

Coping with Mental Illness: Using Case Study Research  
to Explore Deaf Depression Narratives

by

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A Thesis submitted to the Faculty of Graduate Studies of  
The University of Manitoba

in partial fulfilment of the requirements of the degree of

Doctor of Philosophy

Faculty of Social Work

University of Manitoba

Winnipeg

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## ABSTRACT

Optimal health is best achieved through direct access to effective holistic and relevant health prevention strategies, timely and accurate diagnosis, appropriate treatment, and follow-up (K. Woodcock & Pole, 2007). Effective two-way communication is an essential component in all of these stages. It increases the opportunity for a thorough assessment, and thereby contributes to an intervention plan that is appropriate, timely, and suitable to that particular consumer. This study explored how a group of Deaf adults, for whom ASL is their primary language, and all of whom have been diagnosed with depression, managed their symptoms of depression in a health care system that privileges hearing and speaking as the primary mode of communication. A case study methodology with individual, in-depth interviews, and the completion of a hand-drawn person and environment map were used. The participants shared the nature and depth of the barriers that exist and that intersect to prevent their equal access to quality mental health assessment, intervention, and follow-up otherwise available to their hearing counterparts. Faced with these intersecting barriers, negative attitudes from some in the dominant society, and the fear of discrimination from their own collectivist community, participants saw few formal options for managing their symptoms of depression. In most cases participants turned to a strategies of an intrapersonal nature. Some engaged in positive activities such as reading self-help books, volunteering within the Deaf community, walking, and, for two, accessing traditional counseling services. More frequently, however, participants were forced to engage in maladaptive activities such as isolating themselves in an attempt to avoid detection of their symptoms. Some distracted from their feelings of isolation and discrimination through exercise, though others used

alcohol or over-eating as their strategy. A number of changes or enhancements were recommended by the participants, including creation of a comprehensive Deaf Awareness Training plan for professionals and the associated staff, an increase in the number and availability of ASL/English interpreters, and the creation of Deaf sensitive health promotional and prevention materials in modes easily accessible to Deaf visual language users. The study concludes by exploring implications for policy, practice, and future research.

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## ACKNOWLEDGEMENTS

This final paper is but one piece that ultimately formed my academic journey and was ultimately many years in the making. So many people supported me directly or indirectly along the way and I would like to extend my thanks to them.

I would first like to thank the six participants who shared their stories in the hope of making things better in the Deaf community. You were courageous in discussing a most difficult topic. One person reported “things come more slowly to the Deaf community”. I hope the findings from this study can be used to increase the understanding of mental illness in the Deaf community and thus start to dismantle the suffocating stigma that surrounds it. You are ‘winners who have refused to quit’.

Sheila Montney, Len Mitchell, Pastor Barbara Easter, Dr. Michael Stephenson and Rev. Dr. Michael Wilson all contributed to the design and/or recruitment process of this study in some way, many thanks. Jennifer and Terry, and the staff at the Society of Manitobans with Disabilities Inc. Deaf and Hard of Hearing Program provided support and feedback along the way. Special thanks go to Rita Bomak, Sandy Lysochuk, and Bruce Koskie for your additional time and patience with my questions, and your guidance regarding my understanding of Deaf culture.

To my family and friends – you listened, you listened, and you listened again as I talked about my courses, my frustrations, and my successes. I am eternally grateful. In particular I would like to say thanks to Nadine, whose gift with the words “Winners Never Quit and Quitters Never Win” kept me focused throughout, and to Joanne whose support and editing savvy helped with the creation of this final document. And to Nora, my doctoral sister, with whom I shared many a conversation along this journey.

To my sister Shari, thanks, and to brother Darryl and wife Heather, you continue to be my inspiration. Finally, to my mom Anne, and to Audrey and Wray, you again offered unconditional support and encouragement as I pursued *this* journey – I can never thank you enough for all that you do.

Thanks to the University of Manitoba Faculty of Social Work Endowment Fund who provided financial support for my research.

To my committee members; Dr. Denis Bracken, again your patience and insightful comments guided me to a deeper understanding of my goals. I am a better researcher because of it. Dr. Dell Ducharme, your expertise opened my eyes to a more comprehensive understanding of the Deaf community and encouraged my own personal and professional growth. Dr. Brenda Bacon, my committee chair, I am honored that you accepted me as your student. Your wisdom, patience, and gentle encouragement along this entire journey provided me the opportunity to learn, grow and mature as a researcher and professional. I am eternally grateful. And to Dr. Rachelle Hole, thank you for agreeing to be part of this final leg of my journey, your insight, experience and kind words mean so much to me.

Finally, to my kids Kristopher, Bryden and Amanda. You continue to make me proud in all that you do, and all that you are. Thank you for listening as I talked about my classes, my challenges and my research, and for your patience along the way. And to my amazing husband Gord, what can I say, I love you. Yet again you allowed me to the opportunity to follow a dream; always there with words of encouragement and your shoulder to cry on when I needed to. You have been, and continue to be my rock. So many thanks.

## CHAPTER 1: INTRODUCTION

People who are Deaf<sup>1</sup> may sit in the doctor's waiting room, unsure how they will communicate the experiences they are having, the pain they are feeling, or the worries that interrupt their sleep with a doctor they know doesn't understand their language—American Sign Language (ASL)—or understand their culture. Sometimes a family member accompanies the Deaf individual to the doctor's office or hospital; too often that family member also lacks the knowledge or skills necessary in the use of sign language to serve as an appropriate conduit of information between the doctor and patient. The family member, brought to the appointment to assist the Deaf person, may resort to conversing exclusively with the doctor, excluding the patient because neither knows how to include the patient in the dialogue. Occasionally, a sign language interpreter will be called in to assist. More likely, however, when told the patient cannot hear, the doctor assumes the Deaf person can read lips. A battery of questions the Deaf person cannot understand often follows.

When spoken English proves to be an ineffective method of communication, the doctor may resort to writing the question or instruction in English on a piece of paper assuming ASL and English are two modes of the same language (Ebert & Heckerling,

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<sup>1</sup> This paper uses the convention first established by Woodard (1972); the word Deaf (capital "D") is used to refer to those persons who identify as culturally Deaf and part of the Deaf community and for whom American Sign Language (ASL) is their primary or preferred language; the word deaf (small "d") will be used to refer to those persons who are audilogically deaf but do not identify with the Deaf culture or community.

1995). This leaves the Deaf person feeling even more frustrated, angry, isolated, and misunderstood than before. Consequently, mistrust of the patient's physician and the medical system emerges and often interferes with further help-seeking behaviors on behalf of this Deaf ASL first-language user.

### **Population of Interest**

The population of interest in this study is those persons who are prelingually<sup>2</sup> Deaf ASL first-language users and who have also received a diagnosis of Major Depressive Disorder (MDD) as defined in Axis 1 of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR; American Psychiatric Association, 2000) from a health care professional. Persons who self-identify as Deaf are part of a small though collectivist community (Queensland Health, 2008). Collectively this community maintains local, provincial, national, and international organizations related to their Deaf identity, and there are many examples of their collective advocacy resulting in significant change for members of the Deaf community. Often, however, the needs of this population and their successes in change do not reach mainstream society. With the needs of this community remaining largely unknown outside their own collective, it has become a low priority for research, intervention, and policy change.

Those who live with what can best be described, as intersecting oppressions are the focus of this study. They are part of what has been defined as a “multiple-minority status” (Leigh, 2009, p. 144). They are a linguistic minority by virtue of their preference

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<sup>2</sup> Prelingual deafness refers to deafness that occurs prior to the acquisition of spoken language.

for use of a visual language as their primary or preferred mode of communication. This language difference has earned them a ‘disability’ label from the mainstream society that chooses to focus on what they define as pathology associated with degree of hearing rather than acknowledging the cultural significance of the Deaf community. As a result of this label, some persons experience exclusion, marginalization, and communication isolation. This is particularly apparent when one explores the communication disconnect of deaf children, whose first language is visual, from their families, most of whom are predominantly hearing and oral language communicators. Munoz-Baell and Ruiz (2000) have reported that “pathological stigma, negative stereotypes and prejudiced attitudes towards the deaf by those members of the dominant, able-bodied majority disable deaf people more than the pathology of their hearing loss ever could” (p. 42). These experiences associated with the pathological view of deafness can be further compounded for those persons who are also diagnosed with clinical depression as it includes the stigma and discrimination often associated with a diagnosis of mental illness. In fact, Pollard (1996) added that Deaf people report the stigma of mental illness within the Deaf community is a barrier to them discussing their symptoms or experiences with their fellow community members for fear of isolation, marginalization, or exclusion from their own community members.

### **Exploration of the Issues**

The formal, or governmental, and consumer interest in the experience of mental health recovery in dominant society is ever expanding: academic research is being conducted in the area, personal testimonials of lived experiences with mental illness are gaining acceptance as legitimate content, and commissions are being struck around the

world to continue exploring the impact of mental illness on the person, the family, and society at large. In Canada, the Standing Senate Committee on Social Affairs, Science, and Technology (2006) sought to explore and transform mental health, mental illness, and addiction services in Canada. Consumers, practitioners, and service providers shared more than 2,000 stories, both verbally and through written submissions. The committee heard heartbreaking stories regarding the “true state” (Standing Senate Committee on Social Affairs, Science, and Technology, 2006, p. 2) of Canada’s mental health and addiction system. A message consistently recommended by the participants, be they consumers of care, providers of services, or caregivers, supported a national mental health strategy. On November 24, 2005, then Minister of Health Ujjal Dosanjh publically announced the federal government’s intent to create a Canadian Mental Health Commission (Standing Senate Committee on Social Affairs, Science, and Technology, 2006, p. 432). Intended to bring awareness of the prevalence of mental illness in Canadian society into general public consciousness, the committee’s mandate was to seek ways to normalize the reality of mental illness in Canadian society and work towards a comprehensive mental health strategy that would better meet the needs of those living with mental illness and their caregivers.

The new mental health strategy is comprehensive; it is not, however, entirely inclusive (Mental Health Commission Canada, 2012). Strategic Direction 4 focuses specifically on “disparities and diversity” (p. 57). Within this strategic direction, priority 4.2 addresses “immigrants, refugees, ethno-cultural, and racialized” persons (MHCC, 2012, p. 60); priority 4.3 addresses persons from “Northern and remote” (p. 63) communities; and priority 4.4 addresses those from a “minority official language” (p. 66).

Strategic Direction 5 targets First Nations, Inuit, and Métis persons (MHCC, 2012, p. 70). It does not, however, acknowledge the target population of this study—those who not only live with mental illness but who are also part of a linguistic and cultural minority (other than the official languages of Canada), such as those members of the Deaf community. While admittedly the Mental Health Commission's (2012) activities must be targeted, its failure to acknowledge the unique dynamics associated with being part of a linguistic minority who will never become bilingual adds another layer of oppression to the members of this unique community.

Those living with mental illness report oppression resulting from their diagnosis of mental illness. Oppression can be experienced through negative attitudes (prejudice, exclusion, or marginalization) or negative behaviors (discrimination) towards people with mental illness, with its impact potentially debilitating (Canadian Mental Health Association, 2012; Everett, 2006; Mental Health Commission of Canada, 2012). Similarly, the literature written about those members of the community who are Deaf ASL users also report experiences of stigma and discrimination. In the latter case, their experiences of exclusion, marginalization, and isolation occur exclusively as a result of being part of a cultural and linguistic minority. This form of discrimination is distinct from others and is known as audism. Audism is a term first coined by noted Deaf scholar T. Humphries in 1977. He used it to refer to the action of hearing people forming judgments regarding the apparent intelligence of Deaf ASL users because of their use of a visual language that is different from the spoken language of the dominant society. He offered the definition that audism is “the notion that one is superior based on one’s ability

to hear or behave in a manner of one who hears” (Humphries, 1977 as cited in Bauman, 2004, p. 242).

**Two-way communication.** Effective two-way communication is the cornerstone of effective assessment, intervention, and follow-up for those experiencing symptoms of mental illness. The ability to describe to a professional or another helper what one is experiencing, to seek answers or support from others, and to express ones’ needs are all fundamental to recovery (Hill & Nelson, 2000). But for those who are prelingually deaf and use a visual language as their method of communication, effective two-way communication in the language of the dominant society may be difficult, be it with family, friends, or members of the medical or other mental health professions who lack competence in their first (visual) language (Critchfield, 2002). This difficulty results in “information gaps that affect health status and care” (Steinberg, Wiggins, Barmada, & Sullivan, 2002, p. 730). The literature indicates that these gaps are further complicated by the reality that many Deaf ASL users leave high school with a reading level at or below fourth grade due to challenges associated with an educational curriculum that does not meet their communication needs (Critchfield, 2002). For this reason, many Deaf persons have difficulty understanding medical or mental health language or jargon that is communicated in writing during a mental health assessment or during the treatment-planning phase of intervention.

The Deaf person may thus leave a doctor’s examining room frustrated, angry, and bewildered—no further ahead in addressing his or her medical or mental health needs.

The literature also reports, however, that accessible service delivery models that include

sign-fluent professionals or that include ASL/English interpreters in the interactions reduce health care disparities (Steinberg et al., 2002).

**Rationale for the study.** Leigh, Powers, Vash, and Nettle (2004) reported that some professionals who lack expertise or training specific to Deafness and mental health provide services to this population, a reality that is ethically concerning. Leigh and Gutman (2010) added further “quality services for deaf clients have only recently become an aspiration rather than an oxymoron” (p. 3). The profession of social work is positioned to assist individuals in restoring, maintaining, and enhancing their lives through a variety of pathways (Canadian Association of Social Workers [CASW], 2005). This may include encouraging individuals to mobilize their personal strengths by supporting their development of positive coping strategies and resilience or by addressing the structural and environmental realities that hinder these processes (Heinonen & Spearman, 2010; Ontario Association of Social Workers, 2006). These goals stem from the profession’s longstanding commitment to individual self-determination, the pursuit of social justice, and respect for the dignity and self-worth of all (CASW, 2005).

The profession of social work has historically played a specific and critical role in the mental health system. It has done this both by promoting positive mental health and wellness and by addressing challenges associated with mental illness; it continues to do so today. According to the Canadian Institute for Health Information [CIHI] (2009) there were 723 registered social workers in Manitoba in 2009. Of these, 84% were female and 16% male. As documented in the CIHI report, Canada’s Health Care Providers, 2000–2009: A Reference Guide, 84.7% of social workers nationally are employed in the field of mental health. Neither the CIHI, the Manitoba Association of Registered Social

Workers or the Canadian Association of Registered Social Workers inquire about or record how many social workers work directly or indirectly with persons who are deaf/Deaf or hard of hearing provincially or nationally. This number is currently unknown.

This study was intended to explore a unique social justice issue in the field of mental health. The aim was to explore how a small group of minority language users (both by language [ASL] and mode [visual]), who have also been diagnosed with clinical depression, or Major Depressive Disorder [MDD], manage their symptoms of depression when faced with a medical and social service system that is designed around a culture dominated by hearing and speaking. Of particular interest was the nature of the relationship between Deaf ASL users and the medical and mental health professionals with which they engage, the nature of the strategies used to achieve stability with their symptoms of depression, and the strategies used to maintain wellness in a linguistic environment that is not only different from their own environment but is also different from their own community's environment—a community with limited understanding of mental illness.

I believe the findings suggest that this study should be used to ignite thinking about, broadening awareness of, and promoting understanding of the unique nature of the experiences for this group of individuals living with depression. By extension, I intend the dissemination of these findings to promote both the need for a call to action for change in the area of mental health practice and the need for specialized training of professionals in the area to better meet the needs of this population.

This study is particularly timely given the recent releases of the Manitoba

provincial (Government of Manitoba, 2011) and Canadian national (Mental Health Commission of Canada, [MHCC] 2012) mental health strategies. Both are intended to promote awareness of the needs of those living with mental illness and seek ways to promote change. The Manitoba mental health strategy acknowledges the unique and diverse experiences of individuals living within Manitoba, and calls for “increased cultural safety at practice and policy levels” (Government of Manitoba, 2011, p. 11). Similarly, a fundamental goal of the national strategy is to seek ways to “reduce disparities in risk factors and access to mental health services, and strengthen the response to the needs of diverse communities” (MHCC, 2012, p. 78). The findings of the current study should hopefully not only provide insight into the barriers imposed by the current mental health system for persons who are part of the diversity within Manitoba but also support the need for further study in the area.

**Self-reflection.** My interest in the topic of this study is both personal and professional. Personally, I am the youngest in a hearing family with no history of profound deafness until the arrival of my older brother. When first diagnosed with profound deafness, and consistent with the philosophy at the time, my parents were discouraged from learning sign language themselves or from encouraging my brother to gain competence in sign language. As I witnessed and experienced the communication gap in the family, I felt the need to gain the language skills necessary for communication with my brother. After much study, practice, and continued learning, I have acquired a level of competence sufficient for two-way communication in sign language. Later, in my professional life, I applied these same communication skills to my work with a small number of clients who were also Deaf and used Sign Language as their primary language.

The seed for this study was truly planted many years ago during my work with two Deaf clients; unequally fluent in ASL, they were equally challenged in accessing supports and services for their respective personal needs. They, and I on their behalf, consistently met with roadblocks when attempting to secure fundamental services, with us all becoming more frustrated and flabbergasted at every hurdle. As my professional work in the area of mental health expanded, that small seed of research interest grew and finally became visible during my Ph.D. studies. Bearing witness to the challenges experienced by these Deaf clients sparked my own desire to explore further how others who are Deaf ASL users and are diagnosed with depression or anxiety manage their symptoms of depression while living in a predominantly hearing and speaking society.

The dearth of research in the area of mental health and deafness suggests this is an understudied population with circumstances little understood or visible to most in mainstream society including professionals. I hope that these findings can spark in others the same desire I feel to seek the changes necessary to make our existing and emerging mental health system truly responsive and respectful of all.

**Mental health prevalence in the general population.** The mental health prevalence statistics in North America suggest that the majority of North Americans are physically and mentally healthy and able to live self-actualizing lives (Austen, 2006; Leigh & Pollard, 2011). Notwithstanding this reality, it is also reported that one in four Manitobans will experience at least one mental health diagnosis in their lifetime (Mertens, 2004); nationally, the figure cited is one in five (Canadian Mental Health Association [CMHA], 2013). Of these numbers, it is reported that 3% of the population will experience a serious mental illness, with 17% experiencing a mild or moderate

mental illness (Kirby & Keon, 2006, p. 50). Mental health problems can and do affect people of all ages and cultures, cutting across the lifespan and the economic strata.

Around the world, the World Health Organization (WHO, 2013) reported depression is the “leading cause of disability as measured by Years Lived with a Disability (YLDs) (Reddy, 2010, p.1). By the year 2020, the WHO projects that depression will reach the second place ranking for Disability Adjusted Life Years (DALY) for all years (Reddy, 2010, p. 1). The WHO further predicted that by the year 2020, depression would become the second leading cause of disability in the world next to heart disease.

According to the MDSC (2009), between 7.9 and 8.6% of Canadians will experience depression in their lifetime, with women twice as likely to experience depression as men (p. 7). The most common symptoms experienced by Canadians, and those which have the greatest impact on the activities of daily living, are reported to be lack of motivation (90%) and loss of the ability to enjoy one’s favorite activities (80%). As well, 77% of Canadians reported difficulty in concentrating and 74% reported feelings of isolation (MDSC, 2009). Alarming, it is reported that some 90% of persons experiencing depression will not seek needed treatment (Mood Disorders Society of Canada [MDSC] Fact sheet: 2009, p. 7).

**Deaf population.** The statistics regarding the physical and mental health of persons who are Deaf are consistent with those of mainstream society; the majority is physically and mentally well and able to lead self-actualizing lives (Leigh & Pollard, 2011). The literature reports that Deaf individuals are disproportionately victims of trauma when compared to their hearing counterparts. According to Sullivan (1987) “Deaf children are also more than twice as likely to experience physical and sexual abuse compared to their

hearing peers” (as cited in Tate, 2008, p. 2). Further, there are reported differences in the psychological and emotional development between deaf children raised by Deaf adults and deaf children raised by hearing adults. Research suggests that Deaf parents often look forward to the birth of a Deaf child as they feel better able to understand the struggles that may be faced, and better able to offer strategies for managing within the dominant hearing culture (Schein, 1989). The research also suggests that deaf children of culturally Deaf parents have the advantage of early and constant exposure to a Signed Language, to a positive Deaf identity and to a community that supports Deaf culture and Deaf identity. These factors can serve to empower the deaf child as they begin to establish their own Deaf identity and gain social knowledge of the world around them (Munoz-Baell & Ruiz, 1999). Deaf children of hearing parents, however, often do not have access to the same emotional and psychological protective factors deaf children of Deaf adults do and may be at greater risk for emotional and language isolation.

The literature related to mental health and deafness is consistent with the mental health statistics from the dominant community and reports that a percentage of persons who are Deaf ASL users also experience and live with a mental illness requiring mental health intervention. The amount of academic literature related to Deafness and mental health is marginal, however, so it is difficult to assess the actual depth of the issue in this population. Pollard (1994) and Queensland Health (2008) suggested that, at a minimum, the incidence of mental illness in the Deaf community is approximately similar to that in the hearing population. Austen (2006) suggested a higher prevalence of serious mental disturbances in Deaf adults and children when compared to the hearing populous. Hill

and Nelson (2000) suggested the prevalence of mental illness might be as much as four times higher in the Deaf population than in the hearing population.

**Risk factors.** A number of explanations have been forwarded regarding the disparity between the suggested prevalence of mental illness in the Deaf population when compared to the hearing population. Austen (2006) suggested the dynamics in which many Deaf children are raised and the ongoing challenges of living amongst a larger society with a language most will never gain full fluency, can cause ongoing emotional and personal challenges and escalates one's risk for mental illness. Hill and Nelson (2000) found that the experiences of isolation, "daily systemic discrimination" (Executive Summary, p. i) and being a victim of physical and sexual abuses also contribute to the higher incidence of severe stress and trauma in the Deaf and elevate their vulnerability to mental illness. Pollard (2009) added further that, due to the number of assessment, service, and intervention accessibility barriers, only 2% of Deaf individuals needing mental health services actually receive them.

Experts in the field of mental health and Deafness report that the services for this population are, sadly, decades behind where they are in the hearing population (Glickman & Pollard, 2013; Munro-Ludders, Simpatico, & Zvetina, 2004; Steinberg, Sullivan, & Loew, 1998; Tate, 2008). Few medical or mental health professionals or recovery-based resources possess familiarity with ASL and Deaf culture or experience in communicating through a visual language; they thereby lack the skills necessary to communicate directly with this population (Brice, Leigh, Sheridan, & Smith, 2013). Vernon and Leigh (2007) proclaimed, "without doubt, people who are d/Deaf and mentally ill are the most neglected segment of the mentally ill population in the United States" (p. 374).

The need for culturally congruent, appropriate mental health services for the Deaf population is an issue reported around the world. Australia (Queensland Health, 2008), Brazil (Pereira & Fortes, 2010), Norway (Kvam, Loeb, & Tambs, 2006), and the United States (Brice et al., 2013) are but a few countries that have studied and reported on this issue. While the research methodologies have varied, the most consistent theme reported across the literature is the need for a comprehensive understanding of the diversity found within the Deaf community, including language and cultural factors though also possible medical, neurological or other cognitive factors that may be associated with the deafness and impact the “diagnostic picture” (Brice et al., 2013, p. 302). This can occur through advanced training for professionals, community resource staff and support services, as well as through the creation of culturally and linguistically appropriate policies that more accurately meet the needs of this population. It can also occur through encouraging enhanced resilience and individual self-advocacy skills for members of the Deaf community so that individuals and the community collectively can seek changes necessary for competent health care services.

Pollard (1994) found that there are a number of inconsistencies in service assessment and provision between a Deaf and hard of hearing (DHH) sample when compared to a hearing sample. In brief, he found a narrower range of diagnoses attributed to the inpatient DHH clients than to the hearing clients. He also found a higher percentage of files reported deferred, missing, or no diagnosis given. From these data, Pollard (1994) suggested these results might arise from mental health professionals who lack the skills to communicate effectively with the Deaf ASL user inpatient as well as the appropriate knowledge and skills necessary to assess and to diagnose mental illness in

this population accurately (see also Leigh, Powers, Vash, & Nettles, 2004). Lieu, Sadler, Fullerton, and Stohlmann (2007) reported that a language disconnect between a Deaf Sign Language using client and a speaking, hearing professional can lead to “awkward, abbreviated and often aborted communication by one or both parties” (p. 542). Sheppard, 2008) reported similar results in her study. Deaf patients have reported feeling unfamiliar with and thus disempowered in their patient role. They have also reported feeling uncomfortable seeking additional clarification regarding diagnosis or treatment because of the barriers to effective communication. Add to these concerns a lack of available communication technologies or devices to facilitate full access to resources or supports (DeVinney & Murphy, 2002) and a lack of accessible mental health promotion or prevention materials (Baines, Patterson, & Austen, 2010; Pollard, 2009), and the barriers compound to result in health care disparities for this population.

Deaf ASL users and members of the Deaf community are, for most in our society, an invisible population. There are many historical and current examples of the resiliency and power of the Deaf communities locally, nationally, and internationally to make change. The 1880 Milan Convention, for example, resulted in the removal of sign language as a method of instruction for the Deaf around the world for over 100 years with the exception of Gallaudet University who fought back at that time and retained Sign language as the language of instruction. In 1988 students and staff at Gallaudet University challenged the appointment of yet another hearing president in spite of qualified Deaf candidates. The ‘Deaf President Now’ rally at the Gallaudet University closed the university for three days and made news the world over – the power of the rally resulted in the appointment of the first Deaf president in the university’s history. In

1988 members of the Deaf community in Manitoba successfully fought for the establishment of a province-wide telephone relay service, the third province in the country to do so. The same year, the Deaf community in Manitoba was successful in their campaign to have American Sign Language recognized as the official language of the Deaf in Manitoba. Nationally, the Deaf community fought for and won the right for close captioning. Collectively, the Deaf community has demonstrated the power to make change. Individually however, many Deaf people appear to lack the confidence and skills for individual personal self-advocacy. These individual skills could be of benefit to Deaf individuals in all aspects of their life, though particularly in seeking or advocating for health care and other services in the dominant formal and informal support systems that congruently meet their needs.

The number of Deaf ASL users in Manitoba, and North America are small. This number is not indicative however, of the level of need each individual Deaf person living with mental illness has. This level of need, combined with the range of barriers and challenges noted above, collectively form the rationale for this study.

### **Study Overview**

**Focus of the study.** This research explored the nature of the micro-level interpersonal, behavioural, and adaptive strategies used by a small sample of Deaf ASL users who have been diagnosed with mental illness in managing their symptoms of depression when faced with a medical and mental health system that privileges hearing and voice communication. This study was unique because it shifted focus from the relatively known, that of mental illness and mental health recovery strategies in the dominant culture, to the unknown, an exploration of coping strategies used by adults who

communicate through American Sign Language. Also unique is the location of the sample; this study focused specifically on the Deaf experience in locating assessment and intervention supports following a diagnosis of depression, while living in the community. The majority of existing research with Deaf adults living with mental illness focuses on an inpatient population. The research was intended to gain understanding of this phenomenon and seek insight into possible implications for policy, practice, and future research.

**Research questions.** One overriding question guided this study: “How does a group of Deaf adults, for whom ASL is their first or preferred language, and who have received a diagnosis of Major Depressive Disorder, manage their symptoms of depression when seeking services from a medical and mental health system that privileges hearing and speaking?” I developed a semi-structured interview guide around this primary area of interest. To enhance the understanding of this topic, I chose to focus on three primary points in relation to the participants’ diagnosis of depression: the strategies the participants used when first feeling unwell and seeking intervention for their symptoms; the strategies they used following the initial diagnosis of depression to reduce their symptoms of depression and return to wellness; and the strategies they used to maintain wellness. While I acknowledge that the strategies used may overlap across these time periods, I consciously focused on these three periods in the event they were, in fact, different. There is an element of retrospection in the participants’ reporting as they were asked to think about their strategies over the past one-year period. The reader is referred to Appendix A (Interview Guide) for a copy of the questions used to guide this research.

**Methodology.** Qualitative research generally attempts to capture the meaning of peoples’

lives, including the contextual conditions within which the participants' lives take place (Yin, 2011, p. 93). It also attempts to capture the perspectives of the participants in relationship to the phenomenon under study. I conducted this study using a case study research design (Yin, 2011; Stake, 2003). This method acknowledges that investigators attempt to explore an issue or phenomenon through persons with the lived experience of that issue or phenomenon, though also acknowledges one cannot truly have unfettered access to another person's experiences. As Stake (2003) reports, "Qualitative researchers are guest in the private spaces of the world" (p. 154). Admittedly, issues such as time since event(s), comfort in disclosing information, and memory recall can all impact the content shared with the researcher; the intent then is to design the study such that it seeks access to the information sought.

This study specifically incorporated a qualitative research interview as the primary data-gathering strategy for the sharing of experiences, a common research tool in many types of qualitative research including case study research (Crabtree & Miller, 1999). The interview process and question guide were used to "create a listening space where meaning is constructed through an interchange/co creation of verbal viewpoints in the interest of scientific knowing" (Crabtree & Miller, 1999, p. 89). The research interview was also intended to provide the opportunity for me, the researcher, to listen to the participants' stories specifically with the intention of "mining the gold of information stored in participants" (Crabtree & Miller, 1999, p. 89) and thereby providing an opportunity for a deeper understanding of the issue or phenomenon. In keeping with the constructionist tradition, I acknowledge that the nature of the interview process may evolve as data are collected. I also acknowledge that the data would be context dependent

and that the research process would include an inductive data analysis process (Asmussen & Creswell, 1995).

This study was designed as a single case study design; the “case” was bound both by the invisible parameters surrounding those persons who self-define as members of the Deaf community in Manitoba and by time, using current experiences (defined as within the past 12 months) as the focus of interest. Data triangulation occurred through the collection of data from different sources and through different methods of data collection. This provided the opportunity to explore whether two or more sources of information converge to the same finding; the more researchers can demonstrate convergence, the stronger their evidence.

First, I incorporated an adapted version of the ego-centered social network map into the semi-structured interview guide. The social network map is a clinical assessment tool that assists the client to identify potentially useful resources as well as report their perception of those resources (Kemp, Whittaker, & Tracy, 1997, p. 115). I redesigned and re-titled the map the ‘Person and Environment Map’: the focus was intended to be broader than that of the social network map (Abell & Tracy, 1994) used by Hintermair (2009). In brief, participants were asked to hand draw a record identifying the persons, places, and/or things (or activities) each personally used or engaged in to help them manage their symptoms of depression (See Appendix B – Person and Environment Map). The map was intended to provide a visual opportunity for this sample of visually based learners and communicators to share the nature of their strategies for managing their symptoms of depression in a manner that may be more congruent with their visual language. It was also intended as a method of triangulation. Participants began by

drawing a small circle on the centre of the page, which was to represent them. They then were asked to draw a series of increasingly larger concentric circles around that centre circle and place the people, places, or activities they used to assist to manage their depression on the map. The strategies used most frequently were to be placed closest to the centre circle, and those used less frequently placed increasingly farther away.

To supplement the personal interviews, I included one variation of observation, namely videotaping (Crabtree & Miller, 1999, p. 18). I videotaped the interviews and used those tapes to assist in creating the written English transcripts. The videotapes provided me the opportunity to view the signed communication at length and in depth through repeated observation of body language, facial expressions and emotions present thereby enhancing the orally interpreted content.

Finally, though not a traditional method of triangulation as identified by Yin (1994), I maintained a codebook for recording thoughts, challenges, ideas, and processes throughout the study process. These later informed the data analysis and writing processes. In regards to data analysis, I did so using the case study analysis design. Each of these will be described further in Chapter Three, Methodology.

This study was unique in that the interviews were conducted in the participants' first language of ASL. I used an ASL/English interpreter directly or indirectly with each of the 23 interviews I conducted. I then created a transcript based on the oral interpretation of the signed communication. While I created the transcript based on a spoken English interpretation of the signed language used in the interview, I, too, needed a method through which to verify accuracy of the typed transcripts. To accomplish this, I incorporated an opportunity for member content-checking. This inclusion was intended to

accommodate the potential for varied reading levels as consistent with cross-cultural research ethics and to minimize potential content errors resulting from the interpretation process itself.

I analyzed data using an inductive process. This process enhanced my understanding of the challenges faced by this group of visual language users and of the strategies for managing their symptoms. The results of this study are consistent with existing research and literature regarding this population (Steinberg et al., 2002), though further enhances the literature through the focus on personal narratives.

The participants in this study demonstrated resilience in seeking ways to manage their symptoms in spite of the odds they faced. The strategies used were not new or novel when compared to the strategies reported in the literature from the dominant population; what was most obvious was that the range of treatment or therapeutic options available to them was restricted due to communication and other barriers not faced in the mainstream. Finally, participants willingly shared their thoughts on ways to dismantle the existing barriers and enhance the system in a health care and service support system in a manner that would be more culturally congruent and, thereby, safe for this population. The results of this study and the suggestions for change offered by the participants form the basis of my final chapters and the discussion regarding the implications of this research for policy, practice, and future research.

### **Organization of This Dissertation**

The chapters that follow expand on the content reported in this introductory chapter. Chapter Two explores the literature relevant to this study. Chapter Three expands on the nature of case study research, the method used in this study. I discuss the

foundation of the approach, its main tenets, and my rationale for incorporating this approach into this study.

Chapter Four focuses specifically on study findings. I begin with a discussion of the overarching theme of communication barriers. I then discuss the four corollary themes that emerged, highlighting each through statements selected directly from the transcripts. I remind the reader that while the representative statements are enclosed in quotation marks, the quotes are, in fact, the ASL/English interpreters' construal of the participants' ASL-signed stories; they are not a verbatim translation of the language of ASL. I discuss the challenges associated with conducting research through an interpreter, as well as the importance of the member content-checking procedure as an empowering process through which to enhance accuracy of the narratives.

Chapter Five provides a discussion on these findings and offers conclusions arising from this study. Finally, Chapter Six shares a discussion regarding the implications of this research on policy, cross-discipline practice, and future research. I discuss implications of this research in relation to the professionals who are tasked with working in this field, the families of the participants, and the role of the participants themselves in challenging existing structures to encourage change.

## CHAPTER 2: LITERATURE REVIEW

This chapter begins with an introduction to the term deafness. It continues with the three primary views of deafness as reported in the literature. It includes a discussion on the sociocultural aspects of Deaf culture, including the collectivist nature of the Deaf culture. The topic of Deafhood is also introduced. This chapter then continues with a discussion related specifically to mental illness and depression, followed by a review of the findings specific to mental health and Deafness. The challenges, barriers, and factors that reportedly inhibit access to mental health services for this minority population are also discussed. Finally, I discuss the qualitative research method and the rationale for choosing the case study method for this study.

### **Introduction to d/Deafness**

The term deafness, here intentionally reported using a lowercase d, is a complicated issue primarily because conflicting ways of defining deafness compete for control over the “true” meaning of the term (Hole, 2004; Jones, 2002; Lane, 1995). As with other physical, mental, or emotional human differences that are defined as disabilities, and given the diversity found within the population of those who experience deafness, there is no universally recognized meaning of the term (Baynton, 1996). There are currently, however, three dominant constructions of deafness. The three constructions of deafness are (a) deafness as disability, more commonly referred to as the medical model; (b) deafness as difference, as defined through the sociocultural construction (Hole, 2004; Jones, 2002); and (c) deafness as defined through the social model of Deafness. Each offers a different perspective on assessment and intervention as well as the shaping of Deaf people’s identities (Lane, 1995).

The medical model of deafness is the historical view of deafness, though it continues to dominate within medical and educational fields today. The second was developed in reaction to the medical model of disability and can be traced to the 1960's civil rights and human rights movements. The third, a more recent construction first introduced some 30 years ago, considers Deafness as a trait, not a disability (Jones, 2002). This section explores these dominant constructions. It concludes with a discussion on possible implications of these three models on the Deaf identity and access to services, as well as the role each construction plays in the execution of social work practice.

**Medical model of deafness.** The medical model of deafness, also called the pathological model (Lane, 1995) or the infirmity model (Lane, 1999), defines deafness as a personal defect or disability. This model of deafness is based solely on audiological test results or hearing thresholds with little consideration for the social experience of deafness (Queensland Health, 2008; Sheppard, 2008). In this model, deafness is viewed as a “category of oppression” (Davis, 1995, p. xix). Ladd (2003) reported that the medical model “blames the victim” (p. 15), in this case the deaf person, for his or her inability to achieve audiological equality within the hegemonic hearing and speaking culture. Knight (1998) added that, in this view, “It is *their* [the deaf persons'] functional limitation which is the root cause of the disadvantages experienced, and these disadvantages can only be rectified by treatment or cure” (p. 215). In this view, deafness is viewed as requiring treatment or a cure to correct what is believed to be vocational and social challenges associated with the debilitating effects of audiological hearing loss.

The outcome of the medical model is that those individuals who are not cured or corrected to a society's standards of hearing as established by the majority culture are

then marginalized by what society defines as having a disability. Longmore (1995) suggested that the consequences of individuals not being “cured” of their hearing loss results in their marginalization, relegating them to a status of social invalidism. While invalidation may take many forms, social invalidation is viewed as denying the very core of one’s identity, thus being the most oppressive form. Leigh, Corbett, Gutman, and Morere (1996) defined the medical model of deafness as a “compensatory and pathological perspective” (p. 366) that implies something is missing in that Deaf person, and otherwise suggesting a Deaf person is “less than” a hearing person.

Wixtrom (1988) is of the opinion that the medical model distinguishes Deaf people as being “abnormal” in comparison to the “normal” hearing person. Lane (1999) explained further that, within the hearing paternalism of the medical field, professionals view their task as being that of “civilizing” (p. 37) their deaf charges through medical correction. This places the beneficiaries of medical services in a position of dependency on the full range of medical professionals as necessary to assist them to ‘overcome’ their handicap. Sociologist Joseph Gusfield (1989) agreed and added that the medical model can also be viewed as the “troubled persons’ industry” (p. 432), explaining that the industries supporting the medical model, be it to address deafness specifically or disabilities in general, thus serve to “bestow benevolence on people defined in need” (p. 432 as cited in Lane, 1995, p. 81).

Criticisms have been launched of the medical model. Many view it as uni-dimensional and devoid of any phenomenological understanding of the disabled person’s own perspectives or experiences. Lane (1995) is of the opinion that the medical professionals who espouse this model do so for a variety of reasons, not the least of

which is economic. Within the field of deafness there are a range of hearing-specific professions deemed necessary to return the person with hearing loss to “normal”; these include interpreters, audiologists, speech therapists, otologists, and hearing aid specialists (Lane, 1995). These ‘troubled-persons’ professionals serve the clients, while also serving to disempower those same clients and perpetuate their dependency on the medical professionals by virtue of their structural relationship (Lane, 1995). While the medical model of deafness is viewed as relevant for those persons who were born hearing but lost their hearing post-lingually, such as through the natural aging process, illness, or accident, it is viewed by members of the Deaf community as blocking their right to compete for legitimacy in society.

Medically, or audiotologically speaking, hearing is measured both by intensity or volume in units called decibels (dB) and by frequency in units called hertz (Hz). (First years, 2011). When a person’s hearing is tested, the results are plotted on a graph to produce an audiogram; this graph documents the softest sounds a person can detect at various low to high frequencies 50% of the time (First Years, 2011). By way of example, a spoken conversation is measured at an average of 60 dB and ordinary traffic sounds are measured at 80 dB. The pain threshold, such as heard by the sound of jet engines, is reported at 125 dB. Further, vowels are defined as low frequency sounds and consonants (such as /s/, /f/, and /th/) are defined as high frequency sounds. A person whose hearing is within normal range can hear sounds that are less than 25 dB in volume. People requiring levels higher than 25 dB to detect sound are defined medically as having some degree of hearing loss.

Hearing loss is categorized into five distinct levels. A mild hearing loss is

diagnosed if an adult requires sounds at volumes between 20–40 dB to hear. A moderate hearing loss is defined as requiring sounds at volumes between 40–70 dB to hear (in this range persons have difficulty hearing normal conversation volumes, particularly if background noise is also present). Severe hearing loss is defined as needing volumes of 70–90 dB to hear (conversational speech cannot be heard unless a person speaks loudly and directly into an affected ear). A diagnosis of profound hearing loss occurs at 90 dB and above, when speech cannot be understood even if sound is yelled into the person's ear and when most sounds are inaudible (First Years, 2011).

Those with a mild hearing loss generally rely on aural-oral (auditory-verbal) communication as their primary mode of communication, using their available hearing either with or without hearing aids or other assistive devices for communication. They may also take advantage of other visual cues on the part of the speaker (e.g., lip reading) to facilitate communication, though hearing continues to be the primary contributing component of communication. At the other end of the spectrum, those with profound hearing loss generally cannot access available sounds, thereby making communication through hearing and speech unlikely, if not impossible (First years, 2011). Those falling on this end of the continuum may use a visual language as their dominant method of communication. The description of hearing status presented above is quantitative in nature; it does not define or describe the impact of hearing status on that person's life.

Severe or profound deafness is a low-incidence condition, with intergenerational deafness even more rare (Ries, 1994, as cited in Mitchell & Karchmer, 2004, p. 139). According to the National Institute on Deafness and Other Communication Disorders (NIDCD), approximately 2 to 3 out of every 1,000 children in the United States are born

deaf or hard of hearing (NIDCD, 2010). The most commonly reported statistic is that 90% of deaf children are born to hearing parents, with 10% born to at least one d/Deaf<sup>3</sup> parent. More recently, Mitchell and Karchmer (2004) reported that, based on their review of the research over the past 30 years and on their own study, less than 5% of deaf and hard of hearing children have at least one Deaf parent. These families can be defined as living with two languages, both oral English and signed ASL.

**Social model of deafness.** The disability movement of the 1960s provided the impetus for a second view of disability, the social model of deafness. Where the medical model places the disability within that individual's very person or identity, with the medical diagnosis the focus and impetus for intervention, the social model defines the disability as resulting from social oppression and social inequalities. Originally coined by academic Oliver (1983), a person himself disabled, the social model identified society as constructed solely for those who are non-disabled, leaving those with challenges, be they intellectual, physical, mental, or other, at the mercy of charity, benevolence, and munificence (as cited in Oliver, 1990). In this model, persons with disabilities are viewed as the "collective victims of an insensitive and discriminatory society" (Oliver, as cited in Williams, 2001, p. 134).

The social model of disability asserts that all persons are fundamentally equal and therefore entitled to full citizenship regardless of difference. This model contends that it is societies' collective responsibility to ensure that the built environment and related

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<sup>3</sup> When written as d/Deaf it refers to a group of persons that include both those who are audiologically deaf as well as culturally Deaf.

social policies take into account the needs of all persons as the pathway to facilitating equal access and full citizenship of all. A society that fails to accommodate the needs of persons with disabilities, be they mental, physical, intellectual, or other, is viewed as exhibiting social and political discrimination (Ladd, 2003).

The call in the social model of disability is for acceptance of human diversity as simply a form of human variation. It promotes societal change as the necessary catalyst towards reducing disability discrimination, and, by extension, arguing for full social inclusion of all persons with differences into society (Longmore, 1995). Longmore offered a description of the values necessary to promote support for the human rights of all citizens and for societal changes: “not self-sufficiency but self-determination; not independence but interdependence, not functional separateness but person connection; not physical autonomy but human community” (1995, p. 9).

To apply this model to the lives of persons who are Deaf, one looks towards items of accommodation used by some people who are Deaf. This may include items such as flashing lights in place of sound-based alarms, closed captioning on TV, and access to ASL/English interpretation as necessary to facilitate successful two-way communication. While viewed by some as superior to the medical model as it marked a repudiation of the “paternalistic domination” (Longmore, 1995, p. 3) by non-disabled society, there is concern that this model ultimately continues to place a physical marker (in this case hearing loss) in the forefront of identity. Ladd (2003) deemed that Deaf communities have been swept along with the social model movement largely because they have lacked the collective power for self-advocacy and the collective strength to dispute this model. He contended, however, that Deaf people have, more recently, begun to reject the social

model of deafness because of its inherent focus on limitations. Many in the Deaf community have begun to explore their Deaf identity and acknowledge the inherent strengths associated with a positive Deaf identity.

**Sociocultural model of deafness.** The sociocultural model of deafness is the third defined model of Deafness. This model was first introduced some 30 years ago and continues to gain momentum in the Deaf community as the ‘deafness as difference’ model of deafness. This model asserts and supports the Deaf group perspective (Jones, 2002; Longmore, 1995). The ‘deafness as difference’ model is what the late professor and disability activist Longmore (1995) defined as part of the second phase in the quest of disabled persons. Longmore defined the first phase as a quest for disability rights, including social inclusion, equal access, and equal opportunity for those living with disabilities. The second phase, however, is defined as a process of reinterpreting oneself and affirming one’s identity beyond the mainstream social construction and labels associated with disabilities. It is viewed as a quest towards an empowered collective identity beyond the paternalistic domination imposed by those in or associated with the medical profession.

The sociocultural or, more simply, the cultural model is one being promoted by many Deaf persons and their advocates as well as other professionals working within Deaf communities. Proponents of the ‘deafness as difference’ or cultural construction assert that deafness is not a pathology that is in need of repair, cure, or fixing (Dolnick, 1993; Jones, 2002; Lane, 1995 1997; Padden & Humphries, 1988). Rather, as McKee (2008) reported, it is a political discourse of Deaf ethno-linguistic identity that has empowered Deaf people to dismantle the medical model of deafness that centers on

speech. Davis (1995) suggested that many members of the Deaf community have come to view their hearing status not as a disability or as needing to be defined medically but rather prefer it to be “defined socially and politically” (p. xiv). Followers of this model view themselves as being part of a group whose existential situation is that of a cultural and linguistic minority (Davis, 1995; Jones, 2002; Ladd, 2003; Lane, 1995; Leigh et al., 1996; Longmore, 1995; Padden & Humphries, 1988; Parasnis, 1998; Sacks, 1989).

The cultural model rejects the medical model and its focus of locating the “problem” for persons living with disabilities in the bodies of those very same people. It also rejects the suggestion that medical repair, replacement, or correction of the problem (e.g. deafness) is necessary to return these people to mainstream culture (Longmore, 1995; Parasnis, 1998). It asserts a new frame of reference that elevates hearing status to that of difference, akin to “an innate characteristic exhibiting variation, such as race or skin color” (Parasnis, 1996, p. 8; see also Jones, 2002). The focus in this construction is on the identity of the person as a member of the Deaf linguistic and cultural minority (Hole, 2007; Munoz-Baell & Ruiz, 2000; Parasnis, 1998), promoting visual channels of communication and visual languages as different, but equal to, spoken languages (Wixtrom, 1988).

Dolnick (1993) presented a summary of the Deaf culture debate. He drew the parallel that families comprised of hearing parents and a deaf child ultimately belong to different cultures, just as the two parties would in the case of interracial adoptions. This view acknowledges that the majority of profoundly deaf children are born into hearing families who have little prior exposure to deafness. It accepts the child as a bilingual-bicultural minority child who, like those in the gay community, do not share their identity

with their parents and, therefore, do not have the same opportunity for vertical acculturation in the home. It recognizes that deaf children instead must seek and gain knowledge of their culture horizontally through their Deaf peers, through the residential or Deaf school system (Lane, 1999; Parasnis, 1998), or through successful Deaf adults who serve as positive role models and mentors to the horizontal acculturation process (Leigh et al., 1996).

Deaf people are not highly visible in our society, and representations of culturally Deaf people in mainstream media are rare (Garden, 2010). Clinicians who are able to gain knowledge about the emic experience of Deafness and of the Deaf community as a national and international community with their own history, languages, organizations, art forms, and humor can serve as an educated conduit to supporting Deaf identity (Ladd, 2003). They can also serve as a bridge to resources and opportunities, thereby facilitating equal access to the same rights and privileges enjoyed by those in the dominant hearing culture (Wixtrom, 1988).

**A collectivist culture.** The Deaf community historically held a “differential position in the societal hierarchy” (R. Harris, Holmes, & Mertens, 2009, p. 124) and continues to do so today. It is defined as a collectivist culture (Queensland Health, 2008) with views and realities different from most hearing cultures, many of which are defined as individualist cultures. While both cultures express themselves through issues such as identity, loyalty, obligation, and independence, each of these are valued differently in this binary. The Deaf community is defined not by physical boundaries but instead through the existential connection to the values, language, and culture of the community (Padden & Humphries, 1988; Tate, 2012). Fluency in a shared visual language such as ASL, is the most

important bond linking persons to the Deaf culture, though shared residential school experiences and ties, a strong Deaf identity, involvement in Deaf interests, and respect for Deaf theatre, art, poetry and storytelling are also fundamental components representing membership in the Deaf community (Canadian Association of the Deaf [CAD], 2012; Lane, 1999; Queensland Health, 2008). Given the use of a visual language, face-to-face communication is preferred, as are visual means of receiving information (e.g., pictures, diagrams, demonstrations, etc.). Importance is also placed on attendance at and involvement in Deaf events such as Deaf sports, Deaf festivals, sitting on community boards of directors, and teaching ASL within the community. Involvement in the Deaf community is believed to protect and nurture those who remain within its network of primary and secondary social ties and is also believed to cement one's social identity as a member of the Deaf community. Failure to engage in and promote the community's activities, values, and language is viewed as a denial of one's deafness and, by extension, a denial of one's Deaf identity (Emerton, 1996).

The Deaf community, like many collectivist cultures, has a penchant for mutual aid, reciprocity (e.g. favors are more easily requested and granted with less individual accounting), and group decision-making (Queensland Health, 2008; Lane, 1999). There is fierce group loyalty, with the success of individual members viewed as representative of success of the entire community. Members characteristically pool resources, feel a duty to share information, and may maintain strict insider/outsider boundaries (Queensland Health, 2008). It is accepted that non-Deaf persons can become allies of the Deaf community, though to do so one must value and support Deaf culture. A point of great relevance to this study is that members of the Deaf collectivist culture define ostracism

from the Deaf community as the “worst punishment” (Queensland Health, 2008, p. 28).

**Deaf epistemology.** Breivik (2005) defined deaf people as “vulnerable but strong” (p. 18). He reported on the empowering aspects of being sign language users while also being part of a global Deaf movement or a Deaf counter-narrative. While many Deaf are confronted with hurdles when seeking appropriate and accessible mental health services, numerous authors have recommended strategies to dismantle these oppressive structures that debilitate the Deaf. They promote equal access to services via the promotion of sign fluency and Deaf-specific cultural knowledge for medical and mental health staff, as well as the equalization of the accessibility and efficacy of mental health services for the signing Deaf through Deaf epistemology (Brice et al., 2013; Eckert, 2010; Estrada & Beyebach, 2007; Hauser, O’Hearn, McKee, Steider, & Thew, 2010; Holcomb, 2010; McLaughlin, Young, & Hunt, 2007; Moores & Paul, 2012). Epistemology is itself a concept with many definitions. Fundamentally, it asks the question, “How do we know what we know?”

Holcomb (2010) defined the three fundamental aspects of knowledge as being those of belief, truth, and justification. In contrast, however, the sociopolitical origins of Deaf epistemology require understanding of a different path (Holcomb, 2010). Deaf epistemology turns to personal testimonies, experiences, and personal accounts to create and document Deaf knowledge and build a Deaf epistemology. The core components of the Deaf episteme are formed not from the negative aspects of hearing loss or medically defined disability but from a culturally emancipating concept such as Deafhood. Deafhood is viewed as the foundation on which Deaf individuals view themselves, learn to resist audism, remain healthy, and navigate successfully within the hearing world

(Hauser et al., 2010).

Ladd (2003), a Deaf academic and scholar, was dissatisfied with the dependence on the medical term “deafness” to define the Deaf community. He consequently sought to conceptualize a Deaf way of being and knowing. He constructed the epistemic notion of Deafhood. Based on the experience of those persons who were born deaf or were deafened at an early age, Deafhood has a goal of Deaf self-actualization (McKee, 2008). It does not represent a static experience or finite state but is more accurately defined as

a process—the struggle by each Deaf child, Deaf family and Deaf adult to explain to themselves and each other their own existence in the world. In sharing their lives with each other as a community, and enacting those explanations rather than writing books about them, Deaf people are engaged in a daily praxis, a continuing internal and external dialogue. This dialogue not only acknowledges that existence as a Deaf person is actually a process of becoming and maintaining “Deaf,” but also reflects different interpretations of Deafhood, of what being a Deaf person in a Deaf community might mean. (Ladd, 2003, p. 4)

Deafhood is intended to provide a centre for members of the Deaf community from which “new spaces for more sophisticated liberatory discourses to flourish” (Ladd, 2003, p. 81) can be created. As DeClerck (2007) described, Deafhood is intentionally and strategically essentialist (see also Hauser et al., 2010).

The concepts of Deaf identity and the epistemological thinking of Deafhood are factors that have also proven to be of great relevance to the focus of this study. The existential concept of Deafhood appears to have provided a basis for, or contributed to, the internal forces the participants of this study have used in coping with mental health systems and the barriers associated with social policies and systems that currently lack the ability to accommodate members of this specific minority language and minority culture.

For those working in the field of social work or any of its partner services, it is

imperative that the Deaf identity be acknowledged and accepted as a multidimensional phenomenon, with linguistic, cultural, and sensory implications. It has been found that Deaf people regard therapists who at least attempt to use sign language are more highly regarded than those that make no attempt to bridge the communication gap between visual language users and oral language users (Steinberg, Wiggins, Barmada & Sullivan, 2002).

The concept of Deafhood is consistent with the values of social work (e.g., respect for the inherent dignity and worth of persons and the pursuit of social justice), both of which promote social inclusion. It is also consistent with the profession's fundamental premise of supporting change both through helping promote individual strengths and by working to change the very circumstances that have contributed to their distress (Coppock & Dunn, 2010. See also McLaughlin et al., 2007).

Society is organized in such a way that persons with disabilities, or differences, often do not have the same access to the services or advantages as do those without disabilities; the latter are therefore viewed as "more highly valued" (Sandys, 2005, p. 64). In exploring the concept of social inclusion, I turned to Bach (2002, as cited in Sandys, 2005, p. 64), who defined five cornerstones of social inclusion: (a) human development (i.e., nurturing the skills, abilities, and choices available to persons of all ages such that they, and others, see value in who they are and what they do); (b) involvement and engagement (i.e., having the rights and support for individual decision making that affects that person's life directly); (c) proximity (i.e., having the opportunity to share physical and social spaces so as to minimize social distance and facilitate interactions as desired); (e) material well-being (i.e., having access to material resources which provide

opportunities for those along the lifespan to participate fully in the community); and (e) valued recognition (i.e., recognizing and respecting all individuals and groups for their value to the larger society; p. ix). Both Deafhood and the profession of social work respect and promote these cornerstones of social inclusion and, when married, may well represent a conduit through which Deafhood can be directly promoted in mainstream society and, thus, achieve social inclusion for members of the Deaf community.

### **Mental Illness - general**

To continue the exploration into the components of relevance to this study, I now turn to the literature specific to the global issue of mental illness. This is followed by a more focused discussion on depression, then by an exploration of the literature as it relates to Deafness and mental health.

The World Health Organization [WHO] (2013) has reported that mental, neurological, behavioural, and substance use disorders are common worldwide, affecting hundreds of millions of people every year and causing great suffering. Estimates made by the WHO in 2002 suggested that 154 million people globally suffer from depression. The WHO reported further that one in four patients visiting a health service or facility worldwide has at least one mental, behavioural, or neurological disorder. Many, however, have mental illnesses that go undiagnosed and untreated. Globally, across both genders and along the socioeconomic continuum, mental illness, specifically clinical depression, is the leading cause of years lost to disability. The Mental Health Commission of Canada (2012) reported that of the 10 leading causes of disability worldwide, five are mental disorders. The mental health statistics suggest that mental health problems affect people of all ages and from all walks of life. As reported in the new mental health strategic plan

for Manitoba (Government of Manitoba, 2011), approximately one in four Manitobans were diagnosed with one of five mental illnesses (e.g. depression, anxiety, substance abuse, schizophrenia, or personality disorder) over the five-year period from 2001-2006 (Martens, as cited in Government of Manitoba 2011, p. 4). Health Canada (2002) reported that across Canada 1 in 5, or 20%, of Canadians will experience a mental illness in their lifetime. Within these numbers, the CMHA (2013) reported that approximately 12% of Canadians will experience an anxiety disorder and up to 10% will experience a mood disorder, approximately 8% of who will experience major depression in their lifetime (Canadian Mental Health Association, 2013; Health Canada, 2002).

**Depression.** As the diagnosis of Major Depressive Disorder (MDD) is this study's focus, I turn now to the issue of depression. There are three primary types of depression as reported in the American Psychiatric Association's (2000) DSM-IV-TR: MDD or unipolar depression; dysthymia, a chronic and unremitting depression characterized by long-term (i.e., 2 years or longer) symptomology; and bipolar disorder, formerly called manic depression. None of the three types of mood disorders are diagnosable through any formal blood or other medical test; instead, diagnosis is based on a health care professionals' assessment of the constellation of depression symptoms as reported by the person experiencing them.

According to the National Institute of Mental Health [NIMH] (2011), MDD is one of the most common mental disorders in the United States. The statistics report that in people under the age of 65, women are twice as likely to be diagnosed with depression as men (NIMH, 2011). The statistics further report that the two genders often experience symptoms differently, with the causes of depression in women often related to genetics,

brain chemistry, and hormones (NIMH, 2011). The DSM-IV-TR (American Psychiatric Association, 2000) provides insight into the diagnosis of depression. According to this document, in order for a diagnosis of MDD to be made, at least five of the following symptoms must have been present during the same two-week period and be a change in previous functioning for that person with at least one of them; a depressed mood most of the day, nearly every day as made by subjective reports or loss of interest or pleasure in all or almost all activities nearly every day or most of the day. Accompanying these symptoms must be at least four additional symptoms related to feelings, thoughts, and changes in behaviour or physical symptoms over a two-week period.<sup>4</sup>

**Treatments for depression.** Depression is reported to be the most treatable of mental illnesses (CMHA, 2013). It is reported in the literature that, with the right treatment, most people do recover (Beyond Blue Fact Sheet 33; NIMH, 2011). The options regarding treatment for depression are reportedly multiplying, both in quantity and sophistication (Schotte, Van Den Bossche, De Doncker, Claes, & Cosyns, 2006). Schotte et al. (2006)

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<sup>4</sup> These symptoms include change in weight (e.g., change of more than 5% of body weight in a one-month period) or change in appetite; insomnia or hypersomnia nearly every day; observations by others of changes in psychomotor activity, either agitation or retardation, nearly every day; fatigue or loss of interest nearly every day; feelings of worthlessness or guilt nearly every day; reduced ability to think clearly or indecisiveness nearly every day (as reported by others); recurrent thoughts of death, other than fear of dying; recurring thoughts of suicide without a plan; a suicide attempt or suicidal ideation with a specific plan.

reported that in general, and specifically with respect to more severe and chronic forms of depression, a larger number of physicians are incorporating a more sophisticated treatment plan, be it with concurrent, sequential, or crossover combinations of psychopharmacology or psychotherapeutic interventions (Lenze et al., 2002, as cited in Schotte, Van Den Bossche, De Doncker, Claes, & Cosyns, 2006). The biological treatments are also advancing with current psychopharmacological treatments resulting in fewer side effects. The Mood Disorders Society of Canada [MDSC] (2009) reported that a number of psychosocial interventions have proven valuable in the management of depression for some people. These may include psychotherapy (individual, short and/or long term); psycho-education to gain a better understanding of depression itself, its medications and other forms of interventions, and the impact of stigma (intended for both the individual and/or family members); community resources such as self-help groups; and complimentary or alternative therapies (e.g., herbal, homeopathic, or non-pharmaceutical, personal medicines) (Deegan, 2005). Recognizing that each person's path to wellness is unique, it is reported that support from family and friends and participation in self-help groups are critical for some in their recovery from depression (Government of Canada, 2006; Onken, Dumont, Ridgway, Dornan, & Ralph, 2002). The existing literature, however, has not addressed this phenomenon well, if at all, in the Deaf community.

**Deafness and mental health.** As I have noted in this report, the majority of those identifying themselves as members of the Deaf community are physically and mentally healthy, like their hearing counterparts as reported above (Leigh & Pollard, 2011). In actual figures, the number of Deaf persons seeking mental health services is small

(Briffa, 1999; Munro-Ludders et al., 2004). One reason for this is that their actual numbers are small, with Bauman (2004) reporting their numbers as “a miniscule fraction of the world’s population” (p. 241). However, there is a small percentage of the signing Deaf, like those in the mainstream hearing culture, who require mental health intervention. What the literature is unable to proclaim with any certainty in regards to the Deaf community, however, is the prevalence of mental illness in this subpopulation, or the nature of their experiences. As mentioned previously, Pollard (1994) and Queensland Health (2008) suggested that, at a minimum, the incidence of mental illness in the Deaf community is approximately the same as in the hearing population. Austen (2006) suggested a higher prevalence of serious mental disturbance in Deaf adults and children compared to the hearing populous (see also Kvam et al., 2006; Vernon & Daigle-King, 1999), with Hill and Nelson (2000) suggesting the prevalence may be as much as four times higher in the Deaf (40%) than in the hearing (10%) population. Steinberg, Lipton, Eckhardt, Goldstein, and Sullivan (1998) acknowledged that the need for mental health services for the Deaf has received increasing attention over the past decade. Of those who would benefit from services however, few actually receive them due to a variety of barriers, including those of access. Steinberg (1991) summarized the situation experienced by many Deaf sign-language users. She reported,

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. Even today deaf adolescents and adults remain isolated in state hospitals, without means of communication, often misdiagnosed and inappropriately treated. However, the majority of mentally ill Deaf persons are not hospitalized. They live in the community but do not receive the mental health services to achieve productive and independent function. (p. 381)

**Risk factors for culturally Deaf persons.** Culturally Deaf people are viewed to be at a higher risk for mental health issues than their hearing counterparts. The reasons for the

increased vulnerabilities appear to result from a variety of factors. Hindley (2005) reported that deaf children are 1.5–2 times more vulnerable to emotional and behavioural disorders than hearing children (p. 116). He attributed this to a number of factors, the most significant of which are the reduced opportunities for effective communication. Austen (2006) suggested that the dynamics in which the Deaf child is raised can be problematic as can the ongoing challenges of living amongst a larger society with a dominant language in which the Deaf child is unlikely to achieve fluency contributes to ongoing emotional and personal safety challenges, which then increases that child's risk for mental illness. Austen reported further that the Deaf are constantly challenged to “make sense of their position as Deaf people in a predominantly hearing world” (2006, p. S87). Ridgway (2001) added that, for some, one's attitude towards his or her own deafness could negatively affect psychological health. These factors are discussed in greater detail below.

**Etiology.** The etiology associated with hearing and the psychosocial factors associated with deafness, such as increased risk of childhood trauma (e.g., physical, sexual, and emotional abuse), have been found to increase a Deaf ASL user's risk for mental illness (Harmer, 1999). For example, it is reported that 200 types of genetic hearing loss have been found [Harmer, 1999]). Myers & Thyer (1997) note that etiology associated with hearing loss may also affect the person in ways other than just hearing. They recommend incorporating questions related to the etiology of deafness in the therapeutic assessment process. As etiology of the participants' deafness was not a focus of this study, however, this issue was not explored.

**Communication.** People who are Deaf or hard of hearing may experience increased isolation associated with a lack of common mode or method of communication with family, friends, or work colleagues. The issue of language or communication mode becomes the most significant impact on the Deaf receiving appropriate assessment and intervention (Pollard, 1996). It is reported that the act of seeking mental health care itself may also be stigmatizing (Cornes & Wiltshire, 1999) or uncomfortable for signing Deaf individuals. This is particularly true if the service does not employ health care providers who are fluent in the language used by the Deaf person and does not provide interpreting services (Brice et al., 2013).

Differences in communication between the health care professional and Deaf patient and the physician's lack of understanding of Deaf culture can lead to misunderstanding and misdiagnosis (Baines, Patterson, & Austen, 2010; Harmer, 1999; Steinberg et al., 2002). The visual and expressive nature of sign language may be misinterpreted as, or mistaken for, symptoms of mental illness by professionals unskilled in visual language and Deaf culture (Briffa, 1999). If mental health professionals subsequently attempt to remedy their misunderstanding by encouraging the Deaf ASL user to lip-read or communicate through written English, yet other challenges arise. English is a second language for most Deaf ASL users (Shinton & Mairs, 2009). As such, asking a Deaf person to communicate in written English, their second language will often result in written English that is grammatically incorrect. To a mental health professional inexperienced in ASL, this written communication may appear to suggest a formal thought disorder or learning disability (Shinton & Mairs, 2009).

A Deaf persons' access to mental health promotion or prevention materials is often limited because of their reduced level of mental health literacy and resulting limited understanding of mental health or medical technical language or jargon (Baker-Shenk & Kyle, 1990). Further to this, abstractions, and conceptualizations familiar to spoken-English users may further compound the challenges for the Deaf person in seeking and comprehending appropriate services (Briffa, 1999; Shinton & Mairs, 2009). Collectively, these realities can serve to deepen feelings of oppression and inferiority for the Deaf ASL user and create barriers to seeking intervention, which then impact opportunities for mental health recovery (Baker-Shenk & Kyle, 1990; Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008; Brice et al., 2013; Steinberg, et al, 1998; Wilson & Wells, 2009).

Few medical or mental health professions have familiarity with ASL or Deaf culture or with experience in communicating through a visual language; as such Deaf consumers often feel frustrated with the interchange (Brice et al., 2013; Lieu, Sadler, Fullerton, & Stohlmann, 2007; Sheppard, 2008). Professionals may also lack the skills or expertise to form a therapeutic alliance with these patients because of their lack of understanding of Deaf culture and language and the rules of interaction associated with this minority culture (Barnett, Klein, et al., 2011; Harmer, 1999; Leigh & Pollard, 2011; Onken, Dumont, Ridgway, Dornan, & Ralph, 2002; Steinberg, Sullivan, & Loew, 1998. These conflicts may lead to stereotyping of the Deaf client by the professional and result in the client developing frustration, resistance, and mistrust of the helper (DeVinney & Murphy, 2002; Sheppard, 2008; Steinberg et al., 2002).

The literature reports that Deaf persons often felt that their needs were not heard or met (Briffa, 1999; Critchfield, 2002). In addition, some Deaf patients have reported

feeling unfamiliar with and disempowered in the patient role and uncomfortable in seeking additional clarification regarding diagnosis or treatment. It has been reported that culturally Deaf adults are rarely asked directly about symptoms of depression (Sheppard, 2008; Tamascar, Malia, Stern, Gorenflo, Meador & Zazove, 2000), and DeVinney and Murphy (2002) found that fewer treatment options were presented than for hearing adults seeking services.

**Isolation.** Bateman's (1996) ethnographic study found that the majority of deaf people felt politically and socially isolated and powerless to make changes on issues other than deaf-related issues, such as video-relay services, television captioning, and interpreting services. Bateman (1996) also found a number of factors which were barriers to Deaf people becoming involved in political leadership, with these factors potentially also presenting barriers to the Deaf person assuming an effective individual self-advocacy or patient role. One example cited is in relation to Deaf children who are the single deaf family member in a hearing household. It is reported that decisions are often made for the child by a hearing adult (Roots, 1999). The child thus becomes passive in communication and can develop a naivety about his or her ability to help either him- or herself or other Deaf people.

The acquired passivity in home life can be further compounded through the educational setting. Residential schools are lauded as being the first and strongest source for instilling Deaf pride in the students; they are also, however, often defined as paternalistic in nature (Bateman, 1996). This latter view results from educational settings being seen as negligent in promoting or supporting independent decision making or critical thinking, and thereby instrumental in reinforcing the feelings of political

impotence (Roots, 1999). The educational classroom itself is based on what Freire (1970) defined as the “banking” concept of education, whereby the teacher is the conduit of information and the student simply the passive listener. As a passive listener, the student’s responsibility is simply to store information as it is seen and heard rather than being encouraged to engage critically in its content. This reinforces the passive personality and may contribute, along with inaccessible mental and medical health knowledge, to a sense of learned helplessness for many Deaf persons and result in their failing to take an active role in their medical assessment or treatment (Ludders, 1987).

Bateman (1996) reported that some respondents in his study described their lack of involvement in the larger hearing community as creating a sense of isolation from that community or a “Deaf ghetto” (Bateman, 1996, p. 154). Feelings of dependency, isolation, and powerlessness often resulted for these Deaf individuals when isolated.

**Health care disparities.** The dearth of study in the area of mental health and Deafness, in addition to previously noted methodological limitations, poses serious threats to a comprehensive understanding of the issues faced by this population. At the individual level, Deaf persons may be vulnerable to mental illness because of the etiology of their deafness, because of restricted social relationships, and because of social status in the dominant society (Sheppard, 2008). At the societal level, however, limitations resulting from social policies and the societal structures that do not acknowledge and thereby cannot accommodate the linguistic needs of sign language speaking Deaf persons isolate and exclude this population from equal access to services and resources even further (J. Harris & Bamford, 2001). Additional access barriers described in the literature include things such as inappropriate treatment (e.g., being underserved or served in ways that

are not culturally sensitive); being serviced by inexperienced clinicians who overpathologize the presenting issue because of a lack of understanding of the emotive nature of ASL or Deaf cultural norms (Landsberger & Diaz, 2010) or are unfamiliar with Deaf language and culture (Brice et al., 2013); poor coordination of services; funding shortages for appropriate supports such as interpreters; and inability to address concerns regarding confidentiality. These barriers add to the challenges faced by some culturally Deaf adults living with mental illness (Hill & Nelson, 2000). It is further reported that barriers can arise from limited mental health literacy or a lack of mental health content knowledge (e.g., not understanding the difference between words such as psychiatrist and psychologist).

Harmer (1999) reported that the health care culture itself—for example, appointments that are time-limited, task-oriented, and dependent on concrete information from patients, often through a quick series of personal interactions—is contradictory to Deaf culture. In Deaf culture, sharing of information through storytelling is common (Beyondblue, 2011), as is sharing information through a phenomenon defined as ‘the long good-bye’ (Queensland Health, 2008, p. 16). In this cultural norm, Deaf persons departing from a gathering, meeting or event, often continue to visit for an extended period of time to catch up on all the news they may have missed since their last meeting. This may be changing with the popularity of social media, though it is a reality health care and other professionals need be aware of when scheduling appointments or other events time-sensitive events.

It is reported that Deaf people may have unique challenges when in an inpatient setting. Deaf persons may require accommodations such as visual fire and safety alarm

systems, televisions with captioning capacity, and access to communication devices necessary for them to maintain their connection with family and other supports outside the hospital setting (NASMHPD, 2008; DeVinney & Murphy, 2002; Queensland Health, 2008).

Many working within the mental health systems have assumed that the strategies, interventions, and techniques appropriate for the hearing majority are equally effective for the Deaf consumer (Brice et al., 2013; Critchfield, 2002). Systems and professionals in the area of mental health and deafness are beginning to recognize, however, that the needs of the Deaf are different from their hearing counterparts. Written surveys, telephone surveys, questionnaires, and Internet inquiries, which have often been used to study this population, may be inadequate due to low health literacy levels (Barnett, McKee et al., 2011). Finally, it is reported that few reliable assessment tools exist which are meaningful and linguistically meaningful for sign-language users (Briffa, 1999; Connolly, Rose, & Austen, 2006; Haskins, 2004; Leigh & Anthony-Tolbert, 2001; Zazove, Meador, Aikens, Nease, & Gorenflo, 2006). The use of mental health assessment tools that are not appropriate for the linguistic needs of this cultural and linguistic minority can lead to misdiagnosis. This is particularly true when applied by professionals, including psychiatrists, psychologists, therapists, social workers, or other service-providers, who are not familiar with the needs of the Deaf person or are unable to respond to the needs of the Deaf person (Brice et al., 2013; Briffa, 1999; Munro, Knox, & Lowe, 2008). In the absence of an accurate assessment or evaluation, the determination of effective treatment would be difficult, if not impossible.

Vernon and Leigh (2007) found that the historical experiences of Deaf persons in

hearing mental health settings were clinically ineffective, frightening, and in many cases, abusive (p. 160). Kozlowski-Graham (1991) reported that Deaf patients seeking mental health services at that time were often ignored, misunderstood, misdiagnosed, over-institutionalized, and in receipt of care from persons with little knowledge of the impact of deafness on communication or of Deaf culture. In 2005, some 14 years later, Horton (2005) reported that given the paucity of accessible mental health services for the Deaf, the majority of Deaf persons seeking mental health assessment, support, or treatment were still being served by unskilled, non-signing health service staff or mental health professionals who were unable to meet their needs (see also Munro-Ludders et al., 2004; Pollard, 1998).

A number of consequences resulting from the language incongruence between a non-signing hearing professional and a Deaf signing patient have been noted; yet another consequence has been longer hospitalizations for persons who are deaf than for their hearing counterparts (Baines, Patterson & Austen, 2010; Iqbal & Hall, 1991; Steinberg, 1991; Steinberg, Sullivan, et al., 1999). Appleford (2003) found differences in length of hospital stay to be true even in a specialized mental health facility for the Deaf. He suggested that admissions to mental health inpatient facilities might in fact be reserved for those patients with more complex presentations and those for whom outpatient treatment resources are not available. Appleford (2003) further suggested that longer admissions for Deaf persons might be related to a deliberate delay in discharge planning given the limited community resources available to support a successful return to the community for this population. Baines et al. (2010) suggested that additional resources be committed to increase community-based services and resources for this population to

reduce the existing health care disparities (see also Brice et al., 2013).

Based on the review of the literature, it would appear that persons who are Deaf and mentally ill have added vulnerabilities to mental illness because of limitations or barriers at the individual, institutional, as well as structural levels.

**Mental illness in the Deaf community.** Several researchers have sought to explore the experience of specific forms of mental illness in Deaf community. Leigh and Pollard (2011) studied a Deaf inpatient sample. They found the co-morbidity of psychiatric and substance abuse disorders to be relatively high in this population, as were abuse victimization histories and trauma. Mueller (2006) reported post-traumatic stress disorder (PTSD) as “the most common diagnosis found in the Deaf community” (Diagnosis & Treatment section, par. 1). Black and Glickman (2006) found similar results. They sought to explore the needs of those d/Deaf patients who had received services psychiatric services from the specialty Deaf inpatient psychiatric unit they both were employed on. They studied the archival data from a group of 64 adult patients discharged from the Westborough State Hospital Deaf Unit between 1999 and 2004. They found 52% of this sample had a known history of abuse, with PTSD the most common diagnosis in this adult population. As a result of this study, they predict PTSD to be the most common diagnosis in the Deaf community as a whole, particularly given the common experiences of residential school settings, limited literacy due to oralist pedagogy, and, for some, communication challenges.

**Depression in the Deaf community.** The issue of depression in Deaf individuals has received some attention (Kvam et al., 2006). Connolly et al. (2006) explored the issue of depression in the Deaf community through a targeted literature review. Reviewing the

literature in computerized databases such as PsychoINFO and Medline, they found that the documented research with Deaf consumers lagged behind the study of depression in the hearing community. They observed further that many of the studies held limited usefulness for their study due to the age of the original study (published more than 30 years ago). They also found challenges with the lack of representativeness of the samples and the assessment tools used in the research, the latter of which were not necessarily standardized for the language and cultural needs of the Deaf population. These authors were of the opinion that further research is required in the area to better and more comprehensively understand the issue of depression in this population.

Sheppard and Badger (2010) examined how Deaf adults with a diagnosis of depression defined their symptoms of depression. They found no new or novel symptoms of depression reported by their Deaf sample. They concluded, however, that few Deaf adults were being accurately screened for depression, often due to the language incongruence between them and their hearing mental health professional.

Two studies are encouraging for their results in the area of mental health and Deafness, particularly depression. Steinberg et al. (1998) explored the feasibility of translating the National Institute of Mental Health Quick Diagnostic Interview Schedule-III, Revised (Q-DIS-III-R), computer version, for deaf individuals. They found that when the Q-DIS-III-R sections were translated into three modes of communication, including ASL, signed English, and speech reading, the computerized version of the tool showed success as an “effective and accurate assessment tool with most deaf patients” (Steinberg et al., 1998, p. 1603). Phase I results did indicate there was some loss of accuracy among certain components of the original tool, such as “psychological states and constructs and

in the translation of complex time concepts” (Steinberg et al., 1998, p. 1603), though its success suggests the tool could be explored for more widespread use by qualified practitioners to enhance the success of diagnosis with Deaf patients. With an accurate diagnosis, the focus can be on appropriate intervention strategies.

Estrada and Beyebach (2007) explored the effectiveness of solution-focused therapy with depressed Deaf adults following an assessment using the Beck Depression Inventory adapted for use with Deaf people (BDI – II AD). Their results showed the participants in the study successfully moved out of the clinical range of depression following a brief, four to eight session intervention plan with the researchers. This is encouraging and suggestive that tools and resources exist that may improve the experiences of Deaf adults living with depression.

Based on the literature reviewed, it appears that the research in the area of mental health and deafness is scarce, particularly in comparison to the dominant community. While current studies appear promising in terms of advancements in assessments for Deaf adults living with depression, further research is necessary to enhance understanding of the health care disparities experienced by this population and the validity of assessment tools for wider use with this population.

**Mental health stigma and discrimination.** Everett (2006) acknowledged that stigma could come in many forms: stigma against age, gender, language, and ability. She defined the effects of stigma specifically associated with mental illness to be far-reaching and a potential inhibitor to accessing those factors that protect against mental illness, such as stable housing, family and social supports, employment, and income. She also reported stigma to be a potential cause of disease as stigma often leads to denial of opportunity

that can then lead to poverty. Collectively, these factors become an inhibitor for people living with mental health symptoms to seeking early detection or treatment for their symptoms. She did note as well that one form of stigmatization “piled upon” (Everett, 2006, p. 17) another can have an overwhelming effect on identity, self-esteem, and access to opportunity.

Lasalvia et al. (2013) applied the Discrimination and Stigma Scale–version 12 9DISC-12 with 1,082 adults with depression across 35 low- and middle-income countries over the period of January 1 to December 31, 2010. Adult participants from all age groups participated with a 2:1 ratio of women to men. A full 79% of participants reported facing discrimination related to their depression in at least one life domain. The life domains in which stigma was most often reported were “family, making or keeping friends, marriage or divorce” (Lasalvia et al., 2013, p. 58). Participants reported that depression-related discrimination also acted as an inhibitor to social participation and successful vocational integration (Lasalvia et al., 2013, p. 55). These factors combined to result in a lower willingness to seek medical care for the depression.

The intersection of social and structural oppressions and realities that impede the Deaf person’s access to appropriate mental health promotion resources, culturally experienced mental health professionals, relevant mental health services or treatment, and appropriate follow-up care must be addressed. Awareness in the larger society of the depth of these issues can serve as a platform toward change.

**Resilience literature.** Various definitions of resilience abound. Resilience is generally viewed to be a counterweight to psychopathology (Young, Green, & Rogers, 2008). F. Walsh (2003) defined it as “the ability to withstand and rebound from disruptive

challenges” (p. 1). Viewing it as more than simply returning to a former state of homeostasis, she constructed resilience through the metaphor of “bouncing forward” or changing to meet new challenges. F. Walsh (2003) further suggested that resilience is more than an achieved outcome or response to an isolated incident; she defined it as a lifelong way of living and being. This research may indeed provide a foundation into the exploration into mental health recovery in the signing Deaf community.

Rogers, Muir, and Evenson (2003) sought to explore the concept of resilience and those factors that may enhance a Deaf person’s ability to bridge the Deaf and hearing worlds when involved in an educational setting. They began by examining the resilience-related assets identified in the mainstream (e.g., hearing) community that both helped protect against risk of disease and supported “successful adaptation in the face of adversity” (Rogers et al., 2003, p. 222). The authors found 22 separate strengths or resilience-related assets that assisted persons to cope with adversity. The assets were separated into intrapersonal, behavioural, or environmental.<sup>5</sup> In analyzing the data from the study participants, using a positive psychology perspective, the authors concluded that there are a number of internal, behavioural, and environmental factors which may empower a Deaf person to be successful in bridging the Deaf and hearing worlds despite their deafness. The most significant factors while in a postsecondary setting were

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<sup>5</sup> The intrapersonal assets included personality, values, and attitudes; behavioural assets included support-seeking behaviours, self-advocacy, and persistent problem solving; and environmental assets included those related to the school, home, and community environments (Rogers et al., 2003, p. 223).

identified as comfort with solitude, and authenticity (in their deafness). I considered these results when analyzing the data from my study. Though there were notable differences between the Rogers et al. (2003) study and my study, the results of the former can be used to enhance understanding of possible strategies for Deaf adults diagnosed with depression to use to effectively cope with their mental illness.

### **Qualitative Research**

The study of human life and experience is a task that must be undertaken with great respect for the persons of inquiry and with great sensitivity to the impact of such an inquiry on that person as well as their community. With these factors in mind, I chose a qualitative paradigm to explore the phenomenon of interest for this study. Qualitative research aims to understand the social world from the position of the respondents themselves. This often includes the contextual conditions within which the qualitative researchers “are committed to an emic, idiographic, case-based position, which directs their attention to the specifics of particular cases” (Denzin & Lincoln, 2003, p. 16). They secure rich descriptions of the social world of the case under study or the dynamics under which the participant’s life takes place (Yin, 2011). Gilgun and Abrams (2002) asserted further that, by virtue of their design, qualitative strategies encourage more intimate interactions with the participants of the study, thereby leading to a deeper and more holistic understanding of those lived experiences (see also Taylor & Bogdan, 1998). Unlike positivistic research methodologies, qualitative methods are typically more flexible, allowing greater spontaneity and greater adaptation of the interaction between researcher and participant (Mack, Woodsong, MacQueen, Guest, & Namey, 2005).

Qualitative methods are essentially descriptive and inferential (Gilham, 2000).

They provide an opportunity for the participant to express his or her life experience(s) in ways that can empower that participant. They also seek to enhance the understanding of the broader listening, reading, and, in this case, viewing audience, and extend the researcher's understanding of how a particular participant constructs a phenomenon or experience (Hole, 2004).

Qualitative researchers frequently engage in multiple and creative methods to capture as much of a person's reality as possible (Gilham, 2000; Russell & Browne, 2005). This allows the qualitative researcher to attempt to draw attention to issues and uncover the multiple realities or complexities that are beyond the positivistic methods used in quantitative experiments (Gilham, 2000). Ridgway (2001) reported that qualitative research methods are appropriate methods to use when knowledge is sought about complex, little-understood dynamics of a personal, interpersonal, and social nature. In addition, given qualitative research's naturalistic nature, its strength and success can more often be attributed to the researcher's ability to follow and attend to the fluidity of the research conversation than in attempting to control or dominate it (Padgett, 2008). The ideal use for qualitative inquiry is to add to the existing body of knowledge (Stake, 2010) or advance collective thinking (Ridgway, 2001).

**Qualitative research and social work.** The qualitative research process and social work practice share much in common (Burnside, 2008). As with qualitative research, many social work theories are premised on an appreciation of the existence of multiple realities and interpretations, with an expectation that these interpretations need to be acknowledged and incorporated into our understanding of the phenomenon under study (Fook, 2002). Both social work and qualitative research acknowledge and respect

diversity in the areas of culture (Patton, 2002), human relationships (Mack, et al., 2005), and constructed experiences. The two also promote engagement along the demographic continuum, as well as across languages, system sizes, fields of practice, and presenting needs, often doing so through common methods of interviewing, record keeping, and analysis (Burnside, 2008). Finally, inherent to both are respect and appreciation for the experiences of others and the foundational principle of starting “where the client is” (Padgett, 1998, p. 374).

**Case study research.** Drawing primarily on the writings of Yin (2003, 2009, 2011), Stake (1995, 2010), and Creswell (1998, 2014), I used a case study research approach in this study while incorporating components of the transformative-emancipatory approach (Mertens, 2003, 2007). I felt that case study design provided the opportunity to engage with participants in a manner that is most respectful of their language mode and level of written English literacy while also incorporating a common cultural practice—that of storytelling.

The origin of the case study approach or methodology can be traced to anthropology and sociology (Creswell, 2014). It also enjoys familiarity and popularity across a broad range of social sciences or disciplines including psychology (made popular through the writings of Freud), law (defined as case law), and medicine (reported by way of a case analysis). Though there is a dearth of studies exploring mental health and deafness, it is a method that has been used with this population (McKee, 2008; Novodvorski, 2008).

Today there is no common or singular definition of “case study.” Thacher (2006) described case study research as “one of the major research strategies in contemporary

social science” (p. 1631). Creswell (1998) defined a case study as an exploration of “a bounded system or a case (or multiple cases) over time through detailed, in-depth data collection involving multiple sources of information rich in context” (p. 61). Creswell (2014) defined further that the “case” can take the form of an individual, program, event, activity, or group of individuals and be defined as either the “object” of study or the “product” of the inquiry (p. 97).

Denzin and Lincoln (2003) and Creswell (1998, 2014) defined case study research as a method of study. Stake (1995) described further that case study research can also be characterized by its intent, defining case studies as “intrinsic” when used to learn about a particular case, and “instrumental” when used to understand a phenomenon, concept, or other factor (p. 3). Yin (1994) further defined case study as a “comprehensive research strategy” (p. 13). Yin (1994) also suggested that, as a methodology, case study should be selected if research is premised on a series of factors (including “how” and “why” questions), when the phenomenon of interest is contemporary, when the study involves a real-life context, and when it is one over which the researcher has little control (p. 13).

Qualitative researchers recognize that it is not possible to directly access the experiences of others (Stake, 1995), though attempts can be made to access experiences through a number of channels. Qualitative researchers take pride in discovering multiple realities of those with experiences in a particular area of study (Creswell, 1998, 2014; Denzin & Lincoln, 2003; Padgett, 2004; Stake, 1995). An interview, skillfully conducted, can access participant experiences in ways different from surveys, questionnaires, or other strategies; they in fact are often viewed as instrumental in accessing experiences otherwise unavailable through quantitative methods.

Stake (1995) described that while engaging with participants may be easy, getting a good interview is not (see also Padgett, 2004). Conducting effective qualitative research interviews generally require strong interpersonal communication skills, skills similar to those that form the basis of the social work relationship. These skills include active listening, skills of engagement, and recording skills. These, as well as interviewer reflexivity, are incorporated into the research interview and overall process as the researcher strives towards achieving the goal of securing as vivid a picture as possible of that participant's perspective of the phenomenon of interest (Mack, et al.; 2005; Glaser & Strauss, 1967; Stake, 1995). During the interview process, the researcher recognizes the participant as the expert in his or her experiences. In qualitative research the interviewer is in effect the 'student' positioned to listen, hear, and learn from the 'expert' (Mack et al., 2005).

Effective qualitative research interviews should be goal-directed, textual, natural, and iterative, with data collection and research questions adjusted as necessary to adapt to information collected throughout the process (Mack et al.: 2005; Padgett, 2008; Young & Hunt, 2011). Young and Hunt (2011) emphasized that data collection methods must match the language preferences of the person under study. As members of the Deaf community often use storytelling as a method through which to convey information, I viewed a case study design, with interviews conducted in the chosen language of the participants, as the most appropriate and culturally respectful design choice to provide the forum for the participants to construct and tell their story in the manner most comfortable for them.

Case study research incorporates triangulation as a fundamental component of the

data collection process (Yin, 2011). Triangulation is defined as a process of verifying or corroborating the particular event, experience, or fact that is being reported in the study through multiple strategies. Triangulation can occur both by seeking confirmation through multiple sources (otherwise referred to as data triangulation) and through using multiple methods of collection (otherwise referred to as method triangulation). Both of these strategies are intended to enhance the richness and depth of the case or cases studied (Stake, 1995; Yin, 1989, 2009). This process also assists in strengthening the trustworthiness of the data (Yin, 2011).

Interviews are the most common method through which to collect data in case study research. Yin (2009) identified five additional characteristic sources of information: documentation, direct observation, archival records, physical artifacts, and participant observation (p. 102). He suggested that at least three distinct sources be used in any study in order to enhance the level of understanding of the case. I used three of these suggested sources in this study to enhance understanding, plus one not otherwise listed. The sources I used were semi-structured personal interviews, a videotaped recording of the interview, and a participant-drawn person and environment map. In addition, I created and maintained participant-specific and research-process relevant journal notes throughout the entire data collection and data analysis phases. These notes informed the final analysis and, ultimately, this document.

The literature reports on variations in case study research. Notwithstanding these variations in definition, there is general agreement that case study research can be defined by its hallmark, the depth and comprehensiveness of the investigation to seek understanding of the case or cases studied (Creswell, 2014). Given the limited research

with Deaf adults, particularly Deaf adults who live with mental illness, the case study method used here was intended to collect a holistic account of the phenomenon of living with depression when faced with a medical and mental health system that privileges oral communication over signed communication; an account that would be rich or thick with details and descriptive of the experiences involved (Creswell, 2014).

**Transformative-emancipatory paradigm.** Mertens (2003) described the transformative-emancipatory paradigm as placing a “central importance on the lives and experiences of marginalized groups” (p. 139). She asserted that while those working within this paradigm link their research to a broader analysis of inequality and social injustice, more importantly they are encouraged to move beyond exploration and results dissemination in order to link their research to “action” (Mertens, 2003 p. 140). This paradigm is often used by those who work with and on behalf of marginalized groups, a factor of relevance for this study.

All members of this study reported finding comfort and identity as part of a minority linguistic and cultural group, namely the Deaf community. They are, however, also situated in a hegemonic social and political context dominated by the hearing/speaking majority and the medical, mental health, and social support systems all constructed for and by the predominantly oral/aural society in which the participants live. The participants in this study shared optimism that the findings of this study can serve as a platform from which to spotlight the nature of their experiences and challenges in seeking fair and accessible mental health assessment and intervention in a system that, to date, has not operated in a manner which is culturally aware or congruent for Deaf ASL users. There was support from the participants to seek change through the active

dissemination of these findings and creation of an educational or awareness campaign that targets the very professionals tasked with supporting mental health recovery.

**Cross-cultural research dynamics.** Pollard (1992) argued that scientists must employ current or contemporary cross-cultural ethical practices when their research has “cultural bearing” (p. 87). Pollard (1992) suggested that data collection practices must occur through a communication strategy that is both a known communication routine for the research participants and is a culturally appropriate communication routine for the particular topic under study. Baker-Shenk and Kyle (1990) reported on the issues and conflicts experienced in research conducted with, or in some cases on, Deaf people. As noted previously, historically, the Deaf have been viewed exclusively through a medical lens and hence have been viewed as handicapped, “linguistically incompetent” (Baker-Shenk & Kyle, 1990, p. 66), or “a deviation from the normal” (p. 65). Given these views, the focus of medical research was *on* Deaf persons in an attempt to seek ways for correction or cure so that they can be “returned” to the status of the dominant society—namely, hearing and speaking. This view continues today, though this hegemonic attitude is not well received by Deaf consumers.

There appears to be an increasing appreciation for Deaf epistemologies in the field of research (Ladd, 2005). Intended as a counter narrative to the dominant culture, DeClerck (2010) defined Deaf epistemologies as both culture-sensitive and “emancipation oriented” (p. 436). He challenged hearing scholars, researchers, and others to become familiar with and incorporate the consequences of audism and phonocentrism in their studies with this community (see also Pollard, 1992). Others agreed and have implored hearing researchers to engage the services of ASL/English

interpreters or translators, Deaf interpreters, or even cultural brokers when engaging in research outside their language competence (Temple, 2002, p. 844). Pollard (2002), too, has promoted the use of a qualified and experienced sign language interpreter as necessary when the medical, mental health, or other professional or para-professional is not fluent in sign language to ensure a “bridging of the communication and cultural divide” which separates hearing professionals and the Deaf ASL user (Queensland Health, 2008, p. 20,). Conducting interviews in the participants’ first language enables them to share their worldview and essence of their experiences in the language in which they are most comfortable and confident (Pollard, 2002). This is viewed as a strategy that is culturally empowering and consistent with a Deaf epistemology.

Sign language is a visual, emotive language, dependent on facial expression, body language, and hand symbols to communicate; it is not an oral language. Facial expressions are used in ASL as grammatical markers to convey or emphasize a point, to qualify statements, and to enhance ASL signs (Sheppard, 2011). Pollard (2002) reported that video-recording Deaf participants using sign language in research or for other means creates greater risks for breaches of confidentiality than does obtaining written, spoken, or other non-visual participant data (p. 166). Conversely, attempts to disguise or obscure the facial features of the signer to protect identity obscures the language, diminishing the amount of linguistic information available through the facial features—a key feature of the visual characteristic of ASL. Also, each ASL user has a somewhat unique signing style. Given this reality and the complex nature of signed communication, to simply disguise the facial features of a signer does not guarantee disguising that person’s characteristic signing style. To counteract these concerns regarding confidentiality,

Pollard (2002) encouraged researchers to be rigorous in maintaining security of any recording and suggested that erasure or destruction of the recording needs to be completed as expeditiously as possible after the study is concluded. As this study was conducted to satisfy the requirements necessary for completion of a graduate degree in Social Work, the video recordings will be maintained until the successful completion of the graduate studies process. At that time, all electronic recordings of the videos will be erased.

The literature related to cross-cultural research strategies was useful for this study and guided its ultimate design. The strategies not only suggest respect for the participants in the study but also are consistent with key core social work values and principles. In particular, the strategies noted above are consistent with “Value 4: Integrity to professional practice, . . . Value 5: Confidentiality in professional practice, . . . [and] Value 6: Competence in professional practice” (CASW, 2005, p. 4).

This literature is also consistent with the United Nations Convention on the Rights of Persons with Disabilities (CRPD), ratified by Canada on March 11, 2010 (United Nations, 2008). While many persons who are Deaf do not define themselves as disabled, the intent of this convention is to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities” (United Nations, 2008, p. 4), including those with mental health disabilities. The convention does recognize languages, including both spoken and signed languages, as well as other non-spoken languages. In the area of accessibility, it identifies the need to provide various forms of “live assistance and intermediaries”, including though not limited to sign language interpreters (p. 9). Though many Deaf persons reject the disabled

label, viewing themselves as part of a linguistic and cultural minority, in some circumstances they align with this label and with those who are hard-of-hearing to enhance the size of their group and thereby gain access to resources not otherwise available to such a small target group.

Article 25 of the CRPD (United Nations, 2008) states that persons with disabilities must be provided with “the same range, quality and standard of free or affordable health care and programmes as provided to other persons” (par. A, p. 18). Article 25 goes on to say that the care must be “of the same quality to persons with disabilities as to others” (par. D, p. 18). This convention is clear that simply providing the same service is not the same as providing equal access to services. By way of example, a physician sharing a written diagnosis with a Deaf patient would not be the same as sharing a diagnosis orally with an English-fluent hearing person; access to the information would not automatically be equal between the two patients. For it to be equally accessible to both, each patient must be able to understand the information fully. If, however, physicians or service providers are not familiar with this legislation and its implementation, quality and accessible care may not be provided. These realities support the need for comprehensive education and change at the practical, institutional, and societal levels.

### **Summary**

This review of the bodies of literature of relevance to this topic has provided a foundation on the subject of Deaf mental health. It has also provided insight into the nature of the structural oppressions experienced by Deaf adults most often reported as those of ableism and audism. It has provided an introduction into the cross-cultural research components

of importance when conducting research in and with persons from a culture or language other than the researchers' own. Lastly, this literature review has provided an introduction to the resilience literature, including that conducted with Deaf adults. In conclusion, this review has informed of the existing gaps in practice that have, to date, influenced the service received by some Deaf ASL users.

## CHAPTER 3: METHODOLOGY

This research used a single case study design, with multiple units of analysis (Yin, 1994). The design was grounded in social constructivism and incorporated the general tenets of the transformative-emancipatory paradigm. This research study was approved by the Psychology/Sociology Research Ethics Board (PSREB) at the University of Manitoba prior to the recruitment of volunteer participants (Appendix C).

This chapter describes the methodology used in this study. It includes a discussion of relevant methodological issues specific to this population, continuing with a presentation of the specific data collection design and process, and discussion of the data analysis process. Finally, it concludes with a discussion on limitations of this research design, particularly in relation to this population. Details regarding the findings, final discussion and conclusions, and implication for policy, practice and future research will follow in chapters four, five and six respectively. Consistent with case study research and report dissemination, I incorporate three distinct types of quotes throughout the text; I use short eye-catching quotes, quotes embedded within text, and longer quotes, the full length of which is necessary to ensure a comprehensive understanding of the point being made and its context (Stake, 1995).

### **Overview of Research Design**

This study was designed as an instrumental, single case design, with multiple, in this case six, units of analysis or informants, to explore the experiences of a group of culturally Deaf adults who have been diagnosed with Major Depressive Disorder (Yin, 1994). This study was intended to provide a culturally respectful opportunity for Deaf adults, those for whom ASL is their primary or preferred language to share, in their first

language, their experiences with depression while living in the mainstream hearing/speaking culture. The parameters of the transformative-emancipatory paradigm (Mertens, 2007) informed this study, particularly as this paradigm was consistent with the ethical research guidelines suggested for research within this community (Gutman, 2002; Pollard, 2002; Young & Hunt, 2011). The incorporation of this paradigm (Mertens, 2007) was most evident in regards to two key components of the study design, accommodating the participants' first language through the use of qualified ASL/English interpreters and the process of knowledge dissemination.

This study was designed around a semi-structured interview protocol. The interview protocol guided the interviews, though each interview was further shaped in situ with each participant to explore issues arising from that person's unique story (Mckee, 2008). Personal interviews provided the opportunity to probe the issues, experiences and emotions that could not be observed directly, as well as gather a sense of the meanings individuals attach to certain events (Merriam, 2009). With the exception of two of the twelve formal research interviews<sup>7</sup>, all were conducted through the services of a qualified ASL/English interpreter. In two cases, given the unique circumstances of each interview, my own fluency in sign language, and with the approval of the university ethics board by way of an ethics amendment (Appendix D), I conducted the interviews directly in sign language. This was done with the understanding that the two interviews

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<sup>7</sup> In this paper, I define the formal data collection interview as the research interview as distinct from the member checking process. The latter is referred to as the member content-checking interview.

would subsequently be reviewed through qualified ASL/English interpreters for accuracy of content.

Sign language users are inherently visual. Out of respect for this reality, I felt it culturally appropriate and respectful to incorporate a visual tool into this study as a method of data triangulation. An adaptation of the ego-centered social network map, reconfigured as a person and environment map (Appendix B), provided that opportunity (Hintermair, 2009).

**Situating myself in the study.** In qualitative research, the researcher is an “instrument of analysis” (McKee, 2008, p. 522) and must, therefore, make their stance in relation to the study design explicit. While I introduced myself briefly in chapter one, further clarification is warranted. As noted, I am a hearing social worker with spoken English my first language. I am also the youngest sister of a profoundly Deaf brother who attended a Deaf school in the province of Manitoba and who proudly self-identifies as “capital D” Deaf. His first language is ASL. As a teenager, I sought to gain the skills necessary to communicate effectively with my brother in his first language. I later applied these skills to engage with Deaf sign language preferred clients in their first language. My knowledge of Deaf culture and the community prepared me for an advocacy role with these initial Deaf clients, and later others with whom I worked.

My interest in the area of Deafness and mental health stems from a number of intersecting personal and professional factors. I first became gained knowledge of the traumatic life experiences my Deaf clients lived through which included linguistic and familial isolation, chronic substance abuse, and service access barriers. Later in my career, I became more involved in the area of mental health and illness. As I began to

explore the intersection of the two areas, I was drawn to the dynamics that were reported. The literature, when combined with my personal experiences, provided guidance into the design of this study (Connolly et al, 2006; Harmer, 1999; Novodvorski, 2008; Young & Hunt, 2011).

As a result of my personal and professional engagement within the Deaf community, I have developed some trusting relationships within the Deaf community. Given these pre-established relationships, and consistent with the transformative-emancipatory paradigm (Mertens, 2003, 2007), I sought a collaborative relationship with key members of the host (Deaf) community (Hole, 2004; MacKinnon, 2011; Pollard, 2002) at the early stages of this research process. Mertens (2003) reported that the transformative paradigm requires that members of the community affected by the research be involved to some degree in the “methodological and programmatic decisions” (p. 141). As this study was to satisfy the requirements for a PhD in social worker, the methodological decisions needed to be mine. I did, however, meet with various individuals and agency representatives from within the Deaf community to share an early outline of the proposed research intent and methodology. I wanted to both inform the community of my intent, and secure their support to pursue the project. This community engagement process proved particularly valuable at two crucial phases of the study, at the design phase regarding the use of interpreters and at the recruitment phase. This is discussed below.

**Ethical considerations in social research with a Deaf sample.** The general standards of ethical consideration in conducting research with a Deaf sample are no different than those required when engaging other populations (Young & Hunt, 2011). What is distinct

however, as reported by Young and Hunt (2011), is that the “achievement and execution” of appropriate and ethical practice may require specific awareness and adaptations distinct to this population (p. 14).

In designing this study I was conscious of the work of Baker-Shenk and Kyle (1990) who reported on the issues and conflicts experienced or reported when researchers designed research ‘on’ Deaf people versus ‘with’ Deaf ASL users. As noted previously, historically the Deaf have been viewed exclusively through a medical lens. Baker-Shenk and Kyle (1990) reported that many in the Deaf community have faced, and continue to face the self-doubt created by the medical model of deafness and the paternalism associated with living under the oppressive nature of this model. The results of this model and other phonocentric policies have been feelings of apathy and powerlessness for many Deaf people, particularly in relation to the activities of hearing people in relation to them. Early attempts at research revealed complaints from d/Deaf persons of prejudice, discrimination, mistrust and misunderstanding of Deaf people by hearing researchers. I was conscious of these concerns when designing the study.

To enhance the research experience with a minority community rarely involved in research, I incorporated a number of recommended cross-cultural ethical practices in the design and delivery of this study (Baker-Shenk & Kyle, 1990; Critchfield, 2002; Gutman, 2002; Pollard, 2002; Young & Hunt, 2011). As noted above, and to be respectful of the collectivist nature of the Deaf community, I began by introducing myself and my research intent to key political members of the Deaf community in the province of Manitoba in the early developmental stages of the study. In each case, I situated myself within the community, confirming myself as the youngest sibling of a Deaf community

member. I engaged the services of a sign language interpreter for the formal component of each meeting to ensure effective communication though also communicated with each representative directly in sign language to validate my expressive and receptive abilities in signed communication.

There is great language diversity found within those who self-identify as Deaf. Given this diversity, I made every effort to ensure that I respected these language needs during the data collection phase of the study by ensuring that the language preference and communication style of the research participant and that of the interpreter matched (Young & Hunt, 2011). I originally contemplated selecting one or two interpreters to use exclusively for this study as Sheppard did in her 2008 study with Deaf adults living with depression. I assumed this would ensure consistency during the interview process. Based on my community consultations, however, I realized such might jeopardize the distinct needs of each participant interviewed. The community consultants suggested that participants would be empowered in the research process by being provided the opportunity to choose their own interpreter for all research or other interviews with the writer. I incorporated this suggestion, with the expectation of the Human Research Ethics Board that all interpreters used during the study be qualified and registered members of the Association of Visual Language Interpreters of Canada (AVLIC). Participants were thus given the opportunity to select an interpreter with whom they were comfortable, trusted, and with whom they had established linguistic fluency, though who were also registered members with AVLIC.

I believe my long-term personal and professional experience in the Deaf community, as well as the recognized value of the study, contributed to the positive

response I received by each community representative I approached, all of who agreed to assist me in the recruitment process for this study. As required by the university ethics committee, each community resource was informed that my contact with them did not in any way declare my formal affiliation with them or their agency/office in the conduct of this study. My single affiliation was with the University of Manitoba, and this was clearly stated on my recruitment posters (Appendix E – English version, and F – ASL version). I also clarified in the posters that potential participants would not be refused future service from any agency or location at which the recruitment posters were displayed regardless of their final decision regarding the study. I supported each contact's willingness to serve as the conduit for displaying the recruitment posters, though also requested that all questions arising from the posters be directed to myself.

In designing the study I was cognizant of the degree of heterogeneity found in the Deaf community be it in areas of education level, preferred choice of language, and educational philosophy (Steinberg et al, 1998). I, too, respected the literature which suggested that culturally Deaf persons often present at health care settings with a number of unique patient-role challenges when seeking services (Barnett, et al., 2011). As many Deaf adults are reported to assume an external locus of control because of childhood experiences, they often demonstrate less comfort and likelihood than their hearing counterparts to assertively ask questions of the physician. Associated with this, it is reported that Deaf adults often have difficulty being assertive about asking for an interpreter for a health care appointment. Further, because of their level of mental health literacy, it is reported that many Deaf ASL users are less likely to know the names of medications or side effects of those medications than their hearing counterparts (Perlman,

T., Hedding, T., Balfanz-Vertiz, K., Cradock, C., DeGutis, D., & Estarziou, M., 2007). Conscious of all these issues, I incorporated suggested ethical practices to ensure I was not repeating the errors of my predecessors. I supported ASL interpreter choice, created documents in a manner that was more easily accessible to this population, and allocated sufficient time for all interviews to accommodate the language interpretation needs.

**Informed consent.** The document titled ‘The Working Group on Communication Informed Consent to Individuals who are Deaf or Hard-of-hearing’ (NIDCD, May 1999) reports three critical issues related to participation of Deaf adults in research. The key factors are those related to concerns of capacity, comprehension, and voluntarism (NIDCI, 1999; see also Gutman, 2002; Pollard, 2002; Young & Hunt, 2011). All three were incorporated into this study where relevant.

The signing of an informed consent form can create ethical challenges when working with a research participant who is prelingually Deaf (Pollard, 2002). The reality of restricted medical and mental health literacy has been reported previously in this document. This is further compounded by their restricted access to services (Barnett, McKee, Smith, & Peterson, 2011; Critchfield, 2002; Pollard & Barnett, 2009; Pollard, Dean, O’Hearn, & Haynes, 2009), and results in a reduced ‘fund’ of health and other information (Pollard, 2002). The term ‘fund of information’ refers to that collection of information gained incidentally through casual exposure to content or conversations, mainstream media or other sources of information otherwise readily available to members of the hearing community (Pollard, 2002). To accommodate these factors, the consent form used in this study was created in written English though the word choice and sentence structure were intended to be readable and understandable at a basic level of

English reading comprehension (NIDCD, 1999; Ladd, 2003).

My original attempt at creating an informed consent form that would accommodate accessibility needs of potential Deaf participants was viewed by my community contacts as inadequate to meet anticipated reading needs of potential participants. The community members with whom I met identified the English based informed consent document as written in English that was too advanced for many potential participants. On the recommendation of my community contacts, a second recruitment poster was created in written English using ASL grammatical structure (See Appendix F).

Johnson (NIDCD, 1999) reported that the home environment in which many Deaf children are raised creates barriers to Deaf ASL users providing informed consent. As reported some Deaf people comply with authority figures from the dominant language simply by virtue of their assumed status. Deaf ASL users may nod (in apparent agreement) to information provided or to the request to sign a document without fully comprehending its content, or the consequences of doing so (NIDCD, 1999). I took this factor into consideration during the consent review process. At the time of the first interview, each participant was given a series of options regarding their preferred review of the Informed Consent Form (Appendix G). The options included me reading the consent form to the participant and having it interpreted in full by the ASL interpreter; or the participant reading the document themselves with only those parts that were unclear interpreted as requested. The option for the participant to read the document oneself may seem counterintuitive in a sample of Deaf sign language users if the average reported reading level of this population is grade 5. However, not familiar with the level of

education of any of the participants at the consent signing stage, I felt that to not offer the opportunity to read the document oneself could have been oppressive and paternalistic, and, in my opinion, an example of audism. In the end, all participants reported that they had at least 6 months post-secondary education, with some having operated in, or currently operating in an English-based work environment. The offer to read the document oneself was not viewed by any as disrespectful, but rather inclusive of the diversity found within the Deaf community.

In this study, three participants chose to read the informed consent document themselves, seeking clarification through the interpreter only as necessary; three participants chose to have the document read by me and interpreted in full.

The initial interview included a review of a study-specific Interpreter Confidentiality Agreement (Appendix H). As interpreters were to be used during the data collection process, the University of Manitoba Ethics Board requested the creation of an Interpreter Confidentiality Agreement, a document each interpreter was required to read and to sign prior to their involvement in the research interview. The signing of the document was completed during the first interview, with each participant present. To ensure each participant was fully involved in the interview process, I read the content of the agreement aloud and the ASL interpreter interpreted the content in full. This provided the opportunity for the participant to be fully informed of the roles, responsibilities and expectations of the interpreter, including, most importantly, that of confidentiality. The interpreter then signed the document in the presence of the participant. At each subsequent interview, again in the presence of the participant, I reminded both participant and interpreter of the expectations associated with the document, confirming the

interpreters' continued willingness to comply. In all cases, the interpreter confirmed compliance with the process. I made the decision that, as I was bound to confidentiality by virtue of the Research Ethics Process in the role of researcher, it was not necessary for me to sign the formal Interpreter Confidentiality Agreement document in the case of the two interviews I later conducted independently. This issue is discussed further below.

**ASL–English interpreters.** Qualified English/ASL interpreters were incorporated into this study (Pollard, 2002). Though fluent in two-way visual communication myself, the most important reasons for doing this were to provide a level of comfort and control in the communication process for the participants by providing the opportunity for each to have a language facilitator in the room they were familiar and comfortable with. It was also to reduce the anticipated challenge for me in managing competing parallel research tasks, such as respecting the semi-structured question guide while ensuring eye contact with the participant, a fundamental component of a visual language; managing note-taking responsibilities; and being available to attend to any technical issues that may arise all with the minimal amount of disruption to the interview process.

The role of the ASL/English interpreter was to be that of “communication facilitator” (Cornes & Napier, 2005, p. 405), facilitating effective communication between two parties who do not share the same modality of communication to ensure that all have equal access to the content of that interaction. The interpretation process is more than simply that of providing a ‘conduit’ of information (Cornes & Napier, 2005). More accurately the process is defined as a formal “discourse process” with the interpreter tasked with being an active participant in the interaction (p. 404). To be effective, interpreters are expected to understand the unique syntax and structure of the visual

language being used, including the role of body language, facial expression and body positioning in the interpretation process (Lieu, Sadler, Fullerton & Stohlmann, 2008), while also being familiar with the broader topic of mental illness. It was also necessary that the interpreter's language skills closely match the language needs of the Deaf participant including modality (Cornes & Napier, 2005). Sign language is different from English in a variety of ways, including word order and mode. Cornes and Napier (2005) explain that while spoken languages are defined as "linear languages" whereby one word is produced after another in the communication process, signed languages are defined as "visual-spatial languages" (p. 403). Signed languages use a three-dimensional space and have the capacity to produce more than one sign at the same time because both hands are used in the communication process.

Five of the six participants requested a specific interpreter for their interview; one person indicated she did not have a preference regarding interpreter. The request for specific interpreter was satisfied in four of the five requests. One participant had requested a particular interpreter she had used in the past. When this interpreter was not available due to a scheduling conflict, she was comfortable with a different interpreter provided. In each case where a second interview was scheduled, all participants requested the same interpreter be used; in each case that request was satisfied. Of all those requesting a specific interpreter, each interpreter was of the same sex as the participant.

**Video recording.** Research involving the video documentation of sign language-using Deaf participants poses a greater risk of breaches to confidentiality than does data provided through writing, audio recordings, or other modalities where the face is not captured (Pollard, 2002; Young & Hunt, 2011). Attempts, be they simple or

sophisticated, at pixilation or obscuring the face do not guarantee confidentiality of that participant, because each person has a distinct signing style. More importantly, obscuring the facial features of the interviewee would erase that component of ASL expressed through facial expressions (Pollard, 2002). To obscure the face would do no more than simply render the message unintelligible (Young & Hunt, 2011)

All participants expressed some initial reservations to having their identity recorded, questioning the role of the video recording in the overall study process. Concerns were appeased after additional clarification regarding the intended use of the video in the data transcription process, storage of the video documentation and video destruction procedures were provided. As has been found in other studies with Deaf participants, the use of video documentation significantly enhanced the integrity of the interview content (Pollard, 2002; Sheppard, 2008). In the case of this study it also facilitated the transcript creation process.

I shared the nature of the study questions with each interpreter individually either electronically or at the time of the first interview. All interpreters were also informed that a video camera would record the interview. I clarified that I was interested in capturing the communication of the participant and the audio (e.g. from visual ASL to spoken English) of the interpreter, along with the researcher's voice to provide an oral record from which a verbatim transcript would be created. All of the interpreters were comfortable with his or her voice being recorded, though one did indicate that she would simply not participate if there were any expectation that she appear on the videotape. She did not provide any clarification for her statement. The statement caused me concern, as it appeared she might simply not want to be held accountable for her interpretation. As

she had an established relationship with the participant, had been requested by the participant, I could monitor the conversation myself through my own knowledge of sign language, and I incorporated a member-checking process into the study, I felt satisfied proceeding. Some minor interpreter errors occurred during the interview process with that interpreter, though all were resolved during the interview. Later, when reviewing the transcript of that interview, the participant found what she felt was additional errors. I offered to meet with the participant and review the videotape with her to compare with the transcript. We did so. While again some minor errors in interpretation were evident, the participant was confident that the interpretation was in fact mostly consistent with her comments. She approved the use of the transcript with the errors corrected.

As referenced above, in two cases, following an amendment from the Human Ethics Research Board, and with the participants' permission, I conducted the interview directly without the services of an ASL/English interpreter (Appendix D - Human Ethics Amendment Certificate). The two scenarios resulted from unique and unforeseen circumstances. In the first scenario, the interpreter contacted me just as the second interview was to begin to advise that he was having difficulty locating parking at the interview location site. While waiting for the interpreter to arrive, the participant and I conversed. Finally, after waiting for one hour for him to arrive, in the absence of further contact from him and out of respect for the participant's schedule, I offered to conduct the interview myself. The participant and I had been conversing during the waiting period so she was familiar with my signing ability. This offer was made with the condition, as per the Ethics amendment, that the participant could terminate the interview without repercussion if she did not feel communication was fluent. I also clarified that upon

completion of the interview I would book an appointment with the original interpreter, have him watch the entire recorded video and provide the formal oral interpretation that would be used to create the transcript for the interview. This strategy was intended to ensure the participant maintained control of the communication process while also providing consistency with the interpretation process. The participant indicated she was pleased with the options, viewing the options as respectful of her right to fluid communication and the right to have control over the communication process. She confirmed she was comfortable with the interview proceeding directly with the researcher. The interview proceeded with me using the semi-structured interview protocol and questions resulting from her first interview as the guides. As offered, I met with the original interpreter at a later date to have him watch the video and provide the formal verbal interpretation of the communication. In the end, his interpretation of the conversation was consistent with the draft transcript I had created based on the interview I conducted.

In the second situation the participant lived in an area outside the major centre in Manitoba. This centre does not employ an ASL interpreter, have ready access to one, or have access to appropriate video conferencing technology in such a way that confidentiality of the participant could have been guaranteed. As such, the cost of engaging the services of an interpreter from the closest major center for the interview, including both travel costs and interpreting hours, would have been approximately \$350.00, a cost prohibitive for this researcher. As my PhD advisor and I felt it important to provide the opportunity for this interested party to participate in the study given his/her willingness to do so, I inquired if the participant would be comfortable with me

conducting the interview directly, applying the same conditions noted above. After arriving at the site, the participant and I engaged in a conversation to assess my compatibility with his signing skills. The participant was comfortable with our communication so the interview proceeded; it was recorded on videotape. The content of that videotape was then reviewed with the participant through the participant's chosen interpreter at a second scheduled interview.

This second participant was pleased with the draft transcript created from the first interview, confirming the accuracy of the content and interpretation of the communication. This participant was also pleased when I formally acknowledged during the transcription process that there were several signs I had been uncertain about and needed clarification on prior to including them in the final transcript. This strategy was accepted as intended, my desire to be respectful of the participant's first language and right to accurate interpretation. To confirm the participant's intended communication, I demonstrated the sign in question. I then explained the context during which the sign was used. Finally, I sought clarification of the sign from the participant. In all but one of the cases my preliminary interpretation of the specific sign was correct. In the final situation my interpretation was of a related, though less intense meaning [e.g. I read that he was expressing "my father is OK" though in reality he was expressing, MY-FATHER – WONDERFUL<sup>7</sup>]. The word choice did not dramatically change the overall story meaning. This process was a necessary component in cross-cultural ethical research

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<sup>7</sup> Text capitalized this way is an example of a word gloss; each word/phrase represents a particular ASL sign.

practice (Pollard, 2002). A second corrected transcript was created of that second interview and became the formal transcript used for the member checking process and later, during the analysis process.

**Sampling strategy.** The sampling strategies associated with qualitative research are generally based on a different underlying logic than those used in quantitative studies (Warren & Karner, 2005). The sampling used in this study was purposive and criterion driven (Padgett, 2008; Stake, 1995). In this study the sampling strategy was a planned and deliberate process of selecting participants based on their experiences or knowledge in the area of study (e.g. mental illness) and their ability to share information on that particular subject.

It was my intention to recruit a sample as varied in age, education, socio-economic status and employment status as found in the study population. I had to appreciate however, that the low-incidence of deafness, combined with the low incidence of mental illness would dramatically reduce the size of the potential sample. Also I, like Steinberg, Loew and Sullivan (1999), recognized that the highly personal nature of the study intent could negatively influence willingness to participate. Ultimately, all but one person who contacted me to inquire about the study were interviewed; the seventh person was not invited to participate as she did not meet all the inclusion criteria.

It was my intention to select between four to eight cases for this exploratory study. This sample size was chosen as recommended in the literature to be both manageable in terms of data management, and to accommodate researcher time and cost associated with the study, while still providing an adequate number of cases that would begin to highlight the issue. Yin (2003) reported that conducting a case study with

multiple participants can produce more “robust results than using a single case” (p. 135), while Creswell (1998) suggests that no more than four cases should be used in a case study research project, the latter claiming that time associated with a larger sample size can distract or be at the expense of depth of any single case. Patton (2002) reported, “The validity, meaningfulness, and insights generated from the qualitative inquiry have more to do with the information richness of the cases selected and the observation/analytical capabilities of the researcher than the sample size “ (p. 245). Ultimately, the final number of participants (n = 6) was determined by response, willingness to participate, and availability of participants.

The inclusion criteria were as follows: adults who self-identified as Deaf, used ASL as their primary language and had not only the lived experience of depression, but also a formal medical diagnosis of Major Depressive Disorder. I did not restrict which medical profession could determine the diagnosis, though did require a formal, rather than self-reported diagnosis of depression. It was further necessary that potential participants be willing to share their experiences of living and coping with depression with me in an interview setting.

Language mode was the primary inclusion criterion in this study and ultimately formed the basis of this study for a number of reasons. The literature regarding strategies used or suggested for managing depressive symptoms is broad; the focus, however, is almost exclusively on members of the dominant hearing population seeking services in their first language. What is little reported however, is how those from a minority language and visual mode of communication who have been diagnosed with depression cope with their symptoms in a mental health and medical culture that is dominated by

hearing and speaking professionals. I felt this gap in understanding needed to be explored, particularly in light of the reported economic, emotional, social and physical costs associated with mental illness (Government of Canada, 2006; Conference Board of Canada, 2012).

The focus on a diagnosis of depression in this study was deliberate. The literature, as previously reviewed, defines depression as one of the most common mental illnesses diagnosed in the general population (CMHA, 2013). It is also reportedly a commonly reported diagnosis in the Deaf population (Black & Glickman, 2006). The intent to choose a specific diagnosis for this study did come with some reservations, particularly given the reported frequency of misdiagnosis in persons who are Deaf and communicate through ASL (Connolly, Rose & Austen, 2006; Gupta & Caddy, 2007; Harmer, 1999; Steinberg et al., 2006; Zazove, Meador, Aikens, Nease & Gorenflo, 2006). With recognition of the limitations to accurate diagnosis in the Deaf community, it was felt by myself and my PhD committee that this study need focus on a single mental health diagnosis particularly given that it is possible that different coping strategies could be engaged for different mental health challenges. As this is an exploratory study, it was agreed that the focus of this study would be on a single mental health diagnosis, in this case depression.

One exception to the mental health diagnosis was made during the study following consultation with the PhD Committee Chairperson. While depression was the primary diagnostic focus of this study, I did include one participant who, during the screening phase confirmed her diagnosis of depression but later clarified that her diagnosis was in fact, not depression but anxiety. As reported by Griffin (2010), while

depression and anxiety are reported differently in the literature, “they often go together” (WebMD) “with more than half of those diagnosed with depression also diagnosed with anxiety.” While this participant received a formal diagnosis of anxiety, she believed she had depression as based on her review of the available literature. She further believed that the failure of her physician to diagnose her with depression was related more to external circumstances (e.g. language barriers between her and her physician) than to the absence of depressive symptoms. It was decided that she would be included in this study.

There was a single exclusion criterion. Potential participants were expected to be asymptomatic or have their symptoms under control at the time of the study. The reasons for this criterion are several; the writer wanted to ensure the participants would be able to cope emotionally with the intimate nature of the research questions, and physically with the length of the interview process. I also wanted to reduce the possible harm to the participant; if they were actively experiencing symptoms of depression, their participation may lead to further exacerbation of existing symptoms, contrary to ethical research practices. Finally, it was felt that if their symptoms were being managed, it was anticipated that they would be better able to reflect a more comprehensive account of their strategies for managing their illness.

### **Participant Recruitment**

Given the diversity within the Deaf community, a multi-dimensional recruitment strategy was employed in an attempt to broaden the exposure of the study to the largest Deaf population possible in Manitoba, and thereby increase potential for involvement.

Participants were recruited from those living in the province of Manitoba, Canada; ultimately participants from three medium or large-sized centers in Manitoba

volunteered. It is not known exactly how many culturally and linguistically Deaf people live in the province of Manitoba or throughout Canada. According to the 2011 Canada Census, some 25,000 people report using a sign language at home (Statistics Canada, 2011, pg. 4), 15,000 doing so most often, and 9,800 on a regular basis.

The largest center in the province of Manitoba is the capital city of Winnipeg. This serves as the primary source for health care for the province, and is the secondary location for health care services for those living outside the center. There are not currently any primary health care providers who exclusively specialize in or provide counseling or mental health services care exclusively to culturally Deaf adults in Winnipeg. The Deaf and Hard of Hearing division of the Society for Manitobans with Disabilities (SMD) is the primary source for vocational rehabilitation and other related services for Deaf and hard of hearing residents in Winnipeg and Manitoba (SMD, 2012). As well, a hearing psychologist provides psychological services, including to those in the Deaf community; otherwise the services are limited.

**Recruitment strategy.** To locate potential participants for this research study, I focused strategically on those social settings in which Deaf participants frequently congregate and those areas where Deaf adults may share “interlocking social networks” (Warren & Karner, 2005, p. 130). The latter included distribution of the study to the Deaf e-news electronic website. Finally, I attempted to reach potential participants through professionals or community staff who may be providing therapeutic intervention to these individuals, using a snowball sampling method through these gatekeepers. See Table 1 for a listing of the organizations contacted for this study as well as clarification regarding the type of display.

Table 1

*Organizations Contacted to Display Recruitment Posters and Type of Display*

Community Source	Type of distribution
Society for Manitobans with Disability - Deaf and Hard of hearing program staff	Hard copy posting
Manitoba School for the Deaf	Hard copy posting at school for exposure to student's parents
Local family physician providing services in ASL	Hard copy posting
Calvary Temple Deaf Minister	Hard copy posting
New Directions Deaf Foster Family program staff	Hard copy posting and snowball sampling
Local psychologist providing services to Deaf adolescents	Hard copy posting and snowball sampling
Deaf e-news	Electronic distribution
Manitoba Institute of Registered Social Workers	Electronic distribution

The response to the recruitment process began slowly. Upon reflection, it would appear that the process was initially hampered by the stigma in the Deaf community regarding the expectation of admission of a diagnosis of depression, and/or by the language in which the initial poster was created. The initial, English-based, recruitment poster was distributed to a variety of physical and electronic sites of relevance to the Deaf community in and around Winnipeg, Manitoba and also posted on the Deaf e-news website (Appendix E – Recruitment Poster English). After release of the poster I received feedback from one of the local social service agency providing services to the Deaf and hard of hearing who felt the poster was “too English” (e.g. too wordy, too formal, and written in a reading level that may be difficult for some English second-language Deaf users). They invited me to a staff meeting to discuss the poster further. Staff indicated they felt members of the ASL-using Deaf community would not easily understand the content of the poster as created and thereby would not volunteer to participate. It was

suggested that a new, ASL-friendly one be created. On this advice, I met with three representatives of the Deaf community to create a new, written-ASL version. The key points of the English-based version were retained, but wording deemed superfluous for the average visual, English-as-a-second-language user, was removed. A gatekeeper in the Deaf community made a second recommendation regarding the poster, this time regarding the color of the paper on which the poster was printed. It was suggested that, in keeping with the *visual* nature of ASL-language users (italics added for clarification), the posters be printed on colored paper to draw attention to the document.

A new ASL version was created (Appendix F - Recruitment Poster ASL). Both it, and the original English version were then reprinted on blue colored paper and re-posted, together, at all the original locations. The response to the ASL poster was immediate. On the day the ASL poster was distributed, a potential participant contacted me expressing interest in the study, the second, shortly thereafter.

As is consistent with research from a member of the dominant culture with those from a minority culture, I sought and formed a collaborative relationship with two persons from the Deaf community who could best be described as cultural brokers. Both of these are well-respected members of the Deaf community who offered to mediate between the Deaf community and I as needed (Gutman, 2002; Pollard, 2002). The two brokers fielded calls from persons curious about the study, or referred potential participants to me for further information. I ultimately received two participants through snowball sampling.

**Stigma's clutches.** One situation occurred during the recruitment process that demonstrated the impact of stigma of mental illness in this community. A person from

the Deaf community contacted one of the cultural brokers referred to above to inquire about the study. This person expressed interest in participating in the study but was distraught about having to disclose his/her identity to me. The person indicated he/she would only agree to be interviewed by me if I could guarantee that they could keep their face hidden and I not in any way be able to determine their identity. The person suggested he/she be interviewed behind a wall. Given the unique nature of this request, I sought the advice of my committee chair. After deliberation, it was determined that as this person was willing to share his /her story, the comments would be valuable to the study. It was agreed I would make every effort to accommodate the interview requests. The person was to be informed that permission was granted for him/her to participate in an interview behind a physical barrier. The person would not be video taped, though the interpreter's voice would be recorded on audio. I informed the broker of this decision. Shortly thereafter, however, the potential participant determined that he/she was not comfortable with potential risk of their identity being discovered, and withdrew interest. It would appear that the stigma of mental illness for this person was more powerful than their confidence their identity could be protected.

### **Data Collection**

Data were ultimately collected through four distinct tools. A semi-structured interview guide was used to conduct individual personal interviews. (Appendix A – Interview Guide). Each of the interviews were digitally recorded, thereby providing a formal visual record of the three-dimensional nature of the visual language (ASL) and creating a permanent record from which to create the transcripts. A participant-drawn person and environment map (Appendix B) was used as part of the triangulation process to allow

participants to identify the people, places or things/activities individuals' do/did, use or have used over the past one-year to manage their symptoms of depression (Hintermair, 2009). Finally, my own interview specific and general research reflection notes supplemented the participant-created data. I will discuss each in detail below.

**Interviews.** Social science research is a process through which we gain indirect access to a person's experiences or memories. It is acknowledged that both experiences and memories may be influenced by factors of time, emotion associated with an event, and personal motivations for reporting or excluding details of any specific event or memory (Stake, 1995). To access these, it is necessary to ensure the research process and questions are accessible to the persons interviewed (Young & Hunt, 2011).

Accessibility requirements related to the built environment varied based on the participants. As the method of communication was through a visual language, I sought interview spaces that had sufficient overhead lighting or natural lighting to provide sufficient light for visual communication. This was also important given that some participants used some degree of lip reading during their interview. I also searched for interview spaces with a minimal amount of visual 'noise' or distractions, including, preferably, a background wall that was neutral in color or pattern to reduce distraction. To protect the privacy of the participants, I sought rooms that were interior interview rooms void of windows, or interview rooms with controllable window coverings or seating arrangements. In one case the room did not have window coverings as expected; privacy was secured through the seating arrangement. This participant was seated in the corner of the room outside the view of passers-by. The interpreter was seated slightly behind and to the side of me as interviewer, with both of us was seated across from the

participant. This triangle configuration is a common one when using a language facilitator. In all but the case just discussed, I posted an “Interview in Progress” sign on the outside of the room and requested uninterrupted privacy with the room-booking agents. I did not in the case above, as I did not want to draw unnecessary attention to our interview.

Interviews were ultimately conducted in a variety of locations. They occurred in individual rooms at local libraries; in a designated research interview room on the campus of the local university; in an office boardroom; in the minister’s private office of a local church; and in an office at the local train station. In two situations there were not easily accessible interpreter services available in the remote location. In one case I used Video Remote Interpreting (VRI) technology located in a post-secondary educational setting. In this situation, I travelled to the location and sat with the participant in the interview room and connected with the interpreter in a main center through video conferencing technology. The communication between participant and interpreter was through a visual means (ASL), and between the interpreter and researcher through both audio and video. A number of technological challenges did occur in this setting given that the bandwidth connection between the two sites was not identical. This resulted in what is referred to as frame dropping (Steinberg et al, 2006) or the loss of discriminate components of the sign language. Thus, several conversation interruptions occurred with both participant and interpreter needing to seek clarification of some content or requesting the repeating of certain segments of the conversation. The challenges aside, this technology and arrangement provided the opportunity for this participant to engage in the research and have his/her voice heard. The participant reported feeling confident

that their message was understood in spite of the interpreting challenges.

In all cases, the initial research interview started the formal data collection process (Hole, 2004). The questions as noted in the Interview Guide directed the interview. Each interview began with an open-ended or “grand tour” (Brenner, 2006 as cited in Yin, 2011, p. 137) question, “Can you tell me something about yourself?” A conversational approach was maintained to explore three primary / distinct stages of the participant’s experience with depression; *Initial diagnosis*: the experiences surrounding the initial diagnosis [e.g. what were you experiencing at the time that made you seek medical intervention; where did you go to address your experiences; how did you communicate with the medical/mental health staff; did you go alone or did another person accompany you?]; *Becoming well*; [e.g. after your diagnosis of depression, what intervention did you do/use to reduce your symptoms of depression? Examples of resources commonly available for the hearing community were provided: medication, formal supports, informal supports, other?]; *Staying well*: [e.g. once your symptoms had stabilized, what did you do to stay well?].

As is characteristic within the Deaf community when asking questions, examples are often given as possible ways to answer the questions (Perlman, Hedding, Balfanz-Vertiz, Cradock, DeGutis, et al., 2007). In this situation I shared the results of a Chicago study into the experiences of Deaf adults living with depression, sharing examples of those things participants did to manage their depression under the categories of either productive or non-productive activities (Perlman, et al., 2007). Providing examples appeared to reduce the anxiety participants were feeling in responding to the question, giving them some clarity as what types of responses may be expected. In all cases, when

the examples were read by the researcher and shared with the participants through the interpreter, they would either gesture through head nodding in agreement with that example or head shake indicating that it did not apply to them. While gestural head nods or head shakes cannot automatically be assumed to be assurances of agreement or disagreement for ASL-dominant, English second-language users (NIDCD, 2010) the variability of the responses provided by each participant as the examples were read appeared to suggest that respondents were differentially responding to each example provided. To verify my assumption, I confirmed the meaning of their head nods throughout this process.

All but one participant participated in two formal data-collection interviews. Each participant also participated in at least one additional member content-checking contact with the researcher, resulting in a minimum of three interviews per participant. In the case of the participant who was interviewed only once, that participant provided information to all research questions in one interview so a second formal interview was not required. That participant was, however, met on two subsequent occasions for member content-checking purposes. In the case of one participant, an interpreter was requested for the interview as well as the member checking process; in all other cases the participants indicated that they felt communication was clear between the two of us so did not feel an interpreter was necessary.

The total amount of time involved with the data collection interviews varied. Each individual data collection interview was 2 hours long; in five cases a second data collection interview occurred, that was also two hours. No interview in which an interpreter was present was longer than 2 hours. The reason for this restriction was due

primarily to two hours being the maximum time allowed for a single interpreter at an event. I also wanted to respect the time and potential energy level of participants. I had informed each participant that each interview would be no more than two hours in duration so, out of respect for the participants' schedules, that time frame was maintained.

At the end of each first interview, participants indicated that they felt the time went by very quickly, offering or agreeing to be interviewed a second time if additional information was needed. Saturation of information was achieved by the sixth person interviewed, so no additional participants were sought.

**Video-recording details.** Researchers must have an appreciation and respect for, as well as sensitivity to the culture under study (Pollard, 2002; Young & Hunt, 2011). The interviews were videotaped to enhance data content by capturing the complex nature of the visual language [e.g. facial expressions, body language, utterances, changes in the speed of signing and/or the signing space], as well as the voiced interpretation from the interpreter. Videotaping also reduced the need for extensive note taking, which would have been viewed as 'visual noise' by the participant and thereby distracting to that participant. I used a small, hand-sized digital video-recorder and tabletop tripod to minimize the intrusion of the camera. Once comfort was achieved with the camera I placed the recorder in a discreet location on the table. Due to its size, it quickly blended into the background losing its significance as a visual distraction. Participants commented after the interview that the camera became insignificant. One person noted she "...just forgot about it" (the camera) after the interview started. I did take some brief notes during the interviews though this was kept to a minimum and done primarily to record salient

points requiring later follow-up.

The videotape of each participant's first interview was transcribed within 24 hours of the interview. That transcript was then made available to that respective participant for review shortly thereafter, the member content-checking process. In each case, participants were asked if they preferred to review the transcript independently or review the transcript through an interpreter. Four of the participants requested hard or electronic copies of the first transcript to review first on their own personal time, and then to be followed up during the second interview; two requested the first transcript be reviewed exclusively through an interpreter. The second interview was used to introduce and complete the Person and Environment Map.

As anticipated, the video recording of the interview proved to be an invaluable tool during this study. It assisted in the creation of the interview transcript, and a hard copy I could use as necessary during the analysis phase. It provided the opportunity to review the emotive nature of the language and emotionality of key points or experiences expressed by the participants which may have otherwise gone undetected through review of voice interpretation only. It also provided a visual record of the interview, a record used by one participant to verify the nature of their conversation in relation to the transcript created. It satisfied her that the interpretation process was accurate based on her signed communication.

**Person and environment map.** There is a body of literature that defines social networks as necessary in the management of depression symptom management (CIHI, 2012; Onken, et al., 2002; Queensland Health, 2008). Bearing this literature in mind, participants had the opportunity to both verbally share details regarding their network of

activities they used to manage their depression, and visually record their details. The person and environment map provided this visual opportunity, and method of triangulation (Hintermair, 2009).

The hand drawn map was intended to provide qualitative access to the participants' insights into their social relationships, and resources through visual means, in a manner consistent with photo elicitation (Gauntlett & Holzwarth, 2006; Harper, 2002; Hintermair, 2009). Photo elicitation is a process that uses visual stimuli in combination with verbal discourse to access deeper elements in human consciousness that verbal discourse alone cannot. As Harper (2002) notes, the process of photo elicitation elicits not just more information, but different kinds of information than can be accessed through brain processing of verbal questions alone. Interviews with a photo elicitation component can "connect core definitions of the self to society, culture and history" (Harper, 2002, p. 13). It can also "prod latent memory" and "stimulate emotional statements about the informant's life..." (Collier, 1957, as cited in Harper, 2002, p. 14). The inclusion of this visual elicitation component was to provide what Yin (2009) would define as a physical artifact. Finally, the use of this tool was intended to assist the participants to overcome anticipated fatigue and repetition often experienced in a conventional oral-only interview (Collier, 1957, p. 858 as cited in Harper, 2002, p. 14).

A particular strength of incorporating the handcrafted map for this population is that it provided a visual alternative to the expectation of recognizing, comprehending, and verbally describing the nature and strength of various components of one's person, activity and environment network and resources. While written English was the mode through which the map was completed, out of respect for English-second language users,

participants were invited to use simple words, names or phrases they were most comfortable with.

Most participants were initially reluctant to begin the process of creating their map, expressing concern for its relevance to the process. One person asked directly, “Why am I doing this?” In anticipation of this question, I demonstrated the creation of a map using a personal example of a health issue I have experienced, what I defined as “my personal health issue” and the strategies I used to manage this issue. I consciously chose what I defined as my ‘health issue’ as I wanted to formally locate the subject of depression in the medical realm distinct from the myth of depression resulting from a personal weakness. I also referred to a research project that had been conducted with Deaf adults living with depression in Chicago who were asked to share their strategies for managing their symptoms (Perlman, 2007) to set the stage for the activity. All participants agreed it was not a task or activity they had participated in before, but all agreed to complete the task after a more thorough introduction to the tool was provided.

Participants were given a blank piece of paper and pen and invited to create their own map. Participants often narrated short stories throughout the creation of the map and some, even after declaring the task complete and putting their pens down, added additional content once they had the opportunity to visually examine and process their map. Interestingly, and as will be discussed in depth in the Findings chapter, the number of entries on the map was not automatically viewed as an indication of the strength of a person’s support system. In fact, two persons with an equal number of entries viewed that number differently. One person suggested the number of entries reflected a poor level of support, while a second felt refreshed that they in fact had “so many” resources they were

not aware of.

There are concerns reported in the literature regarding a social network map's ability to confirm validity and reliability of the social support networks when the content is self-report (Abell & Tracy, 1994). Abell and Tracy (1994) suggested that validation of perceived social support or convergent construct validity is more likely when other standardized social support instruments support the social network data. Conscious of this reported limitation; I made the decision to maintain this revised tool as a method of data collection for a number of reasons. The current study was an exploratory one, with a visual population that is not characteristically involved in research. It was felt that the inclusion of a visual tool such as this might encourage discussion and provide the opportunity for the participants to conceptualize their supports through a process more comfortable than through their signed communication.

The fourth method of data collection occurred through the active journaling I maintained throughout the data collection and analysis processes. This process provided me a method through which to reflect on the process as it was occurring, and bracket my own interpretations distinct from the participant. I was able to reflect on these observations between interviews and use the notes to confirm or disconfirm my own interpretations (Stake, 1995).

**Translation and transcription issues.** The translation of an interview from a visual signed language to a spoken language creates a number of what Ladd (2003) defined as unique "methodological considerations" (Ladd, 2003, p. 290). (See also Hole, 2007; Young & Hunt, 2011). ASL is a visual and multi-dimensional language that incorporates facial expressions and body language into the meaning along with formal one and two-

hand created signs. As such, transcription creation required not only a simple or “flat” (Ladd, 2003, p. 290) translation of the interpreter’s spoken words but more importantly a three dimensional translation of the emotional congruency between the oral interpretation and visual content to accurately reflect the full “linguistic richness” of the communication (Ladd, 2003, p. 291). To accurately reflect the richness of the conversation I included written indication of relevant grammatical intensifiers. This can be observed through sign repetition such as in the statement (e.g. “YES. YES. YES. YES. YES, that is how it felt!”), a feature not inconsistent with many oral cultures (Ladd, 2003). Translation also required a description of the [physical] emotional enhancers (e.g. “her hands dropped loudly to the table, palms up, eyebrows raised as she released a heavy sigh expressing the frustration of the experience”). To ignore or avoid including the full depth of the expression in the transcript would be disrespectful to the participant and their shared experiences, and increase the possibility of misunderstanding (Ladd, 2003).

The transcription process involved multiple viewings of the video taped interviews to maximize content accuracy. In the first viewing I listened to the voiced interpretation of signed ASL while also observing the body language and grammatical intensifiers [e.g. changes to intensity of the signing to enhance meaning of that sign or thought]; my focus was on the consistency of body language and interpreted content. I watched the tape a second time and then began creating a word-for-word transcript adding relevant physical descriptions as obvious [e.g. “eyes welled up”; “broke eye gaze”; “hands hitting table, palms up in a sign of frustration”]. These details would not have been available through the recording of verbal content only. After completing the first draft of the transcript I watched the video a third time correcting any final errors in

content, and identifying points requiring further clarification for the second interview.

As has been reported, there is no direct translation from ASL to English. Acknowledging this point, the written transcripts used were in fact created from the spoken English interpretation of the ASL-signed narratives. The transcripts from the interviews ranged from between 10 to 30 pages per interview. Once I shared the transcript with the participant, I made any requested changes. One approved by the participant for accuracy, I began the analysis process on that transcript.

**Trustworthiness of the analysis.** Qualitative research uses specific criteria to assure rigor and scientific integrity (Lincoln & Guba, 1985). These methods were adhered to in this study. For example, “credibility”, otherwise understood as the accurate and unbiased presentation of the data (Lincoln & Guba, 1985) was assured through several processes. To begin, typewritten transcripts were created as noted above. These have been maintained and are available for review. Secondly, a member content-checking process was utilized. In this study, the content-checking process was unique in that it involved the participant reviewing not the written text of their own signed-language, but rather a written transcript of the spoken English interpretation of their visual language. The transcript included the overall content, emotion and expression reported by the participant, with the wording representing the [interpreter-specific] English interpreted expression of the ASL content.

Participants were given the opportunity to complete the content-checking process in the way most comfortable to them; three possible options were provided for consideration. The first option was for the participant to review the draft transcript with the researcher through an interpreter at a scheduled meeting, with changes made to the

content as requested by participant at that time. The second option was for the researcher to provide a printed copy of the initial draft of the interview transcript to the participant for them to review and edit at their leisure. I then offered to meet with the participant and interpreter at a later date to review. The final option was for the participant to review the content in private then return any requested submission changes to the researcher electronically. All were informed that I would engage the process most comfortable for the participant.

The preferred strategy for the content checking varied between participants. Four of the six participants asked to review the written transcript of their first interview at their leisure, offering to highlight concerns, corrections, additions, and/or deletions and then meet to discuss. One person of these four asked to review the content of her interview directly with me without an interpreter present, the remaining three asked to discuss the content from their individual review with me at the time of the second interview. The remaining two of the six participants chose to review the transcript of the first meeting through the interpreter directly at the second interview, preferring not to review it independently first. Both of these latter participants felt their command of written English was not sufficient to conduct the review independently. Of these two latter participants, one asked to review the second transcript directly through the researcher and the second chose not to review the second transcript. Five participants chose to receive hard copies of their final approved transcripts, one chose not to receive copies of either transcript.

In reflection, the decision to offer these options for review, and be open to any other suggestions made by the participants in regards to this process, was a struggle

between the desires to avoid practices that may be viewed as examples of audism, and to achieve accurate information. I was cognizant of the literature that suggests that the distribution of both sign (ASL) and English fluency is broad within the Deaf population (Harmer, 1999; Pollard, 1998). I was also cognizant of the reported experience whereby Deaf people often acquiesce to members of the dominant hearing community out of learned behaviors to do so (NIDCD, 2010). Finally, I recognized that all participants in this study were better educated and had broader employment experiences than is reported for the general deaf population in Canada, with all having had completed at least some post-secondary education. I felt it important to respect each person's individuality and abilities by leaving the decision as to how to proceed with the content checking process with each participant.

In the end, this process proved to be an invaluable learning experience, both for myself, and the participants as well. Participants reported that they had rarely had the opportunity to view an English-based written transcript of an interview of them using their ASL language. Some found the experience enlightening, others frustrating. In regards to this point, it is reported that the English language has thousands of idioms (ASL Immersion 2012 course content). The signed language, ASL, however, has but a few, and most are city or location specific. For members of Deaf community in Winnipeg, examples of ASL language-specific idioms are "TRAIN GONE" (English translation – you're too late, you missed it), (YOU) GULP FISH (English translation – you're naïve or you got tricked); GOOD NIGHT (signed at the mouth) (meaning – you will be sorry or regret that). When the interpreter inserted an English idiom unfamiliar to the participant into their oral interpretation, its' presence in the transcript caused

confusion for that participant. Some examples of idioms inserted by the interpreters were, “throw them [the children] out the window” and “had a falling out with my husband.” Words inserted that were unfamiliar to participants included “piqued” and “gossip mill.” The member checking process however, allowed participants the opportunity to identify those words or idioms that were unclear to them and initiate a discussion on that word/idiom. The participant could then make the decision to either allow the word to remain, choose a different word, or alter the phrasing of the idiom. The final document used in the process of analysis was ultimately that as approved by the participant.

Following the confirmation of transcript content, a multi-stage process of data reduction occurred. The final themes were those that emerged inductively from the transcripts. These themes are represented through the presentation of exemplary segments of text extracted directly from the transcripts.

In qualitative research the issue of “dependability” is an important one. It is defined as the ability to deal with emerging issues occurring during the conduct of the research (Lincoln & Guba, 1985). This issue was dealt with by maintaining a chronological recording of issues as they arose from each individual interview and cumulatively from all prior interviews. This allowed me to refine research questions as necessary for each participant and collectively. One example of this was the inclusion of a question regarding the reason(s) for participating in the study. This emerged as relevant given the reported fear of discrimination participants assumed would occur following disclosure of a diagnosis of mental illness in the Deaf community. Ultimately, the reasons provided were to encourage change in the system to better meet the needs of these visual language users.

The issue of “confirmability” is reported as the ability to relate the findings to the original data (Lincoln & Guba, 1985). During the analysis phase there was a continual movement from a review of the whole interview experience to the comments or pieces of comment and back to the whole. I looked for common phrases, themes or patterns emerging from each interview and as they emerged across interviews. I maintained a codebook in which I documented the emerging themes as well as the codename of the participant from which the theme emerged. I also documented the codenames and transcripts in which supporting comments of that theme were found. I then recorded the specific participant and page number of the final transcript from which it was extracted. Specific excerpts used throughout this paper can ultimately be traced back to the original data.

The final issue is that of “transferability.” Data triangulation occurred by comparing the current study findings with the existing research. I reviewed the bodies of literature related to mental health and deafness as well as that related to mental health and resilience. In brief, the findings from this study confirm and extend the findings of earlier qualitative research of a similar topic such as Steinberg, Wiggins, Barmada and Sullivan’s (2002) study of Deaf women’s experiences with the health care system.

**Research limitations.** A number of limitations to the research design are noteworthy. As consistent with case study research, the sample size was small, and, therefore, not necessarily representative, which restricts generalizability of the results to the larger Deaf community. As this was an exploratory study however, generalizability was not the intended goal. It is also not necessarily a characteristic of qualitative research in general. I also acknowledge that, while the participant stories were shared with me in American

Sign Language, they were interpreted into my source language of English, and also analyzed in English (Young & Hunt, 2011). I recognize that there will be some loss of meaning as a result of this translation process (Young & Hunt, 2011). As well, I acknowledge that the process of reporting the study outcome and quotes using English sentence structure may be promoting the dominance of this language. The decision to do so, however, is based on the fact that English is the language of the majority and best understood by those very persons who are decision makers in change. It is my intention, however, to pursue research dissemination processes that both meet the needs of the dominant hearing culture and are fully accessible to ASL first language users. I will disseminate the findings through an interpreter though will also explore the possibility of creating an ASL version of the findings of this study or strategy consistent with Deaf theatre that could be used to make it available to the larger Deaf community.

This study did focus on one particular type of mental illness; it is possible that persons living with other mental health diagnoses could use other methods to cope with their symptoms. Further study in the area may uncover additional insight into effective coping strategies or best practices that could be implemented here in Canada.

There were challenges with the incorporation of the hand drawn person and environment map. As noted above, there was some reluctance on the part of the participants to complete such, given that it was unfamiliar to them and the purpose was not, at least initially, explained as clearly as necessary. Given the participants' initial hesitation to complete the map, I used both a different example to explain the map and made the decision after the first interview to change the focus of the map. Specifically, I made the decision that, as the intent of the study was to explore strategies participants

engage in or engaged in to manage their depression following a diagnosis, I felt it would be less disruptive, yet still effective, to inquire about one time period only, the 6 -12 months prior to the research interview. Only after participants understood that the ‘map’ was not a test, that it would not be judged for accuracy, beauty, or by any other factor, and that completion was voluntary, did all complete the map. It will be prudent, if used again, to ensure that the explanation is more quickly clear to participants thereby reducing any unnecessary stress or anxiety associated with completion of the tool.

One additional limitation may be related to completion of the Informed Consent form. While attempts were made to ensure participants completely understood the content and intent of the form, I could have taken an additional step as used by Pollard, Dean, O’Hearn, & Haynes (2009) of requesting participants to do a ‘back translation’ to confirm their understanding. In brief, I could have asked participants to sign the consent form content back to the researcher through the interpreter to ensure understanding. Such will be included in any future research with this population.

Finally, the participants in this study appear to be better educated than the average Deaf person in the Deaf community. These participants may represent a more highly sophisticated or resourceful sample, which may have resulted in the use of strategies different from what those in the larger Deaf population may use. This supports the need for a study of a broader basis that could provide additional results to enhance understanding. A larger study may also support enhanced resource development.

### **Summary**

The creation of the design of this study occurred following a careful review of the existing literature regarding mental illness in general, as well as research conducted

specifically with members of the Deaf community. The cultural model of deafness ultimately influenced this study. I incorporated a series of relevant recommended ethical research practices with this minority Deaf sample. I also incorporated questions that explored both personal realities as well as ecological ones.

Stigma and service accessibility barriers are reported in the dominant mental health research literature as challenges to mental health recovery. There appears to be little corresponding literature however, reported in regards to members of this minority culture. Engaging a case study methodology, this study was able to access insights into the nature of the mental health experience for this sample of participants. Future research may benefit from a broader recruitment process and methodology such as focus groups to reach a larger sample response.

## CHAPTER 4: DISCUSSION OF FINDINGS

“Walter” (a pseudonym) shared that he faces numerous challenges when attempting to resolve his personal struggles with depression. He reported multiple barriers including those of access, diagnostic, service and treatment barriers. Walter likened his life experiences to the metaphor of a garbage can:

I always keep things in, that is wrong. I should try to get rid of it, but I can't ...I need to talk to someone! [My life] is like a garbage can – it's full! I'm waiting for the garbage truck to come and dump it out, but it's not coming! Now I've got two cans, and three cans, they're all full. I just want to dump them all out, but I can't!

This chapter opens with an introduction to the study setting and continues with a portrait of the research participants. It describes the data analysis process used in this study, and presents the findings. I use participant quotes throughout this chapter in an attempt to illustrate the individual concerns, shared concerns and shared meanings. Again, I acknowledge that the quotes are reported in English; as such they not a direct transliteration of the participant's ASL-shared narratives (Tate, 2012).

### **Study Setting**

This study was conducted with participants residing in the province of Manitoba, located in the center of Canada. According to Statistics Canada (2012), the population of Canada in 2011 was approximately 33,476,688; the population in Manitoba for the same year was approximately 1,208,268. Alongside our two official languages, English and French, the main sign language in Anglophone Canada is American Sign Language, in Quebec it is Langue des signes québécoise (LSQ). Though these statistics are easily accessible, what are less so are details related specifically to the size and make-up of the Deaf community

in Canada or Manitoba.

The Canadian Association of the Deaf (CAD) reports that there is no reliable source of information regarding the number of profoundly Deaf and Hard of Hearing adults in Canada. The primary reasons for this include variation in term definitions, and flaws within the research tools accessing this information in a way respectful to that population and thereby more likely to achieve an accurate response. The 2011 Canadian census suggested that approximately 25,000 Canadians report using sign language: 15,000 most often, and 9,800 on a regular basis (Statistics Canada, 2011). There is, however, no formal record of the number of Canadian who self-declare as culturally Deaf.

The statistics regarding the size of the Deaf community are unclear. What is clear though is that there is no formal geographical setting or location that defines or borders the Deaf “community.” Members of the Deaf community are themselves heterogeneous, and reside throughout Manitoba. There are a number of specific locations identified as general meeting places for some members of the deaf, hard of hearing or Deaf community such as the Deaf Center Manitoba, located in the capital city of Manitoba, Winnipeg. There is no formal bounded physical location or community, however that defines the Deaf community. Members are ‘bound’ simply by virtue of their shared values, language and culture.

The majority of mental health-related social services in general, and for Deaf adults in Manitoba are located primarily in Winnipeg. Services for Deaf adults include vocational rehabilitation, employment and other counseling services offered at the Society for Manitobans with Disabilities; New Directions, for children, youth, adults and

families; and Reaching Equality Employment Services. In Manitoba, it is unclear as to how many professionals, hearing or Deaf are able to provide services directly to signing members of the Deaf community, as there is no central registry that documents this number.

### **Research Participants**

Through the recruitment process, a total of seven Deaf adults volunteered to participate in this study; six (n = 6) were women, one (n= 1) a man. Participants responded through the full variety of channels used in the recruitment process. Two (2) participants saw the electronic [Deaf e-news] posting directly and contacted me; one (1) person was referred from a friend who saw the electronic posting; one (1) was encouraged to participate from a colleague at a social service agency; two (2) were encouraged from a current counselor at a local social service agency; and one (1) was referred indirectly through their mental health worker after the latter was informed of the research posting from a colleague. The colleague is a Registered Social Worker and received notification of the study through the Manitoba Institute of Registered Social Workers member e-mail distribution process. Five of these potential participants contacted me electronically via e-mail, one via text messaging and one through the telephone; the range of contact strategies highlights the diversity across the Deafness continuum (Queensland Health, 2008) even within this small sample. I responded to each person via the channel they contacted me to discuss the study and respond to questions they had. It was through that initial contact that I was able to determine each person's eligibility to participate.

Of the seven who contacted me, the first who responded was excluded because she did not meet the inclusion criteria. The person self-identified as hard of hearing and,

though reportedly diagnosed with depression, did not use ASL as her first or preferred language, a fundamental criterion for participation. I contacted this person to thank her for her interest in my research and explain why I was not inviting her to participate. I ultimately invited the six (6) remaining adult individuals who expressed an interest in the study to participate as all met the inclusion criteria. Of these six, more were women (n = 5) than men (n = 1).

Given the intimate nature of the Deaf community and the highly sensitive nature of the participant stories, identifying details regarding the participants have been changed or deleted in this report to protect their identities. In all cases, the names of participants and other family members, cities in which they live, schools they attended, and places of employment were deleted or altered. Any identifying details reported are placed in parentheses and identified simply by title [i.e. school or boyfriend], rather than by name.

The participants ranged in age from 47 to 56 (mean age = 52.5). See Table 2 – Participant Demographics. The hearing status varied amongst the research participants. All six were born deaf or hard of hearing, or acquired a hearing loss before the complete acquisition of language. As adults, though two are audiologically hard-of-hearing, they all invoked the “political identify marker” (Hole, 2008, pg. 8) of (capital “D”) Deaf.

Of the six persons interviewed, all but one was born to two hearing parents. Of those raised by hearing parents, none of the parents learned to communicate fluently in ASL while the child lived at home, with listening, lip reading and oral communication the communication expectations in the family. All reported learning American Sign Language while attending the public school system; for several of the participants that learning took place after hours when school personnel were not around as signing during

school hours was not allowed.

Table 2

Participant Demographics

Characteristic	Number (%)
Responded: 7	
Female	6 (86)
Male	1 (14)
Interviewed: 6	5 (83)
Female	1 (17)
Male	
Age (median)	52
Age 25-44	0
45-55	3
56-65	3
Marital status	
Married/Cohabiting	3
Divorced/Separated/Widowed	3
Single/Never Married	0
Other	0
Educational level	
<_ High School	0
0 – 12 months Univer/College	2
12+ months Univer/College	4
School <sup>1</sup>	
Deaf Residential	3
Mainstream	2
Other/combined	2
Job status <sup>2</sup>	
Full time/part time	4
Laid-off/Unemployed	1
Other/casual	1

<sup>1</sup> Number is more than 6 due to involvement in multiple school settings for some.

<sup>2</sup> Details at time of interview.

The educational level and post-secondary experiences varied amongst the participants. Every participant in this study not only completed high school, but also reported obtaining some post-secondary education ranging from six months to four years.

Overall, this sample was better educated than is the reported educational level of the average Deaf person. Though all participants attended some post-secondary education, the English-reading comprehension amongst the participants varied. Two persons stated during their respective interviews that because the focus of their public school education was on teaching oral skills rather than academic knowledge, they rated their overall education level as “very low.” One person in fact reported their educational experience this way,

With the education I have because of all the different modes, because the focus was on oral methods, I didn't learn to read because they were so busy focusing on teaching me how to speak. So the focus wasn't on my education it was on speaking.

Of the participants, three are married, and three either divorced or separated. Five of the participants have children; one does not. At the time of the interviews one participant was employed full time, three employed part-time, one casual and one temporarily unemployed.

Regarding the diagnosis of depression; three of the participants received a formal medical diagnosis within the past 5 years, two first received a diagnosis more than 10 years ago and one was not diagnosed with depression but rather anxiety. As has been discussed, the decision was made to include this person in the study even in spite of her lack of a formal diagnosis of depression as she originally reported. The final factor regarding the decision to include this person is the reality that misdiagnosis is common in the Deaf community given the variety of communication and other barriers discussed above. The diagnosis of depression was made by a general practitioner in four cases, and jointly based on the assessment of both a general practitioner and specialist. A general practitioner made the diagnosis of anxiety. Consistent with the literature, at least three

participants reported that they had received more than one diagnosis from their physician, leaving those participants feeling confused and frustrated with the inconsistency.

The participants reported the symptoms they experienced that resulted in their visit to a physician. Consistent with the mainstream literature on common symptoms of depression they included: crying (“crying for days”); loss of interest in activities; changes in appetite (some more, others less); changes in sleep (some more, others less); difficulty concentrating; tired/ lethargic; feels guilty; and suicidal thoughts or attempts. Other symptoms reported included “felt heavy inside, very heavy”, “always mad”, and “drinking to forget the past”.

Four of six participants chose the pseudonym they wanted to be referred to in this report and during any information dissemination activity; I arbitrarily chose the two remaining “names” at the participant’s request.

Three participants attended a school for the Deaf for the duration of their elementary and high school education, while the remaining three attended an oral Deaf school, were mainstreamed, or a attended a combination thereof. In keeping with the Cultural model of Deafness, and out of respect for the participants, I will not report the etiology of the participants’ deafness. Each participant felt it was more important for this study that they self-identified as (culturally) Deaf and as a member of the Deaf community, rather than focusing on the etiology of their deafness.

All participants resided in a major center in the province of Manitoba. The number and range of Deaf-friendly resources, including qualified interpreters, available to the participants varied due primarily to geographical realities. Though the availability and access to services varied, what did not, however, was the feeling that there was an

unequal level and availability of services to these clients because of their deafness and first language in comparison to their hearing counterparts.

**Reasons for participating.** The reason participants volunteered for this study emerged as an area of interest during the initial interviews. This was particularly relevant given the personal nature of the research focus, and the reported level of stigma of mental illness in the Deaf community as greater than that reported in the general public. Consistent with case study research, as it emerged as a question of relevance during the data collection process, so the question was added to the semi-structured interview guide in subsequent interviews.

The second person to contact me ('Natalie') did so the day the ASL version of the Recruitment Poster was released. It appeared simultaneously on a Deaf e-mail news site and in various social gatherings and otherwise significant sites for members of the Deaf community. The release of this second (ASL) version occurred during the running of Bell Canada's five-year \$50 million dollar "Let's Talk" multi-media mental health initiative (Bell Canada, 2012). The campaign was originally launched on September 21, 2011 with Olympian Clara Hughes discussing her experiences with depression. On February 8<sup>th</sup>, 2012, Michael Landsberg, host of 'The Sports Network' (TSN) television program 'Off the Record' reported on Canada AM that he, too, lived with depression. Natalie explained during our first contact that she saw my research recruitment poster on the Deaf e-news site at the same time she saw Clara Hughes discuss her lived experience with depression during this mental health promotion campaign. The impact of these two coincidental events was profound for this participant. She reported to me, "I believe timing is everything—I really believe that. I thought this must be a sign [for me to participate]."

A second person (“Ali”) stated simply that she chose to participate “to support you in your research.” She clarified that while the primary barrier preventing equal access to services is lack of effective communication between the Deaf and hearing/speaking people, she believes the barriers extend beyond simple communication. She believes barriers include lack of equal access to other needs the hearing majority take for granted—like social activities. Ali said,

Maybe that loss of self-esteem we were talking about if there are not resources available for people. ... I wish Deaf people had the same access as hearing people. You know, not just interpreter, lots of time even a simple thing like wanting to take a hobby. There is no one to interpret it. Or, if you have (personal issue) and you know something is wrong, and then if there is a workshop talking about these particular problems, there is never an interpreter available. So it’s not fair – we don’t have equal opportunities. Hearing people have so many opportunities to take advantage of out there. When you don’t hear, you’re relying on someone writing back and forth. So when I heard you were researching this about Deaf and depression, I thought, yeah! I would like to be involved and help.

She added,

Yes, there has to be a lot more education toward that [Deaf culture and sign language], and you are doing that right now. Because your research will help spread the word. And (a professional), me, and others ... I would be pleased to be part of that and the planning.

Additional reasons were given were volunteering for this study. Two participants stated they believed the resources for the signing Deaf were sorely lacking and they saw this study both as a way to raise awareness of the challenges faced by Deaf ASL users and as a platform for change. One person stated clearly,

I am happy, and I am certainly happy to help you make it better for Deaf people. I want to see that. Because like I said, in [city] I saw that it can change. So I have already had that experience and I have relayed that to people and they think it should be the same here, they think that would be nice... But don’t wait too long, because there is a lot of need here! ...It is a smaller fishbowl here. So you need something better than what is here now. (Bobo)

This participant later added, “I would like to work with you, it would be nice” (Bobo).

The findings presented below are not intended to be a basis for generalization, but rather, as Stake (1995) reports, to provide a sense of “particularization” to the issues (p. 8). Every attempt was made to preserve the multiple realities of these participants and their personal accounts.

**Data analysis: Applying a constructivist lens.** The essence of data analysis in qualitative research is to immerse oneself in the details and content of the interview transcript so as to discover important patterns, themes, and interrelationships amongst these patterns and themes (Patton 2002). Tutty, Rothery, and Grinnell (1996) defined it as a process of becoming “intimate” with the data (p. 161). This inductive process is “guided by analytical principles...and ends with creative synthesis” (Patton, 2002, p. 41).

This study is grounded in Crotty’s (1998) constructivist-interpretivist ‘theoretical perspective’ or paradigm, which adopts a hermeneutic and dialectical methodology and Creswell’s (1998) case study ‘tradition’ or strategy of qualitative inquiry analysis.

In keeping with these foundations, and consistent with the methodology as reported by Stake (1995), this chapter will move beyond simply presenting the ‘issues’ of the cases in a storytelling fashion. Instead, I will shift focus to that of understanding the depth of the cases; I will move beyond the ‘problems’ to uncover the components, complexities and coping strategies through a careful selection of relevant vignettes or quotations plucked directly out of the transcripts. This is intended to provide an idiographic and emic understanding of the participants’ realities (Ponterotto, 2005).

I began the data analysis process with a select number of a priori or “prefigured” codes as based on my readings of the related literature (Crabtree & Miller, 1999). I also remained open to new codes, however, as well as major themes (also referred to as

categories), and sub-categories emerging inductively from all sources of data. This included details as observed through the videotapes, from the transcripts, my field notes, and from the person and environment map content. I bracketed my own thoughts, feelings and emotions in my codebook through each step of the process.

All participants were aware that their stories formed the basis of my research and final report. They were also aware that I would be honoring their voices through selected quotes or using what Stake (1995) defined as “uncontestable description” (p. 140) as I co-construct and present these findings to assist in understanding the lived experiences of these participants. Consistent with case study research and reporting, however, I also include references or citations from the literature in the stories to remind the reader that interpretations are grounded in the literature (Stake, 1995).

This cross-case analysis or interpretation is grounded in hermeneutics. According to Patton (2002), hermeneutics focuses on interpreting something of interest, be it text, a photo or a piece of art, though interpretation also extends to the interpretation of interviews. In this case, analysis was done applying the “hermeneutic circle” (Patton, 2002), a process aimed at enhancing understanding by relating “... parts to wholes, and wholes to parts” (p. 497). In essence it purports that to construct the meaning of the whole requires making sense of the various parts of the whole, and to understand the parts requires an understanding of the whole (Schwandt, 2001, p. 112 as cited in Patton, 2002, p. 497). This hermeneutic method is defined as both circular and universal in that every interpretation is both layered onto another interpretation while also dependent of the other.

The challenge in applying this hermeneutic circle method is in determining where

to enter the circle of interpretation. Packer and Addison suggest analysis begins with the researcher's "practical understanding" of the issue, and proceeds from that point, recognizing that the goal of this interpretation is not to achieve a "final construction" or final 'conclusion' per se (1989, as cited in Patton, 2002, p. 298). Rather, analysis and interpretation works to "keep discussion open and alive, to keep inquiry underway" (Packer & Addison, 1989, as cited in Patton, 2002, p. 498). The intention of my interpretation then is to enter the circle of reported experiences and begin to peel back the layers en route towards a more comprehensive understanding of the phenomenon of study.

Consistent with the constructivist-interpretivist lens, my own values and experiences cannot be divorced from the research process (Ponterotto, 2005). I expand on my own position or situatedness in this chapter, and will continue to acknowledge or describe my own experiences, position, values and biases as relevant throughout this report (Ponterotto, 2005).

**Bracketing.** I am acutely aware of the fact that I am a member of the hearing majority writing about members of the signing minority. I am also well aware of the political and ethical sensitivities associated with my position in this process, particularly in light of historical and hegemonic activities and attitudes that have resulted from the paternalistic (oral) educational and medical systems

My involvement with members of the Deaf community continues. I have attended various Deaf-community workshops or other events and continue to enhance my receptive and expressive visual communication skills. In fact, while attending the 2012 ASL Immersion course I was engaged in a three-way conversation with one of the

instructors, also a friend, and a second student like myself. During the conversation, the instructor pointed out to the second student, new to the immersion process, that I was "... a sister, had taken courses before and CONTINUE to take ASL courses" [capitals demonstrating emphasis]. He suggested that it was unusual for a hearing sibling of a Deaf person to remain committed to facilitating communication beyond basic, introductory-level courses. It would appear that, while other hearing siblings have done the same, I may, unfortunately, be in the minority. I believe this does enhance my visibility, and highlights my continued desire to be an ally of the Deaf community.

Given the political sensitivities, I have great respect for the responsibility I have been granted; entrance into the emic experiences of this small group of Deaf adults and permission, at least from these participants and the community organizations through which I consulted for this study, to serve as a conduit for moving these stories into the mainstream culture. I am comforted with the observation made by the participant of my first interview. During the interview I initiated a check-in with her regarding her experience to the questions to that point. She responded that she was feeling OK. She added, "you are not judgmental, I can see that. I can see that you won't pass judgment on me." I felt that observation suggested I was being true to whom I was, someone born into the hearing majority but, more importantly, a supporter of the 'Deafness as difference' view. That being said, the words of Josselson (1996), as cited in Hole (2004) are also relevant as I write my own final report:

My guilt, I think, comes from my knowing that I have taken myself out of a relationship with my participants (with whom, during the interview, I was in intimate relationship), to be in relationship with my readers. I have, in a sense, been talking about them behind their backs and doing so publically. Where in the interview I had been responsive to them, now I am using their lives in the service of something else, for my own purposes, to show something to others. I am guilty

about being an intruder and then, to some extent, a betrayer. (p. 70)

An important component of case study research is to make oneself visible to the readers and participants of this study (Hole, 2004) and to establish the “interactivity between researcher and phenomena” (Stake, 1995, p. 140). Throughout the interview and interactive member-checking processes I remained transparent both to my research purpose [i.e. final requirement for a Ph.D. in social work], and information dissemination intent [i.e. share the findings with members of the social work and other medical /mental health professions to enhance cross-cultural awareness and sensitivity to the experiences of a small group of signing Deaf adults living with depression in a hegemonic hearing culture].

The interpretations presented here are mine; while I consulted with the participants on the content of their transcripts (Yin, 2003), I did not consult with them on my final interpretations.

### **Reading Across the Stories: Shared Themes, Concerns, Patterns of Behavior**

The following narrative provides my interpretation of the shared themes of the six respondents managing a diagnosis of depression while part of the collectivist Deaf community nestled in the dominant and hegemonic hearing/speaking society.

The data analysis process resulted in four shared themes: Impression management—fighting identity rupture; Distracting from the pain; Resilience—doing it my way; and, I am Deaf—that’s all (see Figure 1 – Themes resulting from cross-case analysis). All of these themes however, fall under an umbrella theme that can best be defined as communication barriers. I begin by introducing the dominant theme of communication and the depth of its impact, followed by a discussion related to the four remaining themes.



*Figure 1.* Themes resulting from cross-case analysis.

The case study research methodology is grounded in a detailed and comprehensive exploration of the cases under study as well as a thorough review of the “stage” in which the study is based. This could not be more evident than in this study. While three primary questions guided this study, it quickly became apparent that exploration of one issue was necessary prior to the exploration of the three research questions that guided this study. The issue that most requires unpacking in this study is that of communication. As identified by Wilkins (2004) and Blackstone, Williams and Wilkins (2008), “We must shift our focus from the specific deficits of an individual. It is conversations that are impaired, not the interactants” (as cited in Blackstone & Garrett, 2011, Power point slide 11).

**Theme 1. Communication barriers.** All participants reported that the primary barrier interrupting their ability to secure trusted, effective and comprehensive mental health assessments and intervention was that of inaccessible communication. Participants noted, however, that judgmental attitudes also contributed. The issue of ‘communication barriers’ was in fact the theme that underpinned all participant narratives to at least some depth throughout the interviews. While some participants described strategies for maneuvering around some of the communication barriers, in reality it remained an ever-present ‘elephant-in-the-room’. See Figure 2 – Communication Barriers: Overriding theme.



*Figure 2.* Communication barriers: Overriding theme

The umbrella term ‘communication barriers’ incorporates four primary sub-themes; examples of each will be explored through excerpts from the participant narratives. This term incorporates the barriers related to (1.1) communication with family members and friends who lack a common two-way communication strategy with the

signing Deaf participant. This barrier serves to isolate the Deaf person both from casual family banter, as well as from incidental information, emotional support and camaraderie. The second theme reports on challenges related to (1.2) interaction with medical and related mental health professionals. It refers to those professionals who lack knowledge of Deaf culture and fluency in signed languages thereby rendering much of the professional interaction for the Deaf patient/client bewildering, frustrating, and, ultimately, inaccessible. Theme three relates to challenges within the (1.3) mental health resource system. It refers to a system that fails to acknowledge and respect the mode of communication many Deaf adults use, while also failing to provide an acceptable conduit (e.g. a qualified English-ASL interpreter) through which effective two-way communication can occur. Both of these are reported to block accessibility and participation in treatment resources. This theme includes challenges with health prevention or promotion materials that are inaccessible. Finally, participants reported the barriers associated with (1.4) communication technologies. Each is discussed below.

I have chosen to represent the theme of communication by linking narratives from the interview transcripts to each of the three primary questions that guided this study. In brief, the questions focused on the initial experience with doctor, strategies for achieving wellness (after diagnosis) and strategies for maintaining wellness. Where necessary, and consistent with visual nature of ASL, I will include various emotional and language markers, such as descriptions of body language, and the use of explanation marks to emphasize the nature of the emotions expressed.

(1.1) Communication challenges with family and friends. Several participants reported on the challenges associated with being raised as the only Deaf person in a hearing family.

One person shared the recurring nature of her experiences in a predominantly hearing family. She reported,

For instance, when you go home, your family doesn't communicate with you. They might be able to sign "hello" and "how are you" and "good bye." And that is about it. So we're limited in communicating at home, and that is a common Deaf experience. And I certainly have had that experience. I mean I am not saying my family is not sweet, they are. But there is limited communication between us. And I want to know everything, like, what happened on TV, and I would be asking everybody what they said and they would always tell me, "Wait, I'll tell you later." And I would think, OK, they'll tell me later, but "later" never came. It never happened. And it just kept on and on like that, you know. It was just perpetual, they just sort of ignored me. And I never really got to know the things I was asking about. And that really, really burned me! I was really upset about that. I wanted to know what was going on in the world, you know. Everything is happening. (Ali)

A second person shared the frustrations related to large family gatherings:

For example, all my relatives, cousins, aunts and uncles, we would all get together for Christmas, or anniversaries, or other events. We would all get together. There would be lots of people and we would all be sitting around a long table – but no one would talk to me – no one! They might say one or two small things to me like "hello" or "how are you" or "how is work?" but then they would go right back to eating and talking – lots of talking. I would ask what they were saying, but then I would be told, "Just wait, I'll tell you later." So I would just go back to eating my dinner. And my dinner would be all gone – first. But for the others, because they were all talking, they wouldn't have had a chance to eat much. So mine would be gone, and with no one to talk to, I would get up and go into another room to watch TV. Then my mother would come to me and say, "You're being rude, you need to stay in the other room with everyone else." I said, "I'm bored! There is no one for me to talk to – they all just keep talking amongst themselves!" But she would say, no, you need to go in there and just sit there, and smile at people and listen. (Walter)

The experience of communication isolation for the participants' hearing parents is best exemplified through the experience of a family event when most of the attendees were Deaf ASL users. The parents, who themselves were hearing and had never gained competence in ASL, suddenly felt completely isolated. The Deaf person reported that when asked by his parents what was being said, he responded,

'Oh nothing, nothing.' Exactly the same experience I always had. I said, 'You

didn't learn sign language, I'm sorry. Just go and sit down and watch some TV'. My mom was UPSET! I thought "too bad..." I wanted to show my mother and father how it feels. (Walter)

Other participants reported similar experiences of feeling disconnected from family and the world at large because of a lack of shared common language. Participants reported feeling emotionally isolated, and less a part of the family dynamic than other family members. Some participants felt strongly that the communication isolation from families, when combined with other childhood and later experiences, contributed to their current experiences with depression.

(1.2) Interaction with medical and related mental health professionals. "Natalie."

Natalie began her story by recounting her initial decision to seek medical care when her 'experiences' became alarming for her. A new mom at the time, she reported that a "few situations" that happened suggested to her that she should see a doctor. She said,

I felt mentally and physically that *something else* [emphasis added] was controlling me. I couldn't control it. ... I hesitated in seeking care however, and initially kept things to myself [because] I felt there was some judgment, you know, I mean, they [the doctor] wouldn't understand certain issues.

Natalie reported she tried discussing her feelings with her husband, but said,

He would say, "oh yeah, yeah, I understand," but I don't think he fully understands. It was like he was hearing the words but not listening to what I was saying. When I asked if she ever had that same experience with her doctor [i.e. him hearing her but not listening to the words], she signed emphatically five times, "YES, YES, YES, YES, YES! I've got to reiterate that but yes! I feel the doctor just *takes so long*." (emphasis in original).

She explained her latter comment this way,

Well, my signs and symptoms and the things I've gone through, I've put it out there. It should be clear enough for him, without having to explain the situation, which I didn't want to do. You know, those feelings I've been feeling – tired, exhausted, no energy. Um, sharing this information with him, I've shared it with him a number of times. And ... why is it taking so long for him to put the puzzle pieces together. Like it's [hesitation] he should be able to figure it out. And I think there is a communication barrier, and I do have a trust issue with the doctor.

Natalie attributes some or much of the communication challenge with this first doctor to attitude. She reported the doctor “did not ask too many questions, no.” She explained, “It’s sad that there are many, many people that are judgmental out there. I find it frustrating which makes it hard to speak with a doctor, or other professional about depression. It’s not easy to talk with them, no [shakes head side to side].” She did note however, that she was subsequently referred to a second physician for an additional assessment. Natalie described this second doctor this way: “Wonderful. She asked me many, *many* questions: and I was able to list off many things. I told her everything, this, and this, and this. She [also] gave me information.”

Natalie explained that she did not have an interpreter for the appointment with her general practitioner, though did have for this second appointment with the specialist because she anticipated the questions might be more in depth than the first. Natalie’s diagnosis of depression came only after her appointment with the second doctor, the one she described as “wonderful” and thorough. The second doctor combined the information she collected with that collected by the first physician to provide a diagnosis. While she appreciated a diagnosis, she felt the process was an unnecessary delay and occurred only as a result of the first physicians’ negative attitude and the lack of accessible two-way communication with that doctor.

Natalie explained that shortly after her meeting with her family physician to discuss her symptoms, she made the decision to change doctors. When asked why, she explained simply, “I don’t really remember why I changed but I know I didn’t feel I had a connection with my other doctor. There just wasn’t that communication. The doctor wasn’t bad, but it just...*it didn’t feel right*” [italics added to reflect emotion].”

Natalie described that barriers to communication, as well as what she described as “lack of understanding from others, lack of empathy from others, and other things, together with things piling on” pushed her to her “breaking point.” Thoughts of suicide surfaced. She said, “I felt so alone!” She admitted, “I didn’t have the support around me, which made it harder... so my self-esteem – it was very low, I was always feeling down. Just trying to get along...not having family supports.” She later reported that “I spent days crying, all day crying. [People] not listening to what I was telling them!”

In effect, Natalie was, metaphorically, like an island unto herself; while she could see ‘land’ [family, friends, a mental health system], she could not access any of these resources to help lift her from her depths of depression. Lack of effective communication resulted in isolation, feelings of alienation, despair and a sense of hopelessness. How she coped is discussed in the section below.

“*Ali.*” Ali first sought medical attention for the physical symptoms she was experiencing as an adult because of a dysfunctional relationship. Retrospectively, she believes her ‘depression’ can best be linked to the “heavy discipline” she experienced in residential school. She explained that any time there was any kind of inappropriate behavior in the school, there was discipline. She explained,

There was such severe discipline. They spanked me and I saw them spank other children. I was hit on the back, on the head, on the neck, on my lower back, on my legs and on my hands, on my palms. . . . So I was always scared...The teachers had wooden rulers at that time,...and the wooden brush for erasing the board with. ...It was really awful. (Ali)

She also reported that, “one time a supervisor punched me in the stomach. And that was a big person!” Ali explained that at the time she decided to see a doctor she was crying a lot and wanted to eat constantly, describing food as her “happy pill.” She also had difficulty concentrating, couldn’t stay focused long enough to complete projects she

had started, and slept more than what she felt would be considered ‘normal’ or usual for someone her age. Ali explained that when she visited the doctor she was, to her surprise, not diagnosed with depression, but anxiety. She reported to me that she was not in agreement with this diagnosis, believing she may simply have been misdiagnosed. She experienced what she was certain was depression at a later point in her life following a series of family tragedies, including deaths. She described feeling “heavy inside – very heavy.” The diagnosis, from yet another doctor was, again much to her surprise, anxiety. Medication was prescribed for her anxiety, along with the suggestion she seek counseling.

Ali explained that interpreters were available for some appointments, though not all. What is interesting is that she reported none of the physicians she saw ever conducted a formal assessment for depression; while questions were asked of her symptoms, no formal depression inventory of any kind was conducted. She believes to this day that the diagnoses of anxiety are not accurate, and that in fact she was misdiagnosed on both occasions.

“*Bobo.*” Bobo described a rather graphic experience demonstrating what she feels is the impact of miscommunication. She suggested it was indicative of lack of respect for Deaf culture and for the role of sign language in this Deaf persons’ life. When asked about her diagnosis of mental illness, she began by reporting that because of the isolation and sense of hopelessness she was feeling post-high school, her involvement in dysfunctional coping behaviors escalated to the point where she saw no hope or purpose in life. She contacted a friend to report her plan for suicide. She admitted,

I had no supports for a long time. I was drinking a lot, and drinking made me remember things from the past, and I felt like that was the end. I wanted it all to

end. So then I tried to kill myself, yes.

The friend, taking her threat seriously, contacted 911. An ambulance arrived and took Bobo to the hospital. There she met with a doctor she was not familiar with. Unfamiliar with her, the physicians' response to her emotional pain and cry for help was met with cultural and linguistic ignorance. Though told that she was Deaf, the doctor took action, although not what Bobo was expecting.

OK, the first doctor thought I was angry and that's what they wanted to call it. And they put me in a strait jacket because of that! So obviously you know what that meant – they misdiagnosed me and I couldn't sign or write or anything! All I could do was scream because I was in a strait jacket! So obviously that was my only way to communicate at that time [e.g. scream] because I couldn't use my hands. So of course I was angry. It was silly thing to do to a Deaf person.

Three hours later, after asking her if she was “fine”, the hospital discharged Bobo. They did so, however, without providing her with medication or any form of follow-up. Confused and bewildered, she literally walked out of the hospital, and back to the very same home environment from which she came hours earlier. Her lasting impression from that experience was simple; don't report a suicide plan or they will place you in a straightjacket!

Bobo sought formal intervention many times to address childhood demons. She sought assistance from both doctors and counseling services through a variety of social service agencies in the various cities in which she lived. In regard to medical doctors, she reported,

And then I saw another doctor who said they would give me medication for depression – which I didn't like, then I saw another doctor who said they labeled me as having relationship problems, and that again wasn't it. So I have had a lot of different things [diagnoses].

In regards to counselors, she reported, “ I went to a counselor but that didn't work, and then another counselor and that didn't work.” When asked the reason for the

failure she reported “interpretation.” Bobo explained that, unable to locate a counselor with direct skills in signed language, Bobo was referred to hearing counselors with an ASL/English interpreter present to facilitate communication. For reasons that were unclear at the time, the interpreters assigned to the hearing counselor kept changing, resulting in Bobo having to explain her history and “...start over again and again! [for the interpreters’ sake].” While these experiences with counselors happened years ago, the inaccessibility of resources has resulted in her coping with her symptoms in the best way she can; sleep. “I go to sleep. I sleep a lot, then the next day I forget and its better.”

Bobo reported she also watches TV to help her forget; she allows herself to become engrossed in the story so she can, at least temporarily, forget the demons of her past. Bobo admits that her attempts at escapism are generally short-lived. She reports she lives with many unresolved historical issues, childhood traumas she cared not to discuss in the interview. They remain unresolved because she cannot access personal supports she believes she needs. She admitted she is losing hope that she will ever be able to receive the help she needs.

Bobo described that the barriers to health care remain today. She reported that, while she had a family doctor, she saw him only 2 or 3 times in past four years. When asked why, she reported that he preferred an interpreter be present during their contact but as none was available in the center in which she lived, and she could not afford the cost of the interpreter to travel from the main health care center to her area [specifically, gas costs], she and her physician were forced to communicate through writing. She reported she manages communication to the best of her abilities, admitting that her written English “...is bad”, thereby complicating effective communication and

confidence in her medical diagnosis, treatment, or long-term health future. [The writer had a subsequent conversation with a firm providing interpreting services in which it was explained that clients are not expected to reimburse interpreters for the cost of gas associated with travelling to an assignment, even assignments that take interpreters out of town. There is no way to know if there are others who would benefit from this information. This factor does suggest that knowledge dissemination may not be reaching all those who would benefit; as a minimum, it has not reached Bobo.]

Bobo reported, “Communication wasn’t good – there was miscommunication. It was tough. But then he left [his practice], he just left, he didn’t inform me, he just left!” She recently located a new physician. She is hopeful this new relationship will be successful, though admits her past experiences with medical professionals cause her concern for her future health care needs.

Contrary to the frustrating, frightening and confusing experiences reported by the two participants above, two others were able to report on experiences related to both sides of the communication coin; positive and negative.

“*Walter.*” Walter reported that effective communication with his family doctor results in a positive medical experience. Though hearing, the physician appreciates the need for language support to facilitate effective communication with Walter, a Deaf [signing] patient. The doctor prefers an interpreter be included in all medical appointments. Walter advised that, “he likes to bring an interpreter.... He understands Deaf culture, he’s a wonderful doctor.”

Walter advised that it was as a result of his positive relationship with his doctor that he was diagnosed with depression. It began when the doctor noticed that Walter

looked particularly tired upon arrival for a scheduled appointment. He asked if Walter was OK. Walter explained,

He asked me lots of questions. I told him everything and he listened. The appointment took over 1 hour. He focused on me! He listened. I was worried about his other patients, but he said, no, forget about them, I'm talking to you.

Walter added, "he's very nice – he accepts an interpreter no problem. I am very happy to have him!"

As a result of a comprehensive assessment at that time, the doctor diagnosed Walter with depression. Aware that there are no accessible resources for Deaf persons in the community in which Walter resides, the doctor suggested one-on-one counseling. Walter reported, "He said I need a person to talk with." Walter agreed, using the metaphor of a garbage can, as previously shared.

Walter hoped his experience with counseling would be as positive an experience as it was with the physician – it was not. Though referred for mental health services with some urgency, months went by before the first intake appointment. At that appointment, though well aware that Walter was a Deaf ASL user and required an interpreter to facilitate communication with English-only speaking professionals, one was not scheduled for the interview. The professional used written English forcing Walter to communicate in his second language, one in which he feels he is not fluent. He feels the continued delays in him receiving service are exacerbating his symptoms of depression. "This is bullshit", he says, angrily.

"Joan." Joan, too, has had experiences with both sides of the communication coin. In her experience, clear, two-way communication has promoted both understanding and wellness. Joan explained that her challenges with medical doctors and medical care began as a youngster because, as she explained, "The doctors I had been going to were all

hearing, they didn't use sign language, and didn't use interpreters, so it was writing to communicate with the doctors.”

As a young person and teenager, writing with and comprehending a doctor's written English was difficult, particularly doing so in her second language. Joan's experiences improved, however, when, as an adult she found her current physician. Joan shared that she began to experience parenting challenges with one of her teenage children. Shortly thereafter she began experiencing “grief, ...I was so distraught and crying all the time throughout that period.” Anxious about her past experiences with hearing doctors, she sought the services of a medical doctor in the city who, though hearing, is fluent in ASL. She believes the opportunity for her to communicate directly in her first language (ASL) has facilitated effective medical assessment and care. Joan explained that when she met with her new sign-fluent physician she was able to express herself and explain some of what she was experiencing (e.g. crying, feeling restless, not being able to sleep, no interest in food, loss of interest in activities). Understanding Deaf culture and the visual nature of ASL, the physician then showed her a poster with pictorial representation of the various symptoms of depression. “I went through those pictures and identified a lot of them, said, yes, to matching me. And then I was diagnosed with depression.”

Effective two-way communication with her new physician facilitated confidence in Joan that her medical concerns were not only heard but also, more importantly, understood. She allowed the previously negative experiences and barriers associated with health care staff to become but a memory. Communication also allowed Joan to engage in the treatment planning process in an informed way. Then later, follow-up appointments

with that doctor continued to provide confidence that her needs were being met.

The doctor in Joan's case assessed Joan in her first language and suggested a treatment plan that included medication and encouragement to simultaneously seek counseling. It was at this stage of her intervention plan that the communication barriers rose again. Joan contacted a well-respected social service agency in the large metropolitan area in which she lives to inquire about joining a support group for women. She was told by the agency that she could join the group; there was, however, a caveat. The agency did not have funding for interpreters; as such, Joan would have to participate without. With a look of frustration on her face, her hands dropping onto the table in front of her in frustration, Joan reported, "So that meant I couldn't access the group!" She then sought intervention through an employee assistance program available at her place of employment. She explained that the arrangement also didn't work.

It didn't really work for me though. You know, just having to explain it, I felt like, I didn't feel like I was really heard the way I would be with a, or from a professional who was from the same culture as me... I really didn't feel it was working so I didn't continue on. I saw my doctor again and was then referred to a [different professional] . . . but still, I just felt like, I wasn't understood... There was a complete lack of cultural understanding and what that means in the culture I ascribe to. To this day I struggle with the services I was able to access.

"*Ali.*" Ali, too, reported experiences with professionals that were both positive and negative. She reported she has participated in various forms of counseling over the years to address challenges she had, or is currently experiencing. In all but one situation, the facilitator was not able to communicate in sign language, though interpreters were always provided.

Communication was not always clear, but it was an improvement over lack of any form of language support. The most successful professional relationship, however, occurred with a professional who was herself late-deafened. This person completed

training to become a psychologist after losing her hearing as an adult. She also gained skills in ASL. She currently conducts her practice through ASL and voice. Ali described the professional as being able only to "...sign a little, (but) she could carry on a conversation." That direct line of communication in Ali's first language made it 'better' than through a third-party interpreter. Ali reported that with the professional "it was better; it was private. It was like you were in your own bubble. Yeah, that's better... It was just a more natural interaction, yes. And it did also save some time as well."

Ali explained that misunderstandings could occur in communication when using an interpreter. She referred specifically to the number of interpreter errors that occurred during both her interviews conducted for this study. She reported that the time needed to clarify misunderstandings then wastes valuable appointment time. She clarified that misunderstandings can occur if the interpreter is not skilled in a particular area such as mental health; if there are difficult concepts being discussed; if the interpreter is not familiar with the method of communication of the Deaf person; or even if the hearing person is not familiar with the use of an interpreter in a conversation. Ali advised she preferred services from a Deaf counselor or therapist, though a hearing person who could communicate freely in ASL was also supported.

**(1.3) The mental health resource system.** Several participants raised the issue of inaccessible mental health prevention and/or educational resource information. It was pointed out that educational resources available in the dominant hearing community such as TV commercials and printed pamphlets, were not easily accessible for the Deaf. Joan shared,

Yes, that is exactly my point! Yes, things that are out there in the hearing community are not out there in the Deaf community. You know, just that whole

thought of having it [depression, identified as] an illness versus something that you personally created or caused, that's not something that is understood out there yet in the Deaf community. That is my point.

She added,

And remember, the hearing world is different from the Deaf world; we typically learn things that are happening in the world *after* the wider community hears about it. Like even the issue of abuse; the general community is more aware of it, but the Deaf community does not have that same information yet. Deaf people don't have access to all the same information that the wider community does. Deaf people aren't aware of it in the same way.

There were a number of distinct though related issues reported here. The issues include barriers associated with medical, mental health and allied professionals' lack of knowledge of and respect for Deaf culture. It extends to a lack of understanding of English being the second language for most prelingually Deaf sign language users, thereby limiting access to services provided in spoken or written English. Associated with this was the lack of awareness by the various professionals of the grammatical structure of ASL as distinct from English. Finally, participants felt that the lack of appreciation for the difficulty associated with acquiring competence in lip-reading all contributed to communication barriers that interrupted the creation of an effective and trusted therapeutic alliance between the Deaf person seeking services and the professional tasked with providing/delivering that service.

Participants shared their thoughts on access to community resources. One person said,

But it's still really important to understand that hearing people have a lot of advantages that the Deaf don't – still. And still it's not equitable but...if you can sign directly with someone rather than using an interpreter that is best. I think that would be the ideal. Joan

Joan is unique in that she has access to a physician who is fluent in her primary language, and also knowledgeable about her culture. In reflecting back to the original

question directing this study, while Joan has the opportunity to access medical assessment by virtue of an ASL fluent practitioner, her opportunity for personal “choice” in accessing treatment strategies for managing her symptoms of depression, like all those in this study, was restricted by a number of factors. The primary factor she reported was that of negative professional attitudes and/or ignorance that failed to acknowledge, respect and accommodate her linguistic difference and minority cultural status. This resulted in Joan being expected to participate in a support group without the language support she requires. This extends to other realities such as mental health promotion and prevention materials that are inaccessible, and a lack of accommodation supports such as flashing lights for alarms, and a visual alerting system to a doctor or other appointment.

**(1.4) Communication technologies.** The final sub-theme under the umbrella theme of communication the participants reported are the challenges associated with communication technologies. This includes use of those technologies widely available and commonly used today including both texting and e-mails. These two modes of communication are English-literacy based modes of communication and require a basic command of the language used, in this case English. These place English second-language signers at a disadvantage when communicating with a natural spoken English user by forcing the Deaf person to communicate in a mode and language that is not as familiar to them. Though some in the Deaf community easily use one or both, the dependence on written English grammatical structure and spelling can serve to escalate the risk of spelling errors and grammatical errors and, by extension, the possibility of communication misunderstandings.

An additional area of concern noted by some participants was that specific to

telephone relay services. This technology demands a strong command of English literacy. Some in the Deaf community view it as both slow and tedious. Video relay services are a more recent method of communication technology for the Deaf, though it is not yet available in Canada. Given the realities noted here, the options for supporting effective communication with this population in a linguistically congruent way are limited.

**Summary of communication.** It is well documented that effective two-way communication forms the basis of effective assessment and intervention. It places those involved in the communication as equal partners in the discussion, and later in the decision-making process. Walter, Joan and Ali all reported having experienced both sides of the communication coin, interaction both with medical doctors and resources who understand the culture and/or speak the language, as well as with others who don't. The former provides easy and equal access to services; the latter blocks access to necessary health or other care otherwise available to a non-Deaf person.

The literature reports that structural, communication and attitudinal barriers result in fear, mistrust, and frustration of Deaf persons in health-care settings (Black & Glickman, 2006; Briffa, 1999; Fellingner, Holzinger, & Pollard, 2012; Hill & Nelson, 2000; Tate, 2012; Vernon & Leigh, 2007). All the participants in this study experienced communication barriers of a similar nature as that reported in the literature. This reality has prevented their access to mental health prevention material, thorough assessment, and, in their opinions, effective treatment and symptom management.

**Theme 2. Impression management - fighting identity rupture from disclosure.**

During this study it became apparent that associated with the general and overriding theme of communication is a reality that is so tightly interwoven as to be almost

inseparable – the fear of identity rupture upon disclosure of mental illness. This section reports one example of what can be described metaphorically as ‘feeling alone amongst a crowd’; in this case however, the “crowd” is not the hearing majority, but the participants’ own minority Deaf community. In essence this theme is about what I would otherwise define as ‘conditional belonging’.

The Deaf community is a closed one with defined boundaries; factors of membership or inclusion are tightly defined as has been noted earlier in this report. The community is a collectivist one based on mutual sharing, camaraderie, and support. Surprising to this writer, however, was the response participants provided when asked if they had shared the nature of their depression diagnosis with others within the Deaf community. Based on the literature regarding the Deaf community, I would have expected that some solace, comfort and security would be gained from seeking support from members of one’s own community. The overwhelming response to my question, however, was a resounding “NO.” In fact, for many, the sentiment was made most clear by the repetition of the response, “NO. NO. NO!” Simply put, participants did not feel comfortable sharing the nature of their mental health diagnosis with other members of the Deaf community.

Participants were asked to expand on their response to this question. Joan, for example, described that one consequence of living as a member of a minority and collectivist culture is that, “...it’s like living in a fishbowl.” In other words, while a small and closely defined community provides protection by virtue of its title of “insider”, each person is ultimately held responsible for behaving in a way that reflects in the best light of the community. Consequently, to be diagnosed with mental illness is viewed to reflect

poorly on the entire community (Jones, 2002), hence the reluctance to share the diagnosis. It appeared then that ‘belonging’ as a member of the Deaf community may in fact be conditional to the expectation that belonging requires that one’s actions must reflect positively on the community and in no way draw attention to what might be considered a stigmatizing feature.

The participants in this study discussed the struggles associated with maintaining a façade of wellness. They reported that the pressure to fight disclosure or “hold it in”, a commonly used phrase in the narratives, resulted in many participants withdrawing from family, friends, and the social activities they had previously enjoyed, for fear their symptoms and diagnosis would be discovered. The concerns were described in various ways. In general, participants reported they feared that disclosure of their mental illness would result in them losing the respect of family and friends. They also worried it might result in them losing the respect earned from their accumulated hours invested in their various volunteer positions within the community. Finally, participants feared disclosure could decimate their professional identity and the respect earned within their paid employment positions. More specifically and consistently, participants feared that their respected ‘place’ in the Deaf community would be lost, leaving them feeling discarded or ostracized from the one place they felt safe or empowered as a member of the insider or ‘dominant’ group. Participants feared that disclosure of their mental illness would result in them being viewed through a variety of derogatory identities with words such as ‘mentally retarded’, ‘weak’, unstable reported. Participants also feared they could be viewed as incompetent. Some participants shared that their fear of others finding out about their diagnosis caused some to hesitate in seeking medical care.

For many of those in the Deaf community, contact networks and activities are initiated by factors other than choice; social activities available in the Deaf community are often limited and restricted by virtue of location (urban vs. rural) of residence. Consequently, if one is ostracized from the very community from which that person draws their personal and emotional strength as well as their identity and social involvement, the impact could be devastating. To avoid the risk of losing this connection, participants in this study chose to suppress the pain associated with their depression and tell no one, so as to “appear” to be no different than anyone else in the community.

All participants made some reference to their fear of social exclusion though also to becoming the brunt of gossip in the Deaf community if their mental illness were revealed. The narratives explain these concerns. One person reported, “They would look at me as a weak woman, that’s my perspective.... I’m not comfortable with that.” This participant added in regards to her own family of orientation,

My kids, they see me as a strong woman, a strong mother, who stands strong. So if I tell them I am depressed, that would be in opposition to that. That’s how I feel, so I don’t show them that.

A second participant, when asked the same question reported,

Well, people would laugh, or they would criticize or they would think it is funny. It wouldn’t make me feel good. I prefer talking to people that understand or have some more experiences... Sometimes people will just listen... And I am always concerned that if things are said, and they misunderstand or there is a misunderstanding, then, I don’t want them to say wrong things.

“Natalie” reported that the fear of misunderstanding and ostracism from the Deaf community prevents her disclosure of mental illness to others. She reported, “No, I don’t normally talk about these topics, NO, NO, NO! [Interviewer: You talk to no one?] Her response, “No, no, no, no [shaking head quickly].” She explained that she tries to talk to

her spouse about her experiences but said, “he tries to understand, but it’s hard for him. I don’t talk to anyone else about it, I don’t!”

“Walter” explained that he was prescribed medication for the panic attacks and depressive symptoms he was experiencing. He admitted the need for medication came because he was “hiding” from others; very simply, he refused to leave his home. He was becoming a victim of his fear that disclosure of mental illness would result in discrimination. He reported,

I wasn’t letting my personal feelings out to anyone – I didn’t have anyone I could trust. I was keeping it all confidential. There are some people I don’t trust.  
... There is a lot of gossip, and I just didn’t trust anyone.

Walter was asked if he has since shared the nature of his diagnosis or experiences with others. Involved in the Deaf community through a variety of respected opportunities, Walter feels he has too much to lose personally by disclosure. He reported,

No. No. I haven’t told anyone. I might tell them about [certain things] or that there isn’t an interpreter brought for certain things, but not about personal things.  
[Interviewer: Can you explain why don’t you feel comfortable telling them?]  
Because they would look at me like I am weak, like I am... mentally retarded.

What is most interesting to me is the word choice used by Walter, as well as others in this study; Walter stated definitively that they [members of the Deaf community] “would” look at ‘me’ like I am weak. He did not use words of possibility like ‘may’ or ‘could’, but rather with the conviction and confidence only an insider could use, from the position of ‘knowing’ rather than ‘suspecting’; they would look at me as weak. Participants felt certain that their mental health needs would be looked at unfavorably within the Deaf community and impact their position in the community, thereby forcing them into isolation to prevent rejection and discrimination.

“Bobo” shared a similar sentiment. She said, “But in the Deaf community it was

always the same old thing, and looking for gossip, that's what people wanted, that's what they do there, it's their life there, it's very different.”

During the discussion we turned to the issue of treatment strategies, specifically those treatment strategies “Bobo” would suggest as useful for those in the Deaf community who live with depression. We discussed the possibility of peer support or educational groups for persons living with depression. “Bobo” had mixed thoughts about this, particularly in relation to the make-up of the group participants. She expressed reservations about an all-Deaf support or treatment group setting. She explained,

Well, that would be a little bit concerning if it was all-Deaf really. Because they would know my background then, my past, and then they would already make judgments about me and there would be gossip. So I think that would be tough.

When asked if participants would make judgments even if all were there for the same experience [diagnosis of depression for example], she said, “Oh yeah! Absolutely! For sure they would label. They would!” She reported having success discussing her past experiences with hearing people, but said, with the Deaf, “It's a different thing. I can't share with the Deaf, I can't – it's tough!

One participant added,

My husband, not that he doesn't listen, he just doesn't listen like that. He would listen, but you know not really *listen-listen*. He's a [occupation], he's a happy person, but...does he really listen? Yeah, he would just nod his head as though he does, but he doesn't really understand.

Fearful of the consequences of disclosure, including rejection, stigma, discrimination and possible ejection from the community, most participants saw little option but to “hold it in”, and tell no one about their diagnosis or the nature of their lived experiences. They chose instead to suffer in silence. Some participants reported escaping to their bedrooms, to the safety and security of their beds where they slept, read or tried

to process their experiences from the day, doing so in isolation. “I HOLD IT IN” was a strategy identified by all six participants in this study as the primary way to manage their depression. One participant reported, “I know a lot of people out there, yes, but I still feel alone, still.” Another person offered, “Tell someone? No way!”

**Summary of impression management.** The fear of identity rupture and social ostracism resulting from the stigma of mental illness dominated the interviews beyond the topic of communication. Participants described what they felt would be the social and emotional consequences of disclosure, which would lead to the rupture of ones’ entire Deaf identity. Individuals feared further that this would lead to rupture from the Deaf community thereby forcing them into a linguistic and cultural exile. This fear was driven by the concerns about where one would go for social interaction, cultural enhancement, or identity confirmation. Impression management was a dominant theme directing the strategies these participants chose to manage their symptoms of depression. The reality that all participants in this study chose isolation as one way to manage their symptoms of depression was particularly alarming given the that NIMH (2011) research reports, “try not to isolate yourself, let others help you.” (p. 19)

**Theme 3: Distracting from the pain.** The second research question inquired specifically about the strategies participants use or have used to manage their symptoms of depression. It was evident from the interviews that none of the participants felt they had successfully resolved their issues of depression or truly achieved a level of wellness. “Am I 100%? No.” was a sentiment paraphrased by most. All participants described having achieved some level of improvement or stability following their original diagnosis of depression, with most doing so through a combination of pharmaceutical and informal,

non-pharmaceutical individual strategies. Many participants expressed a sense of powerlessness, however, in achieving long-term wellness. Frustrated by their inability to access traditional mainstream resources such as individual counseling, self-help groups, or group therapy because of communication barriers, negative attitudes and lack of knowledge or trained staff, many of the participants felt handcuffed. They felt forced to adopt their own “self-righting strategies” as consistent with what Deegan (2005) defines as “personal medicines” to manage their depression (p. 29) or other activities to distract from their pain of mental illness.

The strategies reported by the participants were varied. They included watching TV and/or movies, both often excessively, in an attempt to escape from one’s own reality through the actors on screen. One admitted turning to alcohol to dull the emotional pain they were experiencing, resulting both from the depressive symptoms, as well as from the isolation. Still others reported working long hours and/or engaging in physical activity. One participant described how she used food as a way to distract from her emotional pain. Three people smoked excessively. Finally, several participants shared that they turned to sleep “to forget” or as their way to escape from the ever-present demons of their past and the challenges of their present. Inaccessible services and professionals unfamiliar with the needs of these Deaf ASL users prevented them from taking advantage of the formal mental health recovery services available to the dominant hearing community. More specific details regarding these methods of distraction are expanded below. See Table 3 – Strategies for managing symptoms of depression.

Table 3

## Strategies to manage symptoms of depression

Mainstream strategies	Participant strategies
Medication	Medication: have used for 6 months or more - 66% (n = 4) currently use: 17% (n = 1)
Psychotherapy	
- Cognitive based therapy	currently: 33% (n = 2)
- Individual therapy	
Education	Reads self-help books/informational materials – mental health/prevention/attend educational group: 67% (n = 4)
Peer support group(s)	None accessible
Positive lifestyle changes	
- diet	
- exercise	Exercises: 67% (n = 4)
-community engagement	Sit on boards; teaches ASL; volunteers in community; attends activities in community: 83% (n = 5)
Maladaptive activities:	
Smokes excessively	Smokes excessively: 33% (n = 2)
Abuses alcohol	Abuses alcohol: 17% (n = 1) Retreat into isolation self: 100% (n = 6)
Uses food excessively	Uses food as distraction: (e.g. eats excessively) 50% (n = 3)

**Smoking.** Smoking excessively was a response for three participants. One person reported it this way,

Smoking, lots of smoking! In the past I smoked 1 ½ packs a day, sometimes 2. Now, it's less, I smoke about 1 pack every 2 – 3 days. So it is less, but when I smoke less, the stress comes back... My goal is to quit. But, one problem, my doctor says, if you just quit smoking you could blow up; you could start drinking again, you might commit suicide, or you could get angry and kill someone. So better to start reducing your smoking, try to cut back. So I am thinking it is better to take “baby steps.” I know I must try, but I am still depressed, still. “Walter”

**Eating.** Emotional *eating* became “Ali’s” way of managing her pain, isolation and loneliness. She defined food as her “happy pill.” She reported,

I wanted to eat constantly (when I was depressed) ... But, I remember, I would buy a [cake] and I would eat the whole thing, myself! It was small, but I would

eat the whole thing, in one night! And that would go on, weekly. I would keep buying food like that and keep eating. That was my ‘happy pill’ so to speak.

**Sleep.** “Ali” added that she would sleep to help escape from her symptoms of depression. She said, “I would get into bed and I would eat and sleep. You know, I don’t tend to use any kind of drugs for relief, or liquor, nothing stupid like that, I would just eat and sleep.” Later in the interview she added, “I eat and sleep, eat and sleep.”

In addition to Ali, Bobo, too, made reference to her sleeping patterns as a strategy to avoid facing the ever-present demons of their past and the challenges of the present.

For Bobo, sleep became excessive giving her a method to avoid the pain, as did watching TV. She reported, “I sleep, I watch TV, all day and all night”. She later added,

I do that. I watch a lot of TV all day! It helps me, to forget, I watch something funny and I laugh; or I watch a movie, so it does help. The TV helps; it’s the only thing. Because I will hold onto things, and I will watch TV, then I will get into bed and the next day feel better. But of course then it builds, right, so then I watch TV, and it will start to resolve, it’s really up and down.”

She added, rolling her eyes, “Oh, I smoke! I smoke lots!” Now, however, the pattern has changed and sleep eludes her. She reported,

For many years I would sleep 8 hours, but now, I get up early – because there is just so much in my mind. I have so much I haven’t resolved. I guess I am hanging onto many things. I don’t know. Now the most I sleep is 4 or 5 hours, that’s it! I am not being able to relax, for many years now.

**Exercise.** For one participant, working long hours and/or exercising were the chosen strategies to distract from the symptoms of depression and anxiety. It was reported these strategies were used with the intent that they would lead to physical exhaustion and hopefully immediate sleep at the end of the day – sleep that would also an escape or distraction from the pain of depression.

**Summary of distracting from the pain.** The strategies participants described to distract or escape from their pain of depression are not new or novel; these are often reported in

the mental health literature as strategies used by some to manage their symptoms. What is more noteworthy about these strategies, however, is that participants reported that they turned to these strategies because they had no other options; the participants felt powerless to participate in these established resources because of the intersecting barriers they faced in accessing such services. All indicated they are interested, willing, or for one, “desperate” to attend personal counseling to address his/her emotions, past traumas, current challenges, and stigma. The absence of qualified professionals able and competent to assist or support their wellness has resulted in frustration for all and engagement in activities all recognize as less than healthy.

**Theme 4: Resilience—doing it my way.** The powerlessness participants reported resulting from access, service, diagnostic and treatment barriers, was palpable during the individual interviews. Several participants became sad as they described their symptoms and feelings of frustration with a system that is not capable of, or rather unwilling, to meet their needs. While the pain was powerful, what came across equally as powerfully was the level of intrapersonal strength and resilience in each person. This resilience is best demonstrated by the manner in which each chose to manage the symptoms of their depression in the absence of a formal support network.

Consistent with the results of the Chicago study conducted with Deaf adults living with depression (Perlman et al., 2007), many participants of this study engaged in what would be defined as productive symptom management strategies. The primary difference between the participants from the Chicago study (Pearlman et al., 2007) and current participants, in comparison to those in mainstream society, is that the options for the former are less one of choice, than of necessity due to lack of accessible resource options.

With restricted options and supports available, participants felt they had no option but to turn to informal strategies. Several sought out a variety of mainstream, English-based printed self-help resources [e.g. “I read those Chicken Soup books”], health promotion information pamphlets, or visited Internet-related research sites. Still others reported using specific negative thought-stopping strategies when feeling the symptoms of depression approaching. One person said, “And I use my mind to fight the depression – I have to mentally fight the depression so I can [participate in activities in the Deaf community].”

Others shared that if negative thoughts begin to creep into their mind, they seek distractions from their negative thoughts by washing dishes, or taking control of the environment by cleaning their home. These strategies were viewed by the participants as serving two functions; distracting from their negative thoughts, while also providing concrete evidence of their ability to manage their life providing a sense of accomplishment in a job well done.

Some participants reported seeking social support(s) provided a sense of normalcy to their lives and gave them strength. Some in this study reported seeking a confidante to share their worries with; the conversation did not necessarily turn to their symptoms of depression but having someone to share their lives with offered comfort. Of the entire group, five also reported that immersing themselves in various Deaf community-related activities such as sitting on various community boards, participating in volunteer activities or attending community events not only affirmed their sense of Deaf identity, but gave them emotional strength to fight their symptoms of depression. Another reported that providing a mentoring role to younger Deaf members in the community served to

minimize the embarrassment associated with the diagnosis of depression and strengthens confidence in their own abilities and value to the Deaf community.

Healthy lifestyle practices were noted by several participants as strategies used to tackle their symptoms of depression. All participants shared that making the effort to maintain positive and healthy sleeping patterns, healthy food choices, and/or considering some form of exercise, even if just increasing the amount of walking per week, were productive ways to manage their depressive symptoms. Though some appeared to be in the contemplation phase of lifestyle changing, the fact that they recognized the contribution of positive lifestyle changes could be considered personal growth in a positive direction (Prochaska & Velicer, 1997). Taking a bath, and “people watch(ing)” were other strategies reported as ways to cope with symptoms. Finally, crying was identified as an action that provided cathartic value through which to manage their depression symptoms.

One participant admitted that, prior to her involvement in personal counseling, she had been spending excessive amounts of time on the computer or in front of the TV. Through counseling she was able to recognize this as a diversionary tactic to address her depression, isolation and loneliness. Through the assistance of the hearing therapist and interpreter, she was able to reassess her use of time and make the effort to engage with society. She reported,

Now I think, hmmm, what can I do? I now look for things to do. And I am trying not to go to bed late. I used to be addicted to the computer and I think maybe that was contributing to the depression as well. So I try... I have just made some changes.... And we [my counselor and I], we have worked on trying to get me more involved and not kind of retreat from things.

Three participants reported that their children and their role of parent gave them strength. One person explained the power of the parenting role this way, “They [children]

are the key... But when it comes to the mother's bond, - it's the strongest.”

Two participants reported that engaging in interpreter-assisted individual agency-based counseling has provided an opportunity for them to address their concerns with someone outside their family. Challenges remain, with the primary concerns being those as noted above including communication and service provider attitude, but these participants felt this was a way to move beyond their depression, so continue attending. One participant explained that the initial experiences with individual counseling caused great concern and were evidenced by a lack of understanding and respect for Deaf culture. She explained it this way,

The first person I had through [a social service] ...he was just very, off-handish about everything. He just said, “Let it go”, like all these struggles I have with depression and his advice was to just “let it go”? [Brows furrowed] WHAT? [Hands drop to table in frustration]. Just “let it go” Like, how is that useful? Someone telling me that, I lost complete faith, based on that.

This participant continued to seek counseling out of need, particularly when thoughts of suicide arose. In a second attempt of service with the same agency, she demanded a second counselor. This second professional was more understanding, but still the communication and cultural conflict remained. About this arrangement, she reports,

Even today, services don't understand Deaf culture at all. They have NO [emphasis in original] understanding of Deaf culture – nothing, not at all. They think that counseling can be equivalent, regardless of who that person is, you know, whether they are Aboriginal, Caucasian, but they don't understand the cultural element. Like *my* [emphasis in original] values, *my* [emphasis in original] cultural values so then I have to amend them to get counseling from someone that doesn't understand it. It is very hard, not to be understood on a cultural level.

“Joan” went on to explain that she is often forced into an active, or dominant role in the counseling session for a number of reasons. Regarding Deaf culture, she reports,

I had to explain it to her [the counselor], I had to give her some information about ASL, and the importance of Deaf culture...As a Deaf person I am constantly educating the people that I get services from. It's not fair; it's not right for me to

have to do that [educate the counselor] but I know I have to...she doesn't know so that is part of what I am doing when I *receive* services, [I'm educating].

**Summary of resilience.** Participants engaged in a variety of activities to, at some times, hold off their symptoms of depression when approaching and, at other times, to maintain their sense of wellness. Participants indicated they would like to have access to a wider range of formal resources as available to the dominant population. In the absence of accessible resources participants are forced to manage their symptoms in other ways.

**Theme 5: I'm Deaf—that's all.** Out of respect for the heterogeneity found within the Deaf community, each participant was asked to define their identity. One reported, "I'm Deaf – Capital D Deaf." Others paraphrased this statement, though all made it clear that they self-identify as active members of the Deaf community.

Membership in the Deaf community is a personal choice. It is not dependent on degree of deafness, or skill in a visual language. Rather it is dependent on identification with the cultural model of Deafness, including the use of sign language as a primary signifier of group membership (Jones, 2002). This factor is viewed as representative of common heritage and reflective of an expression of common values (Wilcox, 1989 as cited in Jones, 2002, p. 52). For each participant there was clearly a feeling of pride in being a member of the Deaf community, even if not currently an active member due to lack of available community activities. Participants' body language often changed as they described their involvement with the Deaf community; they smiled, sat taller in their chair and appeared to take great pride when discussing the various ways in which they promote Deaf culture. Promotion occurred through a variety of activities including mentoring others in the Deaf community, teaching ASL, participating on community boards or committees, or volunteering at various activities within the Deaf community.

Several participants remained connected to the Deaf community through the electronic website ‘Deaf e-news’; even if not active *in* [emphasis added] the community, participants remained connected *to* [emphasis added] the community.

Participants expressed pride in their connection with the Deaf community. Given their cultural identity, several participants shared their frustration with professionals who operated under the medical model of deafness. Some participants were offended when professionals inquired about the etiology of their deafness and/or linked their depression to their deafness assuming a causal relationship. To some, it felt like the etiology of their deafness was a more important a focus than seeking ways to dismantle the structural barriers that prevent the Deaf person’s equal access to resources. One person described herself emphatically, “I’m Deaf – that’s all. Why do people keep needing to ask me about the cause of my deafness? It doesn’t matter!” Participants reported that they wanted simply to have equal access to the same types of services available to the dominant hearing community irrespective of their degree of hearing.

### **Summary of shared meanings.**

Qualitative research methods characteristically produce a large quantity of data. In my quest for meaning and understanding of the phenomenon of ‘coping’ from those who are members of a language and cultural minority, I explored understanding both through the process of “particularization”, wanting to understand the uniqueness or particularities of individual cases (Stake, 1995, p. 39), as well as through an exploration of shared themes. In this chapter I attempted to demonstrate both.

In brief, participants reported experiences of deep and intersecting oppressions. Participants reported facing the simultaneous consequences of societal attitudes [e.g.

audism] and practices often associated with a lack of understanding and disregard for the cultural and linguistic minority status of the Deaf community. Most frustrating for the participants was that very often these attitudes and practices were by the very professionals tasked with assisting in their health or mental health recovery (Bauman, 2004; Ladd, 2003; Malkowski, 2010). Participants further expressed frustration with the perceived and experienced responses to their depression, both by the professionals tasked to assist them, as well as from within their own community.

All participants expressed that they would like to have access to formal resources to assist in the management of their depression equal to that available to their hearing counterparts. They suggested resources such as self-help groups with others who live with depression and a wider range of individual counseling options. They also suggested the need for Deaf-friendly print and video educational resources that could assist in their understanding of the signs and symptoms of depression as well as effective strategies for managing their symptoms would be useful. While communication was the dominant factor preventing participants' engagement with formal mainstream services, they also noted the scarcity of trained professionals able to communicate fluently in their language or understand Deaf culture [e.g. including its collectivist nature, values, behaviors, use of interpreters associated with the visual culture], and the impact of communication isolation on their past and current lives. Some participants also expressed concern with challenges associated with the quality, professionalism and/or access to interpreting services.

This study did not explore risk factors for depression; the focus was on strategies for coping. During the course of the interviews however, participants often shared stories

of life experiences that created challenges for them and, they believe, may have contributed to their depression. These life experiences included childhood experiences of physical and sexual abuse in the home and/or at the residential schools; the isolation and loneliness associated with growing up as the only deaf person in a hearing family and without a common language; and a lack of community and other resources that could meet their language, social and emotional needs as youngsters.

In spite of the systemic, access, treatment, and follow-up barriers faced by all the participants in this study, what is noteworthy is the resilience of these participants in managing their depressive systems in spite of these barriers. The next chapter will provide a discussion on the overall findings of this study, including that of resilience. The final chapter will offer a discussion on the implications of these findings for policy and practice, including my thoughts on the issue of future research needs in the area. I turn first to a discussion on methodological triangulation process used in this study.

### **Methodological triangulation: Person and Environment mapping**

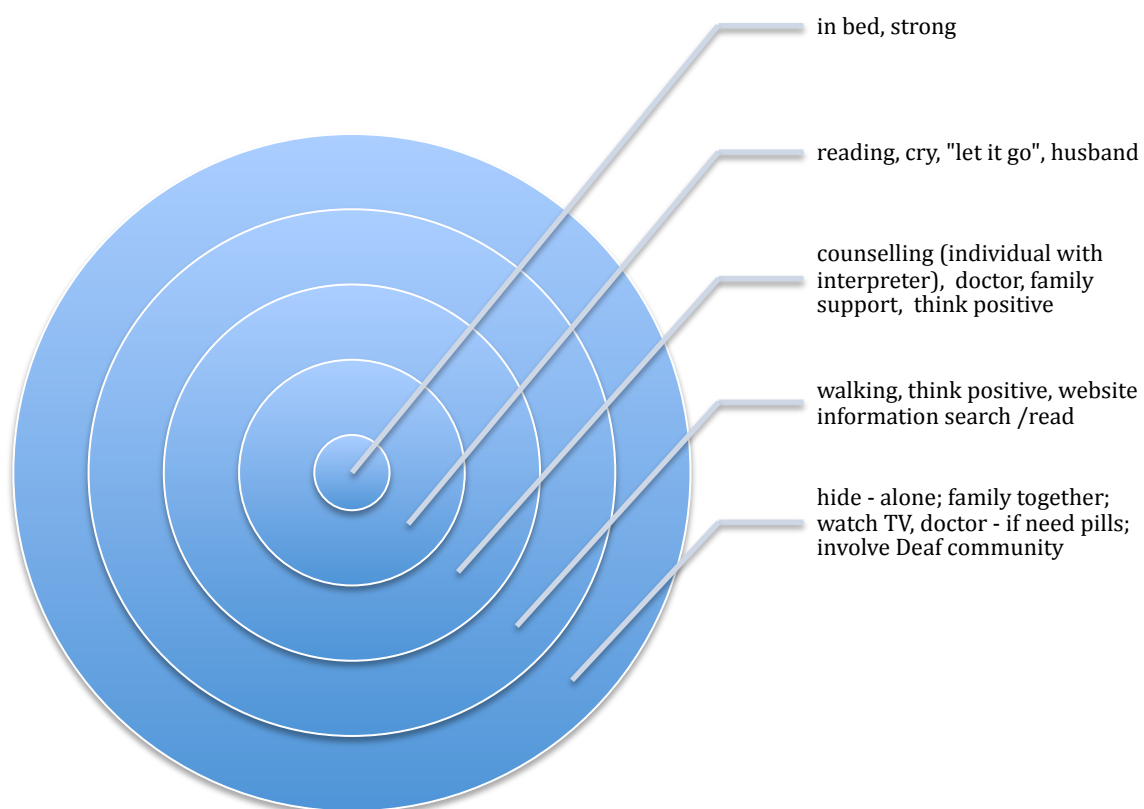
An ego-centered hand drawn person and environment map was incorporated into this study as a form of methodological triangulation (Stake, 1995). With few exceptions, the content reported on the individually hand drawn maps were consistent with the content shared through the personal interviews. Two participants verbally identified siblings as a source of support during the interview, though when first completing their maps initially failed to add them. As the exercise was drawing to a close, however, and the participants were reviewing their maps for completion, both noticed their omission and added their respective siblings on the circle as verbally reported. This triangulated content confirmed the reliability of the content provided.

I have chosen to include a computer-generated representation of one of the maps in this paper to provide a form of visual “quote”: to enhance understanding of the use and applicability of the tool in this study. All of the components shown are reported in the same visual space as the original; on the same ‘circle’ as drawn in the original. To protect the identity of the participant, I have again deleted identifying factors on the map. Specifically I changed identifying factors such as reference to specific family member, replacing it with the generic term “sibling.” I also changed reference to a particular activity that may reveal the identity of the participant, adding a neutral phrase. The purpose of the inclusion of these in the report is to explore the constructed realities and interpretations of the participants (see Figure 3).

As consistent with constructivism, it is the person’s perceptions of a situation that are most important. It became evident when reviewing the maps that it was not the “number” of strategies reported on the map that was important but rather that persons’ perception of the number of resources. Two people had approximately the same number of items added to their map – after reviewing their own map, one person said,

Well, you know, I have tried to determine what it is that I actually value and what I don’t.

That was actually helpful in getting me through that. Like my (family member), number 1 right there (pointing to center of map). That helped me to identify that that is very important to me, the support (that person) provides. And even walking (added at second farthest circle), I realize going through this (exercise) that I am not doing it as frequently as I should be because it would be help. But I have kind of let that go to the wayside. So I do note, like in the inner circle, I put things I can do in my home, (alone) like crying. That’s right there, more central. Like (my special place) seems to be my place, still, still. In (that place) where I can talk, or read, or cry. The other things are more external.



*Figure 3.* Person and environment map – “Joan.”

A second person, one who had only one less entry than the participant above, said, after reviewing the map, “[creating and looking at this map] helps me too, because I see that I don’t have a lot of supports. Oops.” The participant-drawn map both provided a visual method of triangulation for the researcher as well as an opportunity for participants to engage in the study in a manner that is more consistent with their visual mode of communication.

### **Summary of triangulation method**

The creation of the hand drawn map appeared to be a powerful tool for participants by providing the opportunity for each to view the nature of their supports in managing depression. For some, it created distress when they compared what resources they had available to them in comparison to what they know is available for the dominant culture. For others, it was comforting to see how many resources they had available to them. The tool used in this way appeared to reinforce the reality that persons construct their lives, their challenges and their opportunities, differently.

## CHAPTER 5: DISCUSSION AND CONCLUSION

In accordance with the data analysis process associated with case study research, this section expands on the content from the previous chapter by discussing the themes and patterns found within the participants' narratives, and integrating them with the existing professional literature in the areas of mental illness, deafness and mental health recovery. This is a method of data triangulation that provides an opportunity to enhance the existing knowledge base, and create greater justification for change (Onken et al., 2002). This chapter offers insight into the intersecting nature of the complexities experienced by these participants when attempting to both understand the nature of their illness (i.e. symptoms of depression) and access services to assist in resolving them. In some cases the concerns reported were unique to a single participant; in most cases, however, they were shared experiences.

The findings are discussed through five primary themes: communication barriers; impression management – fighting identity rupture; distracting from the pain; resilience – doing it my way; and I'm Deaf, that's all. These themes suggest little awareness of Deaf culture and language, and little respect for cultural safety from the very professionals tasked with assisting in or promoting mental health recovery. As a result of the challenges faced, many participants in this study left medical appointments feeling powerless, misunderstood, confused, and reluctant to return to a system that failed to meet their needs. In most cases the findings of this study are consistent with existing literature, thereby gaining credibility from previous research in the area (Baines, Patterson, & Austen, 2010; Critchfield, 2002; Fellingner, Holzinger & Pollard, 2012; Fusick, 2008; Ludders, 1987; Malkowski, 2010; Perlman et al., 2007; Pollard, 1994, 1996; Sheppard, 2008; Steinberg, et al., 1998). In other cases they enhance existing

literature by expanding beyond what is currently known.

### **Mental Health in the Dominant and Minority Deaf Community**

The field of mental health is, in general, a complex and challenging one to work in. It demands knowledge of complex issues related to mental illness, mental health and wellness, as well as approaches to mental health care intended to meet the diversity of needs of those seeking care. The literature regarding these issues in the dominant population is extensive; that specific to persons from the Deaf community, defined as an “idiosyncratic, low-incidence populations”, far less so (Mertens, 2007, p. 222).

This study offered a unique opportunity to gain entrance into the lived experiences of six adults diagnosed with depression. I believe the intent to conduct the interviews in ASL increased participant interest in the study, as did the study topic. Though depression brings with it great stigma in the Deaf community, those who volunteered to participate reported they did so because they hoped their participation could serve as the impetus for change in the mental health service system for themselves, and for the larger Deaf community. They hoped these findings could be used as a platform from which to dismantle the intersecting attitudinal, structural and educational barriers that lead to health disparities for this cultural group (Barnett et al., 2011; McKee et al., 2008; Steinberg et al, 2002; Vernon & Leigh, 2007). All participants felt immediate change was necessary to better meet their mental health care needs, with physician and health care professional education regarding the dynamics of the Deaf community and their language offered as the most obvious path through which to start the transformation.

Participants reported that professional lack of understanding and awareness of the Deaf community and culture created the first and fundamental hurdle blocking their equal

access to care, from initial assessment, intervention planning and follow-up. The participants eagerly offered direction on necessary educational content for those working within the mental health field. Additional suggestions were offered regarding necessary structural changes to the mental health system as well as specialized health care materials.

I am hopeful that the findings of this study can serve to draw attention to the need for additional research in areas related to this general topic area. These may include an expansion of the use of current and emerging technologies to enhance engagement with geographically isolated Deaf community members (Vernon & Leigh, 2007); a focus on mental health specific assessments relevant to this linguistic and cultural minority; as well as exploration into culturally appropriate intervention strategies (Steinberg et al., 1998, 2002). In the final chapter I explore the implications of the current findings for social policy, practice and future research in the area of mental health and Deafness and offer more concrete suggestions for change.

As noted previously, case study methodology was used to explore the issue of managing depression. The aim of exploring how a small group of participants manage their symptoms of depression while part of a linguistic minority was achieved.

### **Discussion of Findings in Relation to Current Literature**

The bodies of literature most relevant to this study are those of mental health and deafness, mental health recovery, and resilience. Collectively these bodies provided grounding to the discussion that follows. I approach the following discussion through the five dominant themes that emerged from the participant transcripts.

**Communication.** The one theme that dominated this study, and intersected each of the remaining themes, was that of communication. Participants in this study consistently reported that communication barriers with hearing physicians or professionals who appeared unwilling or unable to recognize and accommodate their communication needs hindered their access to services, interventions, and follow up (Cooper, Rose & Mason, 2003; Critchfield, 2002; Ebert & Heckerling, 1995; Fusick, 2008; Ludders, 1987; McKee, Barnett, Block, & Pearson, 2011; Sheppard & Badger, 2010; Steinberg, 1998, 2002). Participants reported they often felt impotent in their interaction with professionals because of the assumed power imbalance inherent in that relationship. Participants who engaged with a hearing professional unskilled in ASL, most often assumed a passive patient role. Participants rarely felt competent to seek clarification of any misunderstanding or actively engage in the treatment planning process due to the communication barriers. This response is consistent with existing literature (DeVinney & Murphy, 2002; Fellingner, Holzinger & Pollard, 2012; Harris & Bamford, 2001; Naish & Clark, 1998; Stienstra, 2012).

A number of participant examples help to clarify the consequences associated with discordant patient-provider communication (McKee et al., 2011). At least four of the six participants shared that they reluctantly accepted prescriptions for medications without fully understanding their purpose, directions for taking, and/or the nature of initial and long-term side effects. One participant continues to take medication to manage her symptoms of depression and a second has decided to return to the medication previously prescribed due to the return of her symptoms. The remaining four, however, stopped taking the medication they were prescribed due to side effects they did not

understand or were not comfortable with. One person stopped the medication after two days because of unexpected side effects; for another, use was stopped within the month for the same reason.

McKee et al. (2011) found that access to what is defined as “language-concordant patient–provider communication” was associated with higher use of appropriate preventative medical services by the Deaf ASL users in their study (p. 75). It is possible the same effect could occur in the field of mental health; language-concordant patient-physician communication may well enhance mental health literacy and thereby assist participants to better understand the purpose and side effects of any proposed medication or other intervention plan. This knowledge could, in turn, empower Deaf consumers to actively engage in the intervention decision-making process in a more informed way (Karras & Rintamaki, 2012; Naish & Clark, 1998). This is consistent with recovery philosophy that encourages the participant’s active participation in the treatment planning process (Smith, 2000; Walsh, 2013).

The issue of communication extended to the role of ASL/English interpreters as the primary supports in the communication process. Most participants in this study reported they would prefer to have ASL-skilled physicians than be dependent on a third-party interpreter to ensure effective communication. Interpreter services were, however, preferred over interactions with medical and/or other professionals through written English or expectations of lip-reading. Some participants proceeded to the medical appointments without requesting an interpreter, however, either because previous requests to the physician for an interpreter had been rejected or they felt comfortable proceeding without. For those whose request for an interpreter was ignored, with the

professional defining the interpreter as unnecessary, participants reported an increased sense of powerlessness. For those participants, the absence of a language support (e.g. interpreter) often resulted in their acquiescence to the communication mode directed by the physician. This occurred most frequently out of fear that their refusal to cooperate with the doctor's request for written English could result in their termination from that doctors' patient list. For those who voiced this concern, the worry was that departure from the original physician would result in an additional burden of having to locate a new doctor who was not only accepting new patients, but also more knowledgeable of, or respectful of accommodating the needs of the Deaf person than the last physician was. To avoid this risk, most participants felt it easier to participate in appointments with doctors they were familiar with, even if without an interpreter and through written English, than to leave a physician for the unknown of a new one.

It is important to note that the participants in this study reported that most physicians did not acknowledge or incorporate Deaf culture into their practice. It is possible that physicians may simply not be aware of Deaf culture. This failure to incorporate culture is contrary to the content of Appendix I, DSM IV TR titled "Outline for cultural formulation and Glossary of culture-bound syndromes." This appendix identifies that the physician is to incorporate the "cultural identity" of the patient, to explore possible "cultural explanations" for the illness, and be conscious of possible "cultural factors related to psychosocial environment and levels of functioning" (p. 878). It further identifies that cultural elements of relevance to the relationship between the individual and the clinician and an "overall cultural assessment" is to be incorporated into the final diagnosis and care of the patient (DSM-IV-TR, 2000, Appendix I). As this study

did not involve the participants' physicians, there is no way to know if the physicians are aware of the existence of a Deaf culture or if the content of this appendix was applied when assessing these participants.

Participants in this study reported that most physicians from whom they sought care did not accommodate their language needs. This statement is moderated however, by the successful experiences reported with physicians who were fluent in ASL, or encouraged interpreter engagement in all their medical appointments. The difficulty lies in the reality that many consumers of health services require the services of health care specialists in addition to their regular physician. Further research similar to that conducted by Ebert and Heckerling (1995) into the knowledge and practices of physicians with Deaf patients in Manitoba is warranted. Ebert and Heckerling (1995) found that while most physicians involved in the research believed that sign language use was preferable to either the exchange of written communication or lip-reading with Deaf patients, in reality, only 22% engaged the services of sign language interpreters into their practice. Strategies to address this issue will be discussed further in the final chapter.

MacKinney, Walters, Bird and Nattinger (as cited in Naish & Clark, 1998, p. 29) found that access to professionally trained interpreters, as opposed to untrained family members or friends, led to both greater health care utilization and increased satisfaction with medical consultations. The skill set of the interpreter was an important component of the interaction. Members of the Deaf community who depend on interpreter services for two-way communication with non-signing hearing people quickly learn the skill sets of various interpreters. They learn who are competent in a wider range of interpreting situations versus those for whom their skill level was still developing. They also quickly

learn which interpreters matched their individual signing style, those with whom they could communicate more easily, and those with whom they felt comfortable. Once found, most participants prefer to request the same interpreter for most of their communication interactions.

Inclusion of an interpreter into the interaction can create unique challenges. It introduces two additional relationships to the interview: interpreter-client and, in this case, interpreter-physician (Farooq & Fear, 2003). The use of an interpreter with little skill in a specialized field can also greatly enhance communication errors through a number of factors. This may be through the omission of information; addition of information not originally stated; condensation of content which may impact the meaning of the message; through substitution of information which may be inaccurate; or even through a role exchange if the interpreter assumes the role of interviewer (Farooq & Fear, 2003). Additional intersecting challenges occur when physicians, unfamiliar with the process of interpretation fail to extend the time allotted for the appointment to accommodate the additional step in the communication process. Many additional problems can arise if an unqualified or inexperienced interpreter is involved in the communication process.

Some participants in the current study shared concerns regarding the use of interpreters in their interaction with medical or other health professionals. Well aware that interpreters are bound by professional codes of conduct for accuracy and professionalism in their practice, an ever-present worry of confidentiality still lingered for some participants. As noted in Naish and Clark (1998), “full trust is not always achieved” when working with every interpreter (p. 27). This may prevent some patients from

discussing subjects that may be considered taboo, such as in the case of mental illness. All participants in the current study acknowledged the role experienced interpreters play in bridging their access to the hearing world. And, while appreciative of this role, most advised they would, nonetheless, prefer to engage with sign-fluent Deaf people who could provide the services directly. Participants strongly supported enhanced educational opportunities for Deaf persons to become direct service providers in the arena of mental health.

A factor that further complicated the issue of communication was that of mental health literacy. All participants acknowledged that they lacked access to incidental health information that may otherwise be shared in casual family, work or other settings. They also lacked access to many health promotion or prevention materials as they were often available only in written format, or at a reading comprehension level that was beyond their reported reading level (Black & Glickman, 2006; Briffa, 1999; Connolly, Rose, & Austen, 2006; Harmer, 1994; Kvam, Loeb, & Tambs, 2006; Naish & Clark, 1998; Pollard, 1994; Steinberg, Sullivan, & Loew, 1998). Finally, some participants reported they lacked access to much of the content of television commercials as none were easily accessible in their first language (Pollard, 2009).

Participants reported that their poor mental health literacy further impacted their knowledge of health symptomology. Some reported that their mental health literacy level limited their familiarity with common symptoms of health problems, and thus prevented some from knowing, recognizing and describing the complete nature of their symptomology during the appointment with a physician.

Participants reported that the physicians' lack of familiarity with deafness and

Deaf culture resulted in misdiagnoses and/or poor follow-up care. When one participant in this study was asked when she was diagnosed with depression, she reported she had received “many diagnoses over the years”, noting that she did not agree with most. This is consistent with the studies by Naish and Clark (1998), and Pollard (1994). The former reported that physicians unfamiliar with components associated with Deafness could report inaccurate diagnoses, with reduced referrals to other necessary professionals or resources common. Pollard (1994), too, found that communication barriers between the patient and health care provider can lead to some physicians feeling overwhelmed when tasked with assessing a Deaf person; the result in some cases is a less than thorough assessment. Pollard (1994) further found that an incomplete assessment could result in formal diagnoses being restricted to the most common ones, being deferred or no formal diagnosis being made at all.

**Isolation.** A sub-theme of communication is that of isolation. It is presented here as a separate entity as it was a reality that often intersected with communication to complicate the participants’ experiences within the mental health system. Some participants reported that because many of their family, friends, colleagues and medical personnel were unskilled in ASL, they often felt socially isolated within their families of origin, within their workplaces and within the larger community. Further to this, fear of discrimination and stigma associated with the disclosure of the diagnosis of a mental illness in both the minority and mainstream communities escalated feelings of inadequacy, isolation and, self-shame. For all, a dominant fear was for the personal repercussions such as ostracism from the family or community upon a disclosure of mental illness. For others the dominant fear was for professional repercussions. These led to some participants

isolating themselves from social activities in the community to avoid detection or disclosure of their mental health diagnosis.

**Choice.** One of the most significant findings of this study relates to the impact of barriers on individual choice. Participants reported that because of the intersecting nature of barriers as reported above, participants felt they had a reduced opportunity to exercise self-determination and actively engage in the intervention planning process (Naish & Clark, 1998; Onken et al., 2002), with the opportunities for intervention choice restricted. As a result, most participants in this study felt they had few options other than isolating themselves from others. The participants made it clear that theirs was a forced, not first, choice. Participants, too, admitted that while their self-imposed isolation and coping strategies may have minimized their symptoms, rarely did their actions resolve the depression fully. Instead, and more accurately, the strategies simply became the ones most available to manage their symptoms of depression in the absence of other more formal strategies for intervention otherwise available to the mainstream community. Participants reported they continue to experience their symptoms of depression, some episodically, others on a more chronic basis.

Participants used a variety of activities to manage their depression. As has been reported, activities included reading self-help books, exploring the Internet for health information, walking, or watching movies, all used by the participants to varying degrees and consistent with that as reported in the dominant literature on depression. For some, however, their use of activities became excessive and a form of distraction or escapism from the reality of their depression. At least three people reported watching TV or rented movies for extended periods of time so to lose themselves in a different reality. Others

turned to food, and one person reported using alcohol as the method to escape their reality or simply “to forget.” Three people reported using smoking as their method of distraction. These strategies were reported specifically as strategies to distract from the symptoms of depression. All recognized that once engagement in the distraction stopped, their symptoms returned. These various strategies are not to be confused with the body of literature that is referred to as alternative or complementary therapies commonly used to treat depression (Kessler et al., 2001), or what Deegan (2005) refers to as “personal medicines” (p. 29), both viewed as generally positive strategies. Rather the participants in this study appeared to use actions that would more accurately be consistent with what Perlman et al. (2007) found to be “non-productive” behaviors – they do not resolve the depression, but rather and more accurately, simply distract from the symptoms temporarily.

**Impression management – fighting identity rupture.** The participants in the current study engaged in activities in the Deaf community that they found self-fulfilling, personally rewarding and affirming as members of the Deaf community. These included involvement in various volunteer and paid positions within the Deaf community. Participants attempted to continue in the level of engagement they had established with the community prior to their diagnosis, but doing so without revealing their diagnosis of depression. As noted, participants live in fear that a disclosure of depression would, in their opinion, crumble their credibility for each of their established roles and thereby rupture the identity they had established in the community.

**I’m Deaf - doing it my way.** Participants reported they would like a range of formal intervention options to assist them as they manage their symptoms of depression, though

in a communication mode that is consistent with their first language and respectful of their culture. Most participants felt they would benefit from participation in some type of education class to inform them of the nature of depression, though opinions regarding the design of the class varied. Some participants preferred a group with all-Deaf members, others a group with mostly hearing members.

Perlman et al. (2007) found in their study of Deaf adults in Chicago that psycho-education classes that integrated evidence-based practice using a linguistically and culturally sensitive model for Deaf persons was both effective and well received. That research team suggested a replication of their psycho-education study design to enhance access to health and mental health care for other Deaf communities. This could be explored for set up in Manitoba.

**Stigma.** Stigma, and the fear of discrimination, physical violence, and possible rejection are reported in the mainstream literature as possible consequences for those living with mental illness (Everett, 2006; MHCC, 2008). The literature also suggests that fear of stigma and discrimination can have a severe impact on how that person perceives him or herself, as well as on their quality of life and on their ability to integrate successfully into society (Wahl, 1999). One of the greatest concerns is that the negative effects of stigma, be it societal or self-stigma, has the potential to increase the severity of mental health problems as it can prevent persons from seeking the assistance they need to manage their illness (Everett, 2006).

Consistent with the stigma literature, fear of discrimination permeated these participants' relationships with their family, the general Deaf community and their engagement with the medical system. Participants' failed to seek support from others,

mostly for fear of discrimination.

Onken et al.'s (2002) study is a useful reference here. This study team sought input from a group of mental health consumers to explore those factors they felt helped or hindered their mental health recovery. A total of 115 hearing individuals shared their thoughts in one of ten different focus groups held in nine different states. Using a grounded theory methodology, the data collected was ultimately reduced to eleven common themes (Onken et al, 2002, pages 21-59)<sup>9</sup>. In brief, the findings reported that engagement in social relationships; peer support; access to formal services, and formal service staff; and availability of choice 'helped' in recovery from mental illness. Conversely, lack of positive supportive relationships, limited choice in recovery options, substandard services, and poor range of services/treatments/options 'hindered' recovery. This report is useful and, if replicated in the Deaf community, may offer deeper insight into how recovery is understood in the Deaf community and which factors may help or hinder recovery.

**Resilience.** The literature on resilience is relevant to this study, in particular the study by Rogers, Muir and Evenson (2003). The resilience-related impact of self-authenticity reported by Rogers, Muir and Evenson (2003) is consistent with the results of the current

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<sup>9</sup>Onken et al. (2002). The study included a series of structured focus groups with a diverse cross-section of consumers/survivors. The themes reported are: basic, material resources, self/whole person; hope/sense of meaning, and purpose; choice; independence; social relationships; meaningful activities; peer support; formal services; and formal service system staff. See pages 25-59.

study; the issue of ‘comfort with solitude’, however, is not. In the current study, participants reported pride in defining themselves as culturally or “capital D” Deaf. This included pride associated with using and promoting their visual language, supporting the values of the Deaf community and promoting the culture in general. For some it was teaching others, for others they demonstrated their ‘self-authenticity’ by participating in or volunteering in various volunteer activities in the Deaf community that promoted their identity.

The issue of solitude took on a different meaning for the participants in this study than it did in Rogers, Muir, & Evenson (2003). As has been reported, the present participants often resorted to periods of solitude to manage their symptoms of depression; they reported this as a forced choice, however, not a free one as found by Rogers, Muir and Evenson (2003). In spite of reduced treatment options, participants in the current study demonstrated resilience in the face of their depression. They continued to engage in the community in various volunteer or other general interest activities. They also generally maintained employment, full time or part time, and made every effort to maintain their respective roles in their families of procreation, in spite of their depression.

The current study, and that of Rogers, Muir and Evenson (2003), suggest that knowledge of the presence of resilient factors in Deaf consumers of mental health services could be useful and contribute to the mental health recovery of this population. This could include activities such as the creation of a speakers’ panel with Deaf consumers of mental health services, similar in format to the speakers’ panel as coordinated by the Schizophrenia Society of Manitoba. Participants in recovery share their stories of recovery, doing so to support their own recovery, educate others on the

mental health recovery process, and also to provide opportunity for audience contact with persons with this lived experience. This exposure has shown to heighten awareness of the needs of this community, which also encouraging mental health recovery from those who share their story. The formal strategies for doing so and suggested educational content will be presented in the final chapter.

**Recovery.** The mental health recovery literature is also of relevance to this study. The dominant model for mental health up until the mid-90's focused on a deficit-based approach with treatment interventions and programs designed around the concept of chronicity. Mental health facilities were thought to be necessary for the provision of long term care (Williams & Collins as cited in Regeher & Clancy, 2010, p. 7). In the mid-90's however, the view of mental illness and the role of the consumer in mental health care evolved with many policy makers and practitioners placing recovery and consumer self-determination in the forefront. The current recovery model for mental health is based on a number of core components including those of empowerment, self-direction, holistic views, non-linearity, strengths-based, respect, responsibility and hope (Vandiver, 2013, p. 190).

Of particular relevance to this study is that the dynamics of the recovery model of mental illness is consistent with the Canadian Association of Social Workers' Code of Ethics (CASW, 2005). The Code of Ethics is premised on several core components, the most significant of which is that of social justice. The Social Work Dictionary (Barker, 2003) defines social justice as, 'An ideal condition in which all members of society have the same basic rights, protection, opportunities, obligations, and social benefits. A key social work value, social justice entails advocacy to confront discrimination, oppression

and institutional inequities' (404-5). The profession of social work has a long history of commitment to human rights (Lundy & van Wormer, 2007) and could play a number of key roles in pursuit of the human rights of Deaf adults seeking mental health services.

In reviewing the literature, it would appear that the role of individual self-advocacy within the Deaf community might be less developed than in the dominant culture. Given social work's established history in this area, it would behoove the profession to work with the Deaf community to create educational content promoting self-advocacy skills of those in the community (Regehr & Glancy, 2010). These skills could assist in the pursuit of a positive therapeutic alliance with the health care and helping professionals. Members of the Deaf community could be informed as to how to advocate on their own behalf, and professionals could be encouraged to gain the skills necessary to facilitate a positive therapeutic relationship with member of this cultural minority. Specific suggestions regarding the manner in which these can be accomplished will be discussed in the final chapter.

Davidson, Stayner, Nickou, Rowe, and Chinman's (2001) study may provide insight into the role of social inclusion in recovery. The authors explored the concept of inclusion as a basis for recovery in a disability paradigm. Their focus was on physical not mental illness but the strategies offer insight for this study. The authors argued that for people with chronic physical illnesses, inclusion need not require cure or success as traditionally defined in the mainstream. Instead, they suggested that inclusion could be viewed as a sense of belonging to the community, noting that it can occur through three elements. These elements include having a meaningful role; having a sense of reciprocity in relationships; and having a sense of hopefulness or affirmation of one's existence

outside their disability (Davidson, et al., 2001, p. 375). They suggest that having a niche or meaningful role in the community can create a sense of belonging to that community that binds that person as a citizen or “full member of a society of one’s peers” (Rowe, 1999 as cited in Davidson et al., 2001, p. 379). This is consistent with the findings of the current study which suggests that the participants who were best able to separate their disability (mental illness) from their active engagement in meaningful volunteer or formal activities in the Deaf community felt the greatest sense of belonging to the community (see Smith, 2000). This is an area that would benefit from further study as it may lead to other strategies through which people from the Deaf community can encourage creation of supportive community resources while encouraging the dismantling of the stigma of depression.

The second element in the Davidson et al. (2001) study is related to the value of reciprocity in relationships. Davidson et al. (2001) found that when people with a disability are engaged in relationships where they can contribute to that relationship rather than just “take” from it, they felt like an active participant in that relationship. Though the Davidson et al. (2001) study was, again, not specific to mental illness, they suggest the concepts are transferable to those living with mental illness. In the case of the current study, participants’ pride in their endorsement of their Deaf community may well come from their active and reciprocal relationship within the community which can occur through such activities as teaching ASL and participating in the awareness of mental illness. This is an area requiring further inquiry.

The third element that may facilitate a sense of inclusion for persons with mental illness is the affirmation of one’s life outside their disability. The participants in this

study did report feeling pride in a variety of activities that separated them from their illness yet provided a link to the Deaf community such as being recognized as a teacher of ASL, sitting on various community boards, and volunteering in the Deaf community. Further study regarding the impact involvement in specific activities might play in recovery is suggested, as is the exploration of ways in which additional opportunities for engagement in the community distinct from mental illness can be created to enhance inclusion.

### **Conclusion**

The current mental health literature suggests that one in five Canadians will be diagnosed with a mental illness in their lifetime. In Canada, the costs associated mental illnesses are multi-dimensional and reach approximately \$20.7 billion dollars annually (Conference Board of Canada, 2012). As has been argued throughout this study, however, is that these figures are based on experiences in the mainstream society; the nature and depth of mental health challenges for Deaf ASL users is less commonly studied. As a result of this reality, the issues of relevance to the Deaf community are less well known to mainstream social work, medical and allied professionals. While this study was an attempt to begin to explore the experience of depression for a small group of Deaf adults, more research is necessary to enhance understanding of the issues and seek ways for structural and attitudinal change to better meet the needs of this linguistic and cultural minority.

Entrance was granted to me into the Deaf community with an expectation that the stories and experiences shared might provide impetus for change. Participants hoped that sharing their first-hand narratives would serve to heighten awareness of the experiences of mental illness for this population by highlighting both the depth and the

intersectionality of oppressions experienced. While a review of the literature grounded me in previously reported challenges for this population, having the opportunity to hear directly from those with these lived experiences, shared in their first or preferred language, provided a unique opportunity for research. It provided a more comprehensive appreciation of the nature of the experiences. I was also able to collect suggested strategies for change.

The findings of this study concur with existing literature regarding existing gaps in the area of Deafness and mental health (Fellinger, Holzinger & Pollard, 2012; Fusick, 2008; Gupta & Caddy, 2007; Naish & Clark, 1998; Pollard, 2009; Queensland Health, 2008; Steinberg et al., 1998; Steinberg, Wiggins, Barmada & Sullivan, 2002). Now, consistent with the transformative paradigm, the results of this study must move beyond simply exploring the nature of the relationship between the mental health system and the Deaf community, by seeking ways to mobilize these findings into sustainable change for this community.

The final chapter provides suggestions for knowledge mobilization as well as implication for future research.

## **CHAPTER 6: STUDY FINDINGS: EXPLORING IMPLICATIONS FOR POLICY, PRACTICE AND FUTURE RESEARCH**

This chapter examines the implications of the key findings of this study for social policy, as well as medical and mental health-related practice.

The intended outcome of this study was that the findings serve as a discussion document or a “call to action” (MHCC, 2012, p. 124) from which to explore change; change in policy and practice as well as research needs. Knowledge regarding the language and needs of the Deaf community must lead to changes in policy that would support the creation of a more insightful, respectful and accommodating mental health system that reduces health care and access disparities for members of this community. These findings must also be used to inform the creation of specific Deaf-sensitive practice knowledge relevant for social workers, medical and mental health professionals, as well as other allied professionals and service staff working within the general social service system through delivery of Deaf Awareness Training (DAT).

The content of Deaf Awareness Training, as suggested by the participants of this study, is offered as the impetus for this change. I believe this content is relevant for professionals working within the health and mental health care fields and also appropriate for all Deaf consumers, the families of Deaf consumers, and the larger Deaf community. This content could serve as a mechanism through which to enhance the mental health literacy of each of these groups. It, along with a series of workshops focused on topics such as Deaf Wellness (Griggs, 2004) could serve as components of a larger strategy through which to empower consumers of mental health services to gain the necessary individual personal self-advocacy skills that would allow each to be more actively

engaged in their health care and, by extension, their own mental health recovery. Both the DAT and Deaf Wellness workshops should be co-facilitated by a hearing and a Deaf facilitator to provide modeling of effective communication strategies between the languages and modes, and provide experiential opportunities to gain confidence in effective self-advocacy. These workshops must also incorporate teaching and learning methods congruent with Deaf culture and language. Content could be presented through the use of Deaf art, Deaf theatre, and through the positive modeling of Deaf community member co-facilitators. As well, existing policies should be expanded to accommodate the creation of mental health promotion strategies in formats easily accessible to Deaf ASL users.

I believe the major contributions of this study are in the uniqueness of the topic and methodological strategies used to conduct the study. Rarely has the topic of mental health coping strategies been explored with this population, let alone with those living in the community. I believe this research can enhance our collective consciousness of the strength, cohesiveness and collective power found within these participants, in spite of the unique challenges these participants face living with a diagnosis of depression. While some experiences were unique to that person, most in this study shared similar narratives regarding the nature of the intersecting barriers to managing their symptoms of depression. The discussion that follows is in keeping with the transformative emancipatory method of research; privileging the voices of those who have traditionally lacked power and presence on a larger scale in a social justice issue such as access to mental health services (Mertens, 2007).

**Deafness**

As noted previously in this paper, profound and prelingual deafness is a low-incidence occurrence with few in the dominant society reporting a personal experience with someone who is Deaf or their culture. Within the dominant medical model of deafness, the focus is on the absence of hearing and the pathology associated with deafness.

Discussions focuses on age of onset, type of hearing loss, degree of loss or etiology of the deafness (Munoz-Baell & Ruiz, 2000). By extension, the focus turns to one of intervention with correction or restoration of the hearing loss such that it will be functional and a contributing component in the oral communication process. Rarely however, does the discussion focus on addressing the challenges that occur, not because of hearing status, but rather as a result of the lack of a common language between the Deaf and hearing person (e.g. low self-esteem, breakdown of social relationships, lack of shared language with hearing family members, etc.). The experiences of the participants in this study form the basis of the content of this chapter as we look beyond the challenges to seek change for this social justice issue.

**Implications for Policy**

The findings of this study have implications for social policy. The narratives shared in this study suggest that some professionals employed in the current medical and mental health system fail to acknowledge and incorporate Deaf culture and language into their practice. This issue was not exclusive to professionals however, as one participant experienced a similar lack of appreciation for Deaf language and culture from the staff at a local non-profit organization from which supportive services were sought. From dealings with professionals to self-help staff, participants provided numerous examples of

what they described as professional insensitivity and ignorance of the essence of their Deaf experience, the nature of their signed communication, and the need for a qualified interpreter to bridge the communication mode of both parties. Some participants, too, expressed frustration with the fact that the focus of their interactions with some medical or other allied professionals was narrow, with the etiology of their deafness appearing to be of greater interest than the nature of the reason for their appointment or request for services. As one participant shared, the general practitioner she saw to address her symptoms repeatedly failed to incorporate all the symptoms she shared with him during her appointment; ones she felt were “obvious” for a diagnosis of depression. The participants in this study are collectively of the opinion that physicians must be held accountable for recognizing human differences and cultures, dismantling their attitudes of audism, and adapting their practice accordingly to meet the needs of each particular patient.

It is indeed possible that the behaviors of these professionals result not from lack of respect but rather from simple ignorance of the existence of a Deaf community that has distinct values, language and rules of behavior different from the hearing community. Discrimination based on language or any factor, however, in effect “closes the door to equal opportunity”, a fundamental right to Canadian citizenship (Canadian Hearing Society, 2007). As referenced previously in this paper, the 1997 Supreme Court of Canada ruled on the right of Deaf ASL users to sign language interpreters in health care settings. The court ruled that the failure to provide sign language interpretation was discrimination and a violation of the equality rights (in this case to health care) enshrined in the Canadian Charter of Rights and Freedoms (*Eldridge v. British Columbia (Attorney*

General), [1997] 3 S.C.R. 624). Though made in 1997, it would appear from the experiences of those participating in this study that many of their respective physicians may have been either unaware of the ruling, unfamiliar with its application, or knowingly failed to heed the direction of this court decision in providing reasonable accommodation to these Deaf people seeking services in their primary language. One would hope that the latter is not the case but rather that, given the small size of the Deaf community, the dominance of the medical model regarding deafness in health care, and lack of Deaf Awareness training, health care staff are simply not aware of the reality of a distinct Deaf culture. The findings of this study could be used as the impetus through which to revisit existing policies regarding the incorporation of this court ruling into practices regarding Deaf ASL users.

The Deaf person's right to access ASL/English interpreters in a health care setting is fundamental. It is crucial, however, that current policy regarding reasonable accommodation to equal access of health services not burden the consumer of service to enforce professional compliance to this; such would be an unrealistic expectation in an already unequal power relationship.

Advances have been made in the "landscape of disability rights" (Stienstra, 2013, back cover). There continues to be a disconnect, however, between existing legislation or policies, and the enforcement of such in regards to Deaf ASL users. Social work can seek to reconnect the pieces of the puzzle and seek change.

**The political arena.** The importance of positive mental health or well-being is receiving greater attention on the local, national and world stage; the reported benefits of positive mental health are recognized as significant both on individual and community levels.

Provincially, the new Manitoba mental health strategy (Government of Manitoba, 2011) reports that adults who are mentally healthy report the fewest number of missed days of work, experience the healthiest psychosocial functioning including having clear goals in life, demonstrate high resilience to challenges, and experience minimal feelings of helplessness. As well, those who experience positive mental health experience fewer chronic physical diseases as they age, and have overall lower health care utilization. These benefits are noteworthy and warrant further exploration.

The Manitoba mental health strategy (Government of Manitoba, 2011) provides the “lenses” through which action may occur in order to work towards a more comprehensive, progressive and meaningful approach to mental health in general in Manitoba. The first of six lenses or ‘pillars’ is that of ‘mental health promotion’; encouraging the creation of environments in which positive mental health can be promoted and supported to flourish, and that “mental health problems and illnesses are prevented wherever possible” (2011, p. 12).

There must be an expectation that medical and mental health professionals participate in Deaf Awareness training with content such as created by the participants of this study to enhance understanding of the socio-cultural model of deafness. In this case, the focus would not be on promoting ways through which to “fix” the Deaf consumer, but rather acknowledge difference (Stienstra, 2013). The issue of professional Deaf Awareness Training and recommended content is discussed in detail below in the section titled, ‘Implications and suggestions for medical practice’.

The United Nations (UN) Convention of Rights of Persons with Disabilities (United Nations, 2008) offers additional impetus for focus on policy changes necessary to

support the social justice rights of persons living with mental illness. Also of relevance, paragraph (a) of Article 25 (Health) notes that States Parties shall “Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons....”. Further, paragraph (d) states the States Parties shall, “Require health professionals to provide care of the same quality to persons with disabilities as others” (p. 18). Finally, paragraph (f) indicates Parties shall “Prohibit discriminatory denial of health care or health services ... on the basis of disability” (p. 18). This document, in combination with Section 15 of the Charter of Rights and Freedoms with a focus on equality rights, and the new provincial and national mental health strategies, should collectively provide the foundation on which to promote policy change in Canada in regards to Deaf minority language users who are seeking services in the area of mental health.

**The role for social work.** As noted in Jennissen and Lundy (2013), “Social workers have a responsibility to promote social justice and in doing so the international human rights declarations and conventions are particularly relevant” (p. 298). Social work is but one profession which must gain a comprehensive understanding of the complicated interrelationship between hearing, language, culture and politics, and challenge labels, attitudes and discrimination often associated both with hearing status, and mental illness.

Social work historically forged a place in the field of mental health justifying its’ relevance. It needs to continue to prove its relevance by expanding the commitment to both individual need and collective action for the greater good of society today, and into the future (Jennissen & Lundy, 2013, p. 298). Through social work’s established skills in advocacy, empowerment and a strengths-based philosophy to social justice issues, social

work can return the spotlight to relevant legislation and policies related to persons with disabilities that demand equal access to public services, interventions and resources for all seekers of services, including those from minority language cultures who also live with mental illness (Regeher & Glancy, 2010). It, too, can shine the light on policies that promote anti-stigma strategies (Corrigan & Gelb, 2006; Corrigan, Edwards, Green, Diwan, & Penn, 2001), preferably through strengths-based practice, and strategies that enhance resilience in various multi-cultural communities.

Deweese (2002) is of the opinion that the profession of social work needs to challenge the existing landscape of mental health practice, and enhance its skills and practices to ensure harmony with the existing demographics of society. Admittedly the Deaf community is but one minority community found within the Canadian landscape; social work must however enhance its skill base to be innovative in meeting the basic values of relationships, advocacy and enhancement of self-determination for all clients (see also Carpenter, 2002).

Individuals in this study, and others as reported in the literature, reported finding comfort and strength from their Deaf identity and with their identification with the larger Deaf community. The findings of this study, however, suggest that participants feared personal and professional rejection if their diagnosis of mental illness were ever revealed. These fears would suggest that acceptance and support from the Deaf community to its members might be conditional, and dependent on factors such as mental wellness. Such is the most significant finding of this study. Given these fears, it would behoove social work to explore and establish a role in working with the Deaf community to address this collective, and reportedly oppressive response to members who have been diagnosed with

mental illness, such that acceptance and membership can truly be unconditional.

**Implications and suggestions for health care providers.** As stated both in this report and the larger body of literature related to deafness, deafness continues to be defined as a pathological condition within the prevailing medical model of deafness (Munoz-Baell & Ruiz, 2000). This pathology perspective seeks intervention with a focus on some form of remediation. As has been argued in this paper and in the literature, however, this narrow view fails to acknowledge the degree to which Deaf people are disabled, not by their hearing status, but by the barriers of the policies, attitudes and structures of the built world around them.

The participants in this study identified a number of health care gaps. A common gap identified was that many of these staff appeared to lack awareness of Deaf individuals or best practices when serving them, making little accommodation such as when calling a patient to an appointment. Many support and health care staff reportedly also failed to acknowledge that English is often a Deaf persons second language, with some type of language support necessary to facilitate effective two-way communication that the Deaf person can understand. All participants in this study reported at least one incident of feeling impotent to either ask questions regarding an intervention prescribed or seek clarification when unclear about medical terminology. Consistent with the findings of the Pearlman et al., (2008) study, the participants in this study also felt these barriers restricted their level of participation in the creation of their healing path.

**Deaf awareness training content for health professionals.** I suggest that active engagement in the health care setting, and skilled self-advocacy will allow Deaf adults to assume an active role in social change (Mertens, 2007). They suggested content include

modules specific to Deaf history, and the role Deaf residential schools and Deaf peers play in the socialization of, and acculturation processes for Deaf children. Also suggested was content specific to the challenges faced by some Deaf children raised in predominantly hearing families, including feelings of isolation that can occur if the hearing family is not able to communicate in sign language.

The dynamics of Deaf culture was viewed as necessary content. Participants felt it necessary to provide information regarding the collectivist nature of the Deaf community, common attention-seeking behaviors, and the significance of the language of ASL. In regards to the latter, content should include information regarding the uniqueness of the language including the grammatical differences between it and English. Finally, it is suggested that this component include details regarding the role of English/ASL interpreters in the two-way communication process and the rules of engagement with an interpreter during the communication process. Lastly, the participants suggested that Deaf-friendly health promotion and educational materials be created; this might include doing so in visual means, be it ASL, or even Deaf theatre.

I suggest that training also include reference to current research related to deafness and mental health. Of particular importance are the details related to the practices that can best serve the needs of Deaf consumers of services (Sinai health System, 2004). For full details please refer to Table 4 – Deaf Awareness Training Content and Checklist. This chart includes educational content though also recommended standards of care for Deaf patients. This may include, though only with the patient's permission, a file notation confirming their identity as 'Deaf' to ensure practices are respectful and linguistically appropriate. This might include the need for a visual cue to

alert the patient to the appointment. It might also support inclusion of appropriate Deaf-friendly health promotion and educational materials including information related to medical tests, referrals to specialists, and prescription-related content such as possible side-effects. The file notation should also flag the need for additional time allotment for the appointment to ensure sufficient time for all questions to be asked. Finally, the file could, again with the patients' permission, note any language support requested, including interpreter service contact information if applicable. All of these are practices the hearing enjoy as part of their "hearing privilege", defined by Tuccoli (2008) as "advantages or entitlements that are enjoyed by people who can hear which are denied to those who are deaf" (p. 23 as cited in Gournais & Aubrecht, 2013, p. 75).

Based on the narratives of these participants, this content should be provided in a variety of formats to accommodate both medical interns starting their practice, as well as practicing physicians, and in ways to accommodate various adult learning styles. Content could be provided as a core course or component of a core course in medical training universities as well as by way of the professional continuing education processes for existing medical personnel. If provided through continuing education, the content could be made available through a variety of methods and formats to ensure it meets the needs both of physicians in large centers with easy access to technology as well as those in isolated rural settings with restricted technology. Further it is recommended that preliminary content be provided through in-classroom settings with facilitators from the Deaf community. These instructors could share information from an insider perspective and also model appropriate practices when engaging the services of an ASL interpreter for effective two-way communication. This would be relevant for physicians, though also

for nurse practitioners, nursing staff, nursing assistants as well as office support staff.

Table 4: Deaf Awareness Training Content and Checklist (template)

Put checkmark to confirm complete	Deaf awareness training content and checklist
	<ul style="list-style-type: none"> <li>&gt;Socio-cultural model vs. Medical model Provide descriptions of both.</li> <li>&gt;Deaf culture               <ul style="list-style-type: none"> <li>prevalence and incidence of prelingual deafness;</li> <li>family of origin; dynamics in hearing / deaf families</li> <li>Deaf schools; mainstreaming; and average reading Comprehension.</li> </ul> </li> <li>&gt;ASL – structure               <ul style="list-style-type: none"> <li>idioms in English and ASL</li> <li>role and use of professional ASL interpreters</li> </ul> </li> <li>&gt;Health literacy               <ul style="list-style-type: none"> <li>medical terminology</li> <li>mental health literacy</li> </ul> </li> </ul>
_____	Reception staff:
_____	Confirm preferred language of patient: _____
_____	(with permission of patient) notation on file “Deaf”
_____	appointments (sufficient time allotted)
_____	used visual cues to alert patient to appointment
_____	Interpreter: Preferred interpreter _____
_____	Availability confirmed: _____
_____	Relevant health promotion materials available in ASL or visual means

This study focused on the lived experiences of Deaf adults in the community.

Literature suggests that the health care needs may be similar for inpatient settings as well (Sheppard, 2008). The proposed content could thus be adapted to meet the unique needs of particular inpatient settings as well.

Recently, staff at McGill University, in partnership with the Canadian Deafness and Research Training Institute, created a basic knowledge-based tool kit for medical

professionals and Deaf ASL users in the English speaking community of Quebec (MacDougall, personal correspondence January 14, 2012). Though not yet ready for public distribution, it is based on research with both hearing medical professionals and Deaf consumers in Quebec. MacDougall (2012) is confident this resource will meet both the needs of Deaf adults in the target Quebec area, as well as professionals tasked with serving this population. The content is available by way of an iBook format, which allows all users access to videos and text content through a tablet format. The content of this could be added to existing knowledge exchange centers such as those created by the Canadian Mental Health Commission (CMHC), and the Ontario Health Association (OHA) to enhance accessibility to the range of health care related professions.

It is recommended that knowledge dissemination occur to communities through strategies most appropriate to that community. In the case of the Deaf community, knowledge dissemination of the findings of this study could be through methods such as Deaf theatre. Deaf actors could be used to portray the lived experiences of Deaf consumers in the hearing medical and mental health system, as well as suggested strategies to enhance individual self-advocacy skills. This idea was introduced to participants of this study, and received near unanimous concurrence for its impact.

A more powerful strategy, consistent with the literature, may be to engage the services of Deaf consumers of mental health services themselves as the 'actors': persons who could offer the most authentic portrayal of the issues. A second emotionally powerful strategy would be to build on the format of the Speakers Bureau developed by the Partnership for Consumer Empowerment office of the Canadian Mental Health Association, Winnipeg Region. The Speakers Bureau, or panel, of Deaf consumers could

be formalized. These panel members could share their stories within the Deaf community and beyond to the larger community to enhance understanding of the effects of audism and ableism. These strategies are consistent with research that supports education and contact as key approaches to challenging the stigma of mental illness (Corrigan & Gelb, 2006; Corrigan et al., 2001).

It is noteworthy, though consistent with the results of this study, that none of the participants felt they would be comfortable playing themselves in any such theatrical vignette given the stigma of mental illness in the Deaf community. This concern alone speaks to the need for enhanced education to reduce the stigma in this community. Participating in the creation and delivery of educational content to professionals others in both the Deaf and dominant community could serve as strategies of empowerment for members of the Deaf community and would be consistent with the Strengths Perspective in social work practice.

**Implications and recommendations for social work and mental health practice.** The profession of social work strives to combat individual and structural oppressions that stifle empowerment for all persons, but particularly those who are vulnerable, live in poverty and, as a result of their life situation, may see little hope for change (CASW, 2005). Based on the bedrock principles of social justice and human rights, it encourages and supports persons from all cultures to enhance awareness of their needs on the social stage and a voice in the social conscience. To achieve this, those working in the profession of social work, similar to medicine, require skills of engagement, effective two-way communication and competence in the area of community advocacy (CASW, 2005). As suggested in the findings of this study, social work also strives to ensure there

is a focus on challenging the policies and practices that are phonocentric in nature and that privilege voice and hearing as the methods of professional communication (Gournaris & Aubrecht, 2013). Failure to do so would be inconsistent with the mandate of the profession.

Social work has a long history of work within the field of mental health and continues to play a significant role in the area. To enhance its position as champion in this field, it must continue to promote culturally congruent mental health practice. It must also support and take a lead role in internal professional training and encourage self-reflection for professionals working within this community. It must also work to provide training in effective group facilitation skills to Deaf community members, support the development of ASL based self-help support groups, and work to create health care specific terminology workshops. These strategies are consistent with social work's mandate and the recovery philosophy (Walsh, 2013).

**Strategies for all.** Mental health literacy improvement strategies for the Deaf community can include public service announcements featuring Deaf actors using ASL to convey mental health messages as the staff of the Deaf Wellness Center in Rochester, New York did (Pollard, 2009). This type of outreach could be explored as appropriate to the context in Manitoba, though not without a simultaneous increase in the number and availability of qualified ASL interpreters and other professionals able to manage the anticipated increased response and request for services. This would require the support of local, provincial and even federal government programs to distribute finances accordingly to meet the need for advanced services and training of staff specific to Deaf ASL users.

Many in the Deaf community use various communication or assistive

technologies in their home and businesses. This might include alerting devices such as flashing lights to signify a phone ringing or use of a teletypewriter machine to facilitate telephone communication (TTY). The latter is dated technology but still used by some, as video relay services are not supported in Canada. The participants reported, however, that few of the professionals they engaged with appeared aware of these technologies or other developing technologies and their role in bridging access communication challenges. For some participants, the use of video conferencing or applications such as Apples' Face time were the methods of choice, for others, the Skype program, and when communicating with persons who are hearing, the Video Relay Service (VRS). Finally, though few in this study had accessed services through tele-health technology, those that had supported the exploration of its use as a method of direct contact with medical and other helping professionals for assessment and/or intervention otherwise inaccessible due to distance. Research has also been conducted on using diagnostic assessment tools translated into ASL as methods of assessment with Deaf persons (Lipton, Goldstein, Fahnbulleh, & Gertz, 1996; Mason, 2005; Steinberg et al, 1998).

Participants reported little use of mental health recovery strategies such as self-help groups, individual counseling services, alternative therapies, or other community based supports (Pistrang, Barker, & Humphreys, 2008). While none were available in the participants' first language, participants also reported access and attitudinal barriers from staff employed in a variety of community-based mental health and related support services. The proposed comprehensive Deaf awareness training would be of value to the staff in these various agencies to both enhance understanding of this community while simultaneously dismantling the stigma that accompanies it.

As has been noted, stigma regarding mental illness is prominent in the Deaf community. Given this concern, the content regarding mental illness/mental health needs be extended to the families of Deaf community members as well as the larger Deaf community to enhance the relevant mental health literacy of both. In both cases, Deaf theatre could be an appropriate medium with a series of educational vignettes developed by these very same members of the Deaf community. These vignettes could then be incorporated into the education process moving into the offices of the professionals, the homes of the Deaf persons and their families, into the community, including the schools.

The experiences shared during Deaf theatre vignettes could begin to put a voice to the experiences and challenges by some members of the Deaf community. It could also serve as the opportunity for persons living with mental illness to participate in the construction of solutions to the challenges their mental illness brings (Rapp & Gosha, 2011). The issue of self-stigma was a problem for some participants in this study. Social work must take an active role in supporting the enhancement of self-advocacy skills such that members of the Deaf community can move this agenda forward in the local and political arenas.

**Implications for research.** The existing body of literature related to mental health and deafness is limited, particularly in Canada. There are significant gaps in understanding the prevalence of mental illness in this population, the experience of mental illness in this community, and effective evidence-based intervention strategies. These gaps indicate additional research is needed in these areas so as to expand our understanding of the needs of Deaf persons living with mental illness to the depth of understanding of the mainstream population (Connolly, Rose & Austen, 2006; Critchfield, 2002; Fellingner,

Holzinger & Pollard, 2012; Kvam, Loeb, & Tambs, 2006; Naish & Clark, 1998; Steinberg et al., 1998; Tate; 2012). This need for additional research is consistent with Goal three of Manitoba's new mental health strategy which strengthens, promotes and supports innovation and research in the area of mental health (Government of Manitoba, 2011 p. 15).

One difficulty in seeking support for continued research in the area is that the small, low-incidence population creates challenges in research design because of the likelihood of small sample sizes, and restricted access to participants (Mertens, 2007, p. 222). The small size of this population also creates challenges regarding a replication of the study, such as the case with the Onken et al. study, which consequently reduces the possibility of generalization of the findings. It may well be that, consistent with qualitative research, the opportunity for generalization is simply accepted as less likely with this population.

Specific areas or strategies of research are offered here. Policy makers require evidence of need prior to dedicating government dollars to a particular area. An environmental scan could be commissioned to explore the size of the Deaf community or, more specifically, the number of persons who are deaf and Deaf, and the prevalence of mental illness in the Deaf community. A study of this nature would be designed in such a way that recruitment extends broadly and reaches those individuals who may be little connected with the larger Deaf community or are otherwise isolated from the larger community. The study would need to accommodate the heterogeneity in this community including language diversity, communication mode, literacy levels, and access to information dissemination methods. The data collected could be used to begin to

demonstrate need and serve as the foundation on which to create policy and practice necessary to address that need.

Research into technology and strategies for reducing accessibility barriers is also encouraged. The focus would be to explore the capacity of existing technology to reduce accessibility barriers. One such example may be the expansion of existing communication technologies such as tele-health services. This real-time technology provides the opportunity for direct contact with the appropriate professional for assessment, intervention and follow-up as needed, without the additional strain of the consumer having to travel for services. These resources must be made available in more centers to enhance its access. It could also be used as a tool to support participation in self-help groups for people living in isolated or rural areas. As evidenced by the findings of this study, neither size of the community in which one lives or its location guarantee access to mental health services for those who are Deaf. Five (82%) of the participants of this study lived in dominant urban centers at the time of the study period, but even for many of these, physicians did not use ASL interpreting services consistently. This resulted in medical or mental health services being offered without necessary sign language interpretation.

Research could be used to explore the role of complementary or alternative treatment therapies to treat depression in this population. Kessler, Soukup, Davis, Foster, Wilkey et al., (2001) reported that participants in their study perceived complementary and alternative therapies including cognitive feedback, (i.e. imagery, relaxation techniques, self-help groups, etc.), other therapies (i.e. lifestyle diet, spiritual healing, etc.) and physical treatments (i.e. yoga, acupuncture, massage, etc.) to be effective for

some in managing their symptoms of depression. These do not appear to have been studied in the Deaf population. Further research could explore the value of these alternative strategies or other new or novel ones in the management of depression.

Two additional and related bodies of literature that may enhance understanding in this population of study are ‘help and hinder recovery’ study (Onken et al., 2002) and the social support literature. Onken et al. (2002) found that not having access to real and meaningful choices in recovery and treatment options impeded recovery. This was consistent with the results of the current study with some participants expressing frustration with the reality that lack of choice in intervention options thwarted self-determination. Participants often felt powerless to take advantage of existing evidence-based knowledge and practices in managing their own symptoms of depression. Onken et al. (2002) reported further that having positive social relationships, whereby at least one person believed in you and viewed you as more than a diagnosis, facilitated recovery. Many participants in the current study reported that they did not feel they had any particular person to whom they felt unconditionally comfortable disclosing the nature of their mental illness. Most reported they “told no one” so as to avoid possible repercussions associated with their disclosure.

The Onken et al. (2002) study could be replicated in a Deaf sample to enhance our learning of those factors that help and hinder mental health recovery in this specific minority community. The findings from a study such as this could provide a more thorough understanding of the specific needs of this community and guide the creation of strategies to assist with mental health recovery in this population.

Dissemination strategies might include expanding the topic areas available through

'vlogs' or video blogs as commonly seen on various websites for Deaf and/or hard of hearing individuals. There could be a series of vlogs created related to mental health or mental illness. A psycho educational DVD could also be created incorporating this vlog and made available to schools, families and the larger community. Within this area, I would also suggest that Deaf mental health awareness be provided through either Mental Health Awareness Week or Mental Illness Awareness weeks in Canada. As one participant pointed out, information is generally slower to reach the Deaf community than is available in the dominant population; the issue could be normalized if released simultaneous to a public campaign in the mainstream society.

I suggest knowledge dissemination requires an expansion of the size of the qualified ASL/English interpreter cadre in Manitoba. This could be facilitated through an expansion of the ASL interpreter-training program offered currently at Red River College in Winnipeg. Very simply, a two-week or longer delay from date of request for interpreter services to service provision cannot be tolerated. While urgent requests for interpreter services are often or generally met, waiting times until availability of interpreter services must be reduced. I also suggest a review of the existing tele-health policies that place medical appointments as its priority. While understandable, is a person's mental health not a medical urgency? I suggest this review seek expansion of the existing parameters of tele-health services to more readily prioritize use of the technology for services such as individual counseling or services such as self-help groups. Expanded access would allow persons isolated by distance and lack of proximity to a large center or professional services to have greater access to, and choice in strategies necessary for mental health recovery.

## **Conclusion**

A group of 6 individuals chose to participate in a study about a topic that carries great stigma in the larger dominant society, and even more in their own minority Deaf community. The participants allowed me entry into their personal experiences with depression, in the hope that their experiences can help make it better for others.

The participants in this study communicate visually and are members of a language minority. Their expectation for equal access to mental health literature, services and supports should be no different, however, than that expected by members of the dominant language and culture. Yet, despite human rights declarations, Supreme Court of Canada rulings, and policy emphasis on the social inclusion of all persons, society has failed to ensure the full and equal participation of Deaf adults in Canadian society in the area of mental health. These failures, as well as attitudinal barriers of health care staff, and reduced mental health literacy intersect to prevent the full and equal participation of Deaf adults in the mental health system.

It is my hope the findings from this study can contribute to our collective and professional understanding and, by extension, to the liberation of professionals from the structures, policies and practices that fail to unconditionally acknowledge and respond to the linguistic and cultural differences of all.

It is further my hope that the process of knowledge dissemination will lead to knowledge mobilization, and social work, our allied professionals can collaborate with Deaf consumers to find ways to respectfully and congruently complete the Deaf mental health puzzle referred to by one of the participants in this study. In the absence of a dedicated focus on these issues, the words of study participant Walter will apply to many

more Deaf Canadians living with mental illness, their 'garbage cans' will continue to get full and multiply, effectively blocking pathways to mental health recovery.

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## APPENDIX A INTERVIEW GUIDE

### Interview Questions

#### Research themes and questions

##### Demographic questions:

-You define yourself as Deaf, can you tell me something about your family - are you the only Deaf member, are your parents Deaf/hearing?

Where did you go to school? What type of program was it? i.e. was it an oral deaf program, mainstream, manual program?

Are you involved in the Deaf community? If so, can you describe how you are involved? i.e. attend sports activities, events, workshops, teach ASL/ immersion course, other?

##### Research questions:

##### Mental illness:

What does the phrase “mental illness” mean to you?

##### Diagnosis:

This study is about the experiences of those who have been diagnosed with depression. You indicated that you have been diagnosed with depression; Can you tell me about your experiences with the symptoms of depression?

1. When you first started to experience symptoms of depression, what did you do? See a Dr., go to hospital, see clinic, other?

Prompts: When you first went to see a Dr. did someone go with you?

-How did you communicate with the Dr.?

-How did you feel leaving there – did you feel your concerns/problems were addressed?

-What did the Dr. do for you that first time? Give medication, refer you to group, nothing?

-Apart from seeing the Dr. did you find anything or anyone else helped you get better? i.e. Did you talk to someone, visit others you knew who also had depression, take medication, other?

##### Getting well

2. What did you do to get better when you were feeling depressed? See a doctor, medication, other?

##### Staying well

3. When you finally got your symptoms under control, what did you do keep the depression away?

Prompts: If you start to experience symptoms now, what do you do to make them stop?

What do you do to make the symptoms stay away? i.e. Do you take medication, go to a group with other people who have same symptoms, talk to family or friends, go to hospital, do you spend more time with Deaf people or less, other?

Prompts: Is there anything else that you do?

#### Person and Environment Map

Interviewer to introduce and demonstrate completion of a Person and Environment Map to visually explore the nature of the people, places and activities participants used at two times, both before experiencing symptoms of mental illness and after experiencing symptoms to help alleviate them.

#### Resources:

Do you feel you get all the help you need for your depression? If yes, how so? If not, why not?

Prompt: What do you think would help you more?

That is all the questions I have – is there anything else you want to add to what we have talked about?

Thank you for your time.

## **APPENDIX B PERSON AND ENVIRONMENT MAP**

This is a free-hand drawn map – it is intended to show us what type of supports you have used as you deal/dealt with your depression.

The circle in the middle represents YOU.

First, think about the people, agencies or other things you have used to deal with your depression (friend, family member, church, medication, other).

Second, place an X on the “map” to represent the amount of support you have received or used each person place or thing you discussed above. Place those that have supported you the most closest to you in the center – those who you used only a little, farthest away from you.

## APPENDIX C HUMAN ETHICS APPROVAL CERTIFICATE



UNIVERSITY  
OF MANITOBA

Office of the Vice-President  
(Research and International)  
Research Ethics and Compliance

Human Ethics  
208 - 194 Dufour Road  
Winnipeg, MB  
Canada R3T 2N2  
Fax 204-269-7173

### APPROVAL CERTIFICATE

December 26, 2011

**TO:** Tracey Bone (Advisor B. Bacon)  
Principal Investigator

**FROM:** Bruce Tefft, Chair  
Psychology/Sociology Research Ethics Board (PSREB)

**Re:** Protocol #P2011:101  
"Coping with Mental Illness: Using Case Study Research to Explore Deaf Depression Narratives"

Please be advised that your above-referenced protocol, as revised, has received human ethics approval by the **Psychology/Sociology Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). This approval has been issued based on your agreement with the change(s) to your original protocol required by the PSREB. It is the researcher's responsibility to comply with any copyright requirements. This approval is valid for one year only.

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

**Please note:**

- If you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to the Office of Research Services, fax 261-0325 - please include the name of the funding agency and your UM Project number. This must be faxed before your account can be accessed.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba Ethics of Research Involving Humans.

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

**APPENDIX D  
HUMAN ETHICS AMENDMENT CERTIFICATE**



UNIVERSITY  
OF MANITOBA

Office of the Vice-President  
(Research and International)  
Research Ethics and Compliance

Human Ethics  
208 - 194 Dafoe Road  
Winnipeg, MB  
Canada R3T 2N2  
Fax 204-269-7173

**AMENDMENT APPROVAL**

March 27, 2012

**TO:** Tracey Bone  
Principal Investigator

**FROM:** Bruce Tefft, Chair  
Psychology/Sociology Research Ethics Board (PSREB)

**Re:** Protocol #P2011:101  
"Coping with Mental Illness: Using Case Study Research to Explore Deaf Depression Narratives"

This will acknowledge your request received March 26, 2012 requesting amendment to the above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must be reported to the Human Ethics Secretariat in advance of implementation.

**APPENDIX E  
RECRUITMENT POSTER (ENGLISH)**

**Seeking Research Participants: Deaf adults and your strategies for coping with depression (Major Depressive Disorder)**

Researcher: Tracey Bone, MSW, PhD candidate  
 Faculty of Social Work, University of Manitoba  
 Contact: \*\*\*-\*\*\*-\*\*\*\* (telephone or TTY)  
[umbonet@cc.umanitoba.ca](mailto:umbonet@cc.umanitoba.ca)

Research Supervisor: Dr. Brenda Bacon, Professor  
 Faculty of Social Work, University of Manitoba  
 Contact: \*\*\*-\*\*\*-\*\*\*\*  
[baconbl@ms.umanitoba.ca](mailto:baconbl@ms.umanitoba.ca)

**Study:**

I am a PhD student in the Faculty of Social Work. I am interested in how Deaf adults who use sign language as their primary method of communication, and have been diagnosed with depression by a doctor, cope with their symptoms.

**Duration:** Participants will take part in one interview that will last approximately two hours – three hours. I will have a series of questions to ask you but more importantly want to hear your story of how you dealt with the initial symptoms of depression, what you did to get better, and, after you got better, how you continue to cope with the symptoms of depression. I am also interested in finding out about your social network in coping with your symptoms, these are the people, places or things that help you cope with your symptoms. Finally, I am also interested in hearing your opinion on the types of resources that are available for Deaf people living with depression.

I am hearing. Though I can communicate in sign language, I will use a qualified and registered ASL/English interpreter to help me conduct the interview in sign language. The interviews will occur in a place we both agree to – can be your home, office, Deaf Center Manitoba or other but must be private and accommodate an interpreter.

**Eligibility Requirements:** The following are required for participation in this study:

- Person is Deaf and communicates in ASL as their preferred or first language
- is between 25 and 60 years of age
- has received a diagnosis from a doctor of Major Depressive Disorder

- the symptoms are currently being controlled through medication or other form of treatment or who is not currently experiencing the symptoms of depression
- is willing to discuss the ways they cope with their depression

This study is associated only with the University of Manitoba. It is not associated with Deaf Center Manitoba, Red River College, or other mental health professional, even if this letter is posted in their office. Your decision to participate or not will not have any effect on the services you receive at any of these places or from any of these people now or in the future. If you have any questions, please contact me directly.

The results of this study will be used in my final PhD dissertation report. The results may also be used in journal articles, presentations or workshops related to Deafness, and mental health. I will not use your name or other identifying information related to you in my reports or presentations. Even though I will not use your name or other identifying factors, there is still the possibility that those who know you well might be able to identify you through the story, particularly as the Deaf community is small.

Please note that your participation is voluntary. If you begin the research, and then later want to withdraw, you can, there will be no problem.

If you would like to learn more about the study or are interested in participating, please contact Tracey Bone (nee Stefura) at \*\*\*-\*\*\*-\*\*\*\* (telephone and TTY) or [umbonet@cc.umanitoba.ca](mailto:umbonet@cc.umanitoba.ca) prior to January 30, 2011.

Thank you.

**APPENDIX F  
RECRUITMENT POSTER – ASL**

**NEED DEAF ADULTS  
“DEPRESSION” – How to deal**

**STUDY** from University of Manitoba... Tracey Bone, social worker is hearing and wants to interview Deaf adults who have depression.

**Who:**

- Deaf people who has depression (past or now)
- between 25 and 60 years old
- ASL
- Doctor told you that you have depression
- Willing share your experience with depression

**How often:** Interview 1 – 2 times

**How long:** between 1 to 2 hours each interview

**Where:** you can choose – must be private, have space for interpreter

**When:** you and Tracey decide

**Interview only:** You, Interpreter and Tracey (want video tape: videotaping for only Tracey to watch then write out your story). Your name will be private. Questions: what you did when first felt sad/depressed; when felt better, what you did; how you keep sadness away. Also what you use (friends, family, programs, other) to help you deal with depression. If meet Tracey then decide you want stop, no problem, won't stop you receiving support from any person or place.

**What for:** To help social workers and others understand better with Deaf adults now and in future.

If you are interest to participate this interview, or any questions, please contact Tracey at \*\*\*-\*\*\*\* TTY or Voice or email at [umbonet@cc.umanitoba.ca](mailto:umbonet@cc.umanitoba.ca) by March 1, 2012.

Researcher: Tracey Bone, MSW, PhD student  
Faculty of Social Work, University of Manitoba  
Contact: \*\*\*-\*\*\*\* (Voice or TTY) [umbonet@cc.umanitoba.ca](mailto:umbonet@cc.umanitoba.ca)

Research Supervisor: Dr. Brenda Bacon, Professor  
Faculty of Social Work, University of Manitoba  
Contact: \*\*\*-\*\*\*\* / [baconbl@ms.umanitoba.ca](mailto:baconbl@ms.umanitoba.ca)

## APPENDIX G INFORMED CONSENT

**Research Project Title: Coping with mental illness: Using case study research to explore Deaf depression narratives.**

Principal investigator: TRACEY BONE (nee Stefura), MSW PhD Candidate  
 Faculty of Social Work, University of Manitoba  
 Telephone/TTY: \*\*\*- \*\*\* - \*\*\*\*  
 E-mail: umbonet@cc.umanitoba.ca

Research Supervisor: Dr. BRENDA BACON, Associate Professor  
 Faculty of Social Work, University of Manitoba  
 Telephone: \*\*\* - \*\*\* - \*\*\*\*  
 E-mail: baconbl@ms.umanitoba.ca

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

### 1. Purpose of Research:

This research is the final project for completion of my PhD. in Social Work. This project is associated with the University of Manitoba only. It is not associated with any other organization such as Manitoba Association of the Deaf, Red River College, Calvary Temple or any other professional. None of these will know who participates in the study and your decision to participate or not will not effect the services you receive from these or any other organizations now, or in the future.

You are invited to be interviewed by the principal investigator – Tracey Bone - regarding the strategies sign-dependent Deaf adults use to cope with the symptoms of Major Depressive Disorder. It is anticipated that this research will enhance knowledge of the Deaf mental health experience in Canada, provide clarification as to the resource and communication challenges experienced by this population, and provide information regarding the issue of service inaccessibility for the Deaf in Canada. I believe the information collected will help social workers, and other mental health professionals gain a better understanding of how Deaf adults cope with depression given the language barriers. It may also assist members of the Deaf community to gain an understanding of how some Deaf adults cope with the symptoms of depression.

## 2. Description of the procedure:

I will be conducting one face-to-face interview with each person. During the interview I will ask a number of different questions about how you coped with your symptoms of depression when you first started to experience depression, what you did to make the symptoms go away or manage the symptoms, and what resources, such as people or professionals, you use to help you cope. I am most interested in hearing the story of how you cope with the symptoms of depression. This interview will take approximately 2-3 hours. Interviews will take place in any location that is agreeable to both of us, that provides privacy for the interview and has room to accommodate the interpreter. The interview could be in your home, office, the Deaf Center Manitoba or other.

I am hearing. I do speak conversational sign language but I will be using an interpreter from E-Quality Communication Center of Excellence (ECCOE) to help me with the interview. All interpreters used for this study have at least 5 years experience as a registered interpreter, and have mental health interpreting experience.

## 3. Recording devices:

With your consent, I will videotape your interview. The videotape will allow me to capture your story, and, at the same time, capture the voice of the interpreter and myself. I believe it is important to capture your story on videotape so I can watch it later while I create a written version of your story. I, and my research supervisor, will be the only ones to watch the videotape unless I need help from the interpreter to understand it. Once I have typed out your story I will give you a copy for you to review – you can read it yourself or the ASL interpreter can translate it for you. I want to make sure I recorded your story accurately. If there are errors, you can make corrections to the story. If there is any information you would like removed from your story, please tell me and I will. Once you approve your story, I will use it to help me understand how some people who are Deaf cope with depression. If you do not want the interview video recorded, I can audio record the interview. If you don't want either, I will take notes throughout the interview.

I will destroy any tape of your interview at the end of this research project, or the latest of December 2013. I will also destroy any interview notes I collect during the interview in December 2013 or sooner if I complete my analysis sooner.

## 4. Benefits to participants:

The benefits to you as participant are that you will be given the opportunity to share your story or experiences of living with depression and how you cope. Deaf people who live with depression are not often interviewed about their experiences – while many hearing people who live with depression have been given the opportunity to share their stories, members of the Deaf community have not. I hope this will assist

you and all the participants to see that you are not the only Deaf person living with depression. I also believe it will help to reduce the stigma of mental illness so that other Deaf people living with mental illness won't need to feel embarrassed or ashamed of their health diagnosis. Finally, I believe it may help your family, friends and the Deaf community to understand how some Deaf people who live with depression cope.

#### 5. Potential risk to participant:

Some people may feel emotional stress from participating in this study because I will be asking you to discuss your experience with depression. It is important to know that you can chose not to answer a specific question if it is uncomfortable for you, or you can withdraw completely (stop) from the study if you do not wish to continue. If you withdraw, I will destroy all the information you provided to me during the study.

If at any time during the interview you want to take a break, or stop and continue another day, I will reschedule the interview. If you want to withdraw from the interview you can; your participation in the study is voluntary.

Your name will not be used in my research. I will keep all personal information private; I won't use your name, place of employment, your school name or other personal facts in any document or presentation I do on this study. I can't guarantee no one will recognize your story though because the Deaf community is small and someone may recognize you in my final report, or people may recognize you if I do presentations to mental health professionals or others who would be interested in the topic.

The risk of harm would be no more than may be experienced by discussing your symptoms with a mental health professional such as a Doctor, mental health nurse or social worker, but it would be more than might be expected in everyday life. To reduce the potential for risk, I will answer any questions you might have related to the study and I will not continue until you are comfortable that you understand it all. I will have water available during the interview. I will schedule at least one break during the research interview, and also let you take any other breaks during the interview if you need to. It is important to remember that you that you can refuse to answer any specific question or even withdraw completely from the study if you chose at any time during the study. Finally, I will have a listing of Deaf-friendly counseling supports available at the interview that you can contact in case you feel upset during the interview or after because of the interview questions. All either has a person on staff who speaks sign language or they are familiar with working with interpreters in their setting. In some cases you will need to coordinate the interpreter yourself.

#### 6. Confidentiality:

I will have your name and other personal information that I collect during the study but I will not share the name, city, school or other personal information with anyone. I, and if needed my research advisor, will be the only people who watch your videotape of the interview. I may ask an interpreter to also look at it though only if I need assistance with interpretation of the videotaped story. I, and again possibly my advisor, will be the only one listening to the tape, if you prefer audiotape. All videotapes and audiotapes will be stored on my personal laptop that is password protected. That password will not be shared with anyone else. I will keep all printed copies of each story or transcripts in a locked cabinet in my personal office; using a lock only I will be able to open.

I will keep the information from this study until December 31, 2013 then I will destroy it all – either shredding or deleting from computer.

#### 7. Credit or remuneration:

I will provide each person with two bus tickets for the introductory meeting if you want one, and for the research interview itself. I will give every person who I invite to participate in the study a \$20.00 gift certificate to Boston Pizza or Tim Horton's (your choice) as a way to thank you for your participation in the study.

#### 8. Withdrawal from research:

If, after you sign this consent form, you decide you no longer want to participate in the study, you can stop the interview and leave. There will be no negative consequence or problem if you decide decision to withdraw. Any information I collected from you will be destroyed by me within 48 hours of the withdrawal.

#### 9. Findings

At the end of this study, I expect to attempt to publish my findings and/or present them at professional conferences. However, in all cases I will do so without revealing identifying characteristics such as names, addresses, and other personal or specific details. Nonetheless, given the relatively small population of Deaf community in Winnipeg, there is a risk that some elements of your story may be identifiable to others. I may use quotations from the interviews but only after removing identifying details, so they cannot be connected to any single person.

A copy of this consent form has been given to you to keep for your records and reference.

If you agree to each of the following, please place a check mark in the corresponding box. If you do not agree, leave the box blank:

I have read or had read/signed to me the details of this consent form.

( )

My questions have been addressed.

( )

I, \_\_\_\_\_ (print name), agree to participate in this study.

( )

I agree to have the interview video-recorded.

( )

I agree to have the interview audio-recorded.

( )

I agree to have the findings (which may include quotations) from this project published or presented in a manner that does not reveal my identity.

( )

A summary of the findings should be available approximately January 2013. I would like to receive a copy of the summary.

( )

How do you wish to receive the summary?

( ) E-mail

( ) Regular mail

Address: \_\_\_\_\_

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

The University of Manitoba Research Ethics Board(s) and a representative(s) of the

University of Manitoba Research Quality Management / Assurance office may also require access to your research records for safety and quality assurance purposes. This research has been approved by the University of Manitoba Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator (HEC) at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature

\_\_\_\_\_

Date \_\_\_\_\_

American Sign Language Interpreter's

Signature \_\_\_\_\_

Date \_\_\_\_\_

Researcher's

Signature \_\_\_\_\_

Date \_\_\_\_\_

**APPENDIX H**  
**ASL INTERPRETER CONFIDENTIALITY AGREEMENT**

I \_\_\_\_\_ do hereby agree to respect the privacy of the research participant and hold in confidence all information heard or received in the course of providing professional interpreting services during the research study conducted by Tracey Bone, MSW, RSW PhD. Candidate. If two interpreters are required during the course of a single interview, I may be required to exchange pertinent information with the second attending interpreter, though this would be done solely for the purpose of providing continuity of service and to maintain a consistent quality of service for the participant. Any confidential information exchanged will be done within the interview room itself with the participant and interviewer present.

Name of interpreter: \_\_\_\_\_

Signature of interpreter: \_\_\_\_\_

Date: \_\_\_\_\_

Name of interpreter: \_\_\_\_\_

Signature of interpreter: \_\_\_\_\_

Date: \_\_\_\_\_