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Biographies of Hearing Loss:

Understanding the Social World of Late Deafened Adults

Through Life Experience Narratives

A dissertation submitted in partial satisfaction of the

requirements for the degree Doctor of Philosophy

in Applied Linguistics

by

Stormy Meriah Iverson

2016

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ABSTRACT OF THE DISSERTATION

Biographies of Hearing Loss:
Understanding the Social World of Late Deafened Adults
Through Life Experience Narratives

by

Stormy Meriah Iverson
Doctor of Philosophy in Applied Linguistics
University of California, Los Angeles, 2016
Professor Susan J. Plann, Chair

This dissertation provides new insights into the world of late deafened adults, a previously underrepresented, minoritized group that has experienced not only a loss of hearing, but in many cases, also a loss of self and cultural identity. Life experience narratives were collected from seven late deafened adults who participated in in-depth, semi-structured qualitative interviews. Video-recordings of the interviews were transcribed in order to identify the major themes, or recurring patterns of meaning (ideas, thought, feelings) within each transcript, as well as patterns of meanings across narratives. Transcripts were

analyzed using interpretive/hermeneutic phenomenology, based on the philosophies of Husserl and Heidegger. Fifteen emergent themes were abstracted and clustered together under four broader, super-ordinate themes or dimensions of the lived experience of late deafened adults. The dimensions included: transformation of self, social interaction, interaction with technology, and deaf advocacy. Although each late deafened adult's lived experience of becoming deafened was unique because of their personal history, context and background, there were similarities in the descriptions of the experience. Themes from the narratives of participants were strengthened when they were confirmed in subsequent interviews, with differences within their experiences adding depth and breadth to the dimensions of the experience. The constituted meanings were then interpreted against the backdrops of wider socio-political and historical contexts that have shaped American Deaf Culture. The findings of this study provide a heuristic tool to restructure the understanding of late deafened adults, shifting from a strictly medicalized paradigm to a comprehensive model based on understanding the social world of late deafened adults.

This dissertation of Stormy Meriah Iverson is approved.

Paul Kroskrity

Christine Littleton

Susan J. Plann, Committee Chair

University of California, Los Angeles

2016

To my children, Evan and Kimi, never give up on your dreams.

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Stormy M. Iverson

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Chapter One

Introduction

Autobiographical Statement

My personal interest in deafness developed when I was an undergraduate student. It was during my first sign language class in college that I learned about Gallaudet University and the culture and history surrounding the iconic institution. My desire to become fluent in American Sign Language (ASL) and to be at the epicenter of deaf¹ culture lured me to Washington, DC for a master's degree at Gallaudet, the first higher education institution in the world for deaf and hard-of-hearing individuals². Being immersed in deaf culture and language as a hearing person is a unique experience that is similar to traveling to a foreign land. Having never met a deaf person before arriving at Gallaudet, I did not realize that I would not necessarily be a welcomed visitor. Deaf people at Gallaudet are very protective of their territory, which includes their language and culture. Early in my time at Gallaudet, my hearing peers and I were often harassed by deaf students and questioned as to our motives for being at "their" school.

¹ The conventional method is to describe those who identify as culturally deaf as 'Deaf' and others as 'deaf.' However, because of shifting dynamics of the deaf community in recent years (Padden and Humphries, 2005), this boundary is not as clear as it once was. Therefore, the 'D/d' convention will not be used in this study, but instead it will be explicitly stated when referring to the culturally deaf, signing community.

² Undergraduate admissions at Gallaudet University are primarily restricted to deaf and hard-of-hearing students. Select graduate programs admit hearing students who have demonstrated competency in American Sign Language and American deaf culture.

Slowly, as I proved to not be a personal affront to the culture, I began to establish friendships with deaf classmates, some of whom were deaf-of-deaf³ and had spent their entire lives in the signing, culturally deaf community, some who had moved from other countries and were also new to American sign language and American deaf culture, and some who had become deaf later in their lives.

I realized later, having at the time been concerned with my own hearing status, that I did not fully consider the social and political position of my deaf friends at Gallaudet who were not deaf-of-deaf. One of my dear friends, “Jay⁴,” lost his hearing at the age of twenty-three as a result of neurofibromatosis type II (NF2). Jay is fluent in American Sign Language and is now a social worker, working with deaf people and their families. Jay once told me that becoming deaf was the best thing that had ever happened to him. It helped him to find purpose in his life and to connect more intimately to a group of people than he ever did as a hearing person.

I later recounted this story to a deaf-of-deaf friend, who in return explained that late deafened people can never be fully accepted by culturally deaf people because they continue to use their voices (this was signed with a clearly derogatory undertone). I considered this and soon after dismissed it as idealistic. In fact, through my studies I had learned that speech and hearing do not define membership in the community, but, instead, membership is defined by fluency in ASL and commitment to upholding the values of the culture – and Jay met that criteria. Besides, at the time I. King Jordan was serving as president of Gallaudet. In my naivety, I believed that if a late deafened adult could become a

³ “Deaf-of-deaf” is a term that is used to represent children who are born deaf to culturally deaf parents. Deaf-of-deaf are generally considered to be at the core of the American Deaf community.

⁴ All participants are referred to by pseudonyms.

celebrated president of the university, surely my friend Jay could also be accepted as a member of the community. And then I set the thought aside.

As a feminist and a member of a stigmatized minority group that has faced marginalization by way of restricted legal rights, I became particularly interested in and sympathetic to the plight of the politically and socially marginalized deaf community. It was this common ground that I shared with the deaf community that spurred my interest, now as a doctoral candidate, to study the political history and culture of the deaf, particularly as it applies to the debate of whether deaf children should be educated using oral or manual language. That being said, I should mention that I am neither an oralist⁵ nor a manualist⁶. I believe that different choices are appropriate for different people, and I support any decision, as long as it is a well-informed decision.

My curiosity about late deafened adults was further aroused while I was conducting research on historical ideologies of deafness in modern day media. As I was perusing television data, I came across a storyline about a college student who became deaf and eventually received a cochlear implant. Being familiar with the politics of the deaf community, I was skeptical of the presentation of the late deafened adult. I also became aware that, with the exception of this questionably educational storyline, resources pertaining to late deafened people were nearly non-existent. Filled with curiosity, I reconnected with Jay, wanting to more fully understand his experience of becoming deaf, of learning a new language, embracing a new culture and developing a new identity. Jay was extremely generous in sharing the details of his life. We emailed back and forth for several

⁵ An oralist is one who advocates for the education of deaf children through oral language.

⁶ A manualist is one who advocates for the education of deaf children through using sign language.

months, and the more I learned about his experience, the more I wanted to understand the experience from the perspective of other late deafened adults, who had different experiences and ideologies about deafness. And hence the topic for my doctoral dissertation was born, from my respect for the deaf community and my nascent interest in late deafened adults.

Background and Relevance of Topic

In the American deaf community, the term *deaf* typically refers to those who are culturally deaf and use American Sign Language (ASL). This is largely true because those who use ASL as their first language—typically persons deaf from birth or from an early age who have signing parents—have defined themselves as the core of the American deaf community.

However, it is estimated that only twenty-two percent of the deaf population lost their hearing before the age of nineteen (Schein & Delk, 1994) and the majority of these individuals did not grow up in signing environments. In other words, the vast majority of deaf people in the United States lost their hearing as adults, after becoming socialized in a hearing culture through spoken English.

Although individuals who become deafened as adults are the largest segment of the deaf population, they remain one of the least represented groups in research. Specifically, there is a lack of research that clearly and accurately describes, from a social and cultural perspective, the experience of becoming profoundly deaf as an adult; instead, late deafened adults are defined in the current literature from a strictly medicalized perspective. Woolley (1987) expresses the dangers associated with the current paradigm:

Read any book on deafened people and the lack of self-confidence and the poor self-image of the deafened person is discussed. But without exception, all see this as being a product of the inability to hear, or faults of the ears and not of society, which does not value us. We are stuck with these pathological models and medical definitions of who we are, when in reality we are not sick or ill people. We are people who are socially, psychologically and politically oppressed. (p. 172-173)

Late onset deafness, in fact, brings about unique linguistic and cultural obstacles that critically impact social interactions and participation in everyday life. When hearing people become deaf, as they learn to define and navigate their new selves, they are forced to make numerous life-altering decisions pertaining to language and to social, cultural, and political allegiance. It is likely that they will reevaluate their identity as part of the dominant hearing culture, and possibly negotiate their place in American deaf culture. For example, late deafened adults, left without access to sound, must establish an effective communication method. The communication method they chose will ultimately determine, and be determined by, their perspective of deafness and their own emerging identity as a deaf person.

Late deafened adults may wish to preserve their hearing identity and “overcome” deafness by continuing to use spoken communication, with the support of lip reading and/or various assistive technologies. This is particularly true for individuals who wish to distance themselves from the stigma that is associated with deafness. Historically there have been fewer social consequences for deaf individuals who are able to function in the

hearing world through spoken language; however, it is to be expected that deaf people who rely on oral language sacrifice full participation in social and communicative activities.

Alternatively, manual languages that rely solely on visual cues may be thought of as a more accessible means of communication for late deafened adults. In choosing to use manual language, deafened individuals embrace their deafness as a difference rather than a defect, which may in turn promote positive identity development as a deaf person. It is virtually impossible, though, that late deafened adults, who have lost their hearing after the critical period for language development, will ever develop native-like sign language skills. Consequently, as a result of inadequate signing skills and differing cultural orientations, those who do choose to join the signing deaf community may find themselves less than welcomed into the exclusive group. To compound matters, many late deafened adults will continue to be surrounded by hearing, speaking family and friends, with whom sign language would likely prove to be useless.

The social, cultural and linguistic choices that late deafened adults face are difficult ones that have serious social and political consequences. Often, without being aware of it, late-deafened adults are launched into a political and ideological debate that is rooted deeply in deaf history. In coming to an understanding of their new position in the world as a deafened person they will, in effect, wade through hundreds of years of repression and stigmatization of deaf people, as well as the resistance and development of the American deaf community.

Given the numerous conceptual and empirical issues that arise from the complexity of the deaf community, a preliminary understanding of the role of deaf culture, history, politics, and ideologies in shaping the identities of deaf individuals in the United States is

needed as a foundation to understand the multiple factors that play into shaping the social world of late deafened adults.

Benefits of this Study and Knowledge to be Gained

In 1938, Sapir suggested that anthropologists were preoccupied with cultural groups rather than examining individuals and their interpersonal interaction as well as intracultural variation. He suggested that instead of starting with a superordinate category of culture, gradually working down to the individual, the opposite should be pursued (9-11). In line with Sapir's suggestion, modern anthropology seeks to understand culture as a dynamic process that is a product of group values, norms, and histories, as well as of individual innovations and life experiences (Bourdieu, 1990).

This study seeks to understand how late deafened adults adapt to their particular life circumstances, given the changing nature of their social worlds. In doing so, this study will uncover the ways in which late deafened adults change, add to, or reject elements of deaf and hearing cultures through their actions in the social world. It furthermore seeks to reconcile the influences of both external social structures and subjective experience of the individual through understanding how the cultural, historical, and political processes of the deaf community influence the practices of late deafened adults in the social world, as a function of their values and beliefs.

In doing so, the life experiences of late deafened adults, those who have acquired severe to profound deafness as adults, will be examined using a phenomenological approach that allows for a rich exploration of participants' thoughts, feelings, and motivations pertaining to their life experiences. In summary, this study seeks to give a voice to a previously underrepresented minoritized group that has experienced not only a

loss of hearing, but possibly also a loss of self and cultural identity; and to offer new insights into acquired deafness against the backdrops of wider socio-political and historical contexts that have shaped the American Deaf community. The findings of this study can be used as a heuristic tool to restructure the understanding of late deafened adults, shifting from a strictly medicalized paradigm to a comprehensive model based on an understanding of the social and cultural world of late deafened adults.

CHAPTER TWO

REVIEW OF LITERATURE

Socio-Political and Historical Underpinnings

An introductory discussion of deaf history and deaf culture will build a necessary foundation for understanding the position of late deafened adults within the deaf community. Deaf people have faced discrimination from their first appearance in recorded history (Groce, 1985), as a result of pejorative views of deafness that stem largely from Judeo-Christian tradition and, according to Van Cleve and Crouch (1989), literal interpretations of the New Testament. Unlike the Old Testament, which encouraged respect for the deaf (Leviticus 19:14), and an understanding that certain people were chosen to be deaf as part of a Divine plan (Exodus 4:11), the New Testament had negative consequences for deaf people. Interpretation of the following scripture resulted in deaf people being thought of as inhabited by an evil presence: “And when the demon was cast out, the dumb spake: and the multitudes marveled, saying, it was never so seen in Israel.” (Matt 9:33).

In another example of Jesus curing deafness by rebuking evil spirits, Mark related the terrifying story of a young deaf boy that was brought to Jesus by his mother. The boy was described as being possessed by a “dumb spirit” that caused him to gnash his teeth and foam at the mouth. The scripture continued as follows: “When Jesus saw that the people came running together, he rebuked the foul spirit, saying unto him, Thou dumb and deaf spirit, I charge thee, come out of him, and enter no more into him.” (Mark 9:25). Again, in this example, Jesus dealt with deafness by admonishing an evil spirit.

Scriptures such as those above gave reason to fear deaf people and justification to discriminate against them. However, it was one sentence, written by Paul to the Romans,

that likely had the most detrimental effect on deaf people; it read as follows: “So then faith cometh by hearing, and hearing by the word of God.” (Romans 10:17)

This verse further grounded the idea that deafness was comparable to sin and that it prevented faith. Deaf individuals, therefore, could not be saved and would be denied entry into heaven. Early Christians viewed any type of disability as a punishment from God for sin (Van Cleeve, 1989). Religious beliefs about disabilities generally shaped attitudes about deafness throughout the sixteenth and seventeenth century. In eighteenth century Europe, deaf individuals were forbidden to contact and communicate with one another and were prohibited from attending mass because they could not speak the words of the Eucharist (Lang, 2007).

In addition to religious misgivings about deafness, there is a long-standing, strongly held belief among many hearing people that deaf individuals, by reason of their deafness, have deficits in ability and intellect. It has been claimed that this discriminatory belief originated from Aristotle’s seminal writing, *The History of Animals*, in which he stated that speech and hearing form the conduit of thought and knowledge. Brueggemann (1999) explains the idea that what it means to be human is intimately tied to speech, and this is the cornerstone of the disability perspective of deafness. She summarizes that, “language is human, speech is language; therefore, deaf people are inhuman and deafness is a problem that must be fixed” (11). While it has been claimed that Aristotle did not intend to link intelligence to speech and hearing (Lane, 1984), the Aristotlean legacy has contributed to negative stereotypes of deaf individuals for more than two thousand years (Roots, 1999).

The effect was set in motion with the Justinian Code, a collection of laws and legal interpretations developed under the sponsorship of the Byzantine emperor Justinian I from

529 to 565 of the common era. The Justinian code was the first legal document to distinguish between deaf and deafened people, with a preference for the latter because of their ability to assimilate into the dominant hearing culture through speech and lip reading. This division was based on a deaf individual's ability to function, through spoken language, in hearing society. Deafened people were defined as those who had developed speech skills prior to becoming deaf and had retained enough memory of speech sounds to aid in speechreading. These individuals who could speak but not hear were referred to as "deaf." Individuals who were prelingually deaf and could not integrate into hearing society though speech were called "mutes." Those who were categorized as mutes, as opposed to deaf, were viewed as sub-human and had restricted legal rights.

The Justinian Code II continued to inspire proliferation of similar ideas. By the eighteenth century, European states had well-established laws prohibiting deaf-mutes from marrying, voting, owning or inheriting property and acquiring a formal education. At the time, there were a large number of deaf aristocrats in Europe, possibly due to inbreeding (Silverman, 1970). The denial of the right of primogeniture was a serious consequence for these families. Faced with the prospect of losing their titles and fortunes if their heirs could neither hear nor speak, noble families sought out extreme pseudo-medical measures, including skull-cracking and head-drilling, in attempts to cure deafness (Lane, 1984). When the drastic attempts to unblock the ears did not work, these wealthy families paid enormous sums of money for years of extensive tutoring by professionals who claimed they could teach their deaf children to speak and lip read well enough to function in the hearing world. The goal of such an endeavor was to teach them to function as hearing people in order to gain full legal "human rights."

By the eighteenth century, opposing philosophies of deafness began to emerge. In France, the Abbe de l'Épée began codifying and documenting the rudimentary sign structure of the deaf, which functioned to turn it into a more formalized communication system. In 1754 l'Épée opened the first school for the deaf that used sign language, *Institution Nationale des Sourds-Meuts de Paris*, which translates to the "National Deaf-Dumb Institute of Paris." By documenting the signing system in a sign language dictionary, the Epée gave the deaf a means of contact and communication, he brought them together and gave them a community (Roots, 1999).

Meanwhile in Germany, army officer Samuel Heinecke, began building a reputation as a skilled tutor of deaf children. In 1768 he opened the first oral school for the deaf, based in the methods prescribed by John Amman in his book *Surdus Loquens* ("The Speaking Deaf"). Heinecke, who later dubbed himself the "father of oralism," improved on Amman's methods and wrote various books on oral methods for instructing the deaf (Neisser, 1983).

By the early 19th Century the tradition of using sign language to educate deaf children was taken to America when Laurent Clerc, a deaf student of l'Eppe, agreed to return to America with Thomas Hopkins Gallaudet to become the first teacher of the deaf in the United States (Van Cleve & Crouch, 1989). Gallaudet had met Clerc during a trip to Europe in which he sought tutelage in deaf education at the request of his neighbor who had a deaf daughter. In Europe, Gallaudet met Clerc, who invited him to his school in Paris and taught him sign language. Together, Clerc and Gallaudet returned to America to establish the first school for the deaf, which opened its doors on April 15, 1817 in Hartford, Connecticut (Degering, 1964). The signing system that was used in the school was one that

the deaf children had developed amongst themselves, combined with the formalized system that Clerc brought from Paris. It eventually evolved into what is known today as American Sign Language (ASL).

The German, oral method of educating deaf children by way of the spoken word was introduced to the American education system in the 1840s (Lane, 1989) by Horace Mann. Mann, an American education reformer, traveled to Germany in 1843 to investigate the European education system and was introduced to the oral method of educating deaf children. The oralists, who prohibited the use of “artificial” signed language, forced students to constantly make use of their voices. Mann, who had no experience in deaf education, no knowledge of sign language, and who had never met a deaf person until his visit to Germany, returned to America and challenged the use of sign language to educate deaf children, insisting that the same methods being used in Germany be employed in the American schools for the deaf. Initially, his demands were ignored by heads of American deaf schools, many of whom had also visited Germany’s oral schools and found their methods to be questionable and their success rates unremarkable (Lang).

Eventually, American Sign Language came under attack again by Alexander Graham Bell, who has been described not only as “the hero of the oral method” (Neisser, 1983) but also as “the most feared enemy of the American Deaf” (Van Cleve & Crouch, 1989: 114). His controversial contribution to deaf history began when he moved to Boston to teach “Visible Speech,” an articulation system that was invented by his father for profoundly deaf people; ironically, Bell grew up using a manual communication system with his mother, who was not deaf, but hard-of-hearing.

On November 28, 1871 Bell staged an exhibition to which he invited the most influential educators in Boston to demonstrate the answer for clear, distinct and intelligible speech of all profoundly deaf people. Coming from a long family tradition of performers, Bell was naturally charismatic and had a flair for attracting attention. There is speculation that Bell's proclivity for theatrics led to the huge success of the exhibition and his life-long career promoting oralism. According to Van Cleve & Crouch (1989), Bell presented three very attractive young women who showed off their speech skills by reciting rehearsed sentences, pronouncing foreign words and decoding 'visible speech' symbols. Of the three girls that performed, one had normal speech and hearing until the age of eight, when she contracted scarlet fever, and another was able to hear with amplification (an ear rod). The third girl, the only one who was prelingually, profoundly deaf, recited the Lord's Prayer, which not only tugged at the emotions of the Boston educators, but was perceived as being more clear than it was probably because of the familiarity of the verse (Van Cleve & Crouch).

By the end of the 19th Century there was growing international debate regarding the use of sign language for deaf children. A meeting was called in Paris in 1878, where twenty-seven attendees who called themselves the 'International Congress for the Improvement of the Conditions of Deaf-Mutes' concluded that "preference should be given to the method of articulation and lip reading" as opposed to manual communication (VanCleve & Crouch, 1989). The meeting drew public attention to the conflicting ideologies of oralism and manualism that had been spreading internationally. The controversy called for a larger meeting to be held in two years that would be the most notable event in deaf history: The Milan Congress.

In preparation for the congress, French oralists submitted a report to the government stating that sign language lacked grammar and its use prevented deaf students from learning French. They succeeded in persuading the minister of the interior to order all schools that were supported by the French government to instruct deaf children in oral French only. Similarly in Italy, Catholic clerics, who completely dominated deaf education and were zealots for oral instruction of deaf children, organized the first Italian Congress of Educators for the Deaf in an effort to have sign language teaching eliminated from Italy's schools for the deaf (Van Cleve & Crouch, 1989).

In America, however, American Sign Language and American deaf culture were flourishing and large residential deaf schools were being opened throughout the country. Deaf people were increasingly becoming active members of mainstream society, contributing through a variety of professional roles. A number of deaf intellectuals founded the National Association of the Deaf (NAD). In August of 1880 they held their first meeting in Cincinnati, Ohio with representatives from twenty-two states. One of the topics on the agenda was the growing assault on the "traditional methods of teaching deaf children." According to the association, there was growing concern within the deaf community that Alexander Graham Bell, hearing parents, and an increasing number of hearing teachers had started to attack Sign Language and residential deaf schools, "claiming that they had pernicious effects on deaf people and American society" (Van Cleve & Crouch, 1989: 93).

On September 6, 1880, 164 delegates from Europe and the United States attended the opening session of the International Conference of Deaf Educators in Milan, Italy; 143 of these delegates were from France and Italy. The five American attendees, including Edward Minor Gallaudet, his brother Thomas Gallaudet, Isaac Lewis Peet, Charles A. Stoddard and

James Denison, the only deaf delegate to the Milan Conference, all held the strong belief that sign language should be used as the language of instruction for deaf children. The Americans, who were vastly outnumbered by the French and Italians, were unaware of the full intent of the conference directors. In his memoir of the event, Edward Minor Gallaudet wrote that “the issue of methods engrossed the time of the Convention to the exclusion of almost everything else.” (Gallaudet, 1881).

Nine speakers at the congress spoke on behalf of oral methods for educating the deaf; three speakers (Edward Minor Gallaudet, Thomas Gallaudet and Richard Elliot, a teacher from England) spoke in favor of the manual philosophy of education. The five-day-long meeting concluded with a two-day long address by the president of the conference, Abbe Guilio Tarra, in which he stated the impossibility of conveying the idea of Divine Being through sign, claiming that only gross, material and untrue ideas could be expressed. He further condemned sign language “in its unsuitableness, not to say the injuriousness, of the signs as a means for conveying moral and intellectual ideas of an elevated kind.” (Gallaudet, 1881). Abbe Tara concluded the conference by proposing the following motion, which passed with only six opposing votes, those of the five Americans and Richard Elliot:

The convention, considering the incontestable superiority of speech over signs, (1) for restoring deaf-mutes to social life (2) for giving them greater facility of language, declares that the method of articulation should have preference over signs in the instruction of the deaf and dumb. (Gallaudet, 1881)

The news of the virtually unanimous decision of the congress in favor of oral teaching spread quickly. According to Van Cleve and Crouch (1989), European news

reporters, who had no knowledge of deafness, wrote about the successful demonstrations and convincing testimony that they had witnessed at the conference, calling the oral method the “miracle of modern pedagogy.” The triumph of oralism as depicted by the newspaper reporters reinforced the idea internationally that sign language was a substandard form of communication and deaf children should be educated using only spoken language.

