unless the conditions are just right for her mother to communicate, "It is like she says [to herself], 'I can't hear so I am just going to keep talking [laughter] and if somebody says something I am still going to keep talking'" (Sharon, 2003, p. 8). Sharon finds she needs to be direct with her mother and say "'you neeeeeed (elongating the word 'need' for emphasis) to listen to me' and you know, really sit her down and slow her down and make her listen" (laughter) (Sharon, 2003, p. 8). When Sharon was asked about these similar behaviours, she responded, "If I am nervous, at a party or something, I can find myself chatting like a magpie—it's because . . . I know I am not going to hear, so I might as well just talk!" (Sharon, 2003, p. 8). The description of her mother's behaviour appears quite similar to Sharon's.

Sharon talks about the energy required to listen.

> Listening to people takes a lot of energy; listening to people takes a tremendous amount of energy because people expect a response eventually! You can smile and nod for so long, but once people know you, they go: 'Did you hear me?' [Sharon laughing] because they know the game's up and you cannot get away with it anymore. (Sharon, 2003, p. 10)

Sharon seems to prefer to try to fool people in matters of her hearing impairment. It appears she would rather pretend she can hear than to have her hearing impairment exposed. She reiterated that she does not want her hearing impairment to be brought forward as an issue. Thus, it would appear Sharon is

not yet able to advocate on her own behalf, to teach people about her needs as a person with a hearing impairment in order for her to engage in effective communication.

Self-Image

Sharon recalls her early years with her grandparents and the acts of kindness they bestowed on others.

> If, say, for instance somebody was working on the railroad with my grandfather in southern Manitoba, if there was a man working on the railroad that didn't have a place to go that night, or didn't have a place to sit down to have supper, then he was at my grandparents' and that's how they were with people, so I think that I was more or less raised to be a giver, not a receiver. (Sharon, 2003, p. 17)

She was regarded by friends in university as being a very good listener and at one point she felt she could have been a good psychologist, attributing listening as the key ingredient for effective practice. Although she has maintained the desire to listen, she finds she cannot sustain her listening for long periods of time and she finds this disheartening. Much of her self-perception appeared to have been embedded in the value she attached to having good listening skills.

Sharon referred to the "shock" (Sharon, 2003, p. 18) she experienced when she was not able to listen to people. "All of a sudden I couldn't do that anymore, [listen to others] so what good was I?" (Sharon, 2003, p. 18). Listening was also something Sharon could do that her mother could not. Through dialogue and through her own critical self-reflection, Sharon appears to be developing a deeper understanding of how she perceived herself and how this

perception has changed following her sudden and progressive hearing impairment.

At the beginning of our work together, Sharon referred to herself as a person who is “deaf” rather than a person with a hearing impairment or a person who was hard of hearing. Her family continuously used this reference in the home. She prefers the term “hearing challenged” (Sharon, 2003, p. 24) because she feels it is less stigmatic and helps maintain her feelings of dignity.

Music

Sharon expressed a passion for music, primarily listening. Music has always been a “saving grace” (Sharon, 2003, p. 29). In describing why she loves to listen to music, she demonstrates an appreciation for its ethereal quality. She also finds the focus and concentration on the sound of the music, when there are no other distractions, gives her a sense of being able to hear. Sharon speaks of her desire to take control over some circumstance in her life. If her ability to listen is gone, then perhaps one of the vestiges of control in her life would be lost.

In regard to her interactions with people, she does not have the same control over other people’s voices that she does with the volume of music. Music appears to provide a rich experience for Sharon. “Listening to people takes a lot of energy. Listening to music doesn’t” (Sharon, 2003, p. 10). Familiar music does not have to be contextualised. Perhaps the familiar pattern of the music reduces the intensity and the emotional and psychological drain associated with listening in conversation. Music can be stable, consistent, and more predictable than normal conversation.

Sharon’s passion for music is clearly indicated by the following statement:

> If I couldn’t hear music anymore, I don’t know if I would want to live (12-second pause) because of everything, everything in my life

> that's probably the one saving grace, the one essential thing . . . [outside of the relationship with her son]. (Sharon, 2003, p. 29)

Sharon refers to music as having saved her. "It's the one thing on Earth when everything else is falling apart, that's there and it's solid . . ." (Sharon, 2003, p. 29).

Critical Reflection

Sharon was surprised to learn that many of her remarks regarding hearing impairment were consistent with statements in the existing literature. It appears she does not have a reference point for understanding her own personal issues with respect to hearing impairment. I believe she confirmed this issue earlier when she expressed uneasiness discussing matters relating to hearing impairment with others. This lack of understanding and feeling of solidarity regarding issues of hearing impairment have contributed to her sense of isolation and to her feelings of alienation. Sharon provides a definition of isolation, stating, "No one does these things to you, you make the ultimate choice yourself" (Sharon, 2003, p. 37). This definition reflects isolation as a choice being made by the individual, whereas alienation demonstrates a decision made by others. She is alarmed when she reflects on the revealing nature of our work together. "That's interesting actually, I am surprised by what has come out (laughter), stuff you are getting me thinking about, stuff I haven't thought about for years, or connections thereof (three-second pause) interesting" (Sharon, 2003, p. 18). The challenge to think reflectively appears to have stimulated different perspectives and different ways of looking at things for Sharon.

I asked Sharon to expand on what she meant by being a "giver" (Sharon, 2003, p. 17) with respect to her willingness to listen. For Sharon, listening was what she felt she did best. Sharon explained how she had never looked at her life in such a way as having a sudden change forced upon her. Whereas she had

been able to use her gifts and talents through listening, she was suddenly no longer able to do so in the same way or to the same extent. Sharon appears to be making a shift and acknowledges she is a person of worth and value, and she will remain so regardless of the level or progression of her hearing impairment.

Independence

As her son has grown and is now well into his teens, Sharon has discovered her own interests to keep her busy. Over the years, she studied sign language, she has written poetry and articles for publication, and she learned to paint. All of these endeavours filled gaps but more importantly, they became the foundation for a new path and direction for her life. However, Sharon does not yet appear to have planned how to direct her interests toward future vocational alternatives.

Uncertainty

"Maybe I think I am going to eventually be stone deaf. Nobody can tell me where this is going to stop. That's scary!" (Sharon, 2003, p. 22). Saunders (1993) refers to the uncertainty as one of the greatest psychosocial problems associated with hearing impairment. "What is not easy is the terror that the concept of deafness evokes. The client feels he [she] has seen the future and it is intolerable" (p. 474). Harvey (2001) refers to the "private terror" (p. 108) which he says is associated with the individual's previous experience with hearing impairment and, consistent with Sanders statement, the uncertainty about what might come. Saunders goes on to say that hearing impairment "creates confusion about identity and personal values, disrupts personal relationships, and creates a feeling of insecurity and apprehension about the future" (p. 474). This appears to be the case with Sharon. She has seen the outcome both with her mother and with her grandfather. What might also be a problem is her tenuous

faith in the medical system. Sharon reiterates these same concerns later during the interview, saying, “There is a part of me that is terrified, because I don’t know where it’s going to stop, and I don’t know when and nobody can tell me that, because I don’t think they know“ (Sharon, 2003, p. 29).

Sharon reflects on career aspirations, possible profound hearing impairment and the storing of memories. She remembers being told that writers must rely on what they hear as a source of material to write about. It appears Sharon is thinking in terms of limitations and not possibilities. There are writers who are deaf and writers who are culturally Deaf. Envisioning herself as a writer, she expressed a fear and wonder about what her writing sources would be if she were no longer able to hear. Therefore, Sharon reminisces about her early years, saying to herself that she must retain the sounds of nature, like a bird’s wings flapping in the wind, because one day she would not be able to hear it. “Knowing that I was going to lose that hearing, in some ways intensified the listening that I did in those years” (Sharon, 2003, p. 31). Sharon likens this to a process of grieving a loss, knowing that the memories will be all that is left, so they have to be stored for future reference.

Employment

While her son was growing up, Sharon received financial assistance from a more lenient provincial government welfare system where single parents were allowed more flexibility than under the current administration. She believed she earned her monthly allowances by saving the system the portion it would have cost taxpayers to have her son in school.

> I always felt I earned my cheque, because of the differential between home schooling a child and paying for him to be in the public school is about seven to eight thousand dollars difference, so I always felt I was somehow earning my cheque. I felt I was

> contributing to at least one human being's better education and I always said 'when Evan goes to public school I will get a job' and coincidentally, it all happened in the same week. (Sharon, 2003, p. 14)

Sharon found local employment as a mail delivery subcontractor and went off the welfare system. She was ecstatic about becoming self-sufficient. The income was greater than she received through the system, and she was independent. She became apprehensive though, as the position was temporary and part-time. "Yes, I do wonder sometimes what's going to become of me" (Sharon, 2003, p. 24) remarking about her employment future and her economic security.

Sharon clearly felt outside the reality of the hearing world with the analogue hearing aids, and now with her digital hearing aids she feels part of the world again.

> I am <u>seeing</u> the world, now. I am not outside of it anymore. When I was outside of the world for the ten years that I had that analogue hearing aid and I felt outside of the world I said: '<u>Fine!</u>
> <u>So be it, that's how it is!</u>' Now that I have the digital hearing aid and I can actually hear sounds better, I feel like I am again <u>part</u> of the world, I am looking at the world and I am saying: 'Well, can I do this? Maybe not!' Could I do this and I think, I never, for ten years I don't think I really thought about what I could to do or couldn't do. I wasn't part of the world, so why would I have bothered. I was in my own little sphere for ten years. I didn't really think, well maybe, really I didn't think: 'Oh, wow what am I going to do when . . .'? (Sharon, 2003, p. 25)

It appears Sharon has re-entered the hearing world after a ten-year sabbatical wondering what her role is in this new place.

Adjustment to Digital Hearing Aids

When fitted with the bilateral digital hearing aids (set at "normal" by the audiologist), Sharon found immediately the sound of the traffic and the noise of children in close quarters, and the music and din of voices in the shopping mall were just too overwhelming. "Oh my God! This is what people hear all the time? I haven't been missing anything" (laughter) (Sharon, 2003, p. 35). From an outsider's perspective, Sharon had been psychologically, emotionally, and physiologically separated from the world of sound, of dialogue, of human contact because of her reduced ability to communicate. As a result, she isolated herself and her son for what she believed was their own protection. She referred to the experience of returning to the hearing world with digital hearing aids as being totally devastating. She describes her trip home by ferry from the technician's office when she was able to listen to the ocean waves, the steady drone of the engine and the rush of the wind and recalls saying to her self, "'My God, I have rejoined the [hearing] world'. And that was the thought that went through my head: 'I am part of the world again', and it was an overwhelming thought, it really was!" (Sharon, 2003, p. 35).

When asked about counselling, Sharon stated she would have welcomed the opportunity to learn more about the adjustment factors with respect to wearing hearing aids. She noted how the technicians are well versed in providing technical information on the care for the devices but she felt inadequately equipped to face the adjustment challenges with new digital hearing aids. Adjustment to the hearing aids was an alienating experience and it felt overwhelming for her.

Empowerment

Sharon commented that at the present time, she listens to what she wishes to hear and when she wishes to hear it. She likens listening to traffic to

reading a romance novel: “Why should I waste my time listening to traffic . . . or waste my eyes reading something that is not going to mean anything in an hour . . .” (Sharon, 2003, p. 36). The power of choice rests with her.

Summary

Sharon experienced progressive hearing loss through her twenties with a substantial degenerative hearing impairment in her forties. With a family history of hearing impairment, Sharon began early adulthood anticipating the worst. As a child she witnessed her mother and grandfather live with degenerative hearing. These experiences included observing how her mother was affected by the degrading treatment she endured from professionals at the workplace due to her hearing impairment. These memories may have been perceived as a foreshadowing of her own destiny, as she withdrew from participation in society and directed towards protecting both herself and her son by making a life for themselves in a secluded environment.

Six months prior to the interview process, Sharon was fitted with digital hearing aids. She was immediately taken from a world of relative silence where she had been living for a decade to a world where she could participate and engage more with others. Along with this transition, she had to confront the challenges of finding employment and reintegrating into the hearing world. She found the challenge of facing the world with dated tools for adjustment to be a formidable task. Sharon’s challenge was to bridge the gap between the decade of silence and seclusion to a more interactive lifestyle. Planning her future career is the focus of Sharon’s life at this time.

Sharon relied on the medical professionals, the audiologists, and the technicians to restore her hearing. When this could not be done, she retreated, and in doing so she focused her attentions on her son. Indeed, Sharon maintained control by creating a safe but very limited world. In a very short

period of time following her fitting of digital hearing aids, Sharon emerged, adjusting quickly, finding employment, gaining economic independence and "rejoining the hearing world." Apart from her heavy reliance on the medical and technical system to help her, Sharon appeared to maintain an internal locus of control. Through critical reflection and dialogue, she was able to see that she possessed the strength to manage her re-entry into the hearing world.

Conclusions

This chapter contains an interpretive analysis of the information obtained using the guidelines and procedures as outlined in Chapter 3. Dialogue with each candidate provided pre-reflective data. Each interview was recorded using an audiotape machine. The information was then transcribed and returned to the candidate. Candidates were asked to review the material for authenticity and accuracy. This demonstrated to the individuals that the information they provided throughout the interview was valuable. Most of the candidates stated that being interviewed by a researcher who asked questions about their life was both a new and unique experience. Indeed, they reiterated that no one had ever shown the level of interest or demonstrated such a strong desire to understand so fully their experience with respect to their hearing impairment.

The researcher read the transcripts repeatedly prior to attempting to extract individual themes. This practice brought new perspectives to light for the primary researcher. While the candidates had many experiences in common, their descriptions were neither highlighted nor categorised quantitatively. As mentioned before, identifying salient themes from each transcript was the only type of categorisation. Therefore, any similarity between two or more candidates was purely coincidental.

By reviewing the transcripts repeatedly, I learned that the reduction of auditory ability may have a major and frequently negative impact, not only on the

individual affected, but on his/her family, friends, or co-workers. In light of the psychosocial issues raised in this study as well as the increasing incidence of hearing impairment worldwide, attention is drawn to various important changes in society's attitudes. For example, there is a growing need for members of our society to reach out to individuals with hearing impairment, to understand their story and to help them reduce the psychosocial impact this condition has on their lives.

In Chapter 5, two candidates are given an opportunity to identify challenges in their lives. These challenges emerge following the retrospective approach discussed in Chapter 3 and from the analysis of data in Chapter 4. Issues emerging from the aforementioned chapter provide material for the action research challenge. The procedure for gathering information is quite similar; however, it uses more interactive dialogue and requires more specificity. As in the phenomenological approach, there is a need for a flexible design; therefore, the action research methodology moves back and forth between the procedural steps of the model to help candidates achieve positive outcomes.

CHAPTER 5. ACTION RESEARCH

Introduction

The approach used in this research consists of a combination of phenomenology and action research. The overall research design was introduced in Chapter 1 with both methods briefly sketched. Phenomenology was then detailed in the methodology chapter,

Chapter 3, with the phenomenological data analysis of all eight participants presented in Chapter 4. Of the eight participants in the phenomenological interviews, two volunteered to continue their involvement into the action research phase. Their interviews were presented as the final two entries of Chapter 4.

Chapter 5 provides a comprehensive overview of action research, including a brief definition, history, and types. The elements intrinsic to this approach are critical thinking, critical reflection, critical self-reflection and transformation perspective. A detailed description of these components is provided. This is followed by reports on the involvement of Andre and Sharon, the two participants.

What is Action Research?

Kemmis and McTaggart (1990) define action research as:

> A form of collective self-reflective inquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out. (as cited in Masters, 2006, p. 3)

For an early description of action research, McKernan (1996) refers to Stenhouse (1981). I find this reference particularly pertinent because Stenhouse

(1981) highlights “personal understanding” of the individual while demonstrating movement from one phase of the approach to the next.

> Action research is the reflective process whereby in a given problem area, where one wishes to improve practice or personal understanding, inquiry is carried out by the practitioner—first, to clearly define the problem; secondly, to specify a plan of action . . . [and applying] action to the problem. Evaluation is then undertaken to monitor and establish the effectiveness of the action taken. Finally, participants reflect upon, explain developments and communicate these results. (p. 5)

Action research, as described by Dick (2006), is characterised by the pursuit of “both action and research outcomes . . . it was a cyclic process, with critical reflection a component of each cycle” (p. 3). For Dick (2006), action research is characterised by its qualitative and participative elements.

Sumara and Carson (1997) present action research not simply as a cyclical process but one of continuous learning which is also within the context of a phenomenological approach**.**

> Action research practices are deeply hermeneutic and postmodern practices, for not only do they acknowledge the importance of self and collective interpretation, but they deeply understand that these interpretations are always in a state of becoming and can never be fixed into predetermined and static categories. (p. xviii)

What is the Goal of Action Research?

McKernan (1996) refers to Rapoport’s (1970) definition of action research as one of the most cited definitions, stating the aim of this approach is “to contribute . . . to the practical concerns of people in an immediate problematic situation” (p. 4). Key to the process of action research is a “systematic inquiry

that is collaborative, self-reflective, critical and undertaken by the participants" (Masters, 2006, p. 3). The themes of action research activities are empowerment of the participants, collaboration through participation with the primary researcher, acquisition of knowledge pertaining to the situation under inquiry and desired change. These goals are achieved by moving through three phases: planning, acting/observing, and reflecting. Action research, therefore, is participatory in nature, as participants become co-researchers in the process.

Tomal (2003) cites Sagor (1992), explaining how action researchers are not concerned about the "generaliseability" of their data. Their objective is not to "identify the ultimate truth" (p. 7). Rather, the goal is to understand what is happening in a given situation and determine what might be done to improve matters in that environment.

Whereas much of the literature relating to the goals of action research take it into the classroom or at least demonstrate its value in group work, the aim in this thesis is directed solely toward individuals in relation to their own life experiences. Furthermore, the emphasis is on improving personal circumstances. No attempt will be made to make generalisations.

Selecting an Action Research Prototype

My early experience with the Kuhne and Quigley (1997) action research prototype during my Masters program demonstrated its flexibility while still maintaining its integrity. Following my degree, I applied this design in a number of different situations. This experience demonstrated further the versatility of this action research prototype.

Minor modifications were made to the approach. For instance, replacing the term "problem" with "challenge" offered a more positive slant and helped avoid the deficit orientation so vehemently rejected by Deaf adults. In addition, the freedom of movement between Steps 1 through 3 invited more spontaneous

and creative thinking from participants. Also, allowing freedom of movement between Steps 1 through 3 invited more spontaneous and creative thinking from participants.

Action Research: An Educational Process

Types of Action Research

Masters (2006) refers to three types of action research, each with varying levels of participation. The first is the scientific and technical approach. The underlying goal for the researcher is to put to the test some action which is based on a "pre-specified theoretical framework; the nature or the collaboration between the researcher and the practitioner is technical and facilitatory" (p. 4). In this approach a hypothesis may be tested. Results are anticipated and the participant follows specified recommendations of the researcher.

In the second type, the practical action research, Masters refers to "phronesis", i.e., the knowing why something occurs. This emerges as a result of applied action and learning from the activity "praxis", i.e., "autonomous deliberative action" (Grundy, 1987, p. 154). There is a more personal theme in this approach and it is therefore more subjective. This type of action research can be influenced by more variables as compared with the scientific and technical approach.

The third type of action research is emancipatory and approximates more closely that being used in this study. This type of action research therefore "promotes emancipatory praxis in the participating practitioners, that is, it promotes a critical consciousness which exhibits itself in political as well as practical action to promote change" (p. 6). The two goals of this approach are to:

> Increase the closeness between the actual problems encountered by practitioners in a specific setting and the theory used to explain and resolve the problem. The second goal, which goes beyond

> the other two approaches, is to assist practitioners in identifying and making explicit fundamental problems by raising their collective consciousness. (p. 6)

Tomal (2003) recognises that there are a number of different styles of applied action research, "although variations on this [action research approach] exist . . . the general framework is similar to Lewin's original [action research approach]" (p. 10-11). Tomal continues to explain how the focus of the action research approach is to deal with a given challenge practically and feasibly. This distinguishes it from other research methodologies which are more focused on scientific inquiry and inductive reasoning. An outcome of the focus on challenges rather than on problems has to be done to make the action research protocol more suitable for work with individuals, particularly those with disabilities.

History of Action Research

One source of powerful influence acting against positivism in the mid 20th century came from the "Frankfurt School" (McKernan, 1996) and from the advancement of critical theory (Dewey, 1933). Another force emerging within the same time frame was action research. Schön (1986) describes how under positivism (the overarching philosophy through the 19th and 20th centuries), "propositions which were neither analytical nor empirically testable were held to have no meaning at all. They were dismissed as emotive utterances, poetry or mere nonsense" (p. 33). It was within this milieu that Kurt Lewin's action research approach emerged. In one of his first articles, "Action Research and Minority Problems", Lewin (1946), demonstrated his commitment to go to the root of community problems and to use this approach to help create solutions for these issues. "Lewin emphasised the need for collaboration and group inquiry in collecting information about social issues and developing action plans to solve these social problems" (Tomal, 2003, p. 8). According to Lewin, action research

could become a vehicle for change. People could use it to transform dreams into the language of action.

Authors including Kemmis, Carr, and McTaggart reignited the spark of action research in the 1980s, thus promoting its resurgence. During the past 15 years, action research has found a prominent place in educational environments. Curriculum development, classroom management, and learning are only a few of the current areas where action research is applied.

Historically then, action research has been applied primarily in groups. In the context of this study, the approach will rely on its educative aspects and apply these concepts with individuals. Everitt, Hardiker, Littlewood, and Mullender (1992) provide an example of the action research prototype with social work practice. Referring to Schön (1983), they describe how

> the practitioner allows himself [sic] to experience surprise, puzzlement, or confusion in a situation which he finds uncertain and unique [challenge identification]. He [sic] reflects on the phenomena before him [sic], and on the prior understandings which have been implicit in his [sic] behaviour [application of critical thinking, critical reflection and critical self-reflection]. He [sic] carries out an experiment [definition of a project] which serves to generate both a new understanding of the phenomena and a change in the situation [implementation and observation]. When someone reflects-in-action, he [sic] becomes a researcher in the practice context. (p. 54)

There are four key elements to action research. They are critical thinking, critical reflection, critical self-reflection, and transformation perspective. A fifth interconnected element is the role of the facilitator. These will now be described in detail.

Critical Thinking

Scriven and Paul (2006) describe critical thinking as . . .

> the intellectually disciplined process of actively and skilfully conceptualising, applying, analysing, synthesising, and/or evaluating information gathered from, or generated by, observation, experience, reflection, reasoning, or communication, as a guide to belief and action. (p. 1)

Further, they explain how critical thinking then has two components. First, there are the skills associated with the generation of beliefs and processing, and second, those used to guide behaviour. These skills are contrasted with those connected with acquisition and retention of information because of the diverse ways in which new information is sought and treated, hence utilising higher intellectual processes. Also, these skills are continuously applied. To effectively employ critical thinking skills, one must assume responsibility for the results and outcomes from their application.

Critical Reflection

According to Hussin (2006), "critical reflection is an extension of critical thinking. It is a process whereby you think about practices and ideas and then challenge and confront your own thinking by asking probing questions" (p. 1).

If teachers apply critical reflection, this can result in their having to face reality and lose their "innocence" (King, 2006). This "loss of innocence . . . is absolutely necessary for the development of wisdom and central to cultivating reflective judgement. But the process of critical reflection, in spite of the risks, is transformational for the teacher and student" (p. 7). According to Brookfield (1995), this risk entails the potential loss of friends and status in the workplace. "A teacher who is challenging assumptions, experimenting with different

approaches, and trying to realise democratic values is an affront to those who have settled for the illusion of control and predictability" (p. 236).

Critical reflection transcends all environments and learning situations. It can be applied in all facets of daily living, including relationships, workplace or community. Like critical thinking, its application is a continuous process. Critical reflection is one of the cornerstones of the educative process.

Through critical reflection, we may become contextually aware of our own actions and ideas. We may then act upon this awareness. Reflection is by its very nature a retrospective process, i.e., looking back on what has already transpired, including behaviours, attitudes, and thinking. In contrast, critical thinking is looking at the current experience and learning the underpinnings of our thoughts, beliefs, behaviours, and/or attitudes. Through critical thinking and critical reflection, participants may become aware of the source of their thoughts, attitudes, and behaviours which have lead them to be where they are with their lives, and action research may become the vehicle for effecting planned change so they can then move to the place they wish to go.

Critical Self-Reflection

Speaking from an adult education context, Mezirow (1991) refers to the purpose of adult education as helping learners "construe experience in a way that allows them to understand more clearly the reasons for their problems and the action options open to them so that they can improve the quality of their decision-making" (p. 203). Cranton (1994) refers to the emancipatory potential of this knowledge if it is gained through critical self-reflection. This process, claims Cranton (1994), frees the individual from constraints created by distorted thinking or inflexible ways of knowing. Therefore, critical self-reflection involves the ability to reflect on our own everyday experiences, to incorporate the knowledge we have gained by this process of learning through doing (Frost & Adams, 2006) and

to affect personal change in our lives. This application of information, self-awareness, planning, and insights, can, as a result, lead to intellectual growth and personal improvement. Cranton (1994) maintains that the process of emancipation requires a supportive and empowering context. Empowerment is not only a product of critical self-reflection but also a prerequisite for this practice to occur.

Any activity of daily life can become part of this experiential learning process. It involves understanding an activity and analysing it, which, in turn, facilitates the application of this learning to other areas of our lives. "Deep learning, achieved through reflection upon everyday experiences, can be seen as the most effective" (Frost & Adams, 2006, p. 2).

O'Neil and Marsick (1994) speak about the value and importance of critical reflection. "Critical reflection is even more powerful because attention is directed at the root of the problem" (p. 23). They add, "individuals learn how to surface, examine and question these beliefs and assumptions that influence their actions and decisions" (p. 28). According to Brookfield (1987, 1995), the essential process of critical reflection is to uncover the underlying assumptions, the taken-for-granted habitual ways of acting, and questioning the reasons and motivations for attaching particular values to thoughts or behaviours in the first place.

The potential power for influencing change through critical reflection is discussed by Cranton (1996).

> It is not until people see themselves as having that power to question systems that social [or personal] reform [or change] can occur. Individuals come to know themselves by becoming conscious of the direct source of their perspectives. When this awareness exists, people are then able to negotiate social change. (p. 141)

Transformation Perspective

Mezirow (1997) is cited in *Wikipedia* (2006), stating transformative learning occurs when individuals change their frames of reference by critically reflecting on their assumptions and beliefs and consciously making and implementing plans that bring about new ways of defining their worlds. Therefore, for Mezirow, critical reflection is essential to this process.

O'Sullivan (2003) offers another definition of transformative learning. There is a deep structural shift in the basic consciousness of an individual's thoughts, feelings, and actions that is both dramatic and irreversible, i.e., the individual's association with his/her world is altered. To accomplish this, an increased level of self-understanding must be achieved. This will include where they stand with themselves, with others in their lives, body awareness, alternative approaches to living and some sense of possibilities for larger world concepts such as social justice and world peace.

When individuals are led to planned action for the purpose of bringing about change to previous patterns of thinking or revision of behaviours and the development of new assumptions, they may be in the process of undergoing a transformational perspective (Cranton, 1994, 1996; Mezirow, 1991, 1994). This new perspective is then subject to the same analysis and scrutiny as the one being replaced. Thus, action research introduces a cyclical process whereby new patterns, possibly transformed perspectives, can be evaluated and tested for their value and utility. This prevents the new perspectives from becoming stagnant or remaining unchanged.

The Role of the Facilitator

Referring to one of the characteristic features of action research and the role of the primary researcher or facilitator, Tomal (2003) states:

> Generally, action research is conducted by a change agent (i.e., consultant, researcher, educator, or administrator) who works with identified subjects within the context of a group (classroom, school, organisation) in conducting the study. The change agent acts as a catalyst in collecting data and then working with the group in a collaborative effort to develop actions to address the issues. (p. 9)

The role of the facilitator in the phenomenological-action research approach is that of co-researcher or equal to the participants. In addition, the facilitator may stimulate the individual's thinking to address some of the thoughts and beliefs which have remained unquestioned for long periods of time. Individuals participating in the process become part of the solution and not simply recipients of outcomes. As a result of learning new skills (an important component of the approach), participants also take on the role of change agent. Therefore, an important component of the action research approach is education of participants to conduct these processes on their own.

Learning is a life-long process and it transcends the boundaries of formal classroom or any other single environment. Sandmann (2006) refers to the "co-learning" approach to adult education as replacing the traditional "expert" approach. Educators "can only create and support the conditions necessary for the emergence of a mutual learning process" (p. 3). The phenomenological-action research approach champions this philosophy of shared responsibility as the participants become co-researchers in the process.

The role of the facilitator is to establish an environment which builds "trust and care and facilitates the development of sensitive relationships among learners" (Imel, 1998, p. 4). According to Taylor (1998), this is a fundamental principle of transformative learning. The facilitator must also be willing to demonstrate his or her own desire to learn, to change and to deepen

perspectives and understand the subject matter itself and know about the process of facilitating learning (Cranton, 1994).

Smith (1997) offers a description of the role of the facilitator-teacher which applies to my work with these participants in this study.

> Students under the tutelage of one who is awake often find the teacher to be a bundle of contradictions, because what is said to one may be completely reversed in instructions to another. This is because the teacher understands the unique needs and capabilities of each, honouring their differences, and knowing what is best for each. The interest of the teacher is not to teach, in the usual sense of imparting well-formulated epistemologies, but to protect the condition under which each student in their own way can find their way. (Smith, 1997, p. 273)

The role of the facilitator of an action research process, according to O'Brien (1998), "is to nurture local leaders to the point where they can take responsibility for the process. This point is reached [when] they understand the methods and are able to carry on when the initiating researcher leaves (p. 11). This is consistent with the goal of this research project, which is to leave the co-researchers with sufficient skill to conduct future projects independently.

Conceptual or Substantive Assumptions

Chapter 1 contained an outline of "substantive assumptions" and for the purpose of continuity, these assumptions are now revisited. They are:

1. Diverse psychosocial implications are associated with hearing impairment, and the degree of their impact on an individual's life will vary**.**

2. An individual's ability to function independently within a community is determined by more factors than whether his/her hearing impairment is mild or profound.
3. Hill and Nelson (2000) maintain that many professionals within the field of social services and mental health have neither the understanding nor the awareness of the unique needs of persons with hearing impairment, nor the skills to serve them effectively.
4. An analysis of the data from the interview will reveal information regarding an individual's unseen constraints, personal assumptions, and habits.

Action Research: Methodology

During the initial interview of the action research phase, a framework was provided to illustrate critical thinking, critical reflection, critical self-reflection, and transformation perspective within the context of the action research prototype. Critical thinking was discussed within the context of an individual's thinking, acting, and beliefs. Five aspects of critical thinking as per Brookfield (1987) were discussed. These are contained in Appendix 3.

The goal of these action research case studies was to adapt an existing research approach and use it as a teaching tool for rehabilitation professionals working with individuals with hearing impairment. It is anticipated that this approach may also be applicable to other service delivery systems for individuals with disabilities other than hearing impairment. Therefore, a successful application of this prototype for persons with hearing impairment may contribute to its use with other populations.

Sumara and Carson (1997) show there is an integral link between phenomenology and action research, placing both in the educational arena.

> We have come to believe that any form of inquiry that seeks to learn about the complexly formed, ecologically organized relations of lived experience [is], of course, a [form] of inquiry, [a form] of *research*. When these forms of research are specifically organized around questions of learning, understanding, and/or interpretation, they are, in the broadest sense, concerned with *education* and thus may be considered *educational*. (p. xxi)

As the primary researcher, I assumed that each candidate might, as a result of the intensive dialogic interview process, uncover some of the unseen constraints which partially constituted the core of his/her lifelong system of beliefs. These were identified as pre-reflective thoughts and verified by the individuals' own admission that they had not previously investigated the issues being brought forth through our dialogue.

Assumptions About the Action Research Prototype

Participants were informed about the underlying assumptions within the context of the action research activity. These assumptions are listed in Appendix 4.

The Action Research Prototype

The adapted Kuhne and Quigley (1997) Action Research Prototype is shown below.

Figure 2. The Action Research Prototype.

Planning Phase

Step 1. Identifying a challenge

Step 2. Defining the project

Step 3. Measurements

Action Phase

Step 4. Implementation and observation

Refection Phase

Step 5. Evaluation

Step 6. If the challenge is successful, the process can stop or another goal can be identified.

Step 1: Identifying a Challenge

To guide this process, questions will be asked of the candidate at the onset of each step. These questions will be prepared beforehand and presented on flip charts and displayed on the walls (See Appendix 5).

The action research process will begin with identifying a challenge. The identification of a challenge arises through dialogue between the primary researcher and the candidate. This may result in an intense level of engagement between the candidate and his/her personal history. Dialogue at this level will require trust to be established between the primary research and the candidate. The process of identifying a particular challenge may require more time than the participant might expect. Part of this process may require the researcher to ask pertinent or probing questions for the purpose of clarifying and understanding context. For the candidate, this might require the application of critical thinking,

critical reflection, and critical self-reflection to broaden the scope of understanding of how the challenge came to be and how prominently the challenge plays out in his/her life. The identification of this challenge could represent an action research process i.e., Step 1: Identifying a challenge.

In discussing the process of identifying a challenge, O'Neil and Marsick (1994) state:

> Problem posing involves raising questions that open up new dimensions of thinking about the situation, whereas in problem solving, a person often looks primarily at solutions without questioning whether or not the initial assessment of the situation is the only one, or the best one that is possible. (p. 22)

The Kuhne and Quigley (1997) prototype uses a challenge identification approach that is valuable, as it involves raising questions which may provide ways of rethinking about a given issue or challenge. This is different from a problem solving approach in that the latter focuses primarily on solutions without considering whether the initial assessment of the situation is the only one or the most appropriate.

Wallerstein (1987) refers to problem posing (challenge identification) as a way of drawing on the person's experience to create a sense of connectedness with the issue being addressed. She refers to the three phases associated with identifying a challenge as "listening, dialogue and action" (p. 35). All of the candidates have been involved in the first two phases, listening and dialogue, and the two candidates for the action research phase will engage in the final phase, i.e., action. Listening and dialogue will be essential to the phenomenological investigation, and action is associated with the action research component.

Candidates will be asked to identify challenges they want to address and make changes. They will be cautioned to ensure that these issues are "solvable"

(Kuhne & Quigley 1997, p. 29) and realistic to endeavour to effect changes. Each challenge will be written on a flip chart as provided by the candidate, i.e., verbatim. In some cases there may be numerous challenges identified. Following this process of identification, candidates will be asked to highlight one particular issue they wish to address and articulate it clearly and succinctly. Once the candidates feel comfortable with the description of the identified challenge, this will become the focus of their action research activity. Examples of issues will be presented later in this chapter in the individual case studies.

The focus of this study is the practical concern(s) that may have gone unattended, unidentified, and possibly never realised. Therefore, as candidates probe their life experiences, and engage in this process, they may be revealing information which has not been previously brought to light.

Step 2: Defining the Project

This step will require that the candidate describe his/her life at the present time regarding a specific challenge brought forward in Step 1. Candidates will be required to discuss their dissatisfaction with life at present in relationship to one or more of these issues. The task of the facilitator will be to record these examples on the flip chart. Following this, the candidate will review the statement to confirm whether it clearly reflected what he/she meant. Once filled out, pages will be taped to the wall, making them clearly visible for easy reference. Recording the information will provide the candidates with an ongoing source of reference regarding what is being said as well as a description of their current life situations. This material can provide the first point of reference and may later become the benchmark for measuring change in Step 3.

The candidates will then be asked to formulate a goal regarding a challenge they wish to deal with or change within their lives. The resolution of

such a challenge will represent the achievement of the goal and be translated into the success of their action research project.

This section will provide an outline of the procedural activities. Each step will be carefully articulated, and a plan for implementation will be devised. The steps will be recorded for immediate as well as future reference. The candidates will be asked frequently if the steps appeared realistic to them and if so, whether they believe these will be achievable. Timeframes will be attached in certain instances. Therefore, accountability rests with the candidate and not the facilitator. The candidate's individual project will emerge from the aforementioned activity. Numerous objectives will be involved within the project leading to its completion and fulfillment of a goal.

Critical reflection can play an important role in the process because it can give the candidate further opportunity to reflect continuously on his/her reason for identifying a particular challenge or issue as being noteworthy and deserving of this level of attention. Each time the individual engages in this reflective exercise, he/she will have an opportunity to examine the issue from a broader perspective, and perhaps at times achieve a deeper understanding.

There may be a natural migration toward the primary researcher continuing to ask clarifying and even probing questions about the source of perspectives, attitudes, or beliefs. Integration of a design of potential outcomes may be discussed.

Step 3: Establishing Measurements

The adaptability of this action research approach can be seen at this point. Flexibility of movement from further clarification of the challenge, refinement of the planned activity to achieve the goal and expected measurements which can demonstrate change can all be discussed. Each of these areas represents a connection with a different step in the prototype.

Without destroying the integrity of the approach, the facilitator and the candidate can move from “Step 2 - defining the project” to “Step 3 - establishing measurements”, switching back and forth between the steps. If the issue is too difficult for the candidate to articulate, his/her present life status can be discussed (an aspect of Step 3) and later on return to Step 1 to identify the challenge. Information is presented visually, therefore eliminating the possibility of losing it. The process of switching between steps as outlined above can be carried out in a logical sequence rather than haphazardly.

This strategy is particularly well suited for individuals with hearing impairment, as it allows the facilitator to apply combined methods of information processing (visual and oral), thus ensuring that the person maintains a clear understanding of the project. As well, the facilitator’s ongoing focus will be to ensure that the process was clear for the participant and eliminated possible ambiguity.

Measuring requires two points of reference. The first one is the establishment of a baseline of the candidate’s life up to the present time. The second is a projection of his/her life choice, i.e., how the candidate articulated a goal or change. The successful outcome of activities conducted between the benchmark identified in Step 2 and the desired outcome represent a level of achievement.

Each session will be approximately one and one half hours in length. The number of steps completed during the initial session may vary between one and three.

The information obtained during each session will be transcribed from audiotapes and the transcript of the session will be forwarded to the participant prior to the next session. The material on the flip chart will be transposed onto standard size paper and sent as an attachment to the transcript. During the next session, the candidate will be able to review the material from the flip charts, as it

will have been rewritten more legibly. Therefore, records of what transpired during the sessions will be provided in several formats. This methodology reinforces the candidates' understanding that the information recorded was their work, their ideas, and they are in control of their process. This approach also emphasises for the candidates the importance of what they had to say and how valuable their contributions were for this research project.

Step 4: Implementation and Observation

Once the project is defined and planned actions are laid out with measurements established, the candidate becomes responsible for implementing his/her own project. Follow-up is essential to the success of the individual projects. When needed, e-mail and/or telephone calls will be used as less formal means of contact. Sometimes meetings may need to be held less formally in places other than the office, i.e., in coffee shops due to time limitations and availability of candidates for reasons of employment, family, community, or other personal responsibilities.

This level of involvement with the primary researcher distinguishes this phenomenology-action research approach from others. Failure of any approach may come from a lack of commitment from the candidates or a sense that they are alone in the process. This can occur if the candidates are left to feel they must complete their tasks and objectives entirely on their own. This is one of the potential follies that I wished to prevent.

These prearranged meeting times will provide a natural opportunity to review progress to date with the candidates. Ongoing support can be provided through listening, asking clarifying questions, rearticulating goals, and even challenging candidates to think critically or to become more reflective. These meetings will also provide an opportunity to celebrate achievement of smaller and shorter-term objectives which may have arisen.

Step 5: Evaluation

The evaluation stage is critical to the success of any project. Measurements will be established for the purpose of determining successful achievement of desired goals. It will be important to have carefully written references articulating the benchmark, desired outcomes, and means to define successful accomplishment. This information will be brought to the evaluation session and will be posted as it will have been done earlier during other steps of this process. Records of dialogues and previous meetings will also demonstrate results.

This will provide an opportunity for the candidate to explain what he/she has learned from the process, what changes he/she has made and what insights the candidate has gained. This will become the forum in which candidates are provided the opportunity to make connections with their learning process over time. This will also be a time for celebrating their success.

As it can be difficult to remember comprehensive details of the events over time, written references of dialogues, e-mail contact or telephone contacts will be made available at the evaluation session as a way of stimulating recall, aiding comparison and assisting the evaluation.

In the following section I will report on the activities of the two candidates, beginning with Andre. These reports represent the evaluation of the action research process for each candidate.

Andre

Andre attended three sessions during the phenomenological component of this study. He described his life with hearing impairment through the early years and into adulthood as frustrating and isolating. He attributed many of his current issues and challenges in life to his lack of assertion in the home, with

family, with friends, and in the workplace. This, he believes, has led to decreased self-esteem and self-worth.

Three action research meetings were held with Andre. These occurred during the summer of 2003. Each session was approximately one and one half hours in length. The focus of the first session was to establish with Andre the action research process and to introduce him to pertinent concepts including critical reflection, critical self-reflection, critical thinking, and transformation perspective. Particular emphasis was placed on making certain Andre had a reasonable understanding of these three concepts. Session two began with a continuation of the discussion on what he saw as the primary challenges he wished to address. Following this, there was an explanation given for how a project could be developed and how measurements could be applied. Finally, in the third session, we formalised plans for the project and detailed how and when follow-up meetings could be established and what we could expect from these engagements.

The five action research steps for Andre will be described first. These will then be followed by a discussion of the action research process for Andre before moving on to Sharon's report.

Step 1 – Identifying a Challenge

During the challenge identification process, Andre listed a large number of areas he felt were important to him and therefore worthy of attention. These were recoded on the flip chart pages using his words. The wide range of different challenges he described seemed to indicate an underlying dissatisfaction with himself. The issues Andre raised were subsequently sorted into a single primary challenge, and a group of secondary challenges were very loosely sorted into attitudes and behaviours. Andre's major focus was on the development of assertiveness skills. In particular, he wanted to become more assertive in the

workplace, in personal relationships (including spouse, family friends, and relatives) and with respect to personal and career goals. The secondary challenges raised during the first session included the following attitudes and behaviours.

Attitudes

1. History of reacting. Would like to think things out on levels other than emotional
2. Being easily influenced by others
3. Being an over-agreeable person [in order to avoid conflict] even it if goes against [personal] beliefs to avoid conflicts. I totally dislike conflicts
4. Outcome –"new Me—make me happier inside because I am expressing myself and not holding it in—avoid resentment"
5. Develop a more positive attitude, not looking at the negative side of things
6. Dislike being seen as a "whiner" or "complainer"

Behaviours

1. Avoiding and changing passive-aggressive behaviours with new effective and positive ones
2. Asserting with new people regarding my hearing impairment. [There is a] need to tell people: "this is what we need to do to avoid communication breakdown"
3. Change [my] perception of [my]self and "doormat" behaviours at home and at work
4. To no longer be a "doormat" or be perceived as a doormat or pushover person who has no say or a person who is taken advantage of
5. To develop communication skills

6. To resolve communication problems
7. Barriers at present include:
    a. too afraid to hurt others' feelings
    b. afraid of saying the wrong thing
    c. fear of expressing myself
    d. not thinking things out—need to think before speaking

Even though some areas were not directly related to the primary challenge, they still became part of the overall focus of our work together. This was because the issues Andre raised all tended to be interconnected, and often dealing with one challenge had a carry-over into secondary issues.

Step 2 – Defining the Project

Frequently, a close relationship exists between issues that are brought forward during the challenge identification stage and the definition of a project. We followed a procedure to establish and understand how he perceived his life at the present time. This constituted a baseline or point of reference for comparison later on. We then engaged in discussion regarding how he would like to see new and different behaviours or changes introduced. Andre believed that if he developed assertiveness skills he could become a more effective communicator. As a result, he also believed he would become a happier person. Critical reflection and critical thinking could lead to the establishment of a positive cycle of thinking and behaving. Therefore, Andre identified a series of upcoming opportunities where he could assert himself at work and at home. These personal situations, he felt, could become an arena for him to apply his assertiveness skills. We discussed at length the origin of his thinking in regard to attitudes and beliefs. We developed strategies he could apply in these specific circumstances. Rehearsing dialogues began to pave the way to alternate thinking and behaving.

His hearing impairment affected all areas of his life. He willingly entered into this research relationship in order to explore the previously held assumptions leading to the development of his present self-perception. Andre demonstrated a great deal of courage in being willing to first admit to his behaviours, thoughts and ideas, and second to plan change.

Step 3 – Measures

A time frame of six months was agreed to, July-December 2003, for our work together. In December 2002, Andre subjectively rated his assertiveness level on a scale (1 to 10) at "1". By July 2003, following the phenomenological interview process, he had increased his assertiveness rating to "3.5". A final reading would be taken in the follow-up evaluation session. Additional measures would include an increase in the frequency of applying problem-solving skills, communication and the description of situations rather than being reactionary. As well, he began to apply critical thinking when he questioned whether he was defaulting and assuming a submissive role when he knew assertiveness could be both appropriate and fair. Additional measures included reporting the instances and frequency of his application of skills such as assertiveness.

Step 4 – Implementation and Observation

The following is a review of some highlights from Andre's perspective in the final evaluation stage of the action research process.

Andre begins with this opening statement: "I have made huge progress in the past six months! I felt that assertiveness was an issue for me and I have come <u>head on to it</u> and I feel I have done a 180" (Andre, 2004, p. 1).

Andre described a situation at home with his wife and extended family which occurred only days before the evaluation (Step 5) interview. Over the years, Andre had become very submissive in his relationship with his wife. The

marriage was reported to be failing. Following our initial work in the action research phase, he explained how he felt he needed to act and speak assertively whenever possible. He had begun this process and had in my estimation made remarkable progress through the previous months. In this instance, he described how he made his needs known and how he acted upon his own interests with both his immediate and extended family. In this situation, he asserted himself with his wife and extended family. Andre explained how he had made plans for an evening and that he had informed his wife of the importance of this previously arranged commitment. He felt bound to meet his obligation. Due to what he felt was poor planning on his wife's part and a perceived lack of regard for his interests, that evening's meal was not ready on time. It was almost one hour late. Had the dinner been on time, he claimed, he would have been able to share dinner and then excuse himself so that he could fulfill his other obligation. However, since it was late, he was faced with a decision. It would mean leaving a dinner with extended family at the very moment everyone was ready to sit down to eat. He recalled the dilemma, saying to himself,

> 'No! It is time for me to test my assertiveness' and I proceeded to go. I made myself a sandwich, a turkey sandwich, and left and it probably shocked a lot of people at the table. There was probably I think 13 or 14 of us, family members! I kept saying: 'Wow' on the ride to the appointment! (Andre, 2004, p. 1)

Andre continues, "I know in the past that I would have just sat there at the dinner table and become angry and beat myself up, saying 'Here I am being a door mat, not doing what I want'" (Andre, 2004, p. 2). This incident illustrated one of the more recent challenges to Andre's assertiveness and demonstrates a level of assertiveness which, according to Andre, did not exist prior to his participation in this project. It shows a remarkable shift from previous behaviours described in Chapter 4 of this thesis. Andre eliminated the resentment by asserting himself for

something he believed was very important to him. Andre struggled with the image of a placatory figure in his marital relationship and emerged as an assertive individual. He risked ridicule by his wife and extended family in order to test his assertiveness. He concludes, “Like I said, I deserve a pat on the back for that and that was a huge step for me!” (Andre, 2004, p. 2). As identified in Step 1, becoming more assertive was his primary focus of change.

By Andre’s own admission, his lack of assertiveness permeated all areas of his life including the workplace. Very recently, Andre was asked to take a job in a different city doing the same type of work.

> I made my company well aware of the issue that I was thinking about going, but I wasn’t 100% sure, but if I was indeed going I was going to be going to a foreman position, a promotion, and I wasn’t taking anything else. And this was a big giant step for me to say something to that effect because I believe that they wanted me to go as a welder, the same position, and I was not going to do that to myself, because I feel I deserve a promotion. (Andre, 2004, p. 3)

This was indeed a major step in Andre’s quest to become more assertive. Fifteen months earlier, during the second interview, he stated, “I don’t have the power or whatever to take that step forward and say: ‘Here I am, I deserve this!’” (Andre, 2003a, p. 13).

Andre believed he was being asked to go as a line welder because the company was very short of competent people in this particular area of operation. He continued to resist subsequent offers to transfer.

In reviewing the early transcripts from Phase One, Andre stated he always wanted a promotion, believed he deserved one but suspected that the company would not place him in such a position because of his hearing impairment. He did not however, test his assumption; yet following his participation in the action

research phase, Andre challenged his company's mandate by being assertive, stating his demands for ongoing work with them in another city and clearly outlining his expectations regarding salary and job responsibilities. Within two weeks Andre was offered the position of foreman with a small crew. During the early stages of his new job, he trained another individual to take over his welding responsibilities.

Step 5 – Evaluation

From the initial interviews with Andre in Phase One of this study, the phenomenological interviews, it was clear that assertion was something Andre avoided. By his own admission he had become a "people pleaser" and he was not happy with this role. Andre appears to be making substantial strides in changing his self-perception.

Andre described another situation at home that could have led to a serious argument. He was able to control his emotions and remain calm while proposing a reasonable solution to the conflict. I asked Andre to describe his process of thinking that allows him to react quickly and effectively.

> I am well aware of the fact that the best way to try and solve a problem—instead of trying to be so defensive and to fall into that trap of arguing over something, is just to sit down and find a different solution. Like my past was either to just let things go everybody else's way, like trying to please everybody else and then the other thing that is a bad habit of mine is just keeping everything inside and often getting angry and defensive. (Andre, 2004, pp. 4-5)

As he reflected on the experience, Andre became more aware of how he does have the skill to manage a potentially negative situation by offering a

conciliatory resolution. Therefore, he was able to control his previously established behaviours and maintain control.

During the first session, as previously stated, I incorporated an educational component by outlining the procedures and benefits of action research and discussing the meaning of the terms critical thinking, critical reflection and transformation perspective. Andre said that this discussion introduced him to concepts and approaches that were new to him.

> The big word is 'reflective', being reflective. I don't think I really have ever done that, I have but not in this way, all I would do is go onto the self-pity stages when I am thinking instead of trying to sit down and find a solution or a procedure, I guess you can say evaluating and being reflective. (Andre, 2004, p. 12)

We discussed how Andre might replace old, disabling ways of thinking with new, more enabling ways. These new ways of thinking would strengthen his ability to confront and resolve difficult challenges. In particular, Andre attributes his lack of sense of personal empowerment and assertiveness to his hearing impairment.

The following statement illustrates an important and rather remarkable change to Andre's attitude and his feeling of personal empowerment. "I find that a little humorous because I think I went on without you. (shared laughter) I am sorry, but it is not my fault. It is funny, okay, I go and carry along without you!" (Andre, 2004, p. 6). This was the highest compliment Andre could have paid a facilitator. Andre completed his part of the task. He adopted new behaviours, challenged old paradigms of thinking and emerged with a new sense of reality. For my part, I fulfilled the role of facilitator and educator. I provided him with some new information and supported him in the development of a plan to incorporate these new ideas and behaviours.

I asked Andre to think about what had changed over the months to influence him so strongly. He explained:

> Definitely what we have been going through here. What you are teaching me, or what I am learning from this and reflecting back to my past behaviour and saying: '*No, that doesn't work! I have to try it this way and I am going to try it this way'* and so far it has been working wonders! (Andre, 2004, p. 5)

Frequently, there may be a close relationship among all of the issues brought forward during the challenge identification phase of an action research process. It is important, however, for the participant to choose only one, otherwise the task can be formidable.

Andre remarked that one of the most difficult challenges he had faced was to adopt an open style of language, "like you said try to think things over and that was the hardest to experience" (Andre, 2004, p. 10). Expressing himself in a non-threatening yet assertive fashion was contrary to earlier behaviours. However, his response to his wife's demands and quick resolution to a potential problem demonstrated his ability to assert himself. Eight months after the first action research session, Andre states:

> The language that I use, I like to make sure that it isn't in an accusatory way, that's the hardest part for me. I feel that I have no problem becoming assertive and I have no problem being communicative instead of keeping it inside. That's a big step! (Andre, 2004, p. 11)

A self-rated scale of assertiveness (1-10 scale) supported Andre's achievement scope. As previously discussed, Andre gave himself a rating of "1" during Phase One, the phenomenological interview. In July of 2003 when we started the action research work, he felt the process of change had begun. He

estimated his rating at “3.5”. During our final formal evaluation session, Andre reported he was clearly at an “8” for assertiveness. This was a remarkable gain.

Andre was asked to describe how he became aware of his insights.

> This whole idea, this thesis I guess you can say, the whole idea of sitting down with me and saying: ‘Hey, let’s think this over and let’s evaluate it and let’s take these steps, let’s take these little baby steps in making this work for you.’ I believe they have! (Andre, 2004, p. 12)

In my work with Andre, it was important to set time aside for debriefing. However, due to his out-of-town work schedule, regular office meetings could not be arranged. Therefore, we held late evening meetings at a quiet coffee shop to discuss his activities during the winter months. These informal meetings provided us with the opportunity to look at the goals and continue to revisit the measurements. This was an essential part of the process.

> It was also nice to have the support system, like you, to discuss with you when we had our coffee. There’s that support system I needed to boost me along: *‘OK, you are doing good!’* Like even a simple thing of complimenting me I think did wonders as well. If you have that positive support group or one individual, that helps a lot and I appreciate that, so I think that’s what is needed as well to keep things moving because I don’t really believe that I did it all by myself. I am the one who has to make the changes, so yes, I did it. (Andre 2004, p. 15)

How This Approach is Different

In the examples discussed, action research can be described fundamentally as a cognitive behavioural approach; in the context of my research, my intention was to take on the role of an educator/facilitator and not

the role of a counsellor. At the same time, it is difficult to separate the role of educator/facilitator from the role of counsellor because much of counselling has pedagogic roots. Andre explains how he perceives the difference between the approaches I took with him during our work together and those used by other professionals in helping relationships. Andre attempted to seek counselling on different occasions with counsellors he respected and liked. He summarised his work with them by stating he believed they were providing answers as if they were being read from a book.

> Whereas you were doing it more one-to-one: 'OK, let's break this down and let's go through this process, let's go way back to when you were a child and review your history and see what do you want to do about it. What do you want to change? You never even mentioned: 'Okay, you should do this or you could do this. You just said, 'Okay what do you want to do about it? What do you think would be a good solution?' And that's what we are doing. We do problem posing and I thought that was kind of unique. Nobody has ever asked me what I thought! The idea that you were reflecting my history made me start to think. (Andre, 2004, p. 18)

Andre identifies the two most important elements in our work together: "It is the trust issue and the support system!" (Andre, 2004, p. 19). He then refers to the combined approach of phenomenology and action research and states:

> Okay, this is the way I am! And I feel it is powerful because I have proven that you can change as a person and I think it is powerful and I really like this approach in doing things because it is more personal, it's more reflective and that's what people have to do, I feel [people need to be reflective] to solve problems. Phenomenology [and action research] are powerful tools. It is very

> consuming, I will say that, but in the end I think it is much more worth it than just to say, 'page 572 says you should do this!' It is more personal. (Andre, 2004, p. 18-19)

Andre's closing remarks regarding the final session emphasise the gains he has made and the effort he has invested in his own growth.

> Okay. I have a sense of pride in being able to accomplish this, because when we first listed all these things I was quite overwhelmed, but I knew they all were interrelated with each other, but still I was quite overwhelmed. There were a lot of goals to achieve there. Now I realise how attainable, how achievable they are! (Andre, 2004, p. 25)

Andre describes the interrelationship between behaviours in general and the absence of some of the basic requirements that may enable him to be happy and successful. As well, he recognises that the power to change comes from within. "The whole thing of being reflective is a new way of looking at things. I have never done that before. I have never been a reflective person in a concrete way" (Andre, 2004, p. 18).

Andre was asked to be the master of ceremonies at the company Christmas party, 2004. It appears he has earned the respect not only of his crew but of management as well. His manager was made aware of his training through the Christopher Leadership Courses in Effective Speaking, and this led him to ask Andre to take on this task. Andre was very pleased to be asked and accepted the challenge without hesitation. This situation is particularly noteworthy because at his previous job with the same employer but with different managers, he asked if he would be considered for the role of Master of Ceremonies. The managers in the region flatly refused to have him be part of it. As well, Andre was recently given a pay rise which he did not request.

Andre has repeatedly demonstrated his ability to diffuse situations with customers, staff, management, family, and extended family. Furthermore, Andre has been able to walk away from these encounters feeling positive and not berating his performance or ability. On one recent occasion, he explained how a customer was angrily shouting at him for blocking her driveway with a company vehicle. He stated he could not hear well enough over the machinery noise to make sense of her claims, so he simply explained he would be stepping away and when she was able to discuss with him quietly, he would listen carefully to the problem. Moments later she returned with an apology and Andre was able to deal with her request immediately. In all of the numerous situations Andre has shared with me, it appears he has demonstrated remarkable tact, diplomacy, thoughtfulness, and good judgement.

According to Andre, his marriage is failing and separation is imminent. Yet Andre does not appear resentful toward his wife, as he had in the past. He appears to be approaching the issue of separation with confidence and fairness and although he is not looking forward to what may come, he is prepared to deal with this next important phase of his life. Andre has had numerous opportunities to date and to live a single life. He maintains his resolution not to date other women until the divorce is final. Andre does not present as the same man he did in December of 2002. His growth is remarkable.

Summary

Andre has made outstanding progress in each of the areas that he identified during Step 1. He demonstrates confidence and assurance in his ability to manage matters of separation, activities in the workplace, and in other areas of his personal life. He has received recognition from his employers on a continuing basis. He approaches problems from multiple perspectives. He appears to have gained the respect from his crew and from his employer. From what Andre

describes, he has demonstrated fair treatment for all of the members of his crew. Andre appears to have developed the strength to deal with the changing marital relationship and remain strong in his values and convictions. His achievements appear to have laid a firm foundation for continued personal growth.

It has been an honour and a privilege to have had the opportunity to have Andre involved in both phases of my study and to be a part of his life to the extent I have. It is a pleasure to see him from time to time because he always has some new experiences and stories to tell me, such as handling situations in ways which continue to impress both of us. Andre is a remarkable individual and a stellar example of personal empowerment, courage, and trust.

Postscript

Since the final interview, Andre has taken responsibility for a second crew in the field. He received a standing ovation for his participation in the Christmas party from over 100 participants—staff, friends, and families. He has also been notified by the company president of his intention to promote Andre to the position of superintendent in the company. His promotion is expected to be in place by 2006. In the interim, he has been asked to be the shop steward and the chairman of the safety committee for the company. Andre has been invited to facilitate a group for newly divorced men and women in his church and once again to serve as the Master of Ceremonies for the company Christmas party. Also, when last asked about his level of assertiveness on a scale of 1 to 10, Andre proudly reports to be successfully maintaining a perfect 10.

Andre's achievements are all his own doing but, as he so willingly volunteered, he found the phenomenology and action research approach particularly helpful. While it is virtually impossible to be able to decide precisely how much these achievements were due to the approach itself or simply having a professional there to pay attention to his well being, or whether it was a

combination of both, the point I would like to make is that for Andre, the process worked. It was a highly effective process and the success he has achieved has given us both an enormous amount of satisfaction and encouragement. Personally, I believe it was not just the professional attention. It was the refined and disciplined process of self-discovery afforded to Andre by the combination of phenomenology and action research that made the difference. The following report on Sharon's involvement further helps to elucidate this claim.

Sharon

Sharon attended two interviews during the phenomenological component of this study. Sharon emerged from a world of relative silence where she had lived for 10 years to a world where she could engage more with others. She found these challenges of adjustment to be formidable. Among the adjustments were seeking employment and reintegrating back into the hearing world.

Three action research meetings were held with Sharon during the summer and autumn of 2003. Each session was approximately one and one half hours in length. The same format used with Andre was used with Sharon where the first session focused on the description of the action research process and the introduction of the concepts of critical reflection, critical self-reflection, critical thinking, and transformation perspective. Emphasis was placed on making certain Sharon had a reasonable understanding of these concepts. Similar to the second session with Andre, session two began with a continuation of the discussion on what she saw as the primary challenge she wanted to address. Following this, an explanation was given of how a project could be developed and how measurements could be applied. Finally, in the third session, we formalised plans for the project and detailed how and when follow-up meetings could be established and what we could expect from these engagements.

The five steps in the action research approach as presented at the beginning of this chapter will now be presented for Sharon. Quotations from the action research interviews will also be highlighted.

Step 1 – Problem Posing

Sharon identified two issues with which she wished to deal. Sharon explained that her lack of confidence was manifested in her personal interactions.

> Whenever I have to go into a situation where I am not sure of the person that I am having to talk to, I feel knots, I am learning how to not do that but that's always an issue. If I want to be able to hear this person, it's always an issue. When I am phoning someone, it's always an issue, unless I know, if I am phoning a company, for example, confidence is always a big issue, because you never know if you are going to be able to understand the person or not. (Sharon, 2003a, p. 8)

The first issue pertains to Sharon's resistance to explaining to others about her hearing impairment, as this becomes a source of constant stress. The second issue refers to Sharon's wish to attain employment while at the same time being able to tap into her creative abilities and stimulate her artistic talent.

Step 2 – Defining the Project

At the time we started our work together in the action research phase, Sharon was working as a postal delivery person for the residents of the island where she lived. This was a part-time (two weeks per month) interim job and it paid more than her income assistance allowance. When her term was nearly completed, she was offered a full time seasonal position at a local pub/restaurant. The income from the restaurant job was substantially greater than the provincial income assistance she had been receiving, and therefore she was able to go off

provincial financial support. Unfortunately, this new job was both emotionally stressful and physically demanding. The stresses were associated with her hearing impairment and the physical demand originated from Sharon's choice to take on heavier work to avoid jobs which required her to listen and respond to commands from the chef or others in the kitchen. A short time after she was hired at the pub, she was diagnosed with bilateral carpal tunnel syndrome and osteoporosis of the spine. Sharon was in a confused and desperate state of mind when we met to begin the action research phase. Now in her early 50's, she was deeply concerned about her future. She was neither happy with the work she was doing nor did she feel she could manage it during the following spring, 2004. She stayed with the pub until the end of the season in October of 2003. The timing of the start of the action research phase was fortuitous.

Sharon took time to explore the current situation in light of her strengths, desires, and limitations. Although she needed to be active, she could not overdo it. At the same time, she could not sit all day for fear this would make positional changes very difficult later on without causing her a great deal of pain. She also expressed how she felt a sense of self-worth did not come from simply working in a job. Instead, self-worth for her came from artistic endeavours. She was anxious to learn whether she could achieve both.

"Life in a day job does not give a sense of self-worth. That comes from artistic endeavours." Finally, she concluded with the question, "Is there a way to make a living doing what I love? Is there a way to combine both?" (Sharon, 2003, p. 19).

Sharon was under the impression that her job with the postal service might be offered to her again on a temporary basis; however, she was not certain. Therefore, following her decision to stop working at the pub, she felt at a loss in terms of employment options. As an additional component of her project, I recommended that Sharon consider applying for the provincial government

pension for individuals who are disabled. The application process was lengthy and quite demanding; however, she agreed to proceed. As she explored alternate options regarding training and employment, she decided to train in floral arrangement, as this would allow her to fulfill her artistic expectations and provide her with a supplemental or even a primary source of income. Having identified both factors and then formulated them into goals, she proceeded to investigate what was required to accomplish them. As well, Sharon would have to contact prospective employers to obtain information regarding opportunities and to determine which training requirements and options were applicable.

Step 3 – Measurements

An additional component of the procedure for establishing measurements required that Sharon record a list of her daily and weekly activities. Thus, she became aware of her time allocation and how much energy she was expending. Furthermore, she was able to plan and set up daily goals, hence reducing stress while building her confidence.

I suggested that Sharon should inform prospective employers that she was hearing impaired and to request a quieter environment during the interview to allow her to obtain information clearly. Thus, an additional measurement included Sharon's degree of confidence and control during our meetings.

The primary objectives were first to establish a source of income that would be permanent and provide sufficient funds for her and her son to manage their monthly living expenses with, and second, to identify some activity which would satisfy her creative interests. Achievement of these two objectives could become the end point for the measurement required in Step 3, and if accomplished, would translate into the achievement of her goals.

Step 4 – Implementation and Observation

As described in Chapter 4, following a sudden decrease in her hearing ability during the early 1990's, Sharon's social withdrawal increased and she moved to the island community where she felt safe. However, as she planned for her future, the possibility of loneliness and dependency became a reality. Sharon admitted to being worried and despondent; however, she regained her confidence by becoming involved in the research process, as it gave her hope "that it was possible, that it was totally possible" (Sharon, 2004, p. 38).

Initially, Sharon required assistance in restructuring her self-image. Sharon's memories of her grandfather and mother were quite vivid. Their adjustment and way of coping with their hearing impairment were the only models available for guiding her life. She was concerned that her hearing impairment would eventually be as profound as theirs. Sharon's process of change in her self-perceptions began early during our work together.

> Well, there have already been changes! If you want to talk changes! There is shame for me, there is a shame and I don't know where that comes from but I feel that it is a shame in not being able to hear, and that it manifests in my own speech because someone says something to me and I don't hear them and I say 'sorry'! And since we started, actually since the first intake [initial interview] I have realised how often I am apologising for not hearing and I am thinking (four second pause) what am I putting into my hard drive! Every time I say 'sorry' to someone, I am apologising to someone because I can't hear! Why am I doing that? So there are already some changes where I really try and catch myself now not apologising when I can't hear something, asking someone to repeat themselves and not saying 'sorry what

> did you say'? Why am I apologising!? It is not my fault I can't hear! (Sharon, 2003b, pp. 22-23)

As we had done with Andre, we began the planning phase with Sharon and she identified two primary goals for the action research phase. The original goal was to find sustainable employment and tap into her creative abilities to satisfy Sharon's creative talent. This goal was articulated in a problem-posing fashion, i.e., "Finding a way to earn an income sufficient to live on while having the chance to develop and use my artistic abilities—satisfying the artist in me" (Sharon, 2004, p. 38). The second goal was to develop confidence and be in control during meetings with people who are not hearing impaired, by advising them of her needs.

As Sharon's medical condition changed, additional barriers were identified and she was no longer able to manage her work in the pub. She decided her primary focus would be to secure a source of income. It would appear that the type of work she was able to carry out would not supply her with a source of monthly income. However, working on a part-time basis with a provincial pension would provide the monthly income she needed. Therefore, she chose to apply for the Persons with Disability (PWD) pension. This is a provincial government-funded pension program for persons with severe disabilities and has the highest level of flexibility, as it allows and encourages people to find part-time supplementary income while receiving the pension. The provincial authorities decide on eligibility for the pension on the basis of three supporting sources of information:

- the applicant's statement describing how his/her disability impacts on managing activities of daily life.
- a physician's report that corroborates the applicant's information.

- one additional assessment should be carried out by another designated health professional who should provide an objective report.

The initial stage of Sharon's project required her to complete the application information. If she qualified for income assistance, and once she finished her work at the pub in October 2003, then she would begin to receive her pension. Part 2 of the action research phase required that Sharon complete multiple tasks over a period of about three months. These tasks were identified as essential components of her project. Keeping in contact through e-mail and office interviews allowed us to plot the necessary strategies to facilitate the successful completion of her plan of action.

Sharon's employment ended in October and she was deemed eligible for basic income assistance from the province, as she had previously received it in the early 1990s. However, she was told she was not eligible for federal Employment Insurance benefits.

As mentioned, Sharon was assigned one task involving the completion of her portion of the PWD application to obtain support from the provincial program for training in her floral design and arranging. Sharon completed all the required tasks by December and funding was approved for the course. She did not start her course until early March 2004. At that time she was also approved for disability benefits. Therefore, while receiving her basic income from a fixed pension, Sharon had the opportunity to earn additional money. Later on, she was offered a position doing postal work on a part-time basis and she accepted. Therefore, Sharon had not only established economic security through her pension and supplementary income from her work but she was on her way to completing her floral design course. The latter will eventually result in part-time employment in an area that fulfills Sharon's creative interests.

Thus, the above factors, i.e., approval of the pension, obtaining funding for training in floral design, and having additional work to supplement her pension constituted measurements of success. While there are no means of actually measuring certain gains, Sharon appeared to have become empowered through an increase in her self-confidence and a successful decision-making process.

Step 5 – Evaluation

Each of the candidates was invited to see a PowerPoint presentation (PPP), which I had prepared a few months earlier. The presentation was originally developed for delivery to the board of directors and staff of a local Vancouver Island agency mandated to serve individuals who are culturally Deaf, late deafened, or hard of hearing. My purpose in designing and delivering this presentation was to inform them of my work with this small group of individuals with hearing impairment. The presentation provided a synopsis of all aspects of the study in a concise manner. Therefore, I felt it would be beneficial for the study candidates to view.

I presented the PPP to Sharon prior to Step 5 of the action research process. During this presentation, I used a statement from Chapter 1 by Mithaug (1996) about how people with disabilities often experience a loss of hope, a growing sense of helplessness and despair, and that this may eventually lead to a downward spiralling cycle where the individual experiences deterioration in personal, social, and economic areas of his/her life. Sharon responded to this particular slide by saying,

> As I wrote you in that e-mail, I thought that my life would become, I would become one of those little old bag ladies or something living in somebody's basement or living in a seedy hotel because (deep sigh) they just don't know how it is when you can't hear! (Sharon, 2004, p. 3)

During the evaluation stage, we discussed primarily Sharon's efforts over the past months. She stated that the action research process gave her hope.

> Without hope why would you bother? But if someone like what you have done here gave me hope and because there was a little flame of hope, albeit through a narrow tunnel but it was there, it was a direction to go in. (Sharon, 2004, p. 7)

As discussed by Mithaug (1966), people with disabilities may have initially a sense of hopelessness, questioning the prospects for their future. However, by engaging in ongoing critical reflection and planned action, this can eventually lead to a sense of personal empowerment. This objective is consistent with one of the aims of this project, i.e., placing responsibility for advocacy on the individual rather than relying solely on professionals.

Sharon talked about her experience while being involved in the action research phase of the study.

> What the project has given me is immeasurable! It has given me a life! It has given me financial security. It is a huge weight off of my shoulders. The project has given back to me ten times over [what her contribution was to the study]. (Sharon, 2004, p. 22)

The project helped Sharon restructure her self-image, as it provided her with the opportunity to understand how she perceived herself as a person with a hearing impairment. She was able to set up a path which had the potential to help her fulfill some of her life ambitions and feel less controlled by circumstances.

While describing her experience with the action research project, Sharon focused on the importance of being part of the solution by assuming control.

> The fact that someone is saying what do you want, and what do you want to do, it is so open, it says that there is someone asking that question that wants you to tell them that is willing to give you

> time to say what your dreams are and what your aspirations are. (Sharon, 2004, p. 28)

One of the greatest benefits to "a client in any interaction with a practitioner," states Boulton (2001), "is the sense of their relatedness to the professional; that they are interested, involved and care" (p. 6). Sanders (1993) explains the need for empathy and understanding between persons with hearing impairment and professionals: "A hearing handicap aggravates other personal concerns and generally erodes self confidence. These problems in turn create a need to share the burden with someone who is able to empathise and has the ability to guide the client" (p. 474).

As stated earlier in the introduction to this chapter, Lewin (1946) described action research as a vehicle for change. Action research could allow people to translate their dreams into the language of action. He envisioned this approach as it became a means to help people increase independence, enhance individual and group autonomy, and foster the spirit of co-operation. In my estimation, this co-operative spirit allows the researcher along with the candidate to work closely in a shared capacity of co-researchers aiming to achieve desirable and planned outcomes.

In her concluding statement following the Power Point presentation, Sharon states:

> Obviously it [the action research project] worked. I think of all that I got. I have my PWD [Persons with Disability] status. I have more confidence. I take more responsibility now for saying that I have a hearing loss rather than just pretending I don't—not telling somebody, not being fair by not telling somebody, I am doing the course that I love which hopefully will give me future employment and if not I still have some financial security that means I will not

> be a funny old bag lady. (Chuckle). Hard of hearing bag lady! So it worked! (Sharon, 2004, pp. 35-36)

Through this, Sharon obtained additional benefits which deserve to be mentioned. As referred to earlier, I recommended that Sharon ask her son to discuss how he perceived her hearing disability as well as her carpal tunnel syndrome and osteoporosis. I believed this would provide Sharon with a broader perspective of her limitations and allow her to write a more precise PWD application for the adjudication committee. Sharon stated:

> I think it was important for him to voice his frustrations and what he saw of the changes [limitations now in his mother's ability to perform certain tasks at home as well as issues surrounding her hearing loss]. That's where I think the dialogue with him, with giving him a forum to talk about his frustrations were common to me when I was that age with my own mother and grandfather and assorted aunts. That was interesting but I think it awakened something in him where he realised something. He helps me more! It changed something in him! (Sharon, 2004, p. 42)

This "awakening" may be equated with a new level of acceptance that Sharon's son attained through their dialogue. In listening to her son's description of his experience, they engaged in a critical reflection about her changing status. Indeed, Sharon was now engaging her son in the same critical reflection process that became an essential part of her initial work. The outcome of their dialogue was mutually enlightening.

> The difference was in asking him and giving him a space to hear how he feels about it. He's frustrated! Of course he's frustrated! I totally understand that but for him he has been so raised by adults and so used to being with adults I think it gave him an importance,

> it said you are important, how you feel is important to me, and I gave it to him and in turn he gave it back! (Sharon, 2004, p. 42)

Some of Sharon's critical reflection revealed to her some of the resentment that had gone unchecked until our action research process began. While preparing her portion of the PWD application, she became aware that of some of her behaviours as an individual with hearing impairment were detrimental.

> I feel like a person who has to work harder than someone who does not have a hearing loss to be accepted in the real world, for example doing the mail—I feel like I had to do an exceptional job because of my hearing loss. (Sharon, 2004, p. 46)

The same issue was echoed at least twice during two separate interviews. In the early action research interview on May 20, 2003, Sharon stated:

> I've got to try harder. You are always trying harder to achieve (ten second pause) because you haven't achieved enough yet. And actually being hearing impaired says you have got to be better than the next person who has no hearing impairment, you've got to do better, to make up for the loss of hearing and you get that normally from your own head, and you get that from other people, you get that sense. (Sharon, 2003b, p. 23)

Sharon reiterated the importance of having to try harder as she discussed her work as a mail carrier. During a latter portion of the interview, as we discussed the same topic, I asked whether she still felt that her performance has to be at a higher level than any one else's. She responded negatively. On further inquiry, she revealed another dimension of her life that had surfaced through critical reflection.

> I think it was connected with shame. And I think I carried a certain degree of shame with not being able to hear. I always felt I had to

> do a better job than the next person because, well, I don't think it was that I was worried that I would be fired or something, it's just that I had to make up for what was missing. (Sharon, 2004, p. 51)

Finally, Sharon elaborated further on this issue and explained that during her work at the pub she could not hear over the din of dishes clanging, pots rattling, orders being shouted, oven doors slamming, dishwashers swirling and so on. As well, she could not hear the orders being called, nor could she hear if someone was calling her to do something. Sharon described what she did to compensate for her difficulties at work: "I stood at the sink and I scrubbed ad infinitum! (Sharon, 2004, p. 52). Rather than trading off the heavy work, Sharon maintained this pace and avoided dialogue or directions, hence allowing others to respond to the needs of the cooks. This behaviour also protected her from the abusive reactions she had already experienced due to her inability to hear.

I asked Sharon how she was able to attain her present level of comfort while informing others about her hearing impairment.

> I think because I let go of the shame. And I think that when you gave me that opportunity to reflect back on what I grew up with and the sort of the genesis of why I have the notions that I have, I think that at that point I was able to let go of a lot of the shame. It didn't belong to me! Not that I have not experienced some discriminatory comments but the great shame belonging to my mother and how she was treated at the hospital by the nurses and doctors. Somehow I took it on at a young age and I have probably been walking around with it ever since. So when my own hearing started to go, that is when the shame kicked in.
>
> (Sharon, 2004, p. 53)

Sharon agreed that the critical reflection process enabled her to let it go. "I never talked about that. By divulging that, the shame disappeared. Now I wonder what else is rattling around in there" (chuckle) (Sharon, 2004, p. 54).

Sharon's following revealing statement emphasises what she believes was the core feature of this approach—listening.

> That is the crux of it! Right there! You are not alone! It is so empowering because you are so used to the lopsided, the half, we are used to the half . . . because that is the world we live in! We live in the world of two-minute doctor visits and we are constantly shunted. That is interesting. All people that deal in the Ministries [government departments serving citizens of British Columbia] should know this stuff! (Sharon, 2004, p. 56)

Sharon demonstrated considerable trust in the process and in our relationship. She was willing to take a chance to involve herself in the process to completion, and this, along with sharing her lifetime experience, took a great deal of courage.

In closing, Sharon stated that her niece would be staying with her for the weekend. "I should sit down with my niece tonight and ask her how she feels about the whole thing with her own mother's hearing loss. I don't think my sister talks about things" (Sharon, 2004, p. 59).

It is quite remarkable that Sharon is willing to engage in the same type of dialogue with her niece as she had done with her son. Once again, she may be providing an opportunity for critical reflection through dialogue, to explore assumptions, ideas, and perceptions that are held beneath the surface of everyday life. The value of this approach is reflected on the ability of those who learn it to internalise and apply them on their own. The student becomes the teacher.

Sharon states she has experienced a substantial increase in her confidence level since the beginning of the project. She added that she now takes chances more than she's ever done in years past. She is sending articles to magazines and various publishers, and this is something she shied away from the previous year. She has volunteered to paint celebratory theme banners for the city. Sharon stated that as she planned to present her ideas regarding designs and use of colours to the co-ordinator, she anticipated strong resistance and even rejection. The co-ordinator's response was simply "Wow!" (Sharon, 2004, p. 59). In addition to the colour being acceptable, a special order was made for the paint. Sharon was assured immediately the adjudicators would approve her work! She concluded, "I walked out of there and I felt ten feet tall" (Sharon, 2004, p. 59).

Discussion

In the action research phase, two distinct modalities were employed, audio and visual. Persons with hearing impairment can be placed in compromising situations if they are required to rely solely on their hearing. This was not the case in this study. Because important information was recorded and later typed and visually presented, the energy normally required to preserve these things could be used for other things.

The use of flip charts allowed me to record information as it was presented by the candidate. This provided validation for the candidate and later proved to be essential to the success of this project. Similar to the way it was done in the first phase, providing candidates with the typed and visually represented summary of the sessions gave them an opportunity to see what it was they had said. Then, in subsequent sessions, candidates were able to "see" their statements neatly written and posted on flip charts on the surrounding walls.

This was yet another verification of the importance of their statements. What is more, this utilised their strongest sense—vision.

This technique was employed during my graduate studies, therefore the importance was obvious to me from the start; however, only while writing this chapter was I able to see the enormous potential this approach has for persons with hearing impairment.

I chose the Quigley and Kuhne prototype in Chapter 5 for three reasons:

1. Flexibility – the stages could be engaged in sequence or not. This was important because insights and ideas which were not associated with the topic at the moment could be recorded, discussed and shown where these might connect in later dialogue, hence never losing the information.
2. Familiarity–I was well versed in this model, having completed my graduate studies in 2000, and I wished to test its utility for one-on-one work.
3. Simplicity–I wanted an approach which could be easily presented and understood. The language of this prototype was consistent with the language of the other approaches used in this study.

Beginning with a dialogic process through the investigative interviews using a phenomenological design, critical reflection was introduced to help candidates discover and understand the rationale behind old perspectives and ideas, unchecked assumptions, and previous ways of behaving in order to shape alternate ways of thinking and acting. Action research took the process beyond the discovery through dialogue to implementation of specific alternative planned changes. The critical reflection process potentially has the power to help individuals reach deep inside to gain a richer understanding. Beyond the value of reflection itself, there is the potential for transformation—new ways of looking at life's experience. This was evidenced by Sharon's comment, "I think when you

gave me the opportunity to reflect back on . . . the genesis of why I have the notions that I have, I think that at that point I was able to let go of a lot of the shame" (Sharon, 2004, p. 53). Discussing the importance of her dialogue with her son regarding her request for him to provide information about how he perceives his mother, Sharon's comments demonstrate how she adopted the role of facilitator herself, and as a result, she witnessed transformative results with her son. "I think it awakened something in him where he realised something. He helps me more! It changed something in him!" (Sharon, 2004, p. 42).

There were several demonstrations of the pedagogic effects of this model. Andre states, "What you are teaching me, or what I am learning from this and reflecting back to my past behaviour and saying: No, that doesn't work! I have to try it this way . . . so far it has worked wonders!" (Andre, 2004, p. 5). Andre continues, "The whole thing of being reflective is a new way of looking at things. I have never done that before!" (Andre, 2004, p. 5). The new way of looking where the text is represented visually is particularly valuable for individuals with hearing impairment who rely on their visual sense.

Recognising the power and authority of the individual is essential. This gives the individual the sense of his or her own value and importance in the process. As Quigley and Kuhne (1997) claim, the approach assures individuals that they have the skills to identify and to resolve their challenges. "Nobody has ever asked me what I thought" (Andre, 2004, p. 18).

Demonstrating the support aspect of the prototype—frequent engagement with the candidate through brief one-to-one contact or e-mail—Andre describes how "if you have that support group or one individual that helps a lot . . . that's what is needed . . . to keep things moving" (Andre, 2004, p. 15).

Further indication of the positive nature of these results is found in Andre's comments, "I felt that assertiveness was an issue and I have come head on to it

and I feel I have done a 180" (Andre, 2004, p. 1). Hence, the intervention techniques resulted in a complete "turn around" for Andre in many of his ways of thinking and acting.

Summary

Introducing action research in this study was primarily aimed at offering participants an opportunity to become actively involved in planning their life goals. This would be accomplished by increasing their awareness of issues that created barriers through critical reflection and by encouraging them to take greater responsibility in achieving personal autonomy and self-advocacy.

The action research phase of this project relied on the insights and ideas generated by the participants to assist in the formulation of goals and procedures to eliminate obstacles in their lives. These insights and ideas arose from their personal critical reflection and introspection. Several challenges posed for the purpose of their action research project were related to their hearing impairment. Critical reflection allowed the issues to be brought to the foreground in a non-threatening fashion. Individuals identified some of the obstacles that prevented them from achieving desired goals. As well, avoidance of some of the obstructive factors was recognised. As a result, participants were able to increase their sense of independence and autonomy and become personally empowered with new strategies for dealing with challenges in the future. Action research may be considered a viable tool for professionals working with persons who are hearing impaired and have been adversely affected by it, particularly in areas of planning and decision making.

CHAPTER 6. SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Introduction

Eight candidates agreed to become part of this study for the purpose of sharing their personal stories of living with a hearing impairment to advance the understanding of professionals. The actions of these participants demonstrated a brave and willing spirit of personal revelation. Their experiences and insights bring into perspective the challenges that this “invisible” disability has presented to them throughout their adult lives. Chapters one through five are now summarised. These summaries will enable the reader to better understand the conclusions and recommendations.

Summary

Chapter 1

Key terms were defined early in Chapter 1. At all times throughout the thesis, the emphasis was on the use of respectful language, in an attempt to avoid a deficit approach or comparison of people with hearing impairment with others. The more generic term “hearing impairment” was chosen in preference to other expressions. The term “hearing impairment”, however, was not intended to include anyone who regards him/herself as Deaf, i.e., someone who identifies with Deaf culture and language as all the participants in this study identified themselves with the hearing culture. While the participants were all hard of hearing, the term “hard of hearing” was restricted in its use because it was thought to be too narrow. Participants of this study have progressive conditions, which may change over time. The term “hearing loss” was also thought to be inappropriate because of the emotional overtones associated with the idea of loss.

The study was set against a background where progressive hearing impairment in adulthood is being internationally documented as an emerging concern that will likely continue to grow as populations age. Claims have been made in the literature that progressive hearing impairment causes major psychosocial disruptions to the individual's ability to communicate orally. Furthermore, there is often a profound lack of awareness regarding hearing impairment and its possible sequelae amongst all those concerned i.e., individuals with progressive hearing impairment, those who come into contact with them in their daily lives, and most concerning of all, the rehabilitation professionals whose job it is to work with these individuals. The absence of awareness and training was made evident through the comprehensive report by Hill and Nelson (2000).

The focus of my inquiry stems from the observations I made over a period of nearly 30 years of work as a helping professional working with individuals with disabilities, individuals who have reduced access to communication, and who often experience patterns of failure that lead to loss of hope and a growing sense of helplessness. In particular, I had a personal interest in working with people with hearing impairment.

For adults with progressive hearing impairment it may take many years before they acknowledge that they have the condition, long after the negative effects have become entrenched. These individuals, therefore, require expert professional assistance. As reported previously in the literature and consistent with my experience with colleagues in my professional work over the years, many professionals are ill equipped to cater for these individuals. This can be partially explained by the theoretical framework informing their practice which is based on research driven by a positivistic perspective which aligns with a medical model that emphasises amelioration of the patient and experts who profess to have "the" answers.

In my research project an ecological model was applied where the person with hearing impairment is viewed in complex interaction with environmental forces. The research focus, therefore, was to investigate using a phenomenological lens to engage in extended conversation with eight adults who are hard of hearing and then to use action research with two individual candidates in particular to help them achieve more positive outcomes in their lives.

The purpose of the study was to develop a model that could be used by rehabilitation professionals who work with individuals with hearing impairment to enable them to achieve an increased level of confidence with decision making. The model developed consisted of the integrated use of phenomenology and action research. The study was deemed to be important to me because of the increasing incidence of hearing impairment in adulthood and the debilitating psychosocial effects on the individual if the condition is left unattended. The issue of hearing impairment affects more than ten percent of the world population directly. This figure rises at least threefold at ages 65 and older.

In my experience as a rehabilitation professional, I have observed a lack of respect assigned for individuals with hearing impairment. A greater emphasis is often placed on the needs of the agency rather than the needs of the individual. Also, during my work in vocational rehabilitation I have been witness to an ever-increasing gap in understanding by professionals regarding the needs of persons with hearing impairment. For many others with more obvious disabling conditions, the need for services and counselling have been understood and provided. By comparison the covert nature of hearing impairment has left persons with hearing impairment virtually ignored. Traditional rehabilitation approaches have been largely criticised as being inadequate because of the emphasis on the limited engagement of the person in the rehabilitation process as defined by the medical approach, and the absence of awareness and training

available for professionals dealing with persons with hearing impairment. By contrast to the medical model, the ecological approach is much more life affirming because it initially provides the professional and the client with a deep understanding of the individual's experiences. The phenomenological and action research approaches support the professional working with the individual to help the person achieve his/her own positive life outcomes through action research.

The phenomenological phase of the study involved four male and four female participants, all from Vancouver Island, British Columbia, Canada. Their ages ranged between 18 and 65, with a hearing impairment of no less than 40 dB loss in their better ear, with amplification. A phenomenological approach was used to determine the meaning of an event for the individual who experienced such. The qualitative research design consisted of the sequential use of phenomenology and action research.

As the researcher, I had dual reasons for conducting this study. I am a rehabilitation professional and I have long held a particular interest in helping people with hearing impairment. During the first year of my professional career I had occasion to work directly with a young man who was culturally Deaf. In order to communicate with him I began taking classes in sign language. In so doing, I began a process of learning more about issues associated with hearing impairment. Since that time I have had additional opportunities to work with numerous individuals with hearing impairment including professionals. Therefore, my interest in this population was stimulated early in my career and I have had large exposure to persons with hearing impairment over the years.

The aim was achieved through extensive engagement with the participants and the use of bracketing interviews for the purpose of minimising the impact of the researcher's own biases. This meant I had a number of issues and past experiences to work through when trying to examine my own personal biases. The engagement followed a six-stage process: initial engagement,

immersion in the topic, incubation, illumination, explication, and creative synthesis.

An important element of the research process was for the participants to engage in critical reflection. The desired outcome of critical reflection is increased insight, personal empowerment, and renewed commitment to effect positive change. I too used critical reflection during the bracketing interviews.

Critical reflection is a vital part of action research. Action research is a type of self-inquiry a person embarks on in order to improve the rationality of his/her own social or educational practices. The particular form of action research chosen for this study was the Kuhne and Quigley (1997) prototype. I made minor modifications to the approach. In particular, I substituted the problem-posing task with identifying a challenge. The change helped avoid focusing on problems. Clients were able to concentrate on identifying positive challenges instead.

Having demonstrated the nature of the phenomena from the literature and from my professional experience, and having indicated the direction I believed this inquiry had to take, I then provided a more thorough analysis of the literature related to critical reflection, critical self-reflection, action research, empowerment, and transformation.

Chapter 2

The review of the literature in Chapter 2 highlighted the marked shift that has occurred over the past 30 years away from regarding hearing impairment principally as a medical problem towards viewing it within a much wider perspective where the whole person's ecology is also taken into account. This shift has provided new opportunities to introduce more psychosocial interventions in conjunction with the current technical and medical ones being employed.

Chapter 2 similarly began with a more thorough exploration of key terms, particularly “hearing impairment”, “hard of hearing,” and “deafness”. The increasing relevance of hearing impairment worldwide and the absence of information and training for professionals in the field of counselling were stressed to construct an argument for more research into how best to assist adults with progressive hearing impairment. In order for this research to adequately inform practice, it must include qualitative information, in particular literature that provides a deep understanding of life experience of individuals with hearing impairment.

From the review of the literature, it is clear that a consistent story emerges supporting the notion that in the past, professionals who used the medical model tended to regard themselves as the experts who not only knew their clients’ problems, but also believed they had the solutions to ameliorate them. This approach tended to focus on the clients’ external handicaps. Nowadays the literature highlights the point that disability is socially constructed and interpreted. Negative interpretations may lead the individual with the disability to view him/herself in debilitating ways. These internal handicapping conditions can be at least as incapacitating as the external handicaps.

The ecological approach, on the other hand, emphasises the necessity for clients to define their own needs and treatments in collaboration with the professional. This multifaceted approach gives prominence to the idea of individualising the involvement while paying close attention to the person’s psychosocial requirements. Although individuals may experience a similar reduction in their hearing levels, the impact and implications of such an impairment can be enormously diverse and are, therefore, unique to the individual, his or her family and significant others. When using the ecological model, the professional becomes a researcher. He/she must value empathy in professional practice. This brings the personal into the professional. There are

two distinctive aspects of progressive hearing impairment within the social and relational context: 1) hearing impairment is “invisible” and 2) it is “insidious”. Therefore, it is the job of the helping professional to gain a deeper understanding of the challenges being faced by the client and to design interventions cooperatively with him/her. One such consideration is through critical reflection. Critical reflection is a useful tool because it is through the reflective process that the client begins to establish new life destinations. Another way to assist an individual’s growth and independence is through focusing on self-determination and empowerment. It is especially important to acknowledge the process of client transition from the relative security of being “able”, to the uncertainty and insecurity of living with a “disability”. The practitioner aims to help the client override the temptation to react in a passive way and to actively seize the opportunities offered by the impairment. Phenomenology and other associated research approaches, including action research, offer the professional a valuable way to gain a deeper understanding of the life experiences of the person with hearing impairment and work with him/her to design new prospects for a more effective intervention.

The potential impact that hearing impairment can have in adult life was explored through the literature and revealed in such a way that it does not recognise boundaries of age or circumstance in life, but affects all family members, friends, relationships in the workplace, and all aspects of daily living where communication is required. Furthermore, the literature evidenced that the magnitude of the problem of hearing impairment is escalating.

As well, the survey of the literature revealed that the effects of hearing impairment are far reaching and include, but are not restricted to, its being considered as a trauma, fear of loss of control, fear of loss of self-image, fear of dependency, fear of stigma, fear of isolation, fear of abandonment, fear of expressed emotion, fear of loss, depression, uncertainty, and demoralization.

Hearing impairment has been defined in the context of the medical model and this has minimised its impact not only for the individual affected, but also for the person's significant others and society at large. Therefore, by defining hearing impairment in the context of a social disability, it may be feasible to deal more effectively with the widespread implications associated with it.

The literature indicates, as well, that the knowledge base available to professionals who deal with persons with hearing impairment is small relative to the growing need and that there are insufficient numbers of trained professionals available to provide services to the large and increasing numbers within this population. Therefore, a study designed to increase the level of information regarding the life issues for persons with hearing impairment as well as the exploration and development of alternative approaches for confronting such matters appears timely.

By using a phenomenological approach, participants may uncover those rich detailed "unreflected [prereflective] experiences" (Secrest & Thomas, 1999, p. 241) of their lives with hearing impairment. Narration then, is one means whereby participants can have an opportunity to become more actively involved in their own planning as they find a venue to tell their story. In so doing, they may have an opportunity to give voice to their experience. This may provide a further opportunity to move from a modernist to a postmodernist perspective and approach as individuals are invited to become increasingly participatory in the planning and execution of their future goals.

Chapter 3

Chapter 3 describes the design of the study based on phenomenological considerations. Phenomenology is the study of human experience. Its initial goal is to seek an understanding of the meaning of lived experience as it becomes part of the individual's consciousness. It involves a close examination of the way

things present themselves to the individual as they are immediately experienced. It is, therefore, introspective in nature. There is an emphasis on obtaining pre-reflective accounts of personal experiences. These accounts occur prior to any attempt of the individual to conceptualize his/her experience. With phenomenology the focus is on understanding the ways in which humans gain knowledge of the world around them. These ways of understanding may be revealed through objects of perception, memory, imagination, and feelings.

The language the individual uses to describe the experience is, therefore, particularly important. The goal of phenomenology, however, can be extended to take on a pedagogical component. Through reflective, dialogic interaction with a researcher the individual is involved in an educative process where he or she learns more about his or her own experiences. The process can therefore also take on a retrospective character, especially once the participant has been provided with the opportunity to read through the transcripts of the interviews and make a judgement about their accuracy.

The study consisted of two phases, the phenomenological interview in phase one and the action research project, in phase two. The methodology for phase one is presented in this chapter. The eight participants (four male and four female, aged between 18 and 65, each with a hearing impairment of no less than 40 dB in their better ear with amplification) were identified through a mail-out to audiologists, medical practitioners, and rehabilitation professionals in the greater Nanaimo and Duncan areas of Vancouver Island. While a concerted attempt was made to choose as wide a range of different participants as possible, including those who were employed or unemployed, living in rural or urban locations, single or married and of different ethnic backgrounds, expediency also became an important consideration.

In phase one there were up to three researcher(myself)-participant interviews of 60 to 100 minutes conducted, at my office. The interview process

was informed by Kvale's (1996) twelve aspects, namely: life-world, meaning, normal language, descriptive, specificity, deliberate naïveté, focused, ambiguity, change sensitivity, interpersonal situation, and positive experience. The interviews were all audiotaped and transcribed. Particular care and attention were given to ensuring that both the language and tone of the interview were accurately recorded. The first interview was aimed at establishing a good rapport, and provided the opportunity for the researcher to introduce the research topic. During this unstructured interview the participant was invited to talk about his/her life experiences as a person with a hearing impairment. During subsequent interviews the participant was able to comment on the accuracy of the interview summary of the previous interview. Further interviews only occurred if the participant wished to expand on his or her description.

All three of Pollio and colleagues' (1997) procedural methods were adopted in this research. During the interviews I regarded the participant as the expert. I simply followed the course of the dialogue and only asked questions to clarify meaning. After the interviews were transcribed, I highlighted particular pre-understandings in the interview text and gradually developed these into themes. I next met with colleagues to discuss how and why these emerging themes were identified. Once this meeting was over I assumed greater responsibility for the thematising and proceeded to complete the analysis of the transcripts. The completed thematised summary of each transcript was then provided to the participant, who was subsequently invited to judge whether the summary accurately captured the participant's experience. Throughout the whole process I placed great emphasis on treating the participants as equals. All participants were reminded on an ongoing basis of their status as co-investigators.

Analysis involved a process of reduction, epoche, or bracketing. As the researcher I tried to free myself of any encumbrances, misconstructions or other

impositions that related to the phenomenon under investigation, namely living with a hearing impairment. Through a process of bracketing or phenomenological reduction, I attempted to free myself as much as possible of theoretical beliefs, preconceptions, and presuppositions. This involved me unmasking my motives for conducting this research by being the subject of a bracketing interview, adopting a language that was consistent with the participants' language and establishing a reference group or critical friend.

I understood the research was not without bias. The bracketing interviews helped me uncover some of my own biases which I had unwittingly held toward persons with hearing impairment. My assumptions about the effects of hearing impairment were based first on early childhood impressions and second by my early professional experience and involvement with persons who were culturally Deaf. Additional biases rose from my experience learning about Deaf culture at the same time as learning sign language and during my years of professional experience since then. I was able to identify the anger I felt toward parents who were seemingly unaware of their children's hearing impairment and the anger toward children who teased and tormented the participants in their earlier lives as students. I reacted in the same judgemental manner hearing about how adults exhibited negative behaviours toward those adults they worked with. I felt shame and sadness for my own professional behaviours when I recalled feelings of frustration with persons with hearing impairment because of the need for constant repetitions that were required. For example in my work I have come to realise how frequently I have prescribed ways for individuals to deal with some of the challenges they presented during interviews. During the phenomenological interviews there were tendencies to offer direction to participants rather than to listen to them. In effect this is a form of patronising behaviour because the individual nuances of a person's life are not always taken into consideration. Through critical reflection and ongoing reflection-in-action, I

have been able to identify some of my own biases which have existed during my practice.

During the analysis process a hermeneutic style of interpretation was applied. At this stage any part of the data was related to the whole of the data for the purpose of understanding the intention and meaning—to make as certain as possible that the intended meaning was understood. Hermeneutic analysis provides a realistic means for gaining a broad and rich understanding of the text under analysis. The hermeneutic cycle was used to safeguard against inappropriate interpretation of text.

Pollio et al. (1997) recommended that between three and five transcripts be used to begin to gain a sense of the descriptive patterns and relationships that characterized the initial interviews. This was carried out in order to avoid what might be considered a linear characteristic arising from the data. The intended process of transformation, which leads from protocols to themes, "involves an insight-like process that comes from a complete immersion with both the original interview in the form of dialogue and its subsequent written form as protocol" (Pollio et al, 1997, p. 52). I endeavoured to capture what the experience was like for the individual using the language of the participant. The process of thematisation denoted the search for essential structures and involved the identification of the constituents or themes that appeared in the descriptions. Themes then were tied to the protocol. The task of the theme was to make the meaning of the protocol clear as to the way (or ways) in which the events derived in the protocols were experienced and lived by the individual. Interpretations were always supported by references (segments of text) from the transcripts. This process of thematic interpretation was a continuous one. It required going back and forth among the various parts of the interview text.

Creswell (1996) refers to interpretation as "making sense of the data"

(p. 144). A key point about the interpretation of all qualitative data, particularly data derived through the use of phenomenology is “Never generalize!” (van Manen, 1997, p. 22). The phenomenological approach is intended to create a way and means for the participant to retrieve his/her lived experiences through purposeful dialogue with a researcher. For the purpose of my thesis, this information is then intended not only to inform the professionals working with the individual with hearing impairment but also to provide a deeper understanding for that individual as a result of his/her dialogue and reflection on aspects of the person’s own experiences.

Chapter 4

Chapter 4 contains an interpretive analysis of the information obtained using the guidelines and procedures as outlined in Chapter 3. Participants were asked to review the interview transcripts for authenticity and accuracy. Most of the candidates stated at this point that being interviewed by a researcher who asked questions about their lives was both a new and unique experience. Indeed, they reiterated that no one had ever shown this level of interest or demonstrated such a strong desire to fully understand their experience with hearing impairment.

I read the transcripts repeatedly prior to attempting to extract individual themes. This practice brought new perspectives to light. While the candidates had many experiences in common, their descriptions were neither highlighted nor categorised quantitatively. As mentioned before, identifying salient themes from each transcript was the only type of categorisation used.

By reviewing the transcripts repeatedly, I learned that the reduction of auditory ability might have a major and frequently negative impact, not only on the individual affected but also on his/her family, friends, or coworkers.

The numbers and titles of themes in the analysis for each candidate vary depending upon the diversity of their individual dialogue. The analysis of data was presented chronologically from the youngest to the oldest candidate except for the two candidates (Andre and Sharon) who volunteered for both phases of the research and who were presented at the end of the chapter. Underlining and bolding of text indicates the candidates own emphasis.

Roxanne

At the time the study began, Roxanne was 18 and the youngest participant. She was experiencing difficulties finding employment because the only work that was available was in areas that were incompatible with her hearing status. Adjustment difficulties during adolescence were compounded by a late diagnosis of hearing impairment. Based on Roxanne's description of her family, it would appear she felt they did not provide her with the support she needed to understand or the help to deal with her hearing impairment during childhood or adolescence.

Support for identification of her hearing impairment and assistance with hearing aids came from outside sources. "My mom was pretty much always involved in her own little world . . . so it was <u>mainly</u> <u>the</u> <u>teachers</u> that noticed." (Roxanne, 2003, p. 3). Roxanne said, "I was kind of ashamed of it [my hearing impairment] . . . it just made me withdraw" (Roxanne, 2003, p. 7). "I felt it was <u>my fault</u>!" (Roxanne, 2003, p. 3). "I was . . . a <u>lonely soul</u>" (Roxanne, p. 25). She felt "totally like an <u>alien</u>" (Roxanne, 2003, p. 23). Roxanne tells the story of being assaulted by a fellow student in Grade 12, a female friend who, without provocation, used her fist to strike her on the ear, breaking the hearing aid and cutting the outer ear. This resulted in Roxanne developing a recurring fear of insecurity regarding her hearing aids. "I am . . . <u>scared of people taking advantage of me because I wear hearing aids</u>" (Roxanne, 2003, p. 13).

Roxanne grew up to become an independent-minded individual who relied mostly on her own talents and strengths to achieve her objectives. Sometimes this process of becoming independent and self-reliant was costly, as it required losing out on some of the typical age-related experiences of growing up. As the interviewer, I often had to remind myself of Roxanne's age. In spite of her youth she presented as someone with many more years of life experience. Roxanne is a remarkable young woman. Among her noteworthy gifts is her tenacity, demonstrated through the nature of the jobs she has held. Despite working in highly incompatible jobs, she was able to keep up with required tasks and succeed against formidable odds.

Aaron

Aaron was 27 years of age when he was first interviewed. He was attending university in an undergraduate degree program. His career objective is to become a teacher. His hearing impairment was not identified until he was 12 years old. He recalled having multiple assessments as a child but his early recollections surrounding identification of his hearing impairment were vague. He is deaf in one ear and relies on a hearing aid for amplification in the other.

Despite the rejection and taunting during his early school years, Aaron emerged seemingly unscathed. Aaron recalls the "big kid" who "got the whole class turned against me. He asked the whole class to raise their hands if they didn't like me . . . and the whole class raised their hands . . ." (Aaron, 2003, p. 12). He persevered in the midst of peer abuse and teasing and found his strength by relying on the support of his parents. "They [his parents] have always been supportive. I had a lot of advantages growing up" (Aaron, 2003, p. 35).

Aaron never mentioned whether his parents intervened to stop the bullying and teasing. Therefore, it is not clear whether his parents knew what was happening or whether they dismissed it as being "just natural" (Aaron, 2003,

p. 20). Aaron reiterates how determined he is to not allow such behaviour to be perpetuated in the school where he will eventually work. Aaron grew six inches taller throughout the summer of Grade seven. Taking advantage of his physical growth, he found communication on the basketball court to be easier. "You can communicate physically but that was an advantage to me because I was the same as everyone else that way and it is pretty easy to be social . . . because you are not talking so much" (Aaron, 2003, p. 16). This, he stated, changed the way in which others perceived him. He was no longer the underdog but rather the "tame Goliath". Aaron did not choose to seek revenge.

Indeed, having lived the experience and knowing what it was like to be on both sides of the fence, he has opted to be on the side of the supporter and seek a future career in teaching. At present, Aaron states he has a trustworthy group of friends, a good job, and a supportive relationship with his girlfriend and with his family.

Sherry

Sherry was 32 years of age at the time of her interview. Most of her work life involved clerical jobs. These jobs required her to use the telephone. "The worst thing is when I am on the phone and people start talking, that's the absolute worst!" (Sherry, 2003, p. 38). Adaptation devices were provided as a result of her own advocacy or in some cases from the benevolence of her employers. The difficulties Sherry described during her childhood were compounded by her hearing impairment. Her hearing impairment was first formally diagnosed when she was 15. While her teachers were alerted to Sherry's difficulties by her behaviour in school, it would appear her hearing impairment continued to be underestimated until later. Some of Sherry's descriptions of her life experiences are consistent with the literature on hearing impairment.

Clearly, the absence of information and detection are among these. During Sherry's childhood, a pervasive lack of understanding of the needs of individuals with hearing impairment prevailed among her classmates at school, her teachers, her family, and also at her workplace as an adult. "They never will understand!" (Sherry, 2003, p. 38).

Sherry has high expectations about her needs being understood at the workplace; however, she is reluctant to assist others to recognise and acknowledge these. "It's like opening up your soul and saying '*This is what's weak about me*" (spoken in an empathic yet quiet and defeated tone) (Sherry, 2003, p. 15). It is interesting to note how some of Sherry's behaviours are similar to those of her father's, particularly since he too had a hearing impairment. Sherry has demonstrated her tenacity, as she plans to go forward by returning to university and training for a new career in teaching.

Rod

Rod was 43 at the time of his involvement in this study. There was a long history of hearing impairments in Rod's family of origin. His hearing was suddenly compromised as a result of an industrial accident in his twenties. In the years following, Rod pursued an academic program in order to avoid working in industry. Although his hearing impairment was evident to others, it was not until he was in his 40s when his search for appropriate interventions led him to acquire his first hearing aids. One of his professors at university encouraged him to be tested. Rod explained his hearing impairment was moderate and the professor concluded, "'I don't think it's moderate anymore'" (Rod, 2003, pp. 5-6). This intervention took place weeks before our first interview.

He believes he has to overcome physical limitations in order to protect and maintain the image he feels society demands of him as an alternative medicine practitioner. "It was frightening, like I felt literally helpless, even with all

the disciplines that I carry, because there is nothing even in my disciplines that would help that" (Rod, 2003, p. 10). Nevertheless, Rod has made huge gains with respect to accepting his hearing impairment. Following years of denial, he is now beginning to reframe his disability into a more positive and acceptable experience. Rod continues to struggle with the views and definitions of disability held by his family. Perhaps one additional challenge for Rod is to rise above the silence with issues of hearing impairment in the family. Within his own family, Rod has made the issue of hearing impairment a matter which concerns everyone. Through his own experience he can see how hearing impairment affects the entire family unit. He realised the change in his own approach when his stepdaughter hugged him and said, "It's nice that you are talking to me and not speaking at me!" (Rod, 2003, pp. 11-12). Rod also raised an important point about justice and corporate responsibility. There are warnings on cigarette packages and warnings on various medication labels and consumer products, but there are no warnings on the use of recreational equipment, musical instruments, or electronics. Activities associated with these and other pieces of equipment are among the major contributors to hearing impairment in society. However, it would appear that no action has been taken on the part of the manufacturers to educate the population on the use and/or misuse and resulting ramifications of such equipment. Furthermore, the manufacturers have not been held accountable for failing to implement such an educational process. These issues are worthy of note for future advocacy.

Mindy

Mindy was 46 at the time of her first interview. According to Mindy, her hearing impairment was minimised by her parents. "He [her stepfather] didn't think that focusing on the hearing loss would be good for my development" (Mindy, 2002, p. 9). "My stepfather never said I didn't have a hearing loss, he

just put it off as not a big deal" (Mindy, 2003b, p. 15). Therefore, she did not become aware of the magnitude of the impact her hearing impairment had on her life until her late 30s when she was provided with her first digital hearing aids.

Mindy's passage from passive to active status occurred as a result of learning to understand and accept her hearing impairment. She has begun to grasp how much her hearing impairment has influenced her life. She has challenged many of the paradigms which had been maintained by her parents regarding her hearing impairment, and as a result, her attitude and perspective regarding the meaning of hearing impairment in her life has broadened. "I have changed a lot of perspectives, a lot that were given to me by my parents that I never challenged before, and one of them is the acceptance that I have a disability" (Mindy, 2003b, p. 34). In terms of physical responses to her hearing impairment, Mindy continues to experience ongoing fatigue and exhaustion. This issue continues to play out and be a prevalent and problematic one in all areas of her personal and work life. She has been able to be her own advocate at her workplace and she gained increased confidence in the process. "So that perspective has changed, I think, [it] has changed the spirit of asking for things [accommodations]" (Mindy, 2002, p. 12). Future plans may require further support and help from outside sources to assist with the structuring and layout of her plans. Counselling and critical reflection have already assisted Mindy in her adjustment process.

Nils

Nils, at age 61, was the oldest of the candidates in the study. His hearing impairment was due to occupational-related noise according to the Worker's Compensation Board of British Columbia. His hearing impairment was preceded by severe tinnitus, which continues to cause him a great deal of discomfort. His work on ships as a crewman and cook exposed him to the drone of diesel

engines 24 hours per day, 7 days per week. In his early career he was exposed to noise from high-pitched machinery. He represents the other end of the spectrum. His hearing impairment occurred in mid life. Now a man in his early sixties, Nils provides a very dramatic description of loss. Along with the sadness and desperation, he feels he has been robbed of the opportunities in life that he was longing to enjoy in later years. "You are sitting there and there's friends and family around and they are all having a wonderful time laughing and I am isolated, totally isolated, because I cannot hear a thing!" (Nils, 2003a, p. 10). His discussion reveals bitterness and anger, as he lives with no sense of purpose or fulfilment in his day-to-day life.

Nils experiences more than isolation. He is alienated by circumstance. The din of the voices alienates him because he has no choice in terms of remaining on site or even attempting to partake in the social activities with family or friends. His analogy of feeling like a person in a glass booth may represent an even greater loss, the loss of his freedom to choose. "It isolates you, totally isolates you, you can't—it's impossible to integrate" (Nils, 2003a, p. 10).

Due to his hearing impairment, Nils may have been robbed of opportunities and enjoyment without a clear reason or explanation other than perhaps "the luck of the draw" as well as the limited understanding of how severely an individual is affected by it.

Nils says that not only the individual with the hearing impairment is affected, but also the spouse, the children, the family, and friends. He refers to the "total invasion of <u>every</u> <u>aspect</u> of your life . . . it gets <u>everywhere</u>, permeates like a cancer . . . yet it is not terminal (three-second pause) but it is lifetime (Nils, 20031, p. 14). Thus, all aspects of an individual's life, i.e., social, intimate, and personal relations are touched by hearing impairment.

Andre

Andre was 35 years of age when he was first interviewed. He was married and had two preschool children. His hearing impairment was identified when he was in primary school. "If it weren't for my Grade One teacher noticing how isolated I was as an individual . . ." (Andre, 2002, p. 1). Adequate interventions were not introduced until he was in his 30s. Andre had two careers, baking and installing underground hydro power lines.

Frustration and isolation describe Andre's early years. Although Andre's parents were caring and loving, from the information provided by Andre it appears that they demonstrated a passive ignorance of the impact that Andre's hearing impairment might have had on his life as well as not knowing what to do to alleviate some of the problems at an early age. As a result of his isolation during these formative years and through his teens, Andre's self-image was battered and he was unable to bond with boys and girls his own age.

Through my experience with Andre, I have found him to be a bright and industrious individual with depth, compassion, and sensitivity. His lack of assertiveness in personal relationships as well as in the workplace affected his self-esteem and self-worth. Therefore, these are areas also that should be examined in order to work with Andre's self-development. As well, Andre has set his own personal objective—that of working on the direction of his marriage and identifying future career goals. In addition, Andre would like to work on ways of expressing his needs in terms of his hearing impairment as well as dealing more effectively with constructive criticism in daily life. "I am a person who takes criticism very seriously and I take it to heart, and it beats me up a lot, I can't take criticism, constructive criticism . . . I have that problem and I always will" (Andre, 2003a, p. 6).

Andre demonstrates insight by stating, "Everything seems to revolve around being more assertive. I guess that would help guide me to become more

directed to my goals—instead of avoiding them" (Andre, 2003b, p. 6). This awareness seems to have emerged during the later stages of the interview process and demonstrates how critical reflection can bring about further insights. "I think assertiveness is the main thing that I have to work on. I haven't been assertive enough with my life. I haven't been assertive enough with my marriage. Just everything with my life just kind of boils down to me being more assertive" (Andre, 2003b, p. 2). Andre carries the focus of assertion to assuming responsibility for letting others know that he has low hearing by saying, "I have to be assertive with letting people know I have a hard of hearing problem. I have to make them aware!" (Andre, 2003b, p. 3).

Sharon

Sharon was 51 years old when she was first interviewed. She is a single mother with limited work experience. Although her hearing impairment was identified in her early 20s, she did not seek interventions until much later. Sharon experienced progressive hearing loss through her twenties with a substantial degenerative hearing impairment in her forties. With a family history of hearing impairment, Sharon began early adulthood anticipating the worst. "So I knew that I hadn't escaped the genetic fault" (eight-second pause) (Sharon, 2002, p. 2). As a child she witnessed her mother and grandfather live with degenerative hearing. These experiences included observing how her mother was affected by the degrading treatment she endured from professionals at the workplace due to her hearing impairment. "Well, yes, okay, this is going to happen to me, but I will never be as deaf as my mother, or I will never be as deaf as my grandfather . . . that's not going to happen" (Sharon, 2003, p. 3). These memories may have been perceived as a foreshadowing of her own destiny, as she withdrew from participation in society and became directed towards protecting both herself and her son by making a life for themselves in a secluded environment.

Six months prior to the interview process, Sharon was fitted with digital hearing aids. She was immediately taken from a world of relative silence where she had been living for a decade to a world where she could participate and engage more with others. Along with this transition, she had to confront the challenges of finding employment and reintegrating into the hearing world. She found the challenge of facing the world without the necessary skills for adjustment to be a formidable task. Sharon's challenge was to bridge the gap between the decade of silence and seclusion to a more interactive lifestyle. "I just want to be part of the whole, not the exception anymore, and maybe that's got something to do with re-joining the world" (Sharon, 2003, p. 21). Planning her future career is the focus of Sharon's life at this time.

Sharon relied on the medical professionals, the audiologists and the technicians to restore her hearing. When this could not be done, she retreated, and in doing so she focused her attentions on her son. "Oh, it is big denial! It's denial big time!" (Sharon, 2003, p. 3). Indeed, Sharon maintained control by creating a safe but very limited world. "Life was very small, it was very contained. It was very safe, but very small . . . I would say I controlled it a lot" (Sharon, 2003, p. 37). In a very short period of time following her fitting of digital hearing aids, Sharon emerged, adjusting quickly, finding employment, gaining economic independence and "rejoining the hearing world." Apart from her heavy reliance on the medical and technical system to help her, Sharon appeared to maintain an internal locus of control. Through critical reflection and dialogue she was able to see that she possessed the strength to manage her re-entry into the hearing world.

Chapter 5

Kemmis and McTaggart (1990) define action research as: "A form of collective self-reflective inquiry undertaken by participants in social situations in

order to improve the rationality and justice of their own social or educational practices" (as cited in Masters, 2006, p. 3). For Stenhouse (1981) the "reflective process whereby in a given problem area, where one wishes to improve practice or personal understanding" consists of three steps "first, to clearly define the problem; secondly, to specify a plan of action . . . [and thirdly to] action to the problem" (p. 5). The emphasis on "personal understanding" of the individual is critical to the application of action research in this study. This is because in this study the application is made with individuals not with groups. Following Stenhouse's three steps "evaluation is then undertaken to monitor and establish the effectiveness of the action taken. Participants then reflect upon, explain developments and communicate these results" (p. 5). As Dick (2006) observes, the action research methodology is a "cyclic process, with critical reflection a component of each cycle" (p. 3).

Chapter 5 contains a description of phase two of the research where action research methodology was used by two candidates, Andre and Sharon, to identify challenges in their life. The interviews for the action research took place in the same offices as the interviews for phase one. It was important to have sufficient room for the flip chart stand and wall space to hang the notes recorded on the flip chart sheets from each session. Challenges emerge following deep personal reflection on their phenomenological stories. These summarised statements were carefully recorded on the flip charts so the candidate could see them clearly and tell whether the written statement accurately represented their intended meaning. Initially the phenomenological stories revealed information which for these individuals was pre-reflective. The stories were then returned to the participants in typewritten format for them to review. The challenges emerged following the post-reflective examination. The potency of this activity can be described more in terms of the actual narrative results than it can in a description of the process. Issues emerging from the aforementioned chapter

provided material for the action research challenge. The procedure for gathering information was quite similar; however, it used more interactive dialogue and requires more specificity. Sometimes dialogue could occur for ten or more minutes before anything was recorded on the flip chart. As in the phenomenological approach, there is a need for a flexible design; therefore, the action research methodology moves back and forth between the procedural steps of the model to help candidates achieve positive outcomes.

Andre

- In the phenomenological interviews, Andre spoke about his own frustration with failure, beating himself up. On conclusion of the action research activity, he demonstrates how he employs a new approach for resolving challenges. "'*No, that doesn't work! I have to try it this way and I am going to try it this way'* and so far it has been working wonders!" (Andre, 2004, p. 5).
- Andre adopts a new approach in his life. He becomes reflective. "The whole thing of being reflective is a new way of looking at things. I have never done that before. I have never been a reflective person in a concrete way" (Andre, 2004, p. 18).
- Andre makes a clear statement in connection with personal changes he has made. He acknowledges that he has accomplished what he set out to do. "I feel that I have no problem becoming assertive and I have no problem being communicative instead of keeping it inside. That's a big step!" (Andre, 2004, p. 11).

Sharon

- Mithaug (1996) talks about the potential pit of hopelessness experienced by persons with disabilities, and Stone (1987) speaks about the "isolation . . . and despair and ultimately . . . the will to live (p. 116) in relation to hearing impairment. Sharon relates how she was able to overcome her fears. "I thought . . . I would become one of those little old bag ladies (deep sigh) living in somebody's basement or living in a seedy hotel because they just don't know how it is when you can't hear!" (Sharon, 2004, p. 3). She overcame these feelings of desperation and talks about her new potential to alter what she perceived as her sealed fate. She came to believe "that it was possible, that it was <u>totally possible</u>" (Sharon, 2004, p. 38).
- Sharon endeavours to break the silence in her own family by applying the skills she learned through the action research process. Talking about her son she states "I think it was important for him to voice his frustrations . . . . That's where I think the dialogue . . . giving him a forum to talk about his frustrations which were common to me when I was that age" (Sharon, 2004, p. 42)
- Through the application of critical self-reflection, Sharon witnesses changes in her son. "That was interesting but I think it awakened something in him where he realised something. It <u>changed something in him!</u> (Sharon, 2004, p. 42).

Cranton (1996) describes critical reflection as one of the vehicles for helping individuals recognise the power they hold for orchestrating changes in their lives. "Individuals come to know themselves by becoming conscious of the direct source of their perspectives. When this awareness exists, people are then able to negotiate social change" (p. 141). The power of critical reflection has

been evidenced by both participants in the action research component. By understanding the source and nature of their own fears, by recognising the barriers preventing them from experiencing a more rewarding life, participants have been able to transcend these challenges and regain a sense of power and begin to achieve positive outcomes.

Conclusions

I will begin the process of drawing conclusions from the research, by revisiting the five original goals listed in Chapter 1. The goals are as follows:

1. To use phenomenology to achieve a deeper understanding of the needs of eight adults with progressive hearing impairment.
2. To use the information gained through phenomenology to inform professionals about the range of experiences these eight individuals have encountered. The intent is not to generalise the effects of hearing impairment to larger populations, rather to help professionals gain an increased awareness of the magnitude of issues associated with living with hearing impairment by being made aware of the particular life experiences of these eight participants.
3. To work with two participants to help them use action research to build on their own phenomenological stories to define an action research project which, upon completion, would help them achieve a positive life outcome.
4. To use a combination of phenomenology and action research to assist two research participants to achieve more positive life outcomes by becoming more self-determining and self-reliant.

5. To develop a phenomenology and action research model which could be used by professionals to inform their own practice when working with adults with hearing impairment.

The eight phenomenological stories form a major part of this research. These stories which first appear in Chapter 4 and then again in summarised form in Chapter 6, provide a rich, thick description of pertinent issues for each of the eight participants. These are given below.

I will now organise my conclusions around these five goals. Major recurrent themes were bullying, isolation, ostracism, and self blame.

Roxanne

- Sudden worsening of hearing impairment in Grade 9 rendered previous coping skills ineffective.
- Identification and intervention mainly a school initiative with little input from her parents.
- Felt ashamed of her hearing impairment, "like it was my fault" (Roxanne, 2003, p. 8); "my main weakness!" (Roxanne, 2003, p. 5), so she began to withdraw socially, becoming lonely, and sad, "I didn't have enough support to . . . work for the better" (Roxanne, 2003, p. 8).
- Heavy emphasis on the visual for learning.
- In Grade 12 she was assaulted on her ear by a fellow female student who broke her hearing aid, cut her ear, and left her feeling physically, psychologically, and socially vulnerable.
- Her employment with communications companies has been highly incompatible with her hearing status.

- She has recently found a boyfriend who is more in tune with her needs and this has allowed her to come out of her shell.
- She is hopefully working towards becoming more independent and increasing her skills for self-advocacy.

Aaron

- He was alienated by his FM system and hearing aids. “I think it was lots more visible . . . with the big straps that came over your chest and the back, you looked like a half robot, you have wires hanging out of your ears” (Aaron, 2003, p. 6).
- Socialisation in the early years was likened to seeing the world through glass, which muted the voices, not being able to hear people or interact with them.
- Aaron met with rejection early, as he was failed in Grade 2. “I think she [his teacher] failed me because of my attitude, not because of my grades . . .” (Aaron, 2003, p. 6).
- Social and interpersonal aspects of life were severely restricted.
- The only children he knew were those at school, and when they rejected him, he was alone.
- “I can still remember that feeling when you were a kid that happened, getting picked on and that I haven’t forgotten . . .” Aaron, 2003, p. 9).
- Aaron demonstrated he understood the importance of internal locus of control as he moved to a new centre to a school where he found new friends and exciting new challenges and opportunities.
- Now at university, Aaron plans to complete his degree in education and teach children where he feels he can make a difference.

Sherry

- Sherry's hearing was first investigated when she was in her early teens by the school rather than by her parents, despite her father's own experience with hearing impairment.
- Sherry was alienated by her peers, she became a "target" (Sherry, 2003, p. 2) for their teasing and bullying. She sought refuge in the company of adults, placing further distance between her and her peers.
- In high school the torment continued. Feeling ostracized became commonplace but the cruelty increased. "People think that if you have a hearing aid then you must be intellectually challenged somehow" (Sherry, 2006, p. 26).
- Much of childhood was lost, spent in isolation, not understanding or engaging with others. "I never knew how to play games . . . they are never written, they are verbalized" (Sherry, 2003, p. 4).
- Hearing impairment is a family issue, "it affects everybody in the family" (Sherry, 2003, p. 9).
- The family maintains the pervasive silence about hearing loss despite several brothers who also have hearing impairment.
- Sherry's experience of isolation and alienation continued through the years where "even in university I felt like an outcast" (Sherry, 2003, p. 8); she is striving to bring a life-long plan of returning to university to complete her degree in education with a plan to teach children.

Rod

- Hearing loss was prevalent at home in the family of origin.

- The impact of his hearing impairment in his immediate family was brought to the forefront by his fiancée and her daughter through tricks to make him aware. "I felt I was being assassinated by them" (Rod, 2003, pp. 8-9). I felt ensnared inside of a helpless situation" (Rod, 2003, p. 9).
- Taking the word of the professionals that technology was insufficiently advanced to help him, Rod stopped pursuing services that might assist his hearing. "Growing up in an Irish household you got told *no* twice, you just kind of say 'okay . . . that's it, they are just never going to help me'" (Rod, 2003, p. 6).
- Pride and unwillingness to explore the challenges before him presented by his hearing impairment drove wedges not only between him and his family but also between him and his patients. "As a professional it was kind of a slap on my ability" (Rod, 2003, p. 9).
- Only the persistence of his fiancée led Rod to seek help.
- With hearing aids he was told his approach for paramedical practice is now "different . . . it has evolved . . . you have become the mature practitioner" (Rod, 2003, p. 11).
- Rod's perception of hearing impairment is that it is "an actual crippling impairment . . . The hearing literally put up barricades . . . it literally locked me into a room, playing the pantomime of '*In a Glass Box'* (Rod, 2003, pp. 12-13).

Mindy

- Mindy's hearing impairment was not identified until she entered school. Her hearing impairment was overlooked by her mother

"because of the subtleties—not really knowing how to pick it up [the nuances of hearing impairment]" (Mindy, 2003, p. 2). Her stepfather "saw I could hear more than he did and so thought I was okay . . . and that I didn't have that much of a hearing loss to worry about" (Mindy, 2002, p. 9).

- Mindy's perspective on life has been altered. "I have changed a lot of perspectives, a lot that were given to me by my parents that I have never challenged before, and one of them is the acceptance that I do have a disability" (Mindy, 2003b, p. 34).
- Being dismissed in the workplace and told something was not important when she tried very hard to hear and understand was described as very frustrating for her.
- In the workplace, struggling to hear what others were trying to tell her, Mindy did not regard herself as a "whole person [because] . . . a whole person does not constantly ask for everyone around them to accommodate them" (Mindy, 2003a, p. 4).
- There was a lack of forgiveness in the home by sisters despite their first-hand experience of hearing impairment with their father; Mindy has broken the silence and brought hearing impairment to bring it to the foreground of her own family, inviting dialogue with her children.
- Finally recognising how her hearing impairment was not only minimised by her father but also by herself. "Oh God, this is what I have done all my life. I have minimised my hearing loss" (Mindy, 2003a, p. 2).

Nils

- Nils experienced tinnitus initially, and with continued work in industrial shops and later working aboard government ships, his hearing was eventually severely compromised.
- Describing the teasing and ridicule by officers and staff, he referred to it as "ignorance and some of it was just down right rude" (Nils, 2003a, p. 6).
- At the end of his stress leave from work on the ships, he never returned.
- Most significant for Nils is the loss of his ability to play music and to sing. Even his own CD collection is strictly for others to enjoy.
- Being exposed to the process of reflection for the first time in such a formal way, he described reading the transcripts of his interview as "very dramatic! It was very dramatic to me!" (Nils, 2003b, p. 4).
- Loss for Nils continued, as retirement options for career change after working on the ships are dashed; "you can't even get a job driving a taxi . . ." (Nils, 2003a, p. 7).
- Nils finds hearing impairment to be pervasive. "I can't think of one aspect in my life that hasn't been affected by hearing loss" (Nils, 2003a, p. 8).

Andre

- Andre's first recollection of the first intervention came from his teacher and the school health nurse and not his parents.
- Early life for him was described as "isolated"(Andre, 2002, p. 1). "I spent most of my childhood not relating" (Andre, 2002, p. 1).

- Two words describe much of the early years for Andre: “confusing” and “frustrating, very frustrating” (Andre, 2002, p. 1).
- In elementary school, Andre found it very hard to develop friendships. This, he believed, was because children were “scared of me” (Andre, 2003a, p. 3). “They thought I was some kind of alien . . . or something” (Andre, 2002, p. 1).
- Andre tried to minimise his hearing impairment. When others were surprised to find out about his hearing impairment, he was pleased to have fooled them.
- Andre maintains his unquestioned and unsubstantiated assumptions to be truths. “They [employers] won’t tell me, but I know for a fact that they won’t hire me as a foremen because they feel my hearing is a disadvantage” (Andre, 2003a, p. 11).
- In his final year of school, he found “social acceptance” (Andre, 2002, p. 6).
- Acceptance for Andre now comes from his children: “Who cares if my Dad is hard of hearing, he’s my Dad” (Andre, 2002, p. 10).

Sharon

- Sharon’s first experience of hearing impairment was with her mother and grandfather—stoicism best describes the examples she was able to observe from early years.
- As predicted by specialists, her hearing “crashed due to a lot of really stressful things happening . . .” (Sharon, 2003, p. 3).
- Sharon chose isolation; “no one does these things to you, you make the ultimate choice yourself” (Sharon, 2003, p. 37) by moving to an island community with her son.

- Describing how she felt with word of her diagnosis, she replied "Horrified! Horrified!" (Sharon, 2003, p. 6).
- Describing her perception of the future course of her progressive hearing impairment, she refers to herself feeling "terrified" (Sharon, 2003, p. 29) because the end result, the degree of her hearing impairment, remains unclear.
- Denial played a large part in Sharon's history.
- Critical reflection has opened new perspectives for Sharon. "I am surprised by what has come out (laughter), stuff you are getting me thinking about, stuff I haven't thought about for years or connections there of (three-second pause) interesting" (Sharon, 2003, p. 18).

I continue to have contact with some of the candidates and they openly share information relating to their adjustments and new understanding about their lives based upon the experience we shared in the study. Beyond the pragmatic understanding and awareness, I felt I was able to reach deep into the life experience of these study participants to learn things about their lives that they had never uncovered before. This was a rich, vital, and tremendously moving experience to feel the trust and belief they felt for me and for the process. They have helped to enhance my level of understanding of the impact that hearing impairment has on their lives, and they have, I believe, made a substantial contribution to society by allowing their unique experiences to be shared.

I have achieved a deeper level of understanding of the value of narration as a tool for helping individuals explore the importance and value of their own voice as a means to inform themselves and even begin a process of healing with themselves and also with important others in their lives. People have a need to tell their stories. The use of narrative can present an opportunity for developing a deeper understanding about the individuals and the barriers they perceived or

experienced throughout their lives. Over the past two years, I have had individuals tell me that they have not felt so “listened to” in all of their lives as they have during my interviews with them. This tells me that the process of asking questions and demonstrating real interest in their stories—all of which is fundamental and integral to the phenomenological approach—provides individuals with a feeling of being respected and understood.

In my experience, forms are frequently designed to gather particular information which can be used to qualify a person for services or conversely to determine they are ineligible for services. By interviewing for the purpose of completing the form and making such decisions, information relating to the person’s experience may not be gathered or may not be considered essential or even important. Therefore, my interview style has changed and is no longer driven by a stylised form used to satisfy an agency or program. Instead, the information necessary for qualifying someone is gleaned from interviews so that I can learn as much about the person as possible during the process. This helps to build rapport and to gain a deeper understanding of the individual through an unstructured approach.

On a broader scale, I have been able to present the phenomenological action research approach to other professionals. I have shared the impact of the experience of the application of this approach on me as a professional and a similar effect was noted by others to whom I had the opportunity to offer training with respect to this approach. As a result I have seen and experienced a more widespread value of the approach. It is not only consistent with the literature, but it has been endorsed by the professional participants as empowering. This was evidenced by the inquiry, as it moved these participants to places a positivistic approach could not. This approach also appears to have the potential to be more widely adopted even when colleagues have not had the benefit I have had of engaging in this extensive inquiry. When presented with the model, they reacted

as though this was the approach they had been waiting for. This suggests evidence of their interest and capacity for change to effectively meet the needs of individuals over the needs of the agency. This indicated to me a remarkable shift for these professionals.

The workshops I presented on the phenomenological interview process were both interactive and participatory. I used PowerPoint, flip charts, handouts, and crafted models to demonstrate the meaning of the phenomenological approach. These presentations provided me with the opportunity to see the value of this approach reinforced by an attempt to have others learn about it and to practice it in the company of colleagues and professionals. There is a requirement for critical reflection and critical self-reflection for the professional participants during and following the workshop along with appropriate homework to reinforce in real-life situations the use of these new or enhanced skills. This is a particularly gratifying outcome from my years of work with this research activity. What is more, professionals have begun to value the ongoing practice of reflecting critically for the purpose of developing deeper awareness of their own biases and understand the ways and means they can employ to help improve their practice.

The phenomenology action research approach used in this study was extremely labour intensive and time consuming and therefore may not be feasible for application with all agencies. The professional would need to be highly skilled and experienced. It would also be an expensive approach to implement. Therefore, some modifications would be required. One way to accomplish this would be through the development of a workbook focused on guiding the participant using self-reflection exercises. As material is recorded this would become the focus of discussion with a facilitator. To formalize this, I would like there to be a consensus for developing a core knowledge base, which would predicate Professional Standards and a code of Practice.

In terms of the outcome for the participants of the action research phase of the study, each of the participants was able to achieve his/her stated goals by the end of the first action research cycle. Each candidate articulated his/her own goals and own set of procedures which they believed were necessary for them to successfully complete the task(s). This was a major accomplishment for each of them. It required determination and tenacity on their part. It also required from each of them a deep faith in the process. In both instances the participants achieved all of what they set out to accomplish. They did this with remarkable bravery and trust. They were willing to sacrifice the possibility of further loss by not achieving their objectives for the potential reward of some level of personal development. They were also willing to expose their lives before others for the purpose of enlightening others about their life experiences with hearing impairment. In both Sharon's and Andre's case, they were successful with all of their objectives, both primary and secondary.

The application of an action research model has allowed me to look carefully at the utility of this approach with individuals who have a disabling condition other than or in conjunction with hearing impairment. In my previous experience I found myself feeling bound or attached to what Brookfield (1995) calls a "hegemonic assumption" (p. 14). He describes these as assumptions which "we think are in our own best interests but that have actually been designed by more powerful others to work against us in the long term" (p. 14-15). He relies on Gramsci (1978) for an early definition of the term "hegemony" as:

> the process whereby ideas, structures, and actions come to be seen by the majority of people as wholly natural, preordained, and working for their own good, when in fact they are constructed and transmitted by powerful minority interests to protect the status quo that serves those interests. (p. 15)

This is an important understanding to arrive at for me as a researcher, particularly as a rehabilitation practitioner, because I feel I am now attached more to my professional ethical code of conduct and my enhanced interpretation of proper practice and less by the demands, expectations or rules dictated by an employer, agency, or company. It is also an important shift because as an employee I found myself at times becoming concerned with what I thought was expected of me and sometimes conforming to these perceived expectations rather than acting on what I believed was correct. These expectations were internal and seldom vocalised to management or colleagues and had therefore created enormous tensions within the workplace. Following my experience with this study, I do not feel I have to bring each interaction to a satisfactory conclusion to suit the needs or mandate of an agency or an employer. Instead, I have learned to focus on the outcome of the individual, ensuring they believe the results will be realistic and achievable. Although I see this type of thinking could create tensions in the workplace, it appears to me to be part of an ethical dilemma that professionals might expect to confront. This approach can, in my opinion, be one way of placing responsibility for the implementation of planned action into the hands of the individual leaving the practitioner to attend to their role of facilitator of process.

As a rehabilitation professional, I have become more aware of the use of respectful language used in this field when referring to individuals with disabling conditions. I have no compunction about informing other professionals of how their use of terms and assumptions may be perceived as detrimental to their clients and also to the relationship they share with other professionals. This is important because after years of work with many of the same professionals, it is easy to become complacent and to lose the sharpness and awareness of respectful reference over time.

In my current work I have been able to apply a phenomenological design to my interview process. Not only has this allowed me to reach a substantial depth of understanding that I was not able to in the past, but the very type of questions and the demonstrated interest has frequently impressed individuals of my sincerity and interest in hearing about their experiences. For many, this has demonstrated an interest which has gone beyond what anyone else has expressed in relation to their disabling condition and life experience. Understanding and practicing the phenomenological interview, therefore, has had a profound effect on my ability to be more effective in my practice.

As a result of my work in this study, I found I had competing interests, the interests of the agency where I worked for 22 years before leaving and the new dimensions of work with people, which emerged as a result of my involvement in this study. For many years I was aware that my values and interests were not compatible with those of my employers. As a result, I made the conscious choice to leave my employment to complete my research and to apply what I was learning through developing my own business. I have experienced a much more demanding pace of work life with a much greater level of fulfillment than I have had at any other time in my previous professional career.

Recommendations

The following recommendations are drawn from the body of the thesis.

- Further research following a phenomenological approach may be useful in exploring responses and reactions of significant others whose lives are impacted by those with hearing impairment.
- Further quantitative research investigating the experience of individuals with hearing impairment to determine the frequency and degree of influence of specific psychosocial factors impacting on their lives and those of significant others.

- A combined phenomenological investigation including significant others followed by an action research approach may lead to the development of an effective design applying group dynamics to assist individuals to deal more effectively with hearing impairment issues within relationships. The psychosocial ramifications of hearing impairment can be provided a forum for exposure, to heighten personal awareness as well as an opportunity for social debate. As evidenced in this thesis, issues of bullying, teasing, isolation, and the assumption of responsibility for associated problems (self-blame) are but a few of the topics that need to be addressed.
- Emotional and verbal harassment in the workplace should be treated with the same degree of sensitivity as other forms of workplace abuse, such as sexual harassment, and be censured as well.
- An action research model may be used in client-centred activities involving participants presenting with other disabling conditions. Similarly, phenomenology can be applied in further research to determine its value to explore issues relating to other disabling conditions of a physical, psychological, or emotional nature.
- Further research should be conducted in the area of critical reflection skills for rehabilitation practitioners as a component of professional development.
- As presented, the phenomenological model could be used to examine and or identify potential ideological biases of professionals, as this could enable them to become less limited by their own preconceptions and provide more freedom to function within a client-centred environment. Such an approach could,

therefore, establish guidelines for an effective professional practice.

- Action research may be regarded as a stand-alone tool to assist individuals to plan and evaluate outcomes. It may also be applied in conjunction with other forms of cognitive therapy to increase client independence, self-determination, and empowerment.
- Further research into the action research approach may lead to the development of interventions and new techniques for the application of self-help strategies.
- Hearing impairment is occurring at an alarming rate worldwide. Given that “baby boomers” are reaching the age of high incidence of hearing impairment, combined phenomenology and action research can be used to increase understanding of this problem and to facilitate methods to ameliorate these issues.
- And finally, a review of college and university programs related to rehabilitation studies to determine whether the psychosocial effects of hearing impairment are addressed as part of the curriculum may lead to the stimulation of interest in further research and provide impetus for curriculum development.

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APPENDIX 1

JAMES COOK UNIVERSITY
Townsville QLD 4811 AUSTRALIA

Tina Langford, Ethics Administrator, Research Office. Ph: (07) 4781 4342, Fax: (07) 4781 5521.

ETHICS REVIEW COMMITTEE
(Human Ethics Sub-Committee)

APPROVAL FOR RESEARCH OR TEACHING INVOLVING HUMAN SUBJECTS

PRINCIPAL INVESTIGATOR	*Joseph Lee MacDonald*
SCHOOL	*Education/Malaspina University College, Nanaimo, British Columbia.*
PROJECT TITLE	***Enabling Adults with Degenerative Hearing Loss***
DATE *23 April 2002 – 31 December 2003*	**CATEGORY** *1*

This project has been allocated Ethics Approval Number with the following provisos and reservations: **H1351**

1. All subsequent records and correspondence relating to this project must refer to this number.
2. The Principal Investigator is to advise the responsible Monitor appointed by the Ethics Review Committee:
   - periodically of the progress of the project;
   - when the project is completed or if suspended or prematurely terminated for any reason.
3. In compliance with the National Health and Medical Research Council (NHMRC) ***"National Statement on Ethical Conduct in Research Involving Humans"*** you are required to provide an annual report detailing security of records and compliance with conditions of approval. The report should very briefly summarise progress.

NAME OF RESPONSIBLE MONITOR	*Dr Malcolm Vick*
SCHOOL	*Education*
APPROVED AT MEETING **APPROVED (Conditions Approved by Monitor)** **EXECUTIVE APPROVAL** **Chair, Ethics Review Committee**	***Date: 27 March 2002*** ***Date: 23 April 2002*** ***Date:***
[forwarded by email without signature] Tina Langford Ethics Administrator **Research Office** Tina.Langford@jcu.edu.au	Date: 23 April 2002

APPENDIX 2

202 – 155 Skinner Street
Nanaimo, British Columbia
Canada V9R 5E8
October 10, 2005

Attn: Sara Vanderwillik
Permissions Department
John Wiley & Sons Canada, Ltd.
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Dear Ms. Vanderwillik,

I am writing to request permission to use a diagram from a particular book and I will provide a brief explanation and then the information as requested on your web site.

I am attaching a letter from Emily Pesa, Permissions Department of John Wiley & Sons, Inc., from February 17, 2000. At the time the attached letter was written, I was requesting permission for the use of the same diagram from the same book for inclusion in my Maters degree thesis. One of the co-authors of the chapter and co-editors the book is B. Allan Quigley. Professor Quigley was my advisor through my Masters degree. I am now requesting permission for the same diagram to be included in my Doctoral thesis.

I am unclear as to whether I should be writing to the New York Office or the Mississauga, Ontario office with this request.

First Name:	J. Lee
Last Name:	MacDonald
Name of Company:	N/A
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City:	Nanaimo
Province:	British Columbia
Postal Code	V9R 5E8
Country:	Canada
Contact Phone No:	(250)714-3307 (Office/Cell) or (250)756-0654 (Home)
FAX:	(250)753-8001
E-Mail Address:	Lee.MacDonald@telus.net
Your Reference:	N/A
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Requestor's Phone:	Same as above
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Reprint (IBSN)	IBSN 0-7879-9816-8
Chapter Pages:	Chapter 2. Page 27 Figure 2.2 Cycles of Action Research
Number of Copies To be Made:	12 copies of bound thesis. Two copies of a PowerPoint presentation will be made for simultaneous presentation for the university required exit seminar on October 31, 2005. Exit seminar PowerPoint Presentations will be destroyed on conclusion of exit seminar. This is a form of thesis defence presented simultaneously in Canada and Australia.
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Copies for Resale:	NO
Title of Your Work:	Using Phenomenology and Action Research to Assist Adults with Hearing Impairment Achieve Positive Life Outcomes
Estimated Print Run Date:	It is expected that the final publication of this thesis will be in December 2005 with publication of 12 copies of the thesis in January 2006.

The rush for this request is due in part because of the required Exit Seminar Presentation which is booked for October 31, 4:30 PM PST.

Since I am unclear as to which office should receive this request—New York, NY or Mississauga Ontario—I am sending to both offices.

Thank you in advance for your cooperation with this important request. Your earliest attention would be appreciated and would help to alleviate the ever-mounting stress of approaching deadlines.

Yours sincerely,

J. Lee MacDonald

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APPENDIX 3

Five Aspects of Critical Thinking

The following is a written framework handout for presented at the start of the Action **Research Phase.**

1. Critical thinking is a productive and positive activity which can be creative, imaginative and innovative. One potential outcome of this process is that individuals may develop a more in-depth awareness of the origins of their thinking, behaviours, attitudes, and opinions and that may, in turn, lead to a greater understanding and respect for diversity.
2. Critical thinking is an ongoing process rather than representing a single event or outcome. Adopting a critical thinking mode infers that all assumptions are subject to question. In other words, there is no single path or universal truth. Consequently, each person takes responsibility for what they believe to be true.
3. Critical thinking will be expressed in different ways. Understanding and practicing critical thinking, may, therefore, be reflected attitudinally, behaviourally, emotionally, or cognitively.
4. Critical thinking is often triggered by positive as well as negative events in life. Therefore, any event or experience can elicit critical thinking.
5. Critical thinking is an emotional as well as a rational activity and is not strictly a cerebral activity. Emotions may be evoked as the sources of actions, behaviour, and attitudes.

APPENDIX 4

Assumptions of Action Research

1. Individuals engaged in action research will directly benefit from their participatory efforts.
2. Participants are part of the process for resolving the challenge(s).
3. Participants can formulate change strategies in the midst of their activities.
4. Several cycles may be required in order to resolve the challenges(s). However, once the strategy is learned, it is expected that further efforts to implement the action research approach can be completed within a shorter period of time.

APPENDIX 5.

Action Research

The following questions written out and copies were provided to candidates to stimulate their thinking about their action research project.

Step 1. Presenting the challenge.

- What is the challenge?
- Why does it exist?
- How was I made aware that such a challenge existed?
- What is the most obvious cause of this particular challenge?
- What ideas do I have for interventions to assist with this challenge?

Step 2. Defining the Project.

- How can I intervene with a new strategy or approach to determine if it will make a difference?
- What can I do differently than what I am doing now?
- How will I do this?
- What are the interventions that I can use?
- Can this be done in such a way as to allow me to manage and observe the activities at the same time?
- If changes occur as a result, do I have the strength to manage those changes beyond the project or will I need additional help?
- Who will assist me with the evaluation of this project?

Step 3. Define the Measures

- What are the baselines that can be uses as points for comparison?
- What criteria will be used to determine success?
- Why are these criteria appropriate over others?
- How long will I have for my project? What is the timeline?
- What methods shall I use to collect information from the project?
- How will the actions and outcomes be observed?
- How will information and observations be documented?
- Can we observe the project in a systematic way?
- What barriers might prevent me from completing the project?

Step 4. Implementation of Action and Observing the Results

- Is the original plan being adhered to?
- Is the data being collected in the manner that was agreed to between the primary researcher and myself?
- Is the data collecting and processing demonstrating that I am on track?
- Can an ongoing summary of data be produced?

Step 5. Evaluating the Results

- What I have learned?
- Were the criteria for success met?
- What have others said about the results of my efforts?