For a long time deaf individuals internalized the ideology that ASL was not a full-fledged language (Schein, 1989). It wasn't until 1965 that ASL officially received linguistic recognition when William Stokoe, a professor of literature at Gallaudet University, became the first linguist to describe the complex structure of the language (see Stokoe, 1965). In his book *Sign Language Structure*, Stokoe described the grammatical system of ASL as independent from English and as powerful as any spoken language. This was the first time in history that ASL had been credited for being a thriving natural language in its own right, rather than a second-rate version English performed on the hands. ASL is now widely accepted as a natural language, and the natural language for the deaf in the United States. Subsequent linguistic and psychosocial studies have further fostered an understanding of the language, and with it the understanding that if ASL is a real language, then a real culture nurtures and is nurtured by it. American Sign Language has moved beyond the confines of deaf schools and is now regularly offered as a second language to hearing students in high schools and universities. According to Padden and Humphries (2005), it is now the second most popularly enrolled language, after Spanish, on many university campuses (2005).

Stigma

Deafness, when viewed through the medical model, is a deficit in the ability to hear, which is considered desirable. When a person possesses a quality that is different and less desired than those of the dominant culture, he or she is reduced in our minds from a whole person and usual person to a tainted, discounted one. Such an attribute is *stigma*. The word 'stigma' originated in the Greek language to describe signs that indicate something out of the ordinary or unfavorable about a person (Goffman, 1963). In ancient Greece, stigma was a mark that was burnt or cut into the skin to symbolize the threat of danger of the stigmatized person.

Most theory and research on stigmatization can be traced to Goffman (1963). Goffman provided a rich foundation for the definition and fundamental issues to be considered when addressing stigma as a social and cultural phenomenon. According to Goffman, stigmatization is a process of global devaluation of an individual who possess an attribute that is deeply discrediting. It is a practice in which social meaning is attached to behaviors or characteristics of stigmatized individuals.

Goffman (1963) argued that stigmatization is best explained as a deviance from the norm. He developed a deviance theory through analysis of individuals who were marginalized from society because of "discrediting" differences, which he labeled as *stigma*. The word stigma, in Goffman's terms, refers to any persistent trait of an individual or group that evokes negative or punitive response. According to Goffman, stigma arises during social interaction when an individual's actual social identity does not meet society's normative expectation of the attributes an individual should have. Thus, the individual's

social identity is spoiled and he or she is assumed to be incapable of fulfilling the role or requirements of social interaction.

Goffman describes three types of stigma: physical deformities, character blemishes, and tribal stigma, relating to race or religion. He particularly focused his work on people with mental and physical disabilities, including deafness. Goffman showed that, by definition, a stigmatized person is viewed by society as not fully human. On this assumption, we exercise varieties of discrimination, through which we effectively reduce the stigmatized person's life chances. However, Goffman believes that because disability is socially constructed, it is therefore changeable.

This type of social exclusion is characteristic of human cultures around the world and throughout history (Ablon, 1981). Goffman (1963) explains that those who are "normals" (i.e. those who do not have a stigmatized condition) engage in discriminatory activities that are based their beliefs that stigmatized people are "not quite human." According to Goffman, normals construct a belief system that enables them to rationalize that stigmatized people are dangerous. Furthermore, people without stigmatized conditions generalize characteristics from a particular disability to a variety of disabilities (Strauss et al., 1984). This theory contributes to the explanation as to why deaf individuals are often seen as mentally defective. The idea that mental deficits are mapped onto deafness is further highlighted in a dissertation written by the director of the Guyot Institute for deaf students, in which Guyot (1824; as cited in Tellings & Tijsseling, 2005) asserted that deaf individuals could not be held completely accountable for themselves, as they were limited in their capacity because of their inability to speak.

Derogatory labels have also been used to reinforce belief systems that stigmatized people are inferior. As an example, Harlan Lane (1992), a hearing psychologist, analyzed literature used to develop courses on the psychology of deafness. He found that deaf people were described as asocial, clannish, disobedient, irresponsible, aggressive, impulsive, depressive, emotionally disturbed, paranoid and unfeeling. This undeservedly negative imagery of deaf people supports Goffman's theory that stigmatized people are constructed as societal perils by normals, seeking to morally justify their otherwise irrational fear of people with differences, including deafness.

Goffman's work has not escaped criticism; however, because the criticisms that have been put forth fail to challenge the fundamental validity of his work (Susman, 1994), they will not be discussed here. For a concise summary of critiques, see Frank (1988).

Since Goffman's seminal work, three other perspectives have been offered. Elliot, Ziegler, Atلمان, and Scott (1982) offered an alternative theory on stigma that defines it as a form of deviance that leads others to judge individuals as illegitimate for participation in interaction. According to Elliot et al., people who are believed to lack the abilities or skills to carry on an interaction and to behave in consistent or predictable ways are a threat to others and to the interaction itself. Moreover, according to Elliot, et al., once a person has been deemed illegitimate for participation in interaction, he or she is beyond protection of social norms and as such may be excluded or ignored altogether.

Jones, Farina, Markus, Miller, and Scott (1984) use the term 'mark' to describe conditions that are deviant from the prototypical norm and that are identified by society as flawed or spoiled. Jones et al. proposed that a person is stigmatized when a mark is linked to dispositions that discredit the bearer of the mark. Thus, a mark of deviance initiates a

process in which people interpret attributes of a person on the basis of the mark and respond to stigmatized individuals in terms of their stigma at the expense of the individual.

In their work, Jones et al. (1984) identified six dimensions of stigma and addressed the functions of stigma on interpersonal roles of the stigmatized. The first and most critical dimension of stigma is concealability. According to Jones, et al., the degree to which a condition is hidden or visible is a critical dimension of stigmatization, in that, the more visible the stigmatizing condition, the greater the negative consequence. If the nonstigmatized person cannot detect the stigmatized condition, he or she may treat the person no differently than anybody else (Jones, et al, 1984).

Other dimensions of stigma, as identified by Jones et al., that affect the degree to which a person is stigmatized include the extent to which the condition changes over time; the strain or disruptiveness the stigma places on the interpersonal relationship; aesthetic quality of the stigma, or the extent to which a condition affects the appearances of the person; cause of stigma; and peril, or danger associated with the stigmatized condition.

Crocker, Major, and Steele (1998) offer yet another perspective on stigma. In their terms, stigma occurs when an individual is believed to possess an attribute or feature that conveys a devalued social identity within a social context. This identity is then socially constructed by defining who belongs to a particular social group and what characteristics will lead to a devalued social identity in a particular social context. Like Goffman, Crocker et al. believe that stigma is at its essence a “devaluing social identity” (p. 505). They further propose that stigma is not located within the individual but occurs within the social context that defines an attribute as devalued. In their point of view, stigma arises from one’s membership in a category that is negatively valued in a specific situation.

In each of the proposed conceptualizations, stigmatization occurs when a person is negatively evaluated. It is thought of in terms of discrediting attributes, perceived illegitimacy, or a devalued element of social life. Deafness, being an invisible disability, is only noticeable when one attempts to communicate. Otherwise, there are no visible indicators about what to expect when approaching a deaf person. However, once the disability is known, the impact of it may be highlighted and perceived as interrupting social interaction (Susman, 1981).

According to Goffman (1963) there are two descriptions for the ways that an individual can experience stigma: discredited and discreditable. Goffman explains that a discredited individual is one who shows visible signs of being different and is thus stigmatized and discredited by others. When people feel discredited it can lead to stressful social interactions. According to Dudley (1983) people handle feelings associated with being discredited through disregarding painful occurrences, isolating themselves into subgroups in order to normalize their attributes, looking for secondary benefits, or resisting and challenging that status quo.

When a condition is invisible to others, the individual is discreditable, but not yet discredited. A dilemma for people with discreditable conditions is managing the information that could lead to being discredited. According to Goffman (1963) there are options as to whether or not to disclose a condition to others. If people decide to tell others about their condition they risk the threat of being stigmatized and therefore discredited. For that reason, many people with invisible disabilities decide not to divulge the information and to attempt to pass for “normal.”

Passing is the deliberate concealment of a condition, with the goal being to become part of the prototypical normal group. According to Goffman (1963) several strategies for passing can be used, including obliterating signs associated with the conditions, attributing any signs of the condition to less stigmatizing conditions, and compartmentalizing the world into the large segment that knows nothing about the condition and a small support group of people who are confidentially notified. However, passing can create a stressful environment for the could-be stigmatized individual, who fears being found out.

The managing of information becomes critical to people with invisible conditions, such as hearing loss. When a person decides not to disclose it is likely based on their belief that the responses of others will be negative, and the person who does not disclose therefore risks rejection and stigmatization. Because of the stigma associated with deafness, late deafened adults may put off disclosing their hearing loss until they are able to let go of their negative interpretation of deafness and adopt a more positive perception of deafness.

According to Dudley (1983), stigmatized individuals often seek subgroups that normalize their attributes. There are two primary support groups available to late deafened adults. Both have chapters throughout the country and hold annual conventions. While both groups are open to all deafened individuals, Hearing Loss Association of America (HLAA) members tend value assistive listening devices (e.g., hearing aids, cochlear implants, FM systems, etc.) and rely on oral communication; a larger proportion of members of the Association of Late Deafened Adults (ALDA) use manual communication, but stay true to their communication philosophy of “whatever works.”

The Deaf Community

The complexity of the deaf community begins with the very definition or meaning of deafness. There are two primary perspectives of deafness in the West. The dominant perspective is grounded in the view that deafness is essentially a medical condition, characterized by auditory deficits. This perspective, which has been labeled the “pathological” or “medical” view of deafness, assumes that deafness entails “a world that is silent, tragic, and empty, devoid of the experience of the stimulating and wonderful sounds of nature” (Baker, 1999, p. 126). From this perspective, deafness is an ailment that necessitates remediation; thus the pathological view of deafness is associated with oralism, lip-reading, hearing aids, cochlear implants, and other technologies that maximize whatever residual hearing a deaf individual may possess. The pathological view of deafness is premised on the idea that deaf people are not only different from hearing people, but that they are, at least physiologically, inferior to hearing people (Bienvenu, 1991). This view of deafness inevitably leads to efforts to try to help the deaf individual to become as much like a hearing person as possible and to assimilate into hearing society. As previously noted, based on this perspective, hearing people have controlled deaf people’s access to education, property, and right to self-determination and have historically favored those who were able to assimilate into the hearing world.

The alternative perspective for understanding deafness is the “sociocultural” model, which describes deafness as a difference, rather than a disability. The sociocultural model came about in the 1980’s after Stokoe, a hearing literature professor, and his colleagues published a decade of research on “The Signs of Language,” which described the elements of grammar of the sign language. It was the first time that what was then called “the sign

language” was recognized as having attributes common to all natural languages. With budding recognition of ASL as a language, linguists and anthropologists set out to describe the linguistic minority group of deaf sign language users as being bound by characteristics common to other cultural communities, emphasizing in particular that deaf people shared linguistic and historical backgrounds. (e.g. see Baker & Battison, 1980; Lane, 1984; Neisser, 1983; Padden and Humphries, 1988; Schlein, 1989; Stevens, 1980; Stokoe, 1980; Wilcox, 1989, etc.). For the first time, information about the language and culture of deaf people, who had previously been a secret group, was becoming public, and the signing community began to view their world in new ways (Padden and Humphries, 2005). While at first the signing deaf community was skeptical about hearing people entering their world, the new knowledge ultimately led to a sense of pride and validation that “deaf people are normal people, who lead normal lives, have their own language, ASL, and do not need extra assistance in order to survive” (Bienvenu, 1991, p. 3).

More recently, researchers have described deaf signers as not only a minority culture, but as an ethnic group (Baker, 1999; Johnson & Erting, 1989; Lane, 2011). Lane argues that “ethnic group” is an apt conceptualization for the linguistic minority of ASL signers because they share culturally cohesive properties similar to other ethnic groups, including a common language, historical knowledge, group solidarity (or bonding to one’s kind), distinct cultural rules and values, a network of in-group social institutions, language and visual arts, ethnic territory, kinship, ancestry, and socialization practices. Lane surveys literature describing the most salient features of the deaf community, which have been advanced by various researchers in the 70’s, 80’s and early 90’s (.e.g., Vickery Van Cleve, Charlotte Baker-Shenk, Arden Neisser, John, S. Schuchman, Susan Rutherford, etc.) to

support the claim that the signing deaf community is an ethnicity. His points will be briefly highlighted here.

1. Language

Language is the central symbol of ethnic groups and an important means of sustaining ethnic identity, purveying cultural norms and values, and linking past to present. American Sign Language unites deaf people as other languages unite other ethnic groups (Lane, et al., 2011). It is not only used for communication but also to convey culture, traditions, rituals, norms, values and language arts. As such, competence in ASL is at the core of deaf identity in the United States (Fischer and van der Hulst, 2003; Valli and Lucas, 1995). In fact, competence in American Sign Language is unarguably the single most important element of American deaf culture (Baker & Cokely, 1980; Erting, 1978; Kannapell, 1993; Padden, 1980; Valli & Lucas, 1995).

A natural language, American Sign Language has many dialects and registers. However, signed versions of English that use signs to convey English word order and parts of English grammar not found in ASL are not natural languages, and are viewed negatively by culturally deaf people. Only ASL is valued by the culturally deaf signers, and any form of manually coded English is rejected as an unwelcome effort to impose the structure of spoken language onto ASL (Lucas, 1989). Pidgin Signed English⁷ is therefore considered appropriate only for communicating with hearing individuals.

The deaf community's attitude toward pidginization of their language is likely due to their strong emphasis on preserving sign language and resistance to its replacement by spoken English. As is the case with other minority languages, ASL has a long history of

⁷ Pidgin Signed English (PSE) is a form of sign language that is a combination of ASL and English.

struggling for survival. Historically, the use of dominant languages has routinely been required by law, a decree carried out through schools, which require the strict use of the dominant language, and punish children who use the minority language (Lane, 2011). In fact, by 1920, four-fifths of all American deaf children were forbidden from using sign language and were taught spoken English, using spoken English itself, which they could not hear, while the rest of their education fell by the wayside (Bayton, 1996).

2. History

An awareness of a long shared history has been defined as a core element of ethnicity (Lane et al., 2011). Members of the deaf community have a strong historical tradition, and this awareness has been passed from generation to generation largely through “oral” (i.e., signed) narratives. Not having a written language, members of the ASL community have a strong historical tradition that has been passed from generation to generation largely through stories and legends (Rutherford, 1993; 1989). Their stories typically include heroes who fought for the rights of the deaf community and the preservation of sign language, people like Laurent Clerc and Charles-Michel de l’Épée; and villains, such as Alexander Graham Bell, who advocated for replacing sign language with oral language, and possibly urged the sterilization of deaf people (Greenwald, 2007).

According to Lane (2011), the history of an ethnic group is generally not judged by its accuracy, but instead by how well it organizes experiences in light of cultural values and by its emotive powers. For example, the American deaf community has appropriated the 1880 Milan Congress for ethnic mobilization. It has come to stand for more than just the single act of congress, but instead it stands for the overall imbalance of power between deaf people and the dominant hearing culture.

As a celebration of their history, each year on December 10, Thomas Hopkins Gallaudet's birthday, deaf schools across the country perform the unabridged legend of the road leading to the establishment of the deaf world as it began in America. Starting with the plight of Alice Cogswell, a deaf girl who, without sign, lived in isolation among hearing people, and continuing through legends of Abbé de l'Épée and Thomas Hopkins Gallaudet, the story culminates with the opening of the Hartford School in Connecticut in 1817, which brought isolated groups of children together into a larger community and led to the emergence of American Sign Language.

3. Group solidarity

Members of the deaf world feel a strong identification and loyalty to the group, as do members of other ethnic groups (Lane, et al., 2011). As Sigmund Freud explained, "What bound me to Jewry was...neither faith nor traditional pride [but] many obscure emotional forces, which were more powerful the less they could be expressed in words...[and also] a clear consciousness of inner identity." (Verkuyten, 1926, p. 41).

Perception of belonging to a group creates solidarity within that group and devalues other groups. In fact, it has been suggested that ethnic loyalty requires an out-group (Tajfel, 1982). According to Lane et al. (2011), it is the bond of protecting their language and culture from hearing people that many deaf people share. In fact, many deaf stories and legends promote loyalty and caution deaf people against forgetting their roots should they excel in the hearing society. Those who use oral language and fail to preserve ties with the deaf community are disparaged for not having deaf pride (Mindess, 2006).

Furthermore, as with various other ethnic groups, many culturally deaf people tend to socialize and marry within their own community. In 1980, Reagan reported an

estimated eighty-six to ninety percent rate of in-group marriage in the deaf community.

Lane et al. reported similar finding in 2011, with nine out of ten deaf people marrying other deaf people. According to Lane et al., when a deaf person marries a hearing person, the hearing spouse almost always has a deaf parent or is otherwise familiar with deaf language and culture.

4. Cultural rules and values

The patrimony that one generation in an ethnic group passes to the next, in addition to language, is cultural rules and values. Like all groups, the signing deaf community has rules for such universal functions as relating to the group, gaining status, managing social interactions, managing information, making decisions that affect the group and so forth (Lane, 2011). Although Lane highlights numerous examples of cultural tradition that add meaning to ethnic member's daily lives and contribute to defining their identity, only a small sample will be provided here.

One example that is an important cultural event in deaf culture is the naming ritual. When deaf children from hearing homes arrive at deaf schools, they generally don't have a sign language name (or 'sign name'). As their ASL and acculturation into deaf culture advances, they are given a sign name by a deaf individual. Sign names are generally the handshape of the first letter of the person's first name at a location on the body that is significant to that person (e.g. at the location of a dimple). Receiving a sign name is considered a right of passage into the deaf world (Lane, 2011). Hearing people who know ASL and are involved in the deaf community can also receive sign names from deaf peers.

Another cultural tradition in the deaf community, albeit less explicit, is the pooling of resources. When a deaf person incurs a debt to another person, by means of work,

favors, or sharing information, there is group reciprocity. Thus, the favor will be reciprocated, but not necessarily by the same person who benefited. For example, if deaf person A helps deaf person B move, then deaf person C will fix A's car. A debt occurred to one deaf person can be paid to another. According to Lane, without keeping track, deaf people have a keen sense of who contributes a lot and who contributes too little.

5. Network of in-group institutions

In all ethnic groups, some institutions die out while others rise and flourish. This is particularly evident in the deaf world. For centuries, deaf children went to residential schools, where they acquired language, cultural identity, values, and knowledge that was passed down from one deaf generation to the next (Lane, et al., 2011). In recent decades, however, enrollments at residential schools have significantly decreased due to the influence of the mainstreaming movement in special education. Thus, the deaf residential school is an example of an institution where vitality has diminished. Humphries and Padden point out that this is not the case with all residential schools. Some have reinvented themselves (i.e., in name and architecture) and continue to attract growing numbers of students from families in the deaf community (2005).

Deaf clubs are another social institution that have played an important role in shaping deaf people's lives, but are now for the most part gone, having been replaced by other social practices (Lane, et al., 2011; Padden & Humphries, 2005). Established to provide a place for deaf laborers to socialize at the end of a hard day, deaf clubs were found throughout the country and, at one time, many boasted membership in the hundreds. The clubs offered events from gambling to beauty pageants. At their height, deaf clubs had

athletic teams that participated under the American Athletic Association of the Deaf (since replaced by the USA Deaf Sports Federation and its twenty-four affiliates).

Most importantly, deaf clubs served as a place to network information about jobs and social life. Deaf clubs were built by deaf people who were employed in factories or who had similar industrial occupations (Padden & Humphries, 2005). Padden and Humphries suggest that the demise of deaf clubs was likely related to changes in the deaf labor force and the growth of the deaf middle class. The new professional class of deaf people, in asserting their middle-class ideals and ambitions, have drifted away from deaf clubs, which they consider an anachronism from the days when deaf people could only do certain types of jobs (Padden and Humphries).

Today, there is a new landscape of deaf social service agencies that provide job training, advocate for civil rights, and provide peer counseling and workshops on medical and social topics. Most states have an association for the deaf with political agendas that are gathered under the umbrella of the National Association for the Deaf (Lane, et al., 2011). There are also professional associations for deaf psychologists, sign language teachers, rehabilitation counselors, academics and teachers of the deaf (Padden and Humphries, 2005).

6. The arts

The arts of an ethnic group serve to entertain, express values and traditions, and reinforce ethnic identity and solidarity. In the case of the deaf community, deaf signers have a rich literary tradition that includes history, stories, tall tales, legends, fables, anecdotes, poetry, plays, humor, naming rituals and sign play (Lane, et al., 2011). Despite various attempts to codify it, American Sign Language is an unwritten language, so deaf

literature such as storytelling and humor carries much cultural information that, in cultures with written languages, would be carried down through generations in script. Deaf story tellers transmit deaf world's heritage and accumulated wisdom. Padden and Humphries (1988) suggested that historical accuracy is not the goal of ASL stories but rather, the legends are intended to symbolize the transition from a world in which deaf people live in isolation to one in which they participate in a cultural, social, and linguistic group.

Professional deaf theater, rich in sign language and dialogue, was first introduced in American mainstream hearing society in 1967 (Padden and Humphries, 2005). Today there are numerous deaf theater groups, including the National Theatre for the Deaf, which is the oldest, most continually touring professional deaf theater group. Deaf West Theatre in Los Angeles is a regional theater that has presented national and international productions of several original ASL plays as well as ASL adaptations of plays written in English, and plays performed in both spoken English and ASL.

Deaf artists have played an important role in creating awareness of deaf culture and the lives of deaf people, beginning in the mid-eighteenth century. Lithographs, oil paintings, watercolors, acrylics, pen-and-ink drawings, sculptures, photography and film are examples of medium that have been used to capture the experiences of deaf people (Lane, et al., 2011). According to Lane, recurrent themes tend to be the renunciations of sign language at the Milan Congress in 1880, and the experiences of American deaf schoolchildren brought up under the regime of using only oral language. Many pieces of art also celebrate sign language and deaf culture. The recent studies of sign language and deaf culture have fostered a particularly prolific art period in the deaf community. Examples of

such art are often to be found at Deaf congresses and occasionally in galleries and museums (Lane).

7. Ethnic territory

Like many other ethnic groups, the deaf world has no single homeland, but instead a mythologized homeland that provides an important source of identity. Members of the signing deaf community often express the enduring vision of “a land of our own,” which is conveyed in folktales, writings, theater, and political discussions (Lane, et al., 2011).

Deaf graduates of residential schools have a strong sense of place associated to their school. In fact, deaf people, when being introduced for the first time, routinely state where they are “from,” meaning which residential school they attended, not where they were born. This tradition, according to Padden and Humphries (2005), continues to be carried out by deaf people who attend modern schools for the deaf. Ties to residential schools can be so strong that vacations are often planned around visiting them and many graduates chose to live in close proximity to their school after graduation (Lane, et al., 2011).

According to Lane et al. (2011) historic sites and monuments also evoke a sense of place for ethnic groups. For the deaf community, examples of such sites include the campus of Gallaudet University, with its statues of Thomas Gallaudet and Alice Cogswell; the first school for the deaf, founded by Gallaudet and Clerc in Hartford, Connecticut; the graveyard on Martha’s Vineyard, where many deaf people lived in the 1800’s; and the birthplace of Laurent Clerc in La Balme-les-Grottes.

8. Kinship

Practices related to kinship in the west are largely based on blood relations. However, in other societies, kinship depends on socialization rather than shared ancestry. Likewise, deaf kinship is grounded not on the genealogical facts but on shared language, culture and physical traits (Lane, et al., 2011). According to Lane, kinship is an expression of cohesion between members of the ethnic group based on shared properties such as physical characteristics and cultural practices and shared language, “the kind of solidarity owed to one’s family but more diffuse” (p. 29). Thus, rather than being biologically accurate, kinship is culturally constructed and nourished by a shared language and culture. As such, the deaf world can serve as a surrogate family for deaf people, 95% of whom have hearing parents, as well as promoting a positive identity and a language model.

9. Ancestry

As opposed to other ethnic groups, deafness is not necessarily passed from parents to children. In fact, only about five percent of deaf babies are born to deaf parents and thus ensured automatic membership into deaf culture. Most deaf people who join the signing deaf community do so through a process of enculturation, typically in childhood.

However, in accordance with the Western definition of ancestry requiring a connection by blood of successive generations, Lane sites the 2007-2008 Gallaudet University Annual Survey of Deaf and Hard of Hearing Children as evidence of shared heredity in the deaf world (2011). According to the survey, about one fourth of children are deaf due to disease, injury or maternal illness, and therefore do not have deaf ancestry by blood. Another fourth are known to be hereditarily deaf because they had deaf parents or siblings. The remaining half were described as “other – or deaf for unknown reasons.”

According to Lane, et. al. there are three reason that most of those children were can be assumed to be deaf as a result of hereditary. The first reason is that if they had been deaf from illness or injury, they would likely have known. Second, the survey did not ask about deaf relatives or ancestors. Thirdly, hereditarily deaf children can have no deaf relatives or ancestors and deafness can skip generations. Thus, according to Lane et al., three fourths of all deaf children that use ASL are deaf due to hereditary. The practice of deaf founding families to unite with others through intermarriage tended to proliferate the deaf trait, expressed or unexpressed. Lane et al. argue, “‘deaf-world’ as an umbrella term, based on shared language and culture, gathers numerous distinct descent groups, each with its own common ancestor” (p. 32).

10. Socialization

Deaf culture teachers and conveys the values, behaviors, and roles of both its members and others, including hearing society, and acts as a socializing agent that teaches the wisdom of the group, as well as how to understand and cope with the hearing world (Padden & Humphries, 2005; Lane et al., 2011). According to Lane, it is during their initial period of socialization that deaf children learn a positive deaf identity. For the deaf child with hearing parents, ethnicity is normally hampered by a language barrier; therefore, deaf socialization is often proxy socialization, conducted by peers or deaf adults to whom the child is not related. Otherwise, deaf socialization may not occur until the deaf individual is able to mingle in the deaf world.

Socialization in formal and informal organizations effectively maintains the cohesiveness of the Deaf community. Historically, deaf clubs and residential schools served as socializing institutions in which deaf people could learn to be deaf (Padden and

Humphries, 2005). Today, as previously discussed, formal organizations for deaf people include state and national associations for the deaf and deaf schools and education programs across the country.

The socio-cultural and ethnic models of deafness that have been put forth here do not relate to all deaf people. There have, historically, been strict standards that govern the criteria of membership in the deaf community, which paradoxically have little to do with hearing levels. In 1980, Baker and Cokely developed a typology of deaf cultural membership, which identifies the measurements of membership as attitudinal deafness. Attitudinal deafness, or 'attitude,' for short, diminishes the importance of audiological deafness as a prerequisite for acceptance. The four elements or "spheres" of typology are: Audiological (extent of hearing loss), Political (holding of positions of responsibility within the Deaf community), Linguistic (mastery of Sign Language), and Social (participation in the social life and events of the local deaf community). This model rejects the pathological view of deafness in favor of a difference model. One of the central features of this model is the term "attitude," whereby a person might satisfy the criteria for all four "spheres" but not demonstrate the "right" attitude toward deaf people, their language, culture, and minority status needed to be accepted into the community. Such a person is said to lack attitudinal deafness. According to Erting (1994) "this way of approaching deafness does not ignore the physical disability deafness imposes; rather it seeks to understand the way it canalizes and constrains social and cultural behavior" (p. 33).

In 1996, Glickman (p. 127) further differentiated between individuals who were pathologically deaf and those who were socioculturally deaf by identifying the following six criteria as the basic values of the culturally deaf community:

1. Respect for ASL and the belief that deaf children must have full access to it from the beginning of their lives.
2. A social-cultural rather than medical-pathological understanding of deafness.
3. Respect for the deaf community and culture and for the idea of deaf people affiliating with their own.
4. Healthy paranoia toward hearing people and resentment of hearing paternalism.
5. A devaluation of speech, lip reading, and the use of hearing aids.
6. A basic belief in the rights and abilities of deaf people to control their own lives.

According to Glickman's model, deaf individuals who rely on spoken language and "think hearing"⁸ cannot be considered members of deaf culture, whereas hearing individuals who possess native-like signing skills and advocate for the rights of the deaf community can be accepted as members. In other words, physical deafness alone does not guarantee membership. Based on Glickman's parameters, researchers have suggested that deafened individuals have neither the signing skills nor the political affiliation to be granted membership into the exclusive group, as deafness is not ingrained into the core identity of people who became deaf as adults (David & Trehub, 1989).

In order to differentiate individuals who identify as culturally deaf from those individuals who have hearing loss but do not reference themselves with the cultural group,

⁸ "Think Hearing" is an ASL term used to denigrate deaf people who "think like hearing people" and/or behave in a subservient manner to hearing people. It is roughly equivalent to the term "Uncle Tom" that is used among black people.

James Woodward (1982) proposed the convention of using “Deaf” to describe the cultural practices within a group; and lower case “deaf” to refer to the condition of deafness. In other words, lower-case-“d”, has historically been designated as a medical label to refer to anyone who lacks the ability to hear, while capital “D” has been used as a sociological identifier referring to only those who are strongly tied to the deaf community.

However, according to Padden and Humphries (2005), the practices of the deaf community have been changing since they were first described in the 1980’s. And while it was once relatively easy to classify “deaf” and “Deaf” individuals, because “Deaf” people were those who attended schools for the deaf and went to deaf clubs, now, decades later, with deaf clubs nearly nonexistent and with less than 27 percent of all deaf and hard of hearing children attending schools for the deaf, the distinction is not as easy to make. According the Padden and Humphries, the deaf community is now more fluid than ever (2005).

Furthermore, as is the case with all cultural and ethnic groups, the deaf community is continuously evolving so that the criteria described by Baker and Cokely (1980) and Glickman (1992) as defining membership in the cultural deaf community may no longer be accurate. As an example, adult members of the deaf community who once adamantly opposed cochlear implants and likened them to cultural genocide (Christiansen & Leigh, 2002), are now seeking out this technology in order to speak English and better interact with hearing speakers of English, while at the same time maintaining and valuing ASL and their membership in the deaf community (Padden and Humphries, 2005).

Furthermore, as previously discussed, the majority of deaf people learn to become deaf through the practices of socialization. While this often happens in early childhood, that

is not always the case. Tom Humphries, for example, a leading scholar of deaf culture, was born deaf but grew up around hearing people, with no contact with deaf people and with no knowledge of sign language (Padden & Humphries, 2005). It was not until he left his hometown to attend Gallaudet University that he was first introduced to deaf culture and sign language. For decades, Humphries has worked for the collective interest of the deaf community and it is doubtful that anyone would deny his membership in the deaf community. Although Dr. Humphries was born deaf, he was not acculturated into the deaf community until he became an adult. It therefore seems feasible that a late deafened adult who uses sign language and upholds the core values of the deaf community could be considered culturally deaf.

While this study acknowledges that the deaf community is not a homogenous one, it also recognizes that there is no single characteristic that is shared by all members of the community. The deaf community, as defined by this author, includes people who become deaf at various stages in their life, people who learn ASL at various stages in their life, and people with varying degrees of hearing loss. Therefore, this study will not follow the conventions of using 'deaf' and 'Deaf,' as the distinction is becoming increasingly blurred. Instead, this study posits that the deaf community is more diverse than has been previously recognized.

Late Deafened Adults

The World Health Organization reports hearing loss as one of the most widespread disabilities, with more than 120 million people in the world having disabling hearing impairments (WHO, 1999). In the United States, more than twenty-eight million people

have some form of hearing loss that can affect both the volume and clarity of sound (NIDCD, 1996).

Moreover, the National Census of the Deaf from 1972, the most commonly cited source describing demographics of hearing loss, reports that more than three quarters of the United States deaf population are late deafened adults. Late deafened adults are individuals who have acquired a severe or profound hearing loss in adulthood. The term *late deafened adults* has been defined qualitatively as, “those individuals who at one time possessed enough hearing to learn language and oral communication through hearing, but who suffer with a loss of hearing so severe that audition is useless for the purposes of receiving oral communication” (Krug, 1969: 99). This study bases its understanding of late deafened adults on Krug’s qualitative definition.

Generally, when people in the dominant culture think of deafened people, they tend to conjures up images of their elderly hard-of-hearing grandmother or grandfather. However, while many people become hard-of-hearing in their old age due to overexposure to noise and other causes, there is a big difference between being deaf and being hard-of-hearing. This misconception implies that deafness is an extreme case of being hard-of-hearing and that deafened individuals, having first been hard-of-hearing, have learned coping techniques by the time they become deaf. In fact, the majority of deafened people go quickly from hearing to deaf with little preparation (Woodcock, 1996). Humphrey, Herbst, & Faurqui (1981) further explain that becoming deafened between the ages 30 and 60 and becoming deaf after the age of 65 is a significant different experience. This difference primarily concerns the level of expectance of “normal running down” of the body

of the latter group compared to an expectation of full functioning in the vocational-age individuals (29).

There are approximately four thousand new instances of sudden sensorineural hearing loss diagnosed in the United States every year (ASHA, 2002a) and according to the National Institute of Deafness and other Communication Disorders, it occurs most frequent in individuals who are between the ages of thirty and sixty (NIDCD, 2000). Sudden sensorineural hearing loss is often the result of genetic predisposition (ASHA, 200a; Luey, 1980, 1995); however according to the National Institute on Deafness and Other Communication Disorders (NIDCD, 2000), only ten to fifteen percent of postlingually deafened adults are aware of the cause of their hearing loss.

A survey of deafened adults conducted at an Association for Late Deafened Adults conference indicated that 41.5% of respondents experienced a progressive hearing loss, 40.5% incurred a medical loss from a specific illness or medication, 12.8% suffered a surgical loss, and 5.2% lost their hearing as a result of a traumatic injury (Boone & Scherich, 1995). A similar survey of late deafened adults in the United Kingdom reported causes of loss as follows: 13.4% congenital, 57.7% medical, 3.9% accidents, and 25% of unknown origin (Heath, 1987).

Medical issues, such as meningitis, can occur from side effects of medications, Meniere's syndrome, and certain virus. Medically induced deafness can occur instantaneously or progressively over a decade and may result in some possible residual hearing. Individuals can also become deaf secondary to surgical issues, specifically after developing tumors on the auditory nerve, a disease called neurofibromatosis type II. The removal of the NF2 tumors on both auditory nerves causes instant and absolute deafness.

Traumatic injury and hereditary genetic issues can also cause deafness. Researchers have suggested that the onset, intensity, and rapidity of hearing loss in late deafened adults are important factors in understanding the psychology of hearing loss (Herth, 1998; Leigh, Corbett, Gutman & Morene, 1996).

Individuals who lose their hearing as adults, after having been socialized as “hearing” and developing a sense of identity as a hearing person, face particular challenges that individuals who are born deaf do not encounter. In fact, researchers suggest that postlingual deafness, both progressive and sudden, is much more traumatic for an individual than is prelingual deafness (David & Trehub, 1989; De Graffe & Bijl, 2002).

Interference with communication is arguably the most encumbering and damaging consequence of acquired deafness because of hearing loss. As stated by Stone (1987), hearing loss “strikes at the very essence of being human because it hinders communication with others.” In fact, communication forms the foundation of all social interaction; it is vital for sharing information, establishing and maintaining personal relationships and directing the behavior of others (Fey, et al., 1998). Effective communication is a complex activity in which communicators must successfully negotiate the meaning of a message by constructing a mental representation of the speaker’s meaning and determining the speaker’s intent in producing the message. Once a message has been received, the listener must be prepared to shift roles with the initial speaker and formulate an appropriate response to a message (Fey, et al.).

Hull (1992) proposed that people with hearing loss often find it easier to withdraw from communication situations than to face the embarrassment of frequently misunderstanding conversation or responding inappropriately. Therefore hearing loss

affects sufficient social communication, which in turn threatens the participation in every aspect of daily life and social interaction, including employment, education, leisure activities, family life, and intimate relationships (Leigh, et al., 1996; Magilvy, 1985; Vernon, et al., 1981).

While some deafened people are able to discern fragments of meaning from speech by reading lip movement, facial expressions and body language, only about thirty-percent of English sounds can be deciphered on the lips. In order to disambiguate sounds one must learn to use linguistic, environmental and other contextual cues (this is called speechreading, as opposed to lip reading). Although it may initially seem that postlingually deafened individuals have an advantage over prelingually deaf individuals in making sense of speech, research shows that there is actually no correlation between age of onset of hearing loss and speechreading abilities (Kaplan, Bally & Garretson, 1985). According to Luey (1980), there are some variables to predict success, but some people simply have a knack for it and others do not. Moreover, at best, speechreading is demanding and tiring. According to Glass (1994), late deafened individuals often have chronic fatigue that is attributed to the stress of attempting to understand speech and a substantial decrease in self-esteem from frequent failures to understand, despite their efforts. Some deafened people find they can no longer function effectively among hearing people.

While many deafened people continue to rely on spoken language and speechreading, others learn some form of sign language. But unfortunately, the acquisition of signing skills does not occur as rapidly as most hearing loss, leaving the deafened individual with a gap between need and ability. Furthermore, late deafened adults are past the Critical Period for language acquisition and therefore will likely never achieve native-like mastery of the

language. In communities where culturally deaf people shun or ridicule those who sign poorly or didn't attend certain residential schools for the deaf, deafened people experience rejection, which in turn prevents them from attending deaf social events where their sign skills could improve. Furthermore, some late deafened adults are warned by their doctors, audiologists, or counselors that learning sign language will prevent them from keeping jobs and/or friends in the hearing world.

Spoken language, though, continues to be an important option for late deafened adults, and for this reason many late deafened adults chose to get cochlear implants. Cochlear implants have been available as a prosthetic device for only slightly more than fifteen years and, in 2006, there were approximately 100,000 people throughout the world who have been implanted (Summerfield, et al., 2006). The most recent report by the National Institute on Deafness and Other Communication Disorders states that as of December 2012, approximately 324,200 registered devices have been implanted worldwide (NIDCD, 2016). Cochlear implants have been heralded in the media as major technological and social breakthrough for people who have profound hearing loss. According to Ross (2001), they have received more coverage on television, in print media, and on the internet than any other technological development ever has. This explains why awareness of cochlear implant technology has reached a vast majority of society, making it often the first consideration for deafened individuals.

The device, however, has not been so readily accepted by some deaf community groups. In their official position statement on cochlear implants, The National Association for the Deaf (NAD) called for a more realistic expectation about cochlear implants (NAD, 2000):

Cochlear implants are not appropriate for all deaf and hard-of-hearing children and adults. Cochlear implantation is a technology that represents a tool to be used in some forms of communication, and not a cure for deafness. Cochlear implants provide [a sense of] hearing, but do not, by themselves, impart the ability to understand spoken language through listening alone. (NAD, 2000)

The call of the NAD to maintain realistic expectations about what cochlear implants can and cannot do highlights their stance that cochlear implants are not a cure for deafness and they do not miraculously turn deaf people into hearing people. The NAD further asserts that even with the device and the increased speech perception it may offer, implanted individuals are still deaf. Deafness is irreversible. (NAD, 2000).

Late deafened people are forced into making decisions about communication. Depending largely on their perspective of deafness, deafened individuals will chose either to learn a visual language, such as ASL or a pidgin for form of ASL; or they will continue to rely on spoken language, with or without the benefit of technology, such as hearing aids and cochlear implants. Regardless of the decision, the communication method that late deafened adults chose to employ will have a strong influence on the social and cultural aspects of their experience of becoming a deaf person. Deafened adults who do not learn effective ways to communicate will likely live an isolated life in the outer reaches of society.

Although late deafened adults make up the largest portion of deaf individuals, they are situated as a minoritized majority within the deaf community (Woodcock, 1996). As such, there is relatively little information and research focused directly on postlingually deafened adults (Harvey, 2003; Hogan, 2001; Luey, 1980; Rutman & Boisseau, 1995). Deaf

literature has effectively ignored this segment of the population, and thus there is currently a lack of information and resources available for late deafened adults. Furthermore, medical and audiological specialists have been criticized for failing to address the psychosocial needs of newly deafened adults (Luey, 1980; Hogan, 2001) and for lacking knowledge and sensitivity regarding this population (Barlow, et. al, 2007). Similarly, Aguayo & Coady (2001) maintain that the medical and audiological professionals fail to understand the complex, psychosocial consequences of acquired deafness.

The nominal amount of research that is available is limited in scope, in that it is primarily written from a medical or clinical perspective, focusing on rehabilitation. Most research pertaining to late deafened adults concerns sensory rehabilitation through technological prostheses, specifically cochlear implants. Research has focused primarily on determining factors that affect auditory performance of postlingually deafened adults who use cochlear implants (Battmer, et al, 1995; Blamey, et al., 1992, 2006) and on examining the efficacy of cochlear implant use in late deafened adults with various cochlear implant technologies, features, and processing strategies; the implication seems to be that enhancement to auditory perception enhances the quality of life of deafened adults. For example, Busby et al. (2004) studied pitch perception using different modes of stimulation in a multiple-electrode cochlear implant, Fitzpatrick (2009) assessed the benefits of using remote microphone technology for adults with cochlear implants, Helms et al. (1997) evaluated the performance of the COMBI 40 cochlear implant in late deafened adults, Okazawa (1996) conducted a PET study to test the efficacy of cochlear implants in transmitting auditory information to the brain, Zwolan (1997) investigated the relationship

between electrode discrimination and speech recognition in late deafened adults who were implanted with a multichannel Nucleus cochlear implant, and so on.

Other researchers have explored speech perception in late deafened adults who use a variety of assistive listening technologies, including those who wear a hearing aid in conjunction with an implant (Ching et al, 2004; Mok et al. 2006; Tyler, et al., 2002), and those who have bilateral cochlear implants (see Grantham et al., 2007; Hoesel & Tyler, 2003; Kuhn-Inacker et al., 2004, Litovsky et al., 2004; Laszig et al., 2004; Summerfield, 2006; van Schleich et al., 2004).

Similarly, several researchers have sought to explain the deterioration of speech quality of late deafened adults. For example, Waldstein (1990) examined the role of auditory feedback in regulating the phonetic precision of speech sounds over a long period of time; Lane and Webster (1991) looked at pitch variation and mean pitch of late deafened adults; Lane (1991) measured lung volume and expenditure during speech of late deafened adults before and after cochlear implantation; and Lyxell et al. (2003) studied correlations between severity of hearing loss and phonological representations of sounds in long-term memory.

Previously, rehabilitation for late deafened adults was focused primarily on speech and sensory management therapy (Boothroyd, 2007). However, as researchers are beginning to recognize the importance of addressing the psychosocial dynamics of hearing loss in the rehabilitation process, more studies that examine this realm of acquired deafness have begun to emerge. The bulk of this research, however, has been conducted outside the United States.

In Canada, David and Trehub (1989) surveyed a sample of twenty-five deafened adults in order to gather information about the general course of their adjustment to acquired hearing loss. They found that the services available to them (e.g., counseling) were limited. Those who did use such services expressed disappointment in the ignorance surrounding acquired deafness, particularly the assumption that the problems of deafened adults are identical to those of culturally Deaf adults.

More recently, in Canada, Aguayo, and Coady (2001), conducted qualitative interviews with eight deafened adults in order to explore the psychological and social effects of being deaf. The results indicated that rehabilitation services for deafened individuals consisted exclusively of medical intervention and the psychosocial needs of patients were being largely ignored. Furthermore, they determined that communication difficulties result in damaged relationships, particularly with family members. They uncovered three themes: *Emotional trauma* – anxiety, grief, shame, embarrassment, and inadequacy; *Oppression* – exclusion and isolation within the family; and *General oppression*, exclusion and social isolation.

Barlow et. al. (2007) conducted a similar study in the United Kingdom. Like Aguayo & Coady (2001), Barlow et al. interviewed eight deafened adults and found that there were adverse influences on many aspects of deafened adults' lives including their sense of identity, family relationships, work and leisure. They also concluded that medical and audiological services tend to ignore psychosocial dimensions of late deafness. They identified five broad themes: *emotional impact of hearing loss, impact of family and social networks/relationships, impact on employment, contact with health and social care professionals, and provision of peer support and training* through the LINK's Intensive

Rehabilitation Program. The LINK center was established in 1972 to advocate for deaf people in the UK. The program offers specialist rehabilitation for deafened people including an intensive rehabilitation program, support groups, and outreach volunteer programs and it covers topics such as communication, lip reading, relaxation and employment.

In Australia, Heine and Browning (2002) examined literature pertaining to older adults who have dual loss (e.g. both vision and hearing) and especially the psychosocial and communicative difficulties that resulted. Heine and Browning found similar results to other studies that older adults with hearing loss feel isolated, vulnerable, exhausted, and less confident and no longer enjoy doing the things they used to do. These psychosocial factors resulted in increased dependence on caretakers, depression, diminished quality of life and increased social isolation. They found that there was a lack of literature that addressed how these psychosocial aspects of sensory loss should be considered when designing a rehabilitation program.

Krabbe, Hinderick and van den Broek (2000) tested the effect of cochlear implant use on the health status of late deafened adults. In their findings, late deafened adults who had received cochlear implants scored higher on quality of life questionnaires than did late deafened adults who were on a waiting list to receive an implant. Their conclusion was that cochlear implants significantly improved the health and overall well-being of deafened adults. However, because they compared individuals who had received a cochlear implant to those who were waiting to receive a cochlear implant, it is possible that their results were biased. Deafened individuals who were waiting to receive an implant had decided to maintain a hearing identity but did not yet have the support of the implant technology. Consequently, they were in an indeterminate state. The results might have been different

had they measured the quality of life of late deafened adults who use cochlear implants and those who have decided against implantation and instead developed a more positive deaf identity and use sign language or another form of communication.

In Sweden, Ringdahl and Grimby (2000) used health-related quality of life questionnaires to measure the bio-psycho-social status of deafened adults, their ultimate goal being to develop medical and audiological rehabilitation programs for people with hearing loss. They found that people with hearing loss suffered from simultaneous dysfunctions including lack of energy, negative emotions, and social isolation. The deafened adults in their study had an overall reduced life satisfaction. They suggested that aural rehabilitation programs include psychosocial support and counseling as well as targeting: improving coping strategies, improved verbal and nonverbal strategies, and improved audio-visual speech recognition.

In Australia, Hogan (1999) made an inventory of psychological problems facing late deafened adults. He interviewed 38 late deafened adults. The responses indicated that psychosocial problems existed, with the most prevalent psychological responses to severe hearing loss being depression and withdrawal resulting in isolation. Fear, anger, low self-esteem, anxiety, confusion, and tension during social encounters were reported psychological consequences of hearing loss in adults.

Researchers at the LINK center in the United Kingdom, a program that provides specialized psychosocial rehabilitation for deafened adults and their families, developed a questionnaire to evaluate the effectiveness of the immediate and long-term impact of attending the center's rehabilitation program. The survey was given to seventy-one late deafened adults who completed the six-day rehabilitation course, in order to evaluate the

overall effectiveness of the service provided by the center. It was determined that benefits in the following areas were demonstrated immediately after completing the program, and lasted up to six months after completion: psychological state, quality of life, communication effectiveness, social functioning. The long-term benefits of psychosocial rehabilitation of late deafened adults were inconclusive.

In a similar study in Australia, Hogan (1997) used semi-structured interviews to qualitatively describe and measure the nature of psychosocial benefits of cochlear implantation programs. He found that cochlear implant programs could result in substantive interpersonal and social gains for deafened people. Specifically, cochlear implants enhanced implantees' interpersonal communication skills, social confidence and reduced social anxiety, particularly when they were linked to community education and employment training.

As demonstrated here, the existing research about the psychosocial aspects of acquired deafness has focused on deaf people living outside of the United States. Moreover, it has most often been written by social workers. The researchers attempting to understand the experience of late deafened adults fail to take into consideration the cultural and political factors that shape the deaf community. As I have noted in this section, there is limited research available on the social, cultural, political, or personal aspects of becoming profoundly deaf, a gap that my study will address. As most research on late deafened adults is written with a rehabilitative focus, this study is ground breaking in that it seeks to de-medicalize acquired deafness by exploring how the experience of late deafened adults is constructed through social, political, and historical norms that operate in

a person's life. This study generates a new understanding of the social world of late deafened adults.

Identity

Self-identity, which is defined as the ways in which a person understands, describes and protects his or her sense of self, is a culmination of an individual's sense of personal skills, capacities, needs, preferences, values, beliefs, aspirations and dreams, including attitude toward deafness and toward persons with hearing loss (Woolley, 1987). Following hearing loss, changes to identity are inevitable. Recognizing and accepting these changes is a necessary part of the adjustment process. Identity can be broadly defined as how one positions self and other (Bucholtz and Hall, 2005); how we build a relationship with the world; as well as our understanding of future possibilities (Norton, 2000). It is primarily drawn from our membership in social groups and is a process that is achieved "through ongoing interactions with other persons" (He, 2006: 7). In other words, people establish roles of self-identity through their interactions with friends, family and work.

Identity is formed through an understanding of a culture's symbols, meanings, and code of conduct, as well as perceiving acceptance within this framework (Collier & Thomas, 1988). Cultural identity is used in a largely socio-historical way to refer to qualities of sameness in relation to a person's connection to others and to a particular group of people. It is achieved when an individual acknowledges that "he or she belongs to certain a group together with some emotional or value significance to him or her of the group membership" (Tajifel, 1981: 255). Cultural identity then is a broad term that is sometimes

used interchangeably with concepts such as *ethnicity*, *social identity*, and *group identity* (Kim, 2008).

Many definitions of cultural identity have been put forth. In Samovar and Porter's (1982) pivotal definition, cultural identity is "the symbol of one's essential experience of oneself as it incorporates the worldview, value system, attitudes and beliefs of a group with whom such elements are shared. The center, or core of cultural identity, is the image of the self and the culture intertwined in the individual's total conception of reality" (392). Building on Samovar and Porter's definition, Casmir (1984), stressed that the process takes place in "an interrelationship with a perceived environment" (Casmir, 1984, p. 2). Thus, in essence, culture is not just surrounding an individual, but also determines who the individual will become. Through interpersonal relationships and affirmation from within one's culture, one forms his or her self-perception.

According to Phinney (1990) the most significant factor in developing a positive cultural identity, which, in turn, indicates a positive self-concept, is related to "the extent to which people have come to an understanding and acceptance of their ethnicity" (508). As it is understood in the current study, *ethnicity* relates to membership in a group that shares a common history and culture, with the most important characteristic of the said group being a belief in their very existence as a group (Waters, 1990).

Numerous identity development theories have been proposed to represent this idea of coming to understanding and acceptance of one's ethnicity. Social identity development models serve as a cognitive map to how people construct their realities at different stages of the acculturation process. Although the full study of identity development is beyond the scope of this study, because parallels can be seen between the identity construction of

deafened people and other ethnic minorities, a brief overview of identity development theories will be provided.

The systematic investigations of the psychosocial nature of identity can be traced back to psychologist Erik Erikson's theoretical framework. Erikson (1950, 1968) described the process of identity development as one in which the two identities – the individual (or the personal) and of the group (or the social collective) – are merged into one. According to Erikson (1968) identity formation is thus “located in the core of the individual and yet also in the core of his communal culture” (22).

Marcia (1966, 1980), operationalized on Erikson's premise by formulating a model of how individuals create an identity. Marcia's work is especially significant because it is similar to the formation to an ethnic identity (Phinney, 1990), in that it categorizes whether or not a person has explored identity options and committed to a specific way of being in the social world. The steps in identity formation, according to Marcia (1980), are as follows:

1. Identity diffusion – individuals have neither engaged in nor made any commitment
2. Foreclosure – individuals have not explored identity options but have made a commitment based on the values of parents, teachers or peers
3. Moratorium – individuals in this stage have experienced an identity crisis represented by their struggle to identify values and goals that fit them; they have begun the exploration process, but have not committed.
4. Identity – individuals achieve identity after completing a process of exploration and making a commitment to a way of being in the world.

It should be noted that Marcia's stages are not hierarchical and it is not necessary to pass through one to get to the next. Furthermore, there is no guarantee that an individual will reach an achieved identity.

Both Erikson's and Marcia's work has been criticized for failing to address social and cultural processes of identity development, placing too much emphasis on individual choices and responses (Kroger, 1996; Peneul & Wertsch, 1995; Wright, 1982) and for reflecting dominant western norms (Rotheram-Borus & Wyche, 1994). Their work, therefore, has not been viewed as reflective of the experiences of groups affected by the oppression of Western culture. Nevertheless, Erikson and Marcia's work has served as a point of departure for the identity development models of race, gender and other socially and historically marginalized categories.

This is true of Cross's (1971) "The negro-to-black conversion experience – a psychology of Black liberation" model. In his model of identity development, which was developed during the civil rights movement, Cross tackled issues of racial oppression and psychological response to oppression as a sociocultural process, rather than as individual choices of Black people. His proposed model consists of the following five stages:

1. Pre-encounter – individual identifies with white people and culture while rejecting black people.
2. Encounter – an experience leads the individual to begin rejecting identification with whites and seeking identification with blacks.
3. Immersion-Emersion – individual identifies everything of value with blackness and abhors everything symbolized as white, followed by a movement away from the either/or immersion experience.

4. Internalization- individual incorporates a positive black identity
5. Internalization-Commitment – individual maintains a positive black identity in spite of societal oppression, and is committed to action that will benefit the minority community.

The underlying concepts of Cross's model are similar to those of Marcia's in that identity development progresses from being unaware, with a preference for the dominant culture; to a period of exploration of one's own ethnicity, which may involve rejecting dominant culture values; to developing an understanding and appreciation of one's own ethnicity (Phinney, 1990).

Cross's model is one of the most often cited works in the area of black identity and appears to be the foundation for research of oppressed minority groups. Stemming from his work and reflecting the steps of the negro-to-black conversion model, a number of scholars have proposed models of cultural identity of oppressed groups to account for individuality in the context of culture.

The most commonly used and cited model for deaf identity development, proposed by Glickman (1993), also appears to have been influenced by Cross's work. In his doctoral dissertation, Glickman developed an instrument to measure deaf identities, including the identities of late deafened adults. His model describes the process by which some deaf people acquire a culturally deaf identity. The four stages, or cultural orientations, of this model are presumed be developmentally related stages; they are: culturally hearing; culturally marginal; immersion in the deaf world; and bicultural, (Glickman).

The first cultural identity, *culturally hearing*, as described by Glickman and Carey (1993) is the stage in which deaf individuals reference of normality is through the

dominant hearing culture, and as such they understand deafness as an abnormality. Deaf people in this stage value oral communication and fit comfortably in the hearing world. According to Glickman, a major paradoxical element for deaf individuals in this stage is that the role of deafness in their identity is minimized and assigned as an inessential role in the person's life.

The second stage of the deaf identity model is *culturally marginal*. This orientation is typical of people who experience themselves as fitting between deaf and hearing worlds, but not being comfortable in either (Glickman & Carey, 1993). According to Glickman, cultural marginality is often a consequence of lack of exposure to positive models of the deaf experience and therefore, deaf individuals form an identity without a well-formed notion of cultural contrast (i.e. deafness vs. hearingness).

The third deaf cultural identity is called *immersion*. It describes a period in which people immerse themselves in the deaf world and identify positively with deaf people. This stage of identity development exemplifies a reversal of what are conceptualized as hearing values. Deaf people in this stage take a strong stance for the use of ASL and rejected all things "hearing" (e.g. using their voices, wearing hearing aids or signing in English word order) (Glickman & Carey, 1993).

The final kind of deaf cultural identity is *bicultural*. Deaf people who have achieved this stage feel a sense of comfort in both deaf and hearing settings and have become skilled in negotiating cultural differences. According to Glickman and Carey (1993) individuals at this stage take pride in their deafness and embrace deaf culture, but also feel comfortable in the hearing world. Furthermore they are able to oppose hearing paternalism and oppression without opposing hearing people.

Fischer and McWhirter (2001) sought to revise the deaf identity development scale, preserving the same four categories established by Glickman. Their results supported the existence of the four independent deaf identities. They furthermore determined that people who were born deaf or who were deaf before the age of two scored higher on the Immersion scale than did people who were born hard-of-hearing, and that prelingually deaf people also scored higher on the bicultural scale than postlingually deafened people. According to Fischer and McWhirter, the onset, severity of hearing loss, and socializing opportunities seem to be related to one's deaf identity development. Thus, for late deafened adults who grow up with hearing identities, whether they move "forward" or "backward" in this model will depend upon the kind of socializing experiences they have.

Two other models of cultural identity development are worth mentioning. While neither was designed to assess deaf identity, both models can be applied to understanding the unique process late deafened adults progress through as they come to understand their new position in the social world. The first model was developed by Kim (2008), with the primary intent being to explain the common adaptive experiences and identity transformation of individuals who are born and raised in one cultural or subcultural environment and have relocated to a new and different one for an extended length of time. This model, however, can be easily applied to the transformation of a deaf identity, and possibly even the absorption of deaf culture, by late deafened adults, who were initially socialized from a hearing perspective.

Kim's (2008) model of identity transformation is grounded in the General Systems perspective (Bertalanffy, 1956), that argues that each person is an "open system" that co-evolves with the changing environment. As such, the theory characterizes a person's

identity as undergoing changes throughout life. According to Kim (2008), "Plasticity, the ability to learn and change through new experiences, is highlighted as one of the most profound characteristics of the human mind and as the very basis upon which individuals acquire an identity"(pg. 363).

As explained by this theory, identity transformation happens through a process of acculturation and deculturation. Through *acculturation*, or the adoption of the behavior patterns of the surrounding culture, individuals acquire cultural practices and language of the target culture. According to Kim (2008) acculturative learning does not occur randomly or automatically following intercultural contacts and exposures, rather it is a process over which each individual has a degree of freedom or control, based on his or her predispositions, pre-existing needs and interests.

According to Kim (2008), as new learning occurs, *deculturation*, the loss or abandonment of culture characteristics, or unlearning of at least some of the old cultural elements has to occur. As the interplay between acculturation and deculturation occurs an underlying psychological evolution progresses from outwardly expressive behaviors to deeper-level changes in fundamental values. At the same time, an identity conflict arises between the resistance to change, on one hand, and the desire to be in harmony with the new culture, on the other. The conflicting forces can be manifested in intense emotional lows of uncertainty, confusion, anxiety, denial, avoidance, withdrawal, or through hostility toward the new reality.

Over time, such conflicts compel individuals to learn new cultural elements. For most people, internal changes take hold as they embrace environmental challenges and strive to stabilize themselves by culture shock and partaking in the act of adaptation. *Adaptation* is

defined from this perspective as “the entirety of the phenomenon of individuals who, through direct and indirect contacts with an unfamiliar environment, strive to establish and maintain a relatively stable, reciprocal, and functional relationship with the environment.” (Kim, 2008: 363). Kim further explains that in order for adaptation to occur, stress is essential. Periods of stress allow for self-(re)organization and self-renewal, and then pass as an individual works out new ways of handling a problem. The stress–adaptation–growth process is circular in that it moves forward and upward in the direction of increased chances of success in a changing or changed environment. Over a prolonged period of undergoing internal change, the diminishing fluctuations of stress and adaptation become less intense or severe, leading to an overall calming (Kim).

For individuals who were born deaf, deafness will be part of their core identity. However, it is not ingrained into the core identity of people who became deaf as adults (David & Trehub, 1989) and is therefore learned through a process of acculturation. Consequently, depending on whether the medical or cultural model of deafness is assumed, the outcomes for a deafened person’s emerging identity can be strongly affected. As described by the previous model of identity transformation, as late deafened adults negotiate their hearing and deaf identities, they will likely face conflicting ideals that may lead to an identity crisis.

Furthermore, because the meanings of deafness assigned by the dominant hearing society conflict with those claimed by culturally deaf people, this can make identity development even more problematic for deafened individuals. According to Gill, individuals with disabilities often view themselves as split, wrestling with those elements of self that are not disabled as good and those attributes that are disabled as bad (1997).

Gill suggests that in order for adaptation and growth to take place, people with disabilities must reject the values of the dominant culture that devalues disability.

For deafened adults that continue to adhere to the values of the dominant hearing culture, self-acceptance and self-definition as a deaf person will be more difficult. A third model, which is not normally cited as a minority identity development model but is actually a prototypical example of the process, describes the identity change associated with “coming out of the closet” as gay or lesbian. In fact, researchers have suggested that as a minority group, deaf people have most in common with gays and lesbians in that, like gays, deaf people often have parents who are different from them, they are discriminated against, they associate with their own kind, they seek to provide positive role models to young deaf children, and they fight for equal civil rights (Sayers, 2011).

As mentioned earlier “coming out” requires a cognitive shift in what it means to be deaf (or gay/lesbian). Models of gay and lesbian identity development are relevant to this study in that they involve an internal wrestling with oneself regarding orientation. Although there is general agreement in the literature on the conceptualization of coming out as a process involving certain recognizable stages, a number of models have been proposed for identity development of gays and lesbians (see McCarn, 1996 for an overview). Cass’s (1979) original model seems to be the most widely cited and the foundation for all other models for sexual minorities. As such, it will be discussed here. Cass’s model of sexual identity development includes the following six stages:

1. Identity confusion – individuals question their sexual orientation.
2. Identity comparison – individuals in this stage feel isolated as the differences between self and non-homosexual others become apparent.

3. Identity tolerance – individuals seek other homosexuals in order to lessen this isolation. However, individuals in this stage still maintain two identities: a public heterosexual identity and a private homosexual identity.
4. Identity acceptance – individuals have increased contact with the homosexual subculture, selective disclosures are made, but a “passing strategy to the dominant culture” is maintained (Cass, 1984, p.152).
5. Identity pride – at this stage everything “homosexual” is seen as important while everything “heterosexual” is devalued.
6. Identity synthesis – individuals in this stage are characterized as having an integrated identity, “homosexual identity is not longer overwhelming *the* identity by which an individual can be characterized. Individuals come to see themselves as people having many sides to their character, only one part of which is related to homosexuality” (Cass, 1984, p. 152)

While Cass’s model of sexual identity development echoes the underlying principles of other models of identity development of minority groups, its distinguishing feature, and one that that makes it of central concern for the current study, is the issue of disclosure and the realization that disclosure may be an option. At the same time, this model recognizes that social context, embedded with stigmatization, may prevent disclosure. This particular issue is not found in other culture identity models. Additionally, this model appears to be more circular, emphasizing that “changing life situations always hold anew the possibility of rejections” (McCarn and Fassinger, 1996, p. 511). In the case of deafened adults, disclosing hidden, stigmatized disability always requires a weighing of the costs and

benefits of disclosure.

Table 2.1 Summary of Identity Models

Black Identity Model (Cross, 1971)	Gay Identity Model (Cass, 1979)	Deaf Identity Model (Glickman, 1993)
Pre-encounter – individual identifies with white people and culture while rejecting black people	Identity confusion – individuals question their sexual orientation.	Culturally hearing , deaf individuals reference of normality is through the dominant hearing culture, and as such they understand deafness as an abnormality
Encounter – an experience leads the individual to begin rejecting identification with whites and seeking identification with blacks.	Identity comparison – individuals in this stage feel isolated as the differences between self and non-homosexual others becomes apparent.	Culturally marginal . Deaf people find themselves fitting between deaf and hearing worlds, but not being comfortable in either
Immersion-Emersion – individual identifies everything of value with blackness and abhors everything symbolized as white	Identity tolerance – individuals seek other homosexuals in order to lessen this isolation. However, individuals in this stage still maintain two identities: a public heterosexual identity and a private homosexual identity	Immersion . a period where people immerse themselves in the deaf world and identify positively with deaf people.
Internalization-Commitment – individual maintains a positive black identity in spite of societal oppression, and is committed to action that will benefit the minority community.	Identity acceptance – individuals have increased contact with the homosexual subculture, selective disclosures are made, but continue to use passing strategy in the dominant culture. Identity pride – this stage everything homosexual is seen as important while everything heterosexual is devalued. Identity synthesis – individuals have integrated identity and come to see themselves as people having many sides to their character, only one part of which is related to homosexuality.	Bicultural . Deaf people who have achieved this stage feel a sense of comfort in both deaf and hearing settings and have become skilled in negotiating cultural differences.

I have attempted to provide a general landscape of identity development theories as well as theories that describe the experience of specific marginalized or oppressed groups. These models offer insight into the identity transformation and development of late deafened adults. All of the models that were presented reflect a movement from being unaware and uninformed to a more existentialist notion of self-actualization. As late deafened individuals move backwards and forwards through the stages of identity development that have been put forth, factors such as socialization opportunities with other deaf people and the ability to make a cognitive shift in paradigms of what it means to be deaf will influence their identity development.

The literature on cultural identity of minoritized groups is especially useful to this study in that provides a means for changing the current paradigm, from a medicalized model of acquired deafness that views it as a functional limitation, to a socially constructed model. According to Meyers (1991) the massive number of “-isms” (e.g., sexism, racism, ageism, and audism⁹) in our culture have an adverse impact on those who are defined as inferior by the dominant way of perceiving. For deafened adults who were socialized as hearing people to feeling physiologically superior to deaf people, it is especially difficult to develop a positive self-identity. According to Erikson (1968):

An optimal sense of identity is experienced merely as a sense of psychosocial well-being. Its most obvious concomitants are a feeling of being at home in one's body, a sense of 'knowing where one is going,' and an inner assuredness of anticipated recognition from those who count (p. 165).

⁹ *Audism* is a term that was coined by Tom Humphries (1975) and is used by the American deaf community to define discrimination against deaf and hard-of-hearing people.

In the process of reaching this sense of psychosocial well-being, late deafened adults must move from a narrow definition of self to a more broad definition. Deafened adults who open-mindedly explore what it means to deaf, from multiple perspectives, will be able to more easily integrate the multiple aspects of their identity, which will ultimately lead to the overall sense of calm discussed by Kim (2008).

CHAPTER THREE

CONCEPTUAL FRAMEWORK

Phenomenology: Exploring the Lived Experience

The theoretical framework for this study of the experience of people with acquired hearing loss is provided by the philosophy of phenomenology. Phenomenology has been defined as acknowledging and valuing the subjectivity of a particular reality in an effort to uncover the meaning of the experience for an individual. The subjectivity enriches the authenticity of perceptions and understanding of the phenomenon (Dreyfus, 1987; Munhull, 1989).

Phenomenology arose in Germany before World War I and has since held a prominent position in modern philosophy. It challenged the dominant epistemological views of the time. The word phenomenon comes from the Greek *phaenesthi*, to flare up, to show itself, to appear (Moustakas, 1994). Thus the motto of phenomenology: “Zu den Sachen” which means both “to the things themselves” and “let’s get down to what matters!” (van Manen, 1990: 184).

Edmund Husserl (1859-1938), a German-born philosopher and mathematician, is considered the founding father of phenomenology. In this philosophy, which integrates psychology and logic, it is thought that the essence of consciousness can be studied through one-to-one interaction with individuals who have experienced a given phenomenon first-hand (Smith, 2003). According to Husserl (1970), the interactions must involve attentive listening, interaction, and observation to create a complete representation of reality, which will in turn provide a universal description of the phenomenon.

The goal of phenomenology then is to capture “an experience” that has large significance in a person’s life. According to Dilthey (1976), people are generally unaware of their flow of experience until it takes on a significant meaning, becoming marked. At an elementary level people are constantly in the flow of everyday life. It isn’t until we become aware of what is happening that it becomes “an experience.”

Husserl’s phenomenology emerged in the late 19th century as a reaction against the then dominant scientific, positivist view of philosophy and psychology. Husserl rejected the Cartesian tradition of dualism of mind and body or consciousness and matter. Descartes maintained that real objects can exist independently of our consciousness. From this perceived viewpoint, the world is objective, orderly, and measurable in an empirical way. This perspective saw subjective experiences as “appearances” and thus privileged science over experience (Hammond, Howarth & Keat, 1991; Thompson, 1990). For Husserl, the separation between appearances and reality or objects and the external world was improbable since experience is always of something (Hammond, et al.). Husserl believed that consciousness is the medium through which objects become known and exist and thus are known only through consciousness (Thompson, 1990). Husserl’s primary concern was epistemological. He was interested in developing a means by which essential or universal knowledge would be produced.

In order to accomplish this, Husserl believed that researchers needed to disengage from the activity and attend to the taken-for-granted experience of it (Moustakas, 1990). He argues that “lifeworld” (*Lebenswelt*) is understood as what individuals experience pre-reflectively, without resorting to interpretations. To Husserl, lived experience involves the immediate, pre-reflective consciousness of life (Dilthey, 1985). Therefore, an attempt is

made to understand the essential features of an experience as free as possible from cultural context. In Husserlian philosophy, this is done through reduction, such as “bracketing” or “epoche,” which aims to put aside preconceived ideas about an experience in order to reflect on that which is experience within the consciousness of the individual. In other words, by suspending natural attitudes, phenomena could be experienced in a new and unconventional way.

German philosopher Martin Heidegger (1889-1976), a student of Husserl’s, agreed with Husserl’s general notion of “to the things themselves” but questioned the possibility of any knowledge outside of an interpretive stance, while grounding this stance in the lived world – a world of things, people, relationships and language. According to Heidegger, our being in the world is always perspectival, always temporal and always in relation to something. While for Husserl context was of peripheral importance, Heidegger believed that humans are hermeneutic (interpretive), being capable of finding significance of meaning in their own lives. For Heidegger, context was of central concern and the understanding of individuals cannot occur in isolation of the culture, social context, or historical period in which they live (Van Manen, 1990).

In his work *Being in Time* (1927), Heidegger proposed that consciousness was not separate from the world of human existence and argued for an existential analysis. His primary focus was ontological and he believed that phenomenology was the meaning of Being (presence in the world). According to Heidegger, to ask for being of something is to ask for the nature of meaning of that phenomenon (Polkinghorn, 1983, Van Manen, 1990). He used the phrase “being-in-the-world” to refer to the way human beings exist, act, or are involved in the world.

Heidegger formulated a view of the human situation and of human beings that was radically different from the traditional philosophical view. He needed a way to refer to human beings and existence that captured the essence of human activity in the background of shared understanding of being (Dreyfus, 1983, 1987). He chose to use the German word *Dasein* (the engagement with the world) to emphasize that individuals cannot extract themselves from various contexts that influence their choices and give meaning to lived experience (Dreyfus, 1987; Thompson, 1990). He pointed out that our access to *Dasein* is always through interpretation. Unlike his predecessor, who was concerned with individual consciousness, Heidegger was concerned with existence itself and with practical activities and relationships with which the world appears to us and is made meaningful to us (Smith, et al., 2009). That is to say, Heidegger believed that humans cannot be separated from the world of objects, rather human beings are an integral component of the world. Socialization and cultural conformity are constitutive of *Dasein* (Dreyfus, 1987). Therefore, Heidegger's philosophy of phenomenology attempts to address the situatedness of individuals' *Dasein* in relation to broader social, political, and cultural contexts (Campbell, 2001).

Such context provides the meaning and interpretation of perception. Because human beings live their lives by experiencing the world and not by "knowing" it, there is no such thing as an objective reality for Heidegger. In this view, people can only know the world through experiencing it; they are already being-in-the-world, in it and of it (Dreyfus, 1983; Heidegger, 1962; Magee, 1987; Thompson, 1990). Being-in-timeness considers the having-been (past) and the being-expectant (future) of individuals that constitutes their particular perspective. The perspective changes over time and is unique for the particular point in time. Heidegger maintains that "truth" for any particular person occurs with that

person's engagement with the world. Rather than polarizing true and false, as in the positivist approach, Heidegger offers a relativistic view of truth and recognizes that truth and falseness can co-exist as they are perceived in a situation at a given time (Heldke, 1988).

The ideas of Dasein and situatedness form the basis of pre-understanding, or in Heidegger's terms, forestructure of understanding (1962). The forestructure of understanding consists of: fore-having, fore-sight, and fore-conception. In other words, all people come to a situation with familiarity or background practices from their own world that make interpretation possible (fore-having), the sociocultural background to provide a point of view from which to make an interpretation (fore-sight), and the socio-cultural background to provide a basis for anticipation of what might be found in an investigation (fore-conception) (Brenner, 1994). Heidegger assumed that the forestructure is closely linked to how one understands the world and thus how one interprets reality.

The interpretive process is circular, moving back and forth between the researcher's forestructure of understanding of an experience and what is learned through an investigation, revealing a blending of meanings that is articulated by the researcher and the participants (Moustakas, 1994). Heidegger (1962) referred to this process as entering into a hermeneutic circle of understanding. The hermeneutic circle is perhaps one of the most important concepts in hermeneutic theory (Smith, et al, 2000). It is concerned with the non-linear relationship between the part and the whole. In condensed terms: to understand any part, you must look at the whole; and to understand the whole, you must look at the parts (Smith, et al).

The dynamic, non-linear nature of hermeneutic interpretation with respect to time, suggests that interpretations will change over time. This change relates to the researcher as well as the participants. For the participants, their interpretation of the experience is different now than it was at the time of the experience, as what has occurred before shapes what is now. The now, in turn, shapes what will be. Similarly, the anticipation of the future will shape the now and the perception of what has occurred before. In this way, the circle is never closed, final, or static.

For the researcher, as more information about the lived experience is learned from successive participants, and as ongoing analysis takes place, the interpretation of the lived experience will evolve. What is learned from participants later in the study will affect how the experiences of earlier participants are viewed by the researcher. The participant's interpretation and recounting of the experience may change with events as well as being shaped by what has gone before. Of particular note, the anticipation and uncertainty of the future for late deafened adults may affect the perception and the meaning of their life experience.

By applying the hermeneutic circle to the idea that "delving into the particular also takes us closer to the universal" (Hermans, 1988: 785), we are thus able to better think about how we and other people might deal with a particular situation being explored, how at the deepest level we share a great deal with a person whose personal circumstances may, at face value, seem entirely separate and different than our own. Hearing loss is one of the most common disabilities in the United States, affecting more than twenty-eight million people. Deafness can happen to anyone, at any stage of life. A comprehensive

understanding of the experience of deafened adults is therefore a valuable tool for everyone.

CHAPTER FOUR

METHODOLOGY

Phenomenology was used to answer the questions: “What is the social and cultural experience of becoming profoundly deaf as an adult?” Phenomenology is based on the beliefs that people have embodied intelligence which allows them to experience situations and derive meaning and that the experience is contextually lived (Heidegger, 1982). Preservation of the subjectivity of the person’s lived experience is the object of phenomenology and the experience must be described in the person’s own words. Raw data for analyses are the verbal descriptions of the lived experience of having acquired deafness. This chapter outlines the phenomenological research method for this study.

Phenomenology, which originated as a philosophy, has become a major research method employed by qualitative researchers to explicate the essence of a phenomenon (Creswell, 2007; Van Menon, 1990). There are two approaches to phenomenology that guide the majority of phenomenological investigations: descriptive and interpretive.

The descriptive approach, based on Husserl’s original theory, uses bracketing or epoché to set aside what the researcher already knows about the life experience under investigation in order to gather data without preconceptions (Giorgi, 2009). Through descriptive phenomenological study, researchers aim to reveal essential general meaning structures of a phenomenon. In doing so, descriptive phenomenologists stay close to what is given to them in all its richness and complexity and restrict themselves to “making assertions, which are supported by appropriate intuitive validations” (Giorgi, 1986: 9).

The Interpretive approach, on the other hand, emerged from the work of hermeneutic philosophers, including Heidegger, Schleiermacher and Gadamer, who argued

for our embeddedness in the world of language and social relationships, and the inescapable historicity of a phenomenon. Interpretive phenomenological analysis is used to describe human experience in relation to historical, social, and political forces that shape meaning. Put simply, interpretive phenomenology is grounded in the belief that experience is contextually lived.

Furthermore, interpretive phenomenology theorizes that people have embodied intelligence that allows them to experience situations and derive meaning in non-reflexive ways (Heidegger, 1982). In other words, things have meaning for people without requiring a conscious thought process. Within this framework, it is therefore impossible to eliminate preconceptions and create a “blank slate” approach, as is called for in descriptive phenomenology. Interpretive phenomenology is conversely grounded in the theory that the researcher and the participant have come to the investigation with forestructure and understanding shaped by their perspectival backgrounds, and in the process of interaction and interpretation, they cogenerate an understanding of the phenomenon being studied. Researchers who conduct interpretive phenomenology research report how their own life experiences shaped the choice of the research topic, question selection and interpretation (Ball, 2009).

Because I believe it is impossible to understand the experience of late deafened adults without taking into consideration the social, historical, and political context of the deaf community, I have chosen to employ an interpretive methodology. In doing so, the specific aims of this study are to examine the social and cultural experiences of late deafened adults, and to uncover the meanings of the experiences of becoming profoundly

deaf as an adult in the social, political and historical context of the deaf community. Using interpretive phenomenology, this study seeks to answer the following questions:

1. What is the social and cultural experience of becoming profoundly deaf as an adult?
2. What role does socio-political and historical context of deafness play in the social world of late deafened adults?

Data Collection

In phenomenological research, the aim is to gain a rich and deep level of understanding and insight into human beings' lived experiences rather than to generalize findings, which is accomplished through using small meaningful samples. (Creswell, 2007; Denzin and Lincoln, 2003; Mason, 1996; Morse, 1998; Smith, 1999). Furthermore, phenomenology uses criterion sampling, seeking participants who have experienced a specific life phenomenon. The criterion for the current study is individuals who become profoundly deaf as adults after having been socialized with normal to near-normal hearing.

After University of California, Los Angeles granted institutional review board (IRB) approval, participant recruitment began. As an initial step in the recruitment process, I attended an annual conference for the Association of Late Deafened Adults (ALDA) and was introduced to potential participants by a late deafened adult whom I previously knew. Later, I e-mailed a request for volunteers to members of ALDA, as well as to those who were affiliated with Hearing Loss Association of America (HLAA) for recruitment purposes. Participants were asked to nominate themselves as well as any other late deafened adults who would potentially be interested in meeting for a face-to-face interview in which they

would share their life experiences for the purpose of this study.

Participant recruitment was achieved through purposive sampling as much as possible. That is, based on my knowledge of the deaf community in general and late deafened adults in particular, I attempted to purposively recruit late deafened adults with diverse experiences in regard to cause of deafness, age at onset, present age, communication preference, gender and geographical location. However, some participants were found based on the recommendation of other late deafened adults. Each participant who volunteered was first contacted by email to further explain the study, determine eligibility, and obtain preliminary consent. Once participants were screened and verified as meeting study criteria, meetings were scheduled either in the participant's home, office, or a mutually agreed upon public location. Written informed consent was obtained prior to data collection in the face-to-face meeting.

In order to obtain an in-depth interpretation of the experience of late deafened adults, a semi-structured interview format was used that consisted of open-ended, factual, descriptive, and evaluative questions that invited the interviewee to engage in storytelling and encouraged reflection and recall. Although conversations were guided by an interview guide (see appendix 1), additional topics related to the research question were often raised spontaneously, and probe questions were used to prompt elaboration and examples of more general statements.

Furthermore, in order for the data to truly reflect the experience of becoming profoundly deaf, as the interviewee experienced it, the content of the interview was determined by the participant's detailed description. Specifically, there was no attempt to limit the scope of the interview, for the reason that the fundamental philosophy of

phenomenology is to let people express what has meaning in the experience for them (Omery, 1983). Also, at the conclusion of the interview each participant was asked if any pertinent aspects of his or her experience had not been covered.

All interviews were video-recorded. The primary purpose of the recordings was to create transcripts that were used for analysis. All recordings were transcribed in English. When sign language was used in the interview, the transcripts were represented as English glosses, based on the researcher's interpretation. When simultaneous communication (the simultaneous use of spoken language and sign language) was used in the interview, the English words were transcribed, with the glosses of the signs provided for additional clarification in the transcription. Any major discrepancies between spoken and signed language were noted in the transcripts. Once all interviews were transcribed, data analysis began, as discussed below.

Participants

Phenomenological inquiry requires small sample sizes, typically ranging between six and eight participants (Creswell, 2007; Smith, et al., 2009). According to Smith, interpretive phenomenology studies benefit from a concentrated focus on a small number of cases. Therefore, of the twelve interviews that were conducted, data were chosen from interviews of seven participants that demonstrated the most balanced, yet broad spectrum of experiences.

The seven participants selected for this study represented a multiplicity of demographic criteria including current age, age at deafness and cause of deafness. Participants ranged in age from 33 to 60 years with the mean age of 48. Age at time of deafness ranged between 18 and 54; and participants have been deaf for as few as 2 and as

many as 31 years. Furthermore, participants represented diverse social and cultural stances that included communication preference, use of assistive listening technology, group membership and social identification and affiliation. (see Table 4.1)

Table 4.1 Cultural and Demographic Variation of Participants

	Jay	Jo	Kat	Liz	Max	Meg	Nell
Years Deaf	17	3	22	31	2	15	12
Cause of Deafness	NF2	unknown	genetic	genetic	Meniere's	Meningitis	unknown
Listening Devices	none	CI & HA	bilateral CI	CI & HA	none	bilateral CI	bilateral HA
Communication Modality	ASL, English	English	English	ASL, English	ASL	ASL, English	ASL, English
LDA Group Membership	ALDA	HLAA	HLAA	ALDA	none	None	ALDA
Deaf Community Involvement	minimally involved	not involved	not involved	immersed	minimally involved	immersed	moderately involved
Primary Social ID/Affiliation	LDA	hearing	hearing & LDA	deaf & LDA	deaf	Deaf	deaf & LDA

In order to employ a small purposeful sample, as prescribed by phenomenological methodology, data analysis commenced when saturation, or redundancy in data, occurred. Five participants were excluded from analysis in this research because they had multiple demographic, social, and cultural commonalities with other participants. (See Table 4.2)

Table 4.2 Cultural and Demographic Data of Participants Not Selected for Analysis

	LDA 1	LDA 2	LDA 3	LDA 4	LDA 5
Years Deaf	28	22	11	9	53
Cause of Deafness	NF2	Unknown	autoimmune disease	genetic	fever
Listening Devices Used	None	CI	bilateral CI	bilateral HA	bilateral CI
Communication Modality	ASL, English	English	ASL, English	English	English
LDA Group Membership	ALDA	HLAA	ALDA	none	HLAA
Deaf Community Membership	moderately involved	not involved	minimally Involved	not involved	not Involved
Social ID/Affiliation	LDA	hearing	LDA	hearing	LDA

Specifically, late deafened adults who were interviewed, but disqualified from the study, exhibited three or more similarities with multiple participants, demonstrating redundancy in the data, as seen in Table 4.3.

Table 4.3 Number of similarities of participants disqualified from this study

	LDA 1	LDA 2	LDA 3	LDA 4	LDA 5
Jay	6	0	4	0	1
Jo	0	5	0	3	3
Kat	0	4	1	3	3
Liz	3	0	4	1	0
Max	1	0	0	1	0
Meg	1	0	3	1	1
Nell	2	1	3	1	0

In addition, two of the five participants did not meet the inclusion criteria for age of onset and degree of deafness. Late deafened adult 4 was disqualified from this study because, although she suspected that she has severe deafness, and self identified as having severe deafness, she had recently been diagnosed with a moderate hearing loss, which does not meet the inclusion criteria for this study. Late deafened adult 5 originally reported becoming deaf at age 43 and self-identified as a late deafened adult; however it became clear in the interview that she was first diagnosed with severe to profound hearing loss at age 10, with her hearing loss possibly beginning as early as age 5 subsequent to a high fever. At age 43 she experienced a sudden loss of all residual hearing. This participant was disqualified from the current study because she was determined to have been socialized as a deaf/hard-of-hearing person from a young age.

Participants who were included in this study had no more than three similarities with no more than one other person, thereby ensuring a broad sample of experiences of acquired deafness. (See Table 4.4)

Table 4.4 Number of similarities between participants included in this study

	Jay	Jo	Kat	Liz	Max	Meg	Nell
Jay		0	0	3	1	1	2
Jo	0		3	1	0	0	1
Kat	0	3		1	0	1	0
Liz	2	1	1		1	2	3
Max	1	0	0	1		3	0
Meg	1	0	1	2	3		1
Nell	2	1	0	3	0	1	

Data Analysis

This study adhered to the step-by-step process for conducting interpretive analysis that has been laid out by numerous interpretive phenomenologists, based on the Heideggerian beliefs (e.g., Benner, 1994; Diekelmann, Allen, and Tanner, 1989; Moustakas, 1994; Omery, 1983; Smith, Flowers, and Larkin, 2009). The steps reflected a process of interpretation that uses the hermeneutic circle, where new understanding will change the explanation and this will, in turn, alter understanding. The following research steps, which are explained here in detail, were used for the interpretation of data in this study.

The first step of analysis in phenomenology was to become fully acquainted with the text. To do this the researcher immersed herself in reading and re-reading the data numerous times, to get a global sense of the experience, without analyzing it. This step was important in order “to get the sense of the whole” experience of late deafened adults (Omery, 1983: 57).

The second step of analysis was to conduct a slow, careful examination of the language and semantic content of the data, identifying transitions, or meaning units. According to (Moustakas, 1994), a meaning unit is a particular portion of an interview in which meaning is expressed. The data was then organized by key phrases and significant statements used by the participants that express a particular meaning within the description of the experience of becoming profoundly deaf. This close analysis resulted in a comprehensive and detailed set of provisional notes and comments about the data that had a clear phenomenological purpose.

The goal of analysis for the third step was to develop emergent themes by mapping connections and patterns between exploratory comments (Smith, et al., 2009). In this step, the meaning units were studied, examined, and then re-described so that the interpretive value of each meaning unit was made explicit. During this step, analysis of the context of participants' concerns helped to make sense of the patterns of meaning in their accounts (Moustakas, 1994). During this portion of analysis, emergent themes were captured that reflected an understanding of the life experience of the participants. Step three resulted in a concise statements of what is important in the various exploratory comments. Therefore, the themes reflected not only the participants' original words but also the researchers' interpretation of those words.

During the fourth step of analysis, texts were compared and contrasted in order to identify any shared practices and common meanings. Any similarities, differences, echoes, amplifications or contradictions across transcripts were noted. During this step, free imaginative variation was be employed to determine which meanings were essential to the identity of the experience of late deafened adults. To do this, the researcher imagines every

possible variation of the attributes of the experience to see how far it can stretch before losing its identity. According to Kleinman (2004), any attributes that are not required for the phenomenon's existence should then be eliminated. As a result, structures were identified, as were their relationships to each other. This process synthesized the transformed meaning units into a consistent structure.

In step five, the final structure of the phenomenon emerged. It was in this final step of interpretive research methodology that the researcher made connections across emergent themes that linked the themes. Themes were mapped together in order to create a structure that highlighted all of the most interesting and important aspects of the participants' accounts. This step was achieved by using: *Abstraction*, grouping like themes into 'super-ordinate' themes; *Subsumption*, giving an emergent theme super-ordinate status in order to group a series of related themes; *Polarization*, creating higher level themes by examining oppositional relationships of emergent themes; *Contextualization*, finding connections between themes by attending to the contextual and narrative elements within the analysis; *Numeration*, taking into account the frequency with which emergent themes appear throughout the transcript; and *Function*, examining emerging themes for their specific function of language use within the transcript. Accuracy of the structure was then ensured by returning to the raw data (i.e. the participants' actual descriptions) to justify the essential meanings and the fundamental structure of the phenomenon of the experience of late deafened adults. This final structure of the phenomenon allowed for understanding the meanings that are prescribed to the social world of to late deafened adults.

Protection of Human Subjects

Approval for this study was obtained from University of California, Los Angeles. Before any participants were enrolled in this study, they were informed that participation in the study was voluntary and that they could withdraw from the study at anytime. Furthermore, if they chose to withdraw from the study, they were informed that their data would not be used for analysis. Each participant was also informed that they were not obligated to discuss any topic with which they felt uncomfortable or any topic that might cause them unwarranted emotional distress.

The participants were notified that all the documents would remain confidential, and that pseudonyms would be used to protect their identity. Furthermore, they were informed that all identifiers, including those of the participants and of other individuals that might be discussed during the interviews would be deleted from written transcripts. Participants were also be given a copy of the consent form for their personal records.

The study documents, including the screening questionnaires and the interview transcripts remained locked and only accessible by the researcher. The list of participants, their corresponding pseudonyms and contact information, along with their consent form, were also kept in a separate locked location that was only accessible to the primary investigator.

CHAPTER FIVE

BIOGRAPHIES OF PARTICIPANTS

To answer the question “What is the lived experience of late deafened adults?” data was collected through semi-structured interviews from twelve late deafened adults. Each of the interviews was video recorded and transcribed by the researcher. From the transcripts, a representative sample of seven interviews were chosen that demonstrated the most depth and breadth. The interviews, in total, yielded 153 hours and 254 pages of raw data.

The following presentation of data includes a biographical sketch of each participant’s experience. In Part II, identification of emerging themes, and examination of common and contradictory meaning units across narratives will be presented. The resulting structure will provide a framework for understanding the experience of late deafened adults.

Participant One: Jay

Jay is a 42-year-old late deafened adult with profound deafness. Jay is fluent in American Sign Language and our interview was conducted using simultaneous communication (sim-com), which uses both spoken English and signs from American Sign Language (ASL), simultaneously. He was interviewed over two sessions for a total of one hundred and fifty minutes.

Born with full hearing abilities, at the age of twenty-four Jay developed a ringing sensation in his left ear and soon after began to notice he wasn’t able to hear as well out of

that ear. Initially, he ignored the problem thinking it likely was temporary; however, after an indefinite amount of time, when the ringing and reduced capacity to hear did not resolve on its own, he went to an ear, nose and throat doctor (ENT). Through magnetic resonance imaging (MRI), it was determined that Jay had neurofibromatosis type II (NF2), a genetic disease indicated by bilateral acoustic neuromas on the eighth cranial nerve. Also known as the auditory nerve, the eighth cranial nerve is responsible for transmitting sound and equilibrium from the inner ear to the brain. Jay was told that because the non-cancerous tumors would continue to grow, surgery, which would sever the auditory nerve, was required to remove them. Without the surgery, the disease could be fatal.

Jay explained that he never had an intense emotional reaction to his diagnosis, but that instead his feelings relating to NF2 and subsequent deafness were very simplistic.

It's almost like it was cut and dry. I had a tumor. It's growing. I needed surgery. I was never emotional about hearing loss. So for me I was never like crying or upset. I typically go through life with what I'm dealt. It was hard – I mean scary.

He explained that in hindsight, this simplistic view of NF2 likely made accepting deafness easier because, in making a basic comparison of risks associated with the removal of the tumor, versus rejection of the operation, deafness was an easy choice.

So, I'm asking the doctor, 'Will I just become deaf or could I become like dying from this?' and he said, 'Well, just deaf.' So I was like, deaf, dying, deaf, dying [gesture: weighing the options]. Well, I guess deaf is not so bad.

Jay furthermore suggested that his family did not display an emotional reaction to his diagnosis. He recollected that he never saw them cry or express intense feelings about

his having NF2, which was how he preferred people respond. He believes this is because they followed his lead of how to handle the information.

I think, in part, it's how a person shares that information, you know. Other people responded to how I responded. So I was more factual. I tend to be the logical type presenting facts and not going emotional beyond the facts. So, maybe behind closed doors they could be upset or emotional but since I wasn't showing emotion, they didn't show emotion to me.

Soon after the diagnosis, Jay underwent an initial surgery on his left ear, which had the larger of the two tumors. As was expected, because of the location of the tumor on the auditory nerve, the nerve was severed during the surgery leaving him completely deaf in that ear. Jay explained that he described himself as hard-of-hearing at that time; because he could still readily communicate both face-to-face and on the phone, he did not feel that the loss had an effect on his life. He, therefore, did not begin to make any adaptations for hearing loss at that point, despite knowing that the tumor in his right ear was still growing and would also need to be removed, which would render him completely deaf. It wasn't until approximately a year after his first surgery that Jay began experiencing ringing and decreased hearing thresholds in his right ear.

I remember that day at work. I was deaf. I can't hear in my left ear and now I can't hear in my right ear. I had no coping skills – skills to handle that. It was one of those scary days that was kind of like to say I'll be deaf soon.

Although Jay had known he would eventually become fully deaf, without a definitive timeline, he was able to postpone the full realization of it. It was not until that day at work

that he began to grasp that a second surgery was imminent and that he would soon be completely deaf.

As an alternative to surgery, Jay's doctors proposed a treatment that would temporarily freeze the tumor, postponing the necessity of the second surgery, and therefore his impending deafness. Jay explains that he viewed the treatment as a temporary fix for the inevitable.

The doctors had mentioned something called gamma ray radiation that freezes the tumor or delays the growth – and for me that wasn't an option, because I was like let's just get it done. I didn't want this thing to hang over my head.

Jay provided a fitting analogy that expressed his feelings about proceeding with the second surgery.

I don't know if it's my personality or what but I just felt like this is what's going to happen and there's nothing I can do to change it. Almost like I was saying it's like getting on an airplane and once I'm on the airplane I have to give up control. I can't fly the plane. So I'm not going to be scared on top of flying. So it was the same idea with being deaf. There was nothing I could do to stop it from happening.

Moreover, Jay felt a sense of relief in identifying as a deaf person, rather than a hard-of-hearing person.

I found 'hard-of-hearing' so vague. How do you explain to a person you're hard of hearing? For me it meant talking louder, which was worse. It was almost like there as an echo so it was hard to understand. I needed somebody to talk slow, clear, more like a whisper. It was almost easier to understand deaf. Hard-of-

hearing was very vague for me and I like having something that is black and white. I'm deaf. That was clear for me. At the time my idea of deafness was very black and white. I didn't realize that a lot of deaf people can hear. You know, at the time I was thinking if you're deaf, you're fully deaf.

Ruling out the possibility of the alternative treatment meant that Jay would be deaf sooner than later. He realized then that it was time to make changes in his life in preparation for deafness, beginning with communication. Understanding that he would need 'some kind of visual language to connect with people,' he found a sign language tutor and began learning some very basic signs. At the time, however, because he wasn't connected with the signing deaf community, he admits his skills did not improve. Around this time, he also began to make contacts regarding changing his career, as he felt his job at a grocery store would not be well suited for him as a deaf person. He applied to Vocational Rehabilitation (VR) and began working with a VR counselor about changing his career.

When asked in what other ways he prepared for his deafness, Jay described a last hurrah in which he indulged in things that he could enjoy as a hearing person, but not necessarily as a deaf person.

I went to a Broadway show – saw a couple of plays on Broadway before I became deaf. In some ways it was liberating. I could live to be seventy-five years old and always saying I could see a play on Broadway – later, later, later; but for me it became now. I enjoyed that.

Although Jay had prepared for deafness by making pragmatic changes to his life, he admitted that preparing emotionally for deafness was not something he knew how to do.

This was largely because he did not know what to expect and did not necessarily want to consider the wide-ranging consequences of deafness. Instead, he decided to, as he explained it, “play it by ear.”

I know people talk about the word ‘denial’ and in some ways denial is a good thing. If I sit there and try to really grasp the whole idea of becoming deaf, it would be overwhelming. I mean I couldn’t deal with that, but I kind of had this act of denial; meaning it wasn’t stopping me from doing things. I understood what I had but I didn’t look at the totality of everything.

Jay recounted that soon after becoming deaf he began to feel a sense of isolation. He spent the majority of his free time reading. He explained that by engaging in solitary activities, there seemed to be a reduced emphasis on the loneliness he felt.

It’s easier to be alone. I stopped doing things – and so in my alone time I would say, ‘Oh I love to read. I never read growing up so I’m really enjoying reading.’ And it’s true. But I wasn’t making any interpersonal connections with people. I wasn’t taking the chance. I was playing it safe by being alone. I was very isolated from the world. That was hard.

Many deafened adults have the option to restore a sense of hearing and therefore maintain interpersonal connections in the hearing world, through cochlear implantation. Jay, however, was not a candidate for the implant. Because cochlear implants function by bypassing damaged or nonfunctioning hair cells of the cochlea and sending a direct electrical stimulation to the auditory nerve, when this nerve is severed in the process of removing acoustic neuromas, patients with NF2 become disqualified as candidates for cochlear implants.

Instead, Jay elected to receive an auditory brainstem implant, which at the time was still in the testing phases of development.

So for me a cochlear implant was not an option. They do have something called an ABI - auditory brainstem implant, which bypasses the nerve. It's very crude, it's not really connected to sound awareness. In 1996 it wasn't approved by the FDA, so it wasn't going to cost me any money, I thought, 'Fine, I'll try it.' But when I got tested later it didn't work. If they turned it all the way up my whole body would twitch. But I would get no sound awareness and they said the array moved a little bit so it lost its signal because they tested it in surgery – or maybe when they tested it they actually got a false positive. Maybe the nerve wasn't really working but it was just sending a signal so they thought it was working.

Because the initial implant was unsuccessful, the surgeon wanted to perform an additional surgery in order to determine the source of the malfunction. Jay, however, accepted the implant failure as a sign that he should begin to accept an identity as a deaf person.

I was like, 'No.' [sign: I give up] I was comfortable with the idea of being deaf. And I'm not really religious but I felt, that the implant didn't work was like God's way of saying, 'You're deaf.' So I was supposed to move towards being deaf and not think about being hearing. And that the ABI didn't work, it changed my path. Maybe had it worked I would have stayed more connected to the hearing world without really absorbing the deafness. So I feel like the ABI not working was really a plus for me.

Pursuant to Jay's emerging deaf identity, he began making friends with other deaf people at a job he obtained at the post office through his VR counselor. Jay explained that although his deaf coworkers were only connected peripherally to deaf culture, and to varying degrees, they were mostly native signers and it was through them that his sign language skills began to really develop.

It was also at the post office that he first began to comprehend the magnitude of challenges that deaf people face, particularly in the work place. This personal realization contributed to his connection with a deaf identity.

The post office job was my first experience with understanding that deaf people were not getting equal access to things. So I got involved with the union working on deaf issues. Really it was like opening my eyes and starting my deaf identity I guess. You know, up until that point I'd always identified myself as a hearing person but once I started working at the post office I started to develop a deaf identity. I don't want to say deaf pride, but the idea that I'm a deaf person and I need certain things from places I work and when I'm not getting that access what do I do? I would identify with discrimination against deaf people, things like that.

Jay provided the following narrative of an eye-opening experience he had at the post office prior to being hired, in which he came to an initial realization of what would continue to be an ongoing struggle with people's ignorance about deafness.

And I was like, 'I'm fully deaf, I hear nothing.' But they said, 'We need to do an audiogram,' not understanding – maybe because my speech was clear, I don't know. So they give the old fashioned audiogram where I put on headphones and

I sat in a room for like thirty minutes [gesture: twiddling thumbs]. When it was finished the person said 'I think the machine is broken because you never responded at all.' And I'm like, 'BECAUSE I'M DEAF!' [shouting]

Later, Jay decided to apply for a window clerk position at the post office. Although this pronouncement was met with opposition from his superiors, who did not believe a deaf person could do the job, Jay fought to convince his supervisors that he had the ability and the legal right to apply for the job and take the postal exam.

If I take the test, how am I not qualified, you know? So fine, they allowed me to do the job. Happy? Probably not – but I feel with the union involved there was no reason they couldn't say I could do the job. So I became the first window clerk who was deaf.

After attaining the window clerk position, Jay's experience interfacing with the general public at the post office further developed his realization that most people do not understand or are unwilling to learn how to make accommodations to communicate with deaf people. In his words "large segments of the population are set in their ways and narrow-minded." He illustrates with the following example from an experience at the post office.

So I had a little sign there saying, 'Please make eye contact,' I'd have paper there, things like that – trying to help communication. Well, one person came in and he says – he said, 'I'd like three books of stamps,' but I didn't get it fully. I was like, 'I'm sorry, what did you say?' 'I want three books of stamps [quickly].' I said, 'Okay, you want stamps. How many books do you want?' 'Three books of stamps [quickly].' I said, 'Can you show me by fingers?' He couldn't do it. He

refused to show me by fingers how many books of stamps he wanted. He wouldn't write it down. Nothing...What would be so hard about saying, 'three' [sign: three (on right hand)] or, 'three' [sign: three (on left hand)] or writing, 'three,' or doing anything like that? He just couldn't get it.

Jay continued to experience prejudice in the workplace and eventually came to the realization that he was not going to be able to advance his position at the post office.

I felt there was no reason I couldn't become a supervisor. I mean, I was intelligent enough but there was a lot of resistance about communication, about how I'd do the job and I actually had one of the head people come up to me personally and he said, 'Do you really want that job?' and I'm like, 'Does he do that to all people?' It was like I had to convince them I'm qualified. But when I started the job they were not making any accommodations that we were suggesting. It was like, 'can't do that, can't do that, can't do that.' And it got to the point where I was really bored. I wasn't doing anything – wasn't getting any opportunities to advance.

Having decided that the post office was not a lifelong career option, Jay began to feel defeated and alone. Not knowing what the next step in his life was going to be, he started seeking out support groups for late deafened adults.

When I first started looking for a group to support me with being deaf, I found Self-Help for Hard-of-Hearing, now HLAA. I went to a couple meetings and there was no sign, there was no CART [Computer-Aided Realtime Translation]. It was basically people with hearing loss. But the emphasis was more on maximizing what they could do to hear more. FM system, t-coil loops, etc... and

that's all great for those people that can benefit but I'm fully deaf. I mean there's nothing you can do to help me do more. I mean maybe I met some people one-on-one and they were nice, they were fine. But there was not group interaction there for me. And also they were older. It just wasn't a match for me. I didn't feel comfortable in that environment.

Feeling even more disheartened, Jay returned to his VR counselor, who referred him to a group called Association for Late Deafened Adults (ALDA). Although there was no local chapter in his area at that time, the group had an upcoming annual convention in Chicago, which was a relatively easy drive from his home.

Honestly, I had no idea what to expect because I'd never really met anyone else who was late deafened – never met anyone with NF2 – so it was a bit scary. And I arrived and had one person who just kind of picked me up. No particular reason, he just said you're coming with me. I just sort of sat with him, he signed, but it was easier to communicate because I didn't have to worry about signing well. You know, people are just communicating. You're just trying to express yourself. And so it was really comfortable for me to be able to communicate with people to where my signing skills were actually good.

When asked to expound upon the ease and connection he felt with fellow ALDAns (members of ALDA), he explained that it was essentially the elimination of the unremitting pressure he felt in everyday conversations and interaction with hearing people.

So going to ALDA, you see all these people who are writing, talking, signing, gesturing. You know their philosophy of 'whatever works' and it's such a

comforting feeling. I mean I tell people it's the one week out of the year where communication isn't work. We work at it. Alright, it's not always easy, but we're in the same boat. I don't have to feel that pressure of having to lipread everything. The pressure of feeling insignificant because I'm not understanding a conversation or I'm missing a joke. Things like that. I'm part of the conversation all the time. It's just a wonderful feeling.

Jay suggested that the ease in which he found communication with follow-late deafened adults was one of the biggest draws to the community.

You're in a barrier free communication environment. It doesn't mean that communication is easy, but you're in a situation where people understand what needs to happen for effective communication. And it's nice for me to just be able to sit back and relax and not have to work to communicate; to be in an environment where after 15 years of being deaf I'm now at a point where people actually look to me for ideas on how to communicate. Not that I'm a leader, but I have more experience. It's nice to be in an environment where I'm higher up on the pecking order, so to speak. You know, I know how to communicate, where in the [signing] deaf community I'm very low. If I'm with hearing people that don't sign, I'm even lower. So it's just more comfortable for me.

Jay further recollected the inspiration he felt after meeting other late deafened adults, including the president of Gallaudet University, who led remarkable lives after becoming deaf.

You see people whose lives didn't stop after they became deaf. I mean it wasn't like my life was necessarily bad, but it was lacking quality. When you meet the president of a university [I. King Jordan] who got that job after he became deaf. It was like, 'Wow, I can do things!' you know? You just meet all these people whose lives continued to be successful or didn't stop being successful after they became deaf.

After seeing the quality of life that so many late deafened adults at the ALDA convention were enjoying, and measuring it against substance of his own life, Jay decided to focus on establishing a career, rather than continuing to work at a job that he saw as a dead end. He decided to return to college. He promptly met with his VR counselor, and with her approval there was no financial burden associated with the decision. Furthermore, Jay learned that CART was available at the local college he had previously attended, thereby alleviating difficulties associated with access.

CART is an extremely efficient mode of communication for deaf individuals, particularly late deafened adults, who tend to rely on written English as their primary mode of communication. CART is an instant speech-to-text stenography system in which a trained stenographer listens to spoken words and simultaneously types what is being said into a stenotype machine. The message passes from the keyboard via a cable to the computer for processing (i.e. translation into English) using Realtime software. The text is then displayed on a computer monitor, generally one to four seconds behind the speaker, and is also saved on a disk so it can be reviewed at a later time (Compton, 2004).

Jay provides the following anecdote about his experience using CART in the classroom:

I think CART is wonderful for meetings, but for me, I felt disconnected from the class. I was looking at it, felt left out reading so I didn't really connect. And I remember one experience I had and I remember one experience where in a class and they are talking and talking and then I see the name [Jay], I'm reading, and then I see '[Jay] question mark, question mark, question mark.' 'Oh, you're talking to me?' And I just felt like I was reading a book. So I decided after that experience CART wasn't for me in school. That I would rather use an interpreter, miss a little of the conversation, but feel a little more connected to the class.

The first class Jay took was called "Cultural Perspectives on Deafness." He described the class as being an eye opening experience for him in conceiving the vast diversity of the deaf community. In fact, in his class there was a culturally deaf person, a deaf-blind person, and Jay himself, a late deafened adult. So even within the confines of the classroom he was able to observe first-hand, a multiplicity of ways to be deaf.

Jay said that one of the things he learned in the class is that ninety-nine percent of deaf children are born to hearing parents, who upon having a deaf child experience a sense of grief and loss at having a deaf child. He felt a strong connection to these families, as he himself had experienced a similar loss.

And I really identified with that because I had lost something – I had lost my hearing. And I felt like, could this be a professional job? And it really led me to want to work with families that are impacted by hearing loss.

Jay described that course as a pivotal point in determining the direction of his education and professional life. He also expressed gratitude for the disability services department on

his campus, through which he was able to get note-takers and other forms of support. Although most of his experiences in college were positive, Jay noted that there are always people who “just don’t get it.”

I had one class called ‘Race, Class and Ethnicity’ thinking this teacher really understands what diversity is, things like that. So I wanted to do a paper on this author who had written some plays. And I asked him where I get a copy. His answer was, ‘Well, I’m not sure you can find that in Braille.’ So I said, ‘Well that’s okay, English is my first language so I think I’ll do okay.’ So he said, ‘Okay, okay so go to the library...’ and blah blah blah. So do you have to – do I want to educate him? Do I want to put him on the defensive? Or do I just want to tell him I’m okay?

In fact, Jay shared that more than a handful of times people have asked him if he wanted something in Braille. He said that he often finds himself in positions where he feels the need to explain deafness, or justify his needs as a deaf person, but generally debates whether or not it is worth the effort. Jay described a number of situations in which he felt utterly frustrated and misunderstood as a deafened person at work, in doctors’ offices, and even on the street where he has been stopped by strangers who wished to pray for his hearing to return.

So it becomes frustrating, you know? Do I want to spend my entire life convincing the world about how to adapt to hearing loss? At times I’m just done with it. I think it’s the nature of life – you’re convincing individuals but the world itself is not really changing.

Jay knew though that he could make a difference in the professional realm and he discovered that he enjoyed learning and was successful as a student. In his previous attempt at college, prior to becoming deaf, he had all but flunked out of college. In fact, Jay credits deafness for giving him motivation and purpose.

My life before coming deaf was like – if there was a barrier I would just give up, I wouldn't look for ways around that barrier....I'm not a religious person, so to speak, but I say for me that deafness was a gift from God. Becoming deaf was like an awakening and motivating factor to say, 'What am I going to do with the rest of my life?' So, you know, it's almost like deafness gave me an identity, it gave me something that made me unique. Before that, I was just who I was, but I don't think there was anything special about me.

Jay's success in college and his nascent desire to work with families coping with deafness lead him to pursue a master's degree in social work at Gallaudet University.

I was in that stage where I very heavily identified with deafness and felt like I needed to be at Gallaudet. The opportunity to be interacting with other people who were deaf, who understand, who could meet my needs as a deaf person broadened my horizons, so to speak.

Although Jay was successful as a graduate student at Gallaudet and found it to be a good opportunity to continue improving his sign language skills, he felt like an outsider during his time on the solely deaf campus, where most of his classmates were culturally deaf and identified with deaf pride.

It had people who really strongly identified with deaf culture and that's not me. I wouldn't say I had a bad experience with the people there but they just

weren't like me. And I'm not talking about everyone, but where there are people who are outsiders – they might feel like we are stepping into a place that's not ours. And maybe it waters down their culture. It's maybe a feeling of – it's hard to describe.

To compound the lack of unity that Jay felt with his fellow classmates at Gallaudet, he also found communication to be difficult; this was especially true in groups, where he fell behind in conversation because, he revealed, “I never got the full grasp of ASL. My mind still thinks in English, but I use ASL.” He also admitted that he found conversations to be lacking in appeal, which he recognized was largely due to differences in social and cultural backgrounds.

I found I'm not really that comfortable. I think a lot of it has to do with my difficulty in groups. Mostly with the deaf groups because I get lost in the translation. It's similar to being in hearing groups where it's impossible for me to lipread and I really can't follow – it's not possible for me to communicate. I find it hard for me to maintain concentration with the signing and the tracking conversation and as time goes on the more and more I'm falling behind, stepping back from the conversation. I've also noticed that the conversation topics aren't interesting to me. I like conversations to have more meat and I find Deaf conversations to be more superficial. And you know my experiences have just been very different, you know. My interests are very different so it's just hard to maybe connect in groups.

Jay furthermore explained that his humor, which he feels is a significant aspect of his personality, does not carry over to into deaf culture. He feels strongly that this is a critical aspect of his not fitting in deaf culture.

I have a hard time making my humor connect in deaf culture because it is very English, it's very dry and I've never done a good job at adapting my humor to make it match deaf culture.

Jay admitted that his lack of connection with people who are culturally deaf was partially self-imposed; and although he still does not feel he connects with the culture, he does think he has become more accepted as his sign language skills have improved.

I never felt connected to deaf culture, but I felt like – okay, more I would say I developed a rapport... more one-on-one with a person was fine, or a few people. But from then and still now, I'm not a part of deaf culture. I've never felt comfortable partly related to my language skills, ASL is not my first language. Part of it is related to my experiences which are very different. But over time, the more my language skills have improved and the more people I know that know me, I would say I'm more accepted.

Jay explained that he has heightened frustration levels when communicating with both hearing and deaf people. However, between the two groups, he indicated that he prefers to socialize with hearing people, because of common background and experiences, although he stressed the importance of communicating with hearing people who either know sign language or are skilled at adapting their communication style to match his.

If hearing people understand what it means to communicate with me one-on-one then I'm more likely – I'd feel more comfortable with the hearing group than culturally deaf. A lot of people don't get that. They don't get what they need to do to make it a shared responsibility. They either will make no adjustment or they will over exaggerate things and make it feel like it's a burden to communicate with me. It's hard to get people to understand that. But I'm most comfortable with hearing people because I've had the same experiences, but finding a group of hearing people who are comfortable communicating with me is hard.

When asked whether or not he was comfortable using his voice with hearing people for communication, Jay explained a clear set of boundaries concerning the circumstances in which he will use his voice and the ones in which he will not. Although this decision is made in part by the negative response he receives when he doesn't voice, Jay's decision of whether or not to voice depends chiefly on the message he is trying to convey, which is not necessarily the message he is overtly communicating.

I found out in some situations for me I didn't want to voice. I would just write to let people know that I was deaf, or gesture. And I noticed that a hearing person would talk to me like I wasn't as smart when I wasn't voicing. You know, they'd talk to me like I was five years old. When I voiced, people talked to me like I was older, more intelligent. I just didn't understand that. I didn't understand the difference between voicing and not voicing. It depends on the situation though. Sometimes it's actually easier for everyone if I don't voice. If they understand that I'm deaf, maybe they'll write, I can just open up a menu and point to what I

want. So, I feel like it helps with communication not to voice. Sometimes I'll voice. In situations where there's an emergency, clearly I'm going to use my voice to make sure that I'm understood. I notice when I'm with hearing people that sign I tend to voice. It's just more natural to add it. If I'm ever in a situation where I get pulled over by the cops, I want them to clearly understand that I'm deaf so I'm not going to use my voice. When I turn on my voice people assume I'm hearing. So I found I need to determine in a situation when is it most helpful for me for them to understand first that I'm deaf and second what I need. Other situations it's more important for them to understand first what I need, and second that I'm deaf. Depending on that I'll voice or not.

When asked how, as a late deafened adult, he presents himself to others, he explained the importance of not mismanaging his identity.

When a [culturally] deaf person asks me if I'm deaf I will explain that I'm a hearing person, lost my hearing, late deafened. Because when they ask me, they want to know if I'm culturally deaf. When a hearing person ask me if I'm deaf I say, 'Yes, I'm deaf' because they tend to be asking from a physical perspective. You know, that's where I feel I need to qualify my deafness with a deaf culture person because I don't want to misrepresent myself with them.

Jay concluded his interview with the following insight:

Becoming late deafened changes your life but it doesn't have to be a bad experience. For me, it's been a very positive experience.

Emerging Themes: Jay

1. Jay was not a candidate for a cochlear implant. He received an ABI that did not work. He considered that a sign from God to embrace his deafness and let go of his hearing identity.
2. He never experienced overwhelming emotions about becoming deaf.
3. Deafness was a positive, awakening and motivating experience. Jay returned to school and began a profession as social worker for families that are coping with deafness.
4. Jay sought out support services, learned sign language and prepared physically for becoming deaf. After he became deaf he sought out disability services, technological assistance (i.e. CART), and he continued to rely on support from his VR counselor.
5. Jay developed an identity as a deaf person, which he felt was more important and unique than his identity as a hearing person, which he called “vanilla.”
6. Jay became sensitive to and fought inequalities and prejudices against deaf people in the work place.
7. He feels that the majority of people don’t understand deafness and are unable to make appropriate accommodations for communication. He often feels he needs to educate people about deafness.
8. Rather than being defeated by hearing loss Jay fought for his rights in the workplace, etc.
9. Jay felt isolated until he met other deafened adults at an ALDA conference.

10. Inspired by late deafened adults at ALDA who had successfully lived their lives, Jay decided to enroll in college with the support of his VR counselor.
11. Feeling connected to his deaf identity, Jay continued his education at Gallaudet university; although he felt, and at times was treated, like an outsider, as he did not connect with deaf culture as much as the majority of students on the exclusively deaf campus.
12. Jay is careful about the labels he uses to describe himself. To hearing people he will describe himself as deaf. To culturally deaf people he describes himself as a hearing person who lost the ability to hear, as not to misrepresent himself as a culturally deaf person.
13. Jay had difficulty communicating with culturally deaf individuals because he thinks in English rather than ASL, and found it difficult to translate his humor, as well as his experiences, which he found to be vastly different.
14. Jay feels that when he uses sign language, rather than voicing, he is treated as less intelligent. Depending on the situation, whether it is more important that the person he is communicating with understand his needs or that he is deaf, he will decide whether or not to use his voice.

Participant Two: Jo

Jo is a female, forty-two-year old late deafened adult with profound deafness. She has a cochlear implant in her left ear and a hearing aid on her right. Jo relies solely on spoken English for communication. Although Jo initially arranged to meet at her office for the interview, she later requested to move the interview to a coffeehouse near her office, as she was embarrassed for her co-workers to see her being interviewed. Jo was interviewed face-to face over one meeting for ninety-five minutes and subsequent correspondances took place over multiple emails.

When we arrived at the coffeehouse, though, loud background music made communication effectively impossible. We then decided to move the interview outdoors, but because of the proximity of the shop to an airport, the interview was frequently interrupted by overhead jet engines. In spite of this, the interview was successfully completed using spoken English and the interview guide, which had been printed in advance.

During the interview, Jo described her journey of becoming a late deafened adult, which began in her final year of college, at the age of twenty. Her hearing loss was discovered after she suffered bouts of tinnitus, for which she went to her university's health clinic hoping to get a prescription for medication that would alleviate the ringing in her ears. Instead, she was informed that she needed a hearing test and was subsequently told that she had significant hearing loss and would need hearing aids. At that time, she was diagnosed with moderate to severe sensorineural hearing loss from an unknown cause. The doctor indicated that it was likely genetic; however, other than some distant cousins who are hard-of-hearing, Jo is unaware of any significant hearing loss in her family and was

shocked by her diagnosis. “I had no idea. I think I just thought people were mumbling.” Jo’s doctor suggested that it was probably “just bad luck” or “a mutant gene.”

Jo’s hearing gradually declined until she became profoundly deaf in her thirties. Such progression of hearing loss is consistent with a common timeline observed by Woodcock (1997) in which people are “hard-of-hearing in high school, no longer able to use telephone in young 20’s, a declining awareness of vowels and environmental sounds by the 30’s” (p. 156). Jo believes her hearing loss had become profound by the time she was in her mid-thirties; however, as is characteristic of individuals with progressive hearing loss, her ability to exploit residual hearing to varying degrees made it difficult for her to pinpoint precisely when she became deaf. Until less than two years ago, when Jo got a cochlear implant, she functioned with bilateral hearing aids.

Asked to elaborate on the development of being diagnosed with hearing loss, Jo described a process that seems overly simplistic and lacking in corroboration and support.

When I look back it was kind of like -- Looking back, they didn’t say anything and I didn’t ask. They said, ‘You need to get a hearing test.’ I got the hearing test. Then, ‘Okay you need hearing aids.’ And then that was it. My dad found a hearing aid dispenser in the yellow pages and we went.

Furthermore, although Jo was diagnosed at her university campus, she stated that she was never provided with information about accommodations for continuing her education, nor did she think to ask. Jo explained that it was this lack of resources that led to one of the greatest disappointments in her life.

I ended up applying to graduate school and tried to go back to school. When I did all that I didn’t know you could get accommodations -- I didn’t know you

could get a note taker and all that. And it was too hard. I think that's -- talking about regrets, one thing I really regret. Because I always loved school and that's one thing I always felt really confident about and I thought I was going to go really far. I thought I was going to get a PhD and do all this stuff and I never finished.

Because of her emotions pertaining to her hearing loss, Jo admits that even if she had been presented with options for living with hearing loss at that stage of her life, she likely would not have been willing to make the necessary changes; however, when it came to school and furthering her education, she would have made an exception. Specifically, she said that had she known could have gotten a note-taker, "that might have changed things."

When asked about her family's response to her hearing loss, she explained that she felt her family did not support her, which was extremely painful for her and caused her to emotionally distance herself from her parents.

I don't really have a strong relationship with my parents. It stems from them not being there for me. It's been a weird thing with my parents, even after my implant surgery, kind of typical of this whole experience, the first time I saw my family after the surgery, not a single person even asked how I was doing. I know it's not like they don't care. I know that my mother loves me, and all that, but it's like they forget that there's this problem. They don't even ask about it. It seems like total apathy. So I haven't really had a strong relationship with them. I don't go to them.

Without the support of her family, Jo admitted that she felt alone and coped with her hearing loss by voiding it. Although her hearing levels continued to wane through her twenties and into her thirties, she lived in denial of her hearing loss for more than a decade.

I didn't want to think about it – it was just really depressing. I didn't really let myself think about it or feel too depressed. I didn't feel as invincible anymore. I kind of just ignored it. I mean, I got the hearing aids, and I was not happy about it, but I didn't really do anything else about it. I wore the hearing aids and for the next ten years I was just in denial.

On the one hand, Jo disclosed feelings of helplessness and an altered sense of motivation, not allowing herself to think about her hearing loss, or at least about the severity and permanency of her impending deafness. On the other hand, she was motivated to prevent and find a cure for her hearing loss. As she put it, “I got the hearing aids and just thought, ‘I’m going to find a cure.’” Jo tried a variety of alternative treatments including the following:

I went to a Chinese doctor, I ate squab heads, shark cartilage, all sorts of things. One of these holistic doctors had a medium and this voice told her that I needed to eat shark cartilage. And so I just did all these things. I was just determined I was going to find a cure for it. The most drastic thing I did was I went to Germany. I found this doctor online who -- and it seems like he's had, I mean there are scientific studies that he's posted -- it seems like he has had success. It's like a low-level laser surgery. It's not really surgery. It's this low level laser treatment.

Jo shared that for a period of ten years she remained determined to find a cure for her deafness; however, as her hearing continued to decline and as more and more treatments proved to be unsuccessful, feelings of helplessness and depression began to set in. Throughout her interview Jo indicated that she did not believe she could live a meaningful life as a deaf person and stated several times that she dreaded the idea of becoming fully deaf to the extent that she preferred death.

To me it was like I'd rather live one hundred percent than half way; it's like what's the point. So that's why I thought I'd rather be dead than deaf. And I still kind of think that way. I mean, I don't want to die, but I still have that feeling.

The idea that Jo could not live fully as a deaf person permeated her narrative and was evidenced by the way she lived her life, for a ten year period, as if she were dying, rather than losing her hearing.

I'm going to be deaf by the time I'm thirty or thirty-five and I want to do all these things before I go deaf. I did things like I went skydiving. I actually got married in that time period, and divorced. I went to Italy. I didn't work. I found an Italian boyfriend, moved to Florence. It was kind of like even though I was really depressed and my self-esteem was getting worse and worse, I had this other part of me that was, 'I'm going to be deaf by the time I'm thirty or thirty-five and I want to do all these things.'

Jo returned to the United States to resume a more conventional lifestyle ten years after her original diagnosis. She explains that it was upon settling down and beginning her career that she realized she didn't fit in the hearing world anymore.

It was kind of like I really have to face it – my hearing loss is getting to the point where I couldn't fake it anymore. I really could tell that I wasn't functioning as well in the hearing world. I didn't feel like I belonged in the hearing world...I felt so alone.

Although Jo was beginning to no longer think of herself as a hearing person, she also was not ready to concede to hearing loss. Jo confessed that, although it was becoming more difficult, she was still determined to conceal her hearing loss “faking it,” by adding timely laughs and nods to conversations that she didn't necessarily hear; even so this task became more difficult as her hearing levels declined. Jo furthermore made it a point to always conceal her hearing aids.

I always have my hair long so I never show anyone my hearing aids. I remember one time I was on a first date and hearing aids were feeding back and the guy didn't know I had hearing loss. So he kept checking his car alarm he said, 'There's something wrong with my alarm.' And I didn't say a thing I just quietly turned my hearing aid off and he'd be like, 'oh, okay.' And then I'd turn it back on and he'd check it again. I just let him believe there was something wrong with his alarm. I just never told anyone, those are the kinds of things I did. I just never told anyone.

Deciding at one point to tentatively explore her deaf identity, Jo took a sign language class. She promptly decided sign language did not fit her lifestyle as a mode of communication, and furthermore concluded that she did not relate to deaf culture and deaf pride, which she first learned about in the class. She explained that it was difficult for her to see deafness as anything other than a disability.

The whole attitude that if they had a choice to be hearing they wouldn't take it – I was shocked by that. You know, I wanted to be able to hear and I wanted to be able to speak. I wanted to be part of the hearing world. It was really hard for me to relate to. I never felt a part of it – I still don't. It makes me feel uncomfortable in a way.

Feeling comfortable neither in the hearing world nor the deaf world, Jo began to experience a deep sense of loss and isolation, realizing that there was no social group with which she identified.

I don't feel comfortable in the hearing world anymore. I think actually when I really started getting depressed it's when I realized I no longer felt comfortable in the hearing world. That's the only world I ever identified with. I think that's part of the challenge of people who lose their hearing later in life. You go through a period, or maybe you stay in that period, where you no longer feel like you're part of a hearing world but you're not part of a deaf world either, and it's like, 'Where do I belong?' You kind of feel like you're all alone out there. I think what magnifies that is that you can't really socialize so it's like that feeling of isolation and withdrawal, combined with not feeling like you belong anywhere.

Because Jo felt that she did not fit in any social environment, she acknowledged that she spent the majority of her leisure time alone. She describes her insecurities surrounding communication as being largely responsible for her withdrawal from social interaction.

I just feel like I am really insecure because of being deaf. Because I don't feel like I can communicate. I mean, to me communication is everything so if I can't do that I feel insecure. I do feel really insecure all the time.

This apprehension primarily stems from anxiousness about not being able to maintain a conversation should she not be able to hear her conversation partner's questions or comments.

I don't really talk to that many people. I avoid a lot, you know, I hardly go out anymore. I don't go to a lot of social things. I'm afraid to say anything because I'm afraid someone will respond and ask me a question about what I said and I won't be able to hear, so I just kind of sit there.

However, Jo's concerns about communication not only hinge on her concerns of not understanding others' speech, but also on her own pronunciation difficulties. Jo characterized this source of embarrassment in the following passage:

The other thing I noticed is because I don't really have the volume up on my TV, I just used captioning. I realized lately, I don't know how to pronounce certain things that are going on in the news, like Alk--al--ki--yada [pronouncing "Al Qaeda"], or whatever. You know, I read it but I've never heard it pronounced. And I thought oh my gosh, I don't know how to pronounce certain things it makes me feel really unintelligent, that if I were to talk to people and this were to come up I would pronounce something wrong.

Jo expressed concern that, as a deaf person, she is not able to express her true personality. She explained that, "You can't just be yourself when you can't hear." She illustrated this point by explaining the difficulty she now experiences engaging in jokes.

Not that I think I was this witty, quick-witted person before, but you never have that kind of banter anymore. I feel stupid now. I know I'm not stupid but I feel stupid in conversations. I feel boring a lot of times because I don't participate. I just sit there.

Jokes are particularly difficult for people with hearing loss because of the importance of timing, coupled with the lower volume in which punch lines are typically delivered. This makes it particularly difficult for deaf and hard-of-hearing people to hear and to respond to in a timely and appropriately manner. More still, asking for clarification generally ruins rhythm and therefore the anticipated humor of a joke.

Because she can no longer be spontaneous or engage in banter like she could prior to losing her hearing, Jo believes that her personality has changed since losing her hearing. She recognized that 'I just even feel like I don't even know what my personality is anymore.' Jo described the loss of her former personality in terms of an emerging personality that she perceives as "stupid" and "boring." This identification is based largely on how she believes she is being perceived by others. The fear of being perceived as stupid was highlighted throughout her narrative.

I think just not being able to participate in conversations makes me feel stupid. I feel like I don't know what people are talking about and I'm trying to figure it out, or somebody says something that everyone is laughing at, and I don't know why they're laughing. It makes me feel stupid.

In addition to concerns about being branded as stupid and boring, she fears that when she doesn't hear, people who don't know she is deaf assume she is ignoring them by

reason of a personality flaw. She relates concerns about being identified as snobbish in the following example:

When I started working with my boyfriend I realized that people were saying things I didn't know. We'd be walking and he'd say, 'Oh, she just said that she likes your clothes.' And had he not said that I would have just walked right by the person without knowing or saying thank you. So that made me think, people must think I'm just a bitch. Because that happened several times where he pointed out that people were talking to me. I'm sure I ignored people a lot of times just because I didn't hear them.

Because Jo avoids social interaction, she acknowledged that she feels a deep sense of loss in not being able to make social connection, even in small talk.

To me connecting to other people, that's part of really what makes life so rich. Just even like in the grocery store and checking out and you know the cashier starts a conversation. Even if it's just like 'Oh, how are those chips?' or whatever. Just making those little connections in everyday life.

She furthermore stated that she no longer feels united even to her closest friends. She provided an example of a bachelorette party in Las Vegas in which she felt completely detached from her friends.

So we went to Las Vegas for the bachelorette party and I spent the whole weekend feeling like I didn't belong. I was the maid of honor but I felt so out of place because I couldn't hear anything. We'd go out to dinner, I couldn't hear. It's so noisy there and just feeling like you can't converse. I couldn't connect with people.

After the dissolution of her brief marriage, Jo tried dating, but quickly gave up after finding the communication barrier to be too difficult.

I was at the point where I just wasn't going to date anymore, I don't care. It was too hard. I tried online dating but I never did meet anyone face-to-face. And then I tried this dating service where they say go to this bar and so you don't have to call anyone, they do everything for you. You just go and you meet the person, but I found that the actual dating was really hard for me because you can't just can't talk and laugh and enjoy it. I just kind of gave up on dating. Whatever, I'm just not even going to try.

This loss of connection to people and long suffering isolation eventually led Jo to seek out support groups for deaf people, more than twenty years after she was first diagnosed with hearing loss.

I had emotions that were depression, helplessness, loneliness. I felt totally alone. I didn't know what to do; I was helpless. That's when I started looking for support groups. I found this hearing loss chapter.

Jo initially had no idea where to begin looking for a support group. The first deaf event that she attended was a holiday party at which everyone signed. Although she “felt out of place because they were all culturally deaf and signed,” it was at that party that she was referred to her local chapter of Hearing Loss Association of America (HLAA).

Jo joined HLAA at a time when she claimed to have hit rock bottom and was desperate for support. The group has provided a sense of community and belonging for Jo. Events hosted by the group are now her primary source of social life. Being able to make

connections with people who share a similar experience to hers has lessened her sense of isolation.

I honestly don't know where I would be without this group. I was so depressed when I found them. I was rock bottom. It really was a lifesaver for me. It just really made me feel like maybe I'm not alone. I felt a sense of belonging I hadn't felt in a really long time.

According to Jo, because of being around the other, more well adjusted late deafened adults in the support group that she has been able to gain much more acceptance about her condition.

Prior to joining the hearing loss support group, Jo had seemed resigned to the idea that she could not have a relationship as a deafened person, with the exception of a brief marriage that she agreed to only because she thought, "this person will accept me even if I go deaf." It wasn't until she joined the support group that she saw it was possible to be deaf and have a relationship: "I saw hearing husbands with their deaf wives and that really helped me have hope."

After years of avoiding romantic connections, Jo began dating a man she worked with. She explains in the following excerpt that it was easy and natural to begin a relationship with him because he already knew she was deaf:

And then I started working here. My boyfriend sits right next to me. So I think because we worked together, I wasn't thinking I was going to date this person – and I had to tell everyone at work about my hearing loss – so I think that right away he knew, so I didn't have to go through that whole thing of trying to get to know someone, telling them about my hearing loss and all that stuff. He

already knew all that. We went to the beach on our first date and played scrabble, so it wasn't a loud place. He was just really open to just doing whatever was easiest for me and that was important.

As Jo began to accept the reality of her deafness and meet other late deafened adults who were managing their hearing loss, she began to consider getting a cochlear implant. This had previously not been an option for Jo, because she saw cochlear implants as a treatment for incurable deafness – a condition to which she was not ready to surrender. In the following dialogue Jo depicts her thought process leading up to getting implanted:

Basically before the implant my biggest fear was getting to the point where I would have to get an implant. That is when I used to say I'd rather be dead than deaf. I never wanted to get an implant. It signified to me that I was totally deaf. I got to the point, and it seemed like people in the group who had so much success with the implant, I finally mustered up the courage to actually start considering it and get evaluated, and seeing that maybe it was a good option for me. So I finally decided, 'Okay, I'm going to do it.'

Although Jo was feeling positive about the procedure and was assured she was a good candidate for the technology, a year and a half after the procedure, she is not receiving the auditory benefit from the implant that she had expected.

I got the implant and it hasn't been working well for some reason. I've had hardly any progress. The comprehension has gotten a little better but the sound quality has remained really, really bad. Where most people after a month or two months, things start sounding normal, mine still sounds like chipmunks or, you know, how people describe the robots. It's like birds squawking. It's been

really challenging. I feel like I've reached that point in my mid 30's when I was rock bottom and I feel like in the last year I've gone through that again. [crying]. It's been really, really challenging, so that's where I am now.

The lack of success with her implant and the constant squawking in her ear, which she further described as, “Mickey Mouse in a deep, deep well,” has lead to feelings of frustration and hopelessness that are reminiscent of the emotions she described after her initial diagnosis.

I thought, 'Okay, I'm going to try Western medicine, I'm going to try something that has actually worked for people, that has validity and scientific support', and that still hasn't worked. I think about all those things I've tried over the years, all those holistic things. I've tried all those things and nothing has worked. This is just one more thing.

Jo's disappointment in the efficacy of her implant has clearly re-initiated a cycle of grieving; although this time she admittedly has better coping skills and the support of her boyfriend and the hearing loss group, “which has been a savior.” She also pointed out that she is seeking the support of a professional counselor, who isn't particularly experienced with deafness but has nevertheless helped her tremendously with the depression and anxiety that stem from deafness.

While on the one hand Jo admits that she regrets getting the implant, “because it's just horrible” and because it destroyed any residual hearing that she had remaining in her left ear, on the other hand she feels she made the right decision based on the information that was available to her.

I know I made the right choice for me based on statistics. The cochlear implant company's website says there's a one hundred percent success rate. Every person I know who has gotten one is doing great, so I can't say I regret it. I feel like I made the right decision.

Jo continues to seek help from a cochlear implant specialist, to no avail. After a recent trip to John Hopkins Hospital, she reported, "The audiologist couldn't really help me, it appears to be something wrong with my brain not adapting to the C.I." Jo is unsure whether or not she will continue use of the implant. She admits that it does help with speech comprehension but the sound quality continues to be nearly unbearable.

It does help with comprehension. I notice when I take it off I don't hear as well because I'm just relying on the one hearing aid. So it helps me hear people better; but then when I have it on I hear this horrible, horrible voice. So I don't know what to do. It's been really awful and frustrating.

Jo also explained that because of the support of the group, she is now less likely to hide her hearing loss and is more comfortable revealing it to people. "That's one thing about this hearing group that's really helped me to accept it and start telling people about it. I've gotten much better about that." However, although Jo feels she is coming to terms with her deafness and learning to advocate for her needs, she still admits difficulty managing this information. Because she has difficulty pinpointing when and how to appropriately reveal her hearing loss, she often ends up missing the opportunity.

It's like, well, recently we took a trip by train, my boyfriend and I. So we sat down and the people -- I thought we were just going to read the entire time -- well we ended up sitting across from a couple and they were so talkative and

outgoing and fun and I had been sitting there and just going along with it and was like 'oh ha-ha' just laughing when everyone else did. And then it was a half an hour later and I thought, 'They're going to just keep talking.' And they wanted to play games and by that point I was too embarrassed to say, 'well, actually I'm deaf,' after half an hour of faking it and pretending I heard everything. So I still do that a lot.

In fact, Jo continues to have mixed feeling about having an invisible disability. She admits that while she sometimes still wants to conceal her disability, she also wishes for more understanding and acceptance of the issue. As she put it:

And I think that's kind of a blessing and a curse. I speak normal so I don't think people realize the magnitude of it. It's great in a way that people think you're normal and that everything is great. But it's an invisible disability and it's ignored and it's misunderstood.

Jo largely blames the media for misrepresenting deafness. In the following quote she explains her frustration about how deafness is portrayed in the media.

You see Marlee Matlin and Heather Whitestone, you see all these people that are just great and not that I want to say what they are doing is horrible, but I think that whole thing about this disability is to me it is really, really challenging and really, really devastating and I wish more people knew that part of it. I think it's great that Marlee Matlin is a role model for deaf people, but at the same time that's not representative of who I am at all. I don't feel I can do all those things because I can't communicate the way she does. So there's part of me that really wants to say that's not who we are. That part of

me is getting stronger and stronger. It's almost like I get angry sometimes just thinking how I don't feel like anybody really knows. It's so misunderstood. So that is something I get frustrated about. I don't want to sound like a victim and it sucks and it's so hard. But it is hard. I think when people see these stories of 'Oh, she put on this implant and she can hear again,' and they think everything is great and you're cured. I feel like it is so misunderstood. I mean I think it's great that some people are doing great but it's like the things you see on TV are far from the truth a lot of the times and it just causes misunderstandings in the general public.

Jo is currently journaling her memoirs and hopes to someday turn them into a book in order to increase public awareness about the realities of deafness, as she experiences them, and to support other late deafened adults through their journeys.

Emerging Themes: Jo

1. Jo spent more than ten years in denial about her hearing loss. She sought out numerous cures for her deafness in that time period.
2. She often thought that she would rather be dead than deaf.
3. Jo spent a period of time enjoying things that she thought she could only enjoy as a hearing person and wanted to experience before becoming deaf. These activities were not necessarily related to hearing. (skydiving, living abroad, etc.)
4. Jo does not have the support of her family
5. Jo feels that her inability to effectively communicate has affected her personality. She feels stupid and snobbish in social situations.

6. Jo avoids many social situations and is largely isolated because of her deafness and difficulty with communication. Her social interactions are now primarily with other late deafened adults.
7. Jo took one class to try to learn sign language. She decided it was not a functional mode of communication for her.
8. Jo does not relate to deaf culture and finds the entire premise of deaf pride strange; however, she also feels she no longer has a connection with hearing culture.
9. Jo tries to mask her hearing loss by “faking it” in conversations she can’t necessarily hear. She covers her hearing aids, cochlear implant.
10. Jo relies heavily on her boyfriend for communication and interaction.
11. Jo receives support from late deafened adults she met through HLAA and has been inspired by the success other members have had with technology, particularly cochlear implants.
12. Jo’s worst fear was that she would need a cochlear implant; however, she later accepted that it was a good option for her and proceeded with the surgery.
13. Jo has inner conflict about unfulfilled expectations of the cochlear implant. The lack of success of the technology has re-instigated feelings of helplessness that she felt after her original diagnosis. She described it as hitting rock bottom again.
14. Jo feels that deafness in the media is not representative of the struggles she faces as a late deafened adult. She feels that people need to be made more aware of the experience of late deafened adults and the negative impact deafness can have on their lives.

15. Jo is currently writing about her experience becoming deaf and hopes to publish a book.

Participant Three: Kat

Kat is a 51-year-old native Argentinean. Although born in Argentina with Spanish as her first language, she moved to America with her family at the age of nine, and has since used English as her primary mode of communication. Kat was interviewed over two meetings, in her home, for a total of one-hundred and twenty minutes.

In her late twenties, Kat started noticing difficulty hearing with her right ear, especially on the phone. By her mid-thirties she was diagnosed with a rare “cookie bite” hearing loss¹⁰, which typically indicates a genetic origin; she is unaware of any other deafness in her family other than age-related hearing loss. At the time of diagnosis, Kat was told she would likely become deaf; and over the next ten to fifteen years, her hearing progressively declined until she was profoundly deaf in her mid thirties. At the time of diagnosis she was an executive at a major television network; she and her husband now operate a small business out of their home in which they do consulting work for the television industry. She depicts the origin of her hearing loss in the following passage:

So my hearing was normal all through school. I went all through school, I went all through college, I majored in design with a bachelors. And then I was working, and in my late twenties I think I started noticing that in my right ear I had trouble on the phone. I kept thinking ‘Oh, we have a bad connection.’ and I would switch ears and I was fine.

¹⁰ A “cookie bite” hearing loss derives its name from the specific form of the hearing curve in the audiogram of a person suffering from this particular kind of sensorineural hearing loss. The curve resembles the form of a cookie that has been bitten. It is a relatively rare hearing impairment and is characterised by the inability of the sufferers to hear mid-frequency sounds, although they manage to preserve a good perception of high and low frequency sounds. (Oates, 2002)

Kat's inability to use the phone persisted until she was no longer able to ignore it, at which point she decided to seek medical attention from her family doctor.

He was an internist and the first thing he did was check for a tumor. He was concerned about a tumor so he did a CAT-SCAN. He said he thought that what happened was I got a flu and it settled in my ear and caused damage. He said, 'but since your other ear is fine there really isn't anything to do.'

Deciding there was no cause for concern about her hearing, Kat continued to go about her life as normal, until the hearing in her right ear declined to an unmanageable level. At the same time, she also suspected she was beginning to lose some hearing in her left ear, as well. Starting to feel her hearing difficulties might be more significant than she first thought, Kat made an appointment with an otolaryngologist (ENT).

So then I went to a second doctor and he wasn't a very nice person. He thought that I had – that what happened was the bones had extra bone growth. So he thought he could go in and scrape that off and my hearing would return. So he did it in my better ear, he tried fixing it. I remember kind of waking up out of surgery and he said, 'Well, I couldn't do anything.' And he left. So the nurse packed my ear and they sent me home and I was totally confused as to what was going on. Also, my packing started getting really painful and I called and I said I need painkillers and he wouldn't get on the phone with me and so the nurse approved the pain killers but he wouldn't talk to me. So finally I went in after the two weeks to get my packing removed and he just literally pulled it out and it had become stuck to my eardrum. And it was so painful that I was like a cat on the roof. I said 'Ouch! That hurt!' and he said, 'It didn't hurt that

much.' I said, 'Yes, it did!' I said 'So, what's wrong with me?' He said, 'I don't know. I can't help you.' And he left the room and that was it, he left the room. I followed him and said, 'What do I do now?' He said, 'I don't know.' And that was it. He was very offended that he couldn't fix me, that's what I felt. He felt that it was a personal affront to him as opposed to just saying, 'I really don't know.' I wasn't mad. I just wanted to know what to do.

Left with more questions than answers, Kat spent several years feeling “really freaked out” and eventually began looking for answers on her own. It was then that Kat came across information about the House Ear Institute and promptly made an appointment for an evaluation.

They said, 'You have a very weird hearing loss. You have a "cookie bite." which means I was losing middle ranges not high and low which is very unusual. They said it's a very rare form of genetic hearing loss that shows up in adulthood. 'You're going to go deaf. You're always going to have sound, you're not going to go completely deaf', like I am now, but they said, 'At some point you won't be able to understand speech at all.' And it was just shattering. And I said, 'You can't do anything?' They said I'd have to get hearing aids and just do the best I can. They gave me a little pamphlet about telling your family about hearing loss.

Kat was undeniably shocked after receiving the diagnosis that she would become deaf; and although she sensed that from that point onward her life would never be the same, the full consequence of her impending deafness did not have an immediate affect on her. She explains her reaction to becoming deaf in the following excerpt:

The hardest thing is accepting that your life won't be what you thought it was going to be – that you're going to be different from what you thought. You're not going to be whatever normal is. I think the shock of just having somebody say, 'Um, you're going to go deaf.' I just kept thinking, 'Like Beethoven?' And it was just like, 'You're kidding me!' You know, 'Really?' And I think that that's what it is. From that day forward your life is different. There's that sense of, 'I never saw this coming.'

While on the one hand Kat was experiencing shock about her diagnosis and anticipating what life as a deaf person would look like; on the other hand, she was determined that through pure determination she could overcome deafness.

I was like totally freaking out but what's weird about it is in my mind I went in total denial for years. I assumed, because I'm a type-A personality, if I just work hard enough, I can hear. I tried like crazy.

Kat took the first step in conquering hearing loss and maintaining her hearing status by being fitted for hearing aids.

I got hearing aids. The first person I went to see said, 'What hearing aids do you want?' And at the time I didn't know so I said, 'I guess the small ones.' You know, the digital ones? So I spent all this money and I started putting them on and I hated them. I never liked hearing aids, they never worked for me.

Kat explained that she tried to wear them everyday, especially at work, despite the pain and discomfort she was experiencing from them. She described immense annoyance with her hearing aids that resulted in her spending a considerable amount of her day, “taking them out, and putting them back in, and taking them out.” She later found out, not

through her audiologist, but through talking with other people with hearing loss, that the difficulties she had been suffering were symptoms of recruitment¹¹.

What happened was I had recruitment, which I'd never heard of. No one ever told me. No medical person ever told me about this. They said to wear them all the time, but I would go insane.

Despite the high cost of hearing aids, Kat went through several pairs, looking for a combination of comfort and functionality. She learned from a new audiologist that her first hearing aids weren't powerful enough for her hearing loss. She then graduated to the bigger, and more powerful, behind-the-ear hearing aids.

I went through three sets. They got bigger. I was just like, 'I'll try anything.' And I actually liked the bigger ones much better. The little ones, they – I had a weird twist inside my ear and so they'd get really – the mold kind of hurt. So I actually like the bigger, behind-the-ear ones anyway. The best audiologist I had with my hearing aids said my first set wasn't strong enough already – when I got them. And they're like thousands of dollars so it's like you really need someone who knows what they're doing.

Over the next several years, as Kat's hearing levels continued to decline, and as she came to realize she was indeed going to become completely deaf, the emotions stemming from the loss began to surface as anger, depression, and frustration. She explains the manifestation of these emotions:

¹¹ Recruitment is a common condition in individuals with hearing loss that causes the perception of sound to be exaggerated; so that even though there is only a small increase in the noise levels, sound may seem much louder, become distorted and cause discomfort (Clark & Martin, 2014).

I was mad. I was depressed. I didn't want to do anything. I remember writing a sad poem about, I just want to take these off [gesture: pulling hearing aids off] and not talk to anybody and not hear anybody. I'm sick of you people – hearing people. I hate them. I'm just going to read books and watch movies with captioning and that's it. Because you do, you get tired. And I felt like everything was a wall. It was like life was too much work. And so I completely understand people when they get depressed. It's hard to get up in the morning and face the world. It's hard.

Kat described her mental state at that time as “going through a mental crisis,” in which everything hurt her feelings and felt like a personal attack. While, to a certain extent, she realized she was acting defensively, she also thought that people were proving to be “unhelpful” and “un-open” to making any accommodations to communicate with her. She relived the following story about such an incident:

You get defensive so you come off defensive to other people. I got into so many fights with cashiers. I remember going to the market and I don't remember if one of my hearing aid batteries went out or something but I was freaking out. I was freaking out when I got to the cash register and I don't know what the cashier asked me. I was prepared for 'paper or plastic' but then she asked something else and I said, 'What?' and she said, 'blah blah blah.' I said, 'I can't make it out. I have trouble hearing.' And she got defensive. And I'm sure I came off angry and she said, 'It's not that loud in here.' And I said, 'I'm deaf, okay!' And I started slamming stuff around and she got freaked out. And then I burst

into tears and I ran home and I said, 'I'm never going to the market again.' It was just horrible. It was just a nightmare.

Kat admitted that because she generally dealt with her hearing loss defensively, people often, in return, responded in a defensive manner. She explained:

What happened a lot was that instead of saying, which now I do. Now I just say, 'Look, I'm deaf I wear these [pointing to ears], but I miss a lot. What did you say?' and if you say it like that they don't get defensive. But if you say it already like you did something wrong and then they're like [gesture: boxing stance].

It took time and a little help for Kat to let go of some of the anger associated with her hearing loss and come to see it instead as masked pain.

I had a lot of resentment. A long time ago I went to a therapist and she said however mad you are is how sad you are. It's a disguise for sadness. And I think I was really sad about my loss. But it came off as anger and frustration because that's easier. It's easier to bang stuff around than it is to say, "Oh, I'm so depressed."

Kat emphasized that when people lose their hearing late, it becomes all-consuming and it touches on every part of their life. For her, it affected her career as well as her relationships with her husband, her friends and her family.

With her husband, with whom she also worked, the most difficult task was to establish boundaries of what was being helpful and supportive and what was crossing the line of not allowing for her autonomy.

My husband and I were friends for many years. He's known me since I heard perfectly. I think, at the beginning, when we got together romantically too, he

was really pushing for me. I had to learn to say, 'I need to do it,' because he can't do it for me. Because he'd be like [gesture: macho posture] 'Hey, she needs this and that.' Which was great, but you don't want that, you know. You have to do it yourself, because otherwise, that kind of puts you down, too, without meaning to. But you know, he's been really good. We've had trouble. I mean, I can't say it's always easy. Sometimes I catch him rolling his eyes at me.

As her hearing loss advanced, Kat said she got to the point where, some days, in some situations she “couldn’t hear a thing,” and “couldn’t function at all.” As she was having more and more difficulties successfully fulfilling her role in her work, she realized she did need some support.

To no avail, Kat explained to her supervisors that her hearing loss was affecting her ability to do her job, especially on the phone, and asked for assistance in obtaining basic accommodations, such as an adaptable phone. She described their attitude about her request and about her hearing loss, in general, as indifference. Her husband, who was at that time her friend and colleague, decided to take matters into his own hands and ordered a phone for her, himself. She explained the scenario as follows:

I couldn't hear on the phone at work and they said, 'Well, get a new phone. Contact the phone guy.' So I tried to do that and he kept blowing me off. All I wanted was a better phone for hearing loss but I didn't know what to ask for. So [my husband], who was my good friend then, he called directly to the phone company. He ordered a phone and it was like fifty bucks and you could turn it up and it had a handset. And we got in trouble because we didn't follow proper channels but proper channels were totally not responding, at all.

Still wanting to exert some independence and foster some understanding amongst her colleagues, Kat decided to send out an interdepartmental email “coming-out” about her hearing loss and explaining her needs for effectual communication. She was devastated when there was no response.

I sent out a memo to the entire department, which I cried through saying, ‘I’m losing my hearing and really need your help, you know all the obvious things: look at me when you talk to me, don’t stand with light behind you,’ all that stuff. And I sent it out to like thirty people, not one person said a word. And I actually had to ask my friends, ‘Did you get my memo?’ And [my husband] said, ‘Yeah it went out.’ and one person said, ‘Oh, I feel bad for you.’ and that was it. Nobody said, ‘What should I do?’ And nobody acted any differently. And I was just crushed because that was really hard for me. It didn’t change anything. Nothing happened.

The perceived disregard to Kat’s emotionally charged “coming-out” email was not only hurtful, it also triggered insecurities in that she began viewing the negligence of others in facilitating successful communication as personal attacks.

I was very mad. I had a lot of anger for a long time. And when people would forget to look at me I always thought they were doing it on purpose. ‘Why do I keep having to remind people? Why don’t they remember?’

Kat continued to have difficulty at work and after multiple attempts to explain what her limitations at work were, she continued to be assigned jobs in which she couldn’t function in noisy work conditions. She gives the following example of working on photo-shoots:

Another thing that happened was I was used to doing photo-shoots with actors. Every year we would be assigned to television shows and we would do massive photo-shoots, in massive studios or outdoors, with actors and I was supposed to art direct them. And what happens is they play music, and you have hair people, and you have wardrobe people, and their agent, and other actors and everybody is talking at one time in these giant rooms with big ceilings and I just couldn't do them after a while. I just couldn't or I would say the wrong thing. And I asked my supervisor and I said, 'You know, I can do them as far as directing, but I need someone to help me hear.' And she didn't get it and kept assigning me photo-shoots without any assistance.

Frustrated, Kat decided it was time to defer to the human resources department, who proved to be supportive of her disability but less than helpful in offering solutions that would enable her to perform her job duties.

Their attitude was, 'Well, if they're prejudice against you, they can't be. They have to treat you equally because of ADA [Americans with Disability Act].' And it's like, 'Yes, I understand the legal ramifications but I'm not threatening to sue, they aren't threatening to fire me, it has to do with I don't know how to deal with this.'

Kat acknowledged that one of the biggest obstacles she faced when asking for help at work was knowing what to ask for. She was never made aware of Assistive Listening Devices that could help her in the work place. In fact, she felt that after being given the diagnosis that she would become deaf, she was not provided any support or guidance from audiologists.

That's my big problem with audiologists is that you give people the news that they have X-amount of hearing loss and they don't say and I understand that there are emotions, but still, when people are hit with something that heavy you should give them something written, some websites to look at, something they can go home and say, 'Okay, what do I do now?' because it's just like you're just falling through the floor and there's nothing to grab onto.

Finally, after not receiving any accommodations or assistance at work that would have enabled her to successfully do her job, Kat left her position with the television network and started a consulting business with her husband in which she was able to, for the most part, create a safe and comfortable work environment.

What happened was we started our own business and that helped me a lot because I just worked with my husband. We work at home. He did all the phones and everything else. I just did email or talked to him so that I created my own safe little, like, bubble, where I just had my family, my friends and my husband.

Kat explained, though, that while working for herself with her husband was a less stressful environment, it wasn't always without difficulty. At times, she was thrown into unexpected situations by clients. She illustrates:

For instance, we had Fox as a client and one day they said, 'Come on in. We're going to show you a pilot.' We thought, 'We'll be there, in house, look at the pilot, and come home.' No! It was a full day of all their pilots, which weren't captioned, and then we're going to sit around and come up with ideas. I heard

nothing all day. I mean, nothing. I mean I was just like [shaking head and putting hand on face]. It was the longest day of my life.

It was after her experience in that meeting that Kat came to realize that she had become expert at faking her way through these types of situations and conversations; nodding along and pretending she heard what was said. She was confident that no one suspected exactly how lost she was.

They didn't know. I faked it all day. I mean they knew I was hard-of-hearing but they thought I was getting it. And I wasn't getting anything. My husband would give me cues here and there. But that's the most I've sweated in my entire life. And I was such a nervous wreck that I was actually hearing less well than I should have; because I was just like, 'No one talk to me.' I mean, especially when we were in a big group because my husband was making suggestions and stuff and so we looked like we knew what we were doing, which we did but I just couldn't hear anything, it was just, uh, what a nightmare.

Lack of understanding about her hearing loss was not confined to the workplace. When Kat disclosed her hearing loss and her imminent deafness to her family she felt that, much like her coworkers, they just did not grasp the gravity of her situation.

I don't think they really got it. I think they were trying to be sympathetic but I don't think they really understood that it was going to turn into what it turned into. I think they thought, 'Oh, just some trouble, um, you know, hearing.' But I think they thought it was just this thing where they'd have to talk a little louder or, you know, be a little more careful; but I don't think they really got it. And I don't think they got how freaked out I was.

She explained that any acknowledgement of her hearing loss from her tended to be blanketed in mocking connotations.

My family has a tendency to tease. When I first started losing my hearing they were joking about it. And it's like, 'No, you guys. This is serious.' And they were like, 'I guess she's not taking a joke very well.' But people do, they will – you'll say, 'I have trouble hearing.' And they'll say, 'What?' Like that's really funny. That happens all the time. Or they'll start talking without a voice; they'll go [gesture: moving lips as in speech]. And I'll go, 'Gee, I've never seen that before.' I don't know why people think that's funny. It's like so irritating and it happened like hundreds of times.

Kat has observed that there seems to be a double standard about what is acceptable to say to hard-of-hearing people, but not to deaf people. She explained that, “For whatever reason it is okay to make fun of hard-of-hearing people, but it's really not cool to make fun of deaf people.” Kat expressed a bit of leniency toward her family, but suggested that, in general, if people were to make fun of culturally deaf people the way they do of hard-of-hearing people, “they would rightfully get punched right in the face.”

In interactions with family and friends, Kat asserts that she usually feels like she is living in a foreign country, where communication with locals is an arduous task that results in her gleaning only bits and pieces of conversation.

I felt like I moved to a foreign country and everyone was talking in a language and I couldn't understand. Every now and then I would pick up a word but most of the time it was a foreign language even though everything looked the same.

When she attended social events, Kat would often depend on her friends and family to function as her “hearing dogs,” serving to facilitate communication, but instead they often left her out of conversations. She describes it as follows:

My friends, or my family, or my husband – they became my hearing dogs. And so all of the sudden it turned to Penn and Teller. You’re the person standing next to the person who talks. So the other people start going, ‘So how’s she doing?’ and you’re standing right there. And it’s like you resent the other person, which is really mean because you’re putting this big burden on them. In a way it’s totally unfair and sometimes they get really tired. But, you know, and then they do the famous thing where it’s like if I miss something I’d say, ‘Well, what did they say?’ and they’d say, ‘Oh never mind. It was stupid.’

With her frustration gradually increasing as her hearing level and access to speech decreasing, she became increasingly aware of changes in her interactions with others and, eventually, she started to avoid social situations all together.

I think that’s the part that’s the hardest is you lose your sense of fun. In the sense of I get nervous meeting people. I became very, ‘I don’t want to go to new places. I don’t want to go to parties.’ And everything became – things that now – if you walk into a room and you’re a hearing person and you think, for whatever reason, you think the crowd is kind of snotty and you don’t have a good time you just figure, ‘Well, they’re jerks or maybe I’m shy or whatever.’ When you have such bad hearing it all becomes about you. It all became, ‘I would’ve had a great time but I couldn’t hear.’ Or, ‘They didn’t like me because I couldn’t hear.’ Or ‘They think I’m stupid.’

Kat described a loss of self, in that she no longer felt like the gregarious, quick-witted person that she once perceived herself to be.

And if you're a person who has achieved, you know, felt good about achieving, and all of the sudden people are acting like – I'm a talker and I think of myself as clever, whether I was or not, and you can't do any of that. And I dropped back and back and back. And I stopped talking and stopped wanting people to talk to me and then I didn't know how to deal with anything.

By avoiding uncomfortable social situations, Kat had become more and more isolated.

It's a horrible isolating feeling. It was like it kind of took over my life in some ways in a sense that everything became about whether I was going to understand or not. I lost some of my sense of self. What I thought I was, I wasn't, anymore. I don't think people get it. I don't think they understand what it feels like to be that isolated and that worried all the time.

The sense of isolation that Kat experienced, she explains, not only happened in social situation, but in many other situations where she felt she was not connected to her environment. She described the following experience at an airport in which she felt totally alone, which led to feelings of fear and anxiety:

You lose your sense that it's going to be okay. You know that you're going to have bad days. And certain things panic, and some things still panic me – like airport announcements. I had things, which in hindsight are funny, but not so funny at the time. I was supposed to go to Argentina. I was very hard-of-hearing at the time and I don't use Spanish very much. So, you know, you get, I don't keep up with understanding it. So, the plane it delayed like three hours. I

told my family, you guys go ahead and I'll tell the people at the desk that I'm hard-of-hearing and I'll be sitting here reading and then I'll just get on the plane. So they left. So, I'm sitting there reading and I tell the lady and she says, 'Oh, you have two and a half, three hours.' So I'm sitting there reading and I don't look up and then all of the sudden I look up it's empty. And then all of the sudden I hear my name, just because it has a certain ring to it. So I run up to the desk and they tell me that they had forgotten that they were supposed to come and get me if I didn't hear. And they said, 'Oh, the plane moved up an hour. It's all loaded we're just waiting for you.' And I had to run onto the plane. I almost missed an international flight.

Kat explained that her experience at the airport, along with numerous other uncomfortable instances in which a lack of hearing, or mishearing, has led to her being perceived by others as less than the intelligent woman she is.

It's like people think you're really stupid and you want to walk around saying, 'I'm not stupid, I just have trouble hearing.' But it makes you seem really lost and out of it. And then people have a tendency to talk over your head or just think you're slow.

In an effort to confront her fears and overcome isolation, and thinking it would still be a somewhat independent activity, Kat decided to sign up for a writing class. The plan backfired, however, when she realized just how little she could hear and follow the classroom discussions and activities.

I liked writing and I've always liked writing and I decided to take a writing class at night. The first thing the teacher did was say to go around the room,

one person starts a story and then each person continues. I didn't hear anybody in the whole class.

It was this experience in her writing class that led to Kat's realization of how much hearing she had already lost, and that she was, in fact, becoming deaf. She recounts the moment of sudden realization:

That was a night that it hit me in the face and I knew from then on it was real. Because in the whole room, I didn't hear anybody. I sat way in the front so I could hear the teacher and when she got to me and told me to continue the story and I said, 'I wear hearing aids I couldn't hear anybody' and he said, 'Don't be shy, continue the story.' And I said, 'No I really didn't hear.' And he didn't believe me and I was so defensive. I was just ready to burst into tears because I was so shocked that I didn't hear anybody. So I walked out. I cried all the way home. I thought, 'It's really happening. I'm going deaf.'

Faced with the recognition that she was going to be deaf sooner than later, and was now barely functioning as a hard-of-hearing person. Kat and her family were at a loss for what to do.

My family didn't know what to do, they were like, 'Do we take sign? What do we do?' and finally after some time [my husband] and I were working together after starting our business, and he said, 'You know there's an ASL class, why don't you try taking that?' and I said, 'I don't want to go because I won't understand the ASL teacher when he talks.' And he said, 'I'll go with you. We'll go once, if you hate it we'll leave and you never have to go back.'

As it turned out, the ASL teacher in her class was also a late deafened adult.

He had NF2 and he was actually hard to understand because his face was kind of frozen but he was so patient. And the minute he realized I had hearing loss he was very good with me and he invited me to a group he was starting out with somebody which was an ALDA group.

Kat began attending Association of Late Deafened Adult meetings and joining group activities. She said that the group was particularly favorable because of the comfort level she felt in different interactions, and for the life-long friends that she made.

I joined ALDA. So that kind of started and we did a lot of, um, a lot of what we did were activities, because of lot of what people want to do was get together with a bunch of people that they feel comfortable with and they don't have to worry about saying, 'What?' or, 'I didn't understand.' So it makes it really comfortable.

Kat explained that she was particularly comfortable at the support group social functions because they didn't "do all the stuff you do at parties that makes it more difficult." For instance, at the ALDA functions, they did not play music, the lights were never dimmed, and for all sporting events and movies there was captioning.

In addition to getting connected to other late deafened adults through ALDA, it was through her ASL class that she first learned about deaf culture.

I didn't realize. That's what was good about the classes. The teacher, being completely deaf, was familiar with both sign language and – but he never claimed to be a great signer, he was more of an English signer, but he explained to us about deaf culture and he explained to us about ASL versus cochlear

implants or whatever and that was really helpful because a lot of people don't really understand the differences.

Although deafness was becoming a focal point of Kat's life, in that she felt that every aspect of her life and every interaction she had at that time was affected by her hearing loss, she reported never considering joining the signing deaf community or even using sign language as her primary mode of communication. However, as she learned the language and the culture, she came to appreciate the beauty of American Sign Language. She explained her impression of the language as follows:

I think ASL is beautiful. In performances when there is captioning and ASL I like watching the interpreters. There's a beauty to it that is just different than speech. It's just a different thing. Um it's almost like a dance. You know, it's just really nice. But I didn't know anyone who was deaf except my sign language teacher and he also talked. Had I known anyone who was deaf I might have been tempted. But the problem was everyone I knew, my family, was hearing. It would have been a really hard thing for me.

Kat furthermore explained that in addition to the impracticality of choosing sign language as a means of communication, there were other factors that prevented her from considering joining the signing deaf community, including an admitted level of uneasiness about interacting with culturally deaf individuals. She gave the following example of an interaction that took place in an ASL classroom, with her instructor who was culturally deaf:

I think I was kind of afraid of deaf people, not because they were deaf, but because I just thought I wasn't going to fit in. And then I had sort of a bad

experience too. I took an ASL class through adult education and the woman was very deaf culture. And then what happened to me was she was just signing so we were all lost, that was fine. The whole class was lost. But then she started to speak and to have somebody in the class who knew some sign to translate into sign. Well I couldn't look at the teacher and not look at the person signing, because I couldn't understand without looking at the interpreter. And she yelled at me and said, 'It's really rude to not look at me,' basically. And I said, 'I know but I can't do it. I can't understand what everyone else is understanding.' She said, 'Don't look at her, look at me.' 'I understand for deaf people it's rude to look at the interpreter because they aren't supposed to be there, but I can't do what you're asking me to do, you know, because then I'll be lost.' I actually wrote her a really nasty note. I quit the class.

Kat realized, when looking back, that her own emotional vulnerability played a significant role in the negative experience she had with her ASL teacher; however, she still holds onto that experience, which enhances her fear of communicating with the signing deaf community.

I realize a lot of it was my own over-sensitive, emotional state because I shouldn't have gotten mad. I should have gone back and hung out and made it work. But it was like I felt attacked and I just wasn't strong enough to handle that.

Furthermore, she explained that there are inherent differences in people who grew up signing and those who were socialized as hearing, speaking individuals who later became deaf.

I think because we come from such completely different views, different viewpoints, to us we lost something, to them, um, they feel defined. And I'm not saying that deaf people don't have issues and things they are dealing with. I know they went through persecution and all sorts of stuff all the time, but if they're healthy about their deafness, um, they just say, 'Okay, this is what I am. I'm deaf and I use sign, and I need an interpreter.' End of story.

Kat expounded on the idea that there is a clear division between culturally deaf, signing individuals and late deafened adults. Kat explained that she thinks there is more to the indoctrination into deaf culture than just learning the language, and that she believes it is difficult for late deafened adults, who were socialized as hearing people, to join deaf culture.

There's a shared sense of sensibility that I don't share and I would feel a little odd. My feeling is we were born into a hearing world and so it would mean starting over, much later in life to go into deaf culture and trying to catch up.

Kat also explained that she believed she was best able to express her true personality, and just be herself in the language she was most comfortable with – spoken English. She shared the following analogy to illustrate her point:

Well, it's like my dad's first language is Spanish. And he comes over and stays with us. My husband doesn't understand anything he's saying, ever, because of his accent. He used to live here but then he went back to Argentina, he doesn't practice English very much. He understands everything, he reads English perfectly, he watches BBC at home, you know, but he has a heavy accent. And my dad speaking English is a very serious kind of guy; when he tries to joke,

people go, 'What?' In Spanish, he's a very outgoing, happy guy. My husband goes, 'He's like a totally different guy when he's with his Argentine friends.' And that's what it's like. It has to do with more than just 'I can speak this language.' Even if I could sign, 'Hi. How. Are. You.' It would never be that ease of 'Oh, let me tell you something funny...blah blah blah blah.' You know, there's that kind of division.

Although Kat seemingly feels less than comfortable in the signing deaf community, she did find strength in replacing the label "hard-of-hearing" with that of "deaf." She explains here how people respond differently to the two identifications:

Actually, the big change for me was actually saying "deaf" instead of "hard-of-hearing." I don't like "hard-of-hearing." Um, "person with hearing loss" is fine. And you know, whatever people want to call themselves is great, but for myself, that's too hard to explain to people, and when you say "deaf," they get it. Now, they may ask you if you speak sign, you know, if you use sign. And you say, 'No,' but at least they get it. They take it seriously. Hard-of-hearing, they go, 'Me too! I don't hear anything.' You know, they think it's okay to tease. You know what I mean? Um, but, so there's a seriousness to saying, 'I'm deaf.' End of story. So look at me when speaking, whatever. When I say, 'I'm deaf' and then go on from there, people are paying attention. So for me, using that word was very liberating.

Kat is convinced that maintaining spoken English as her primary mode of communication was the right decision for her. However, she disclosed that if cochlear implants would not

have worked for her, she would have felt that she had no choice but to join the signing deaf community.

Now, had these not worked [pointing to cochlear implant] – basically that's what it came down to. I thought, 'Well, this is it. If this works, great, if it doesn't work, then I will know and I will just totally learn ASL. I'm just going to have to learn it and that's it. I will just do immersion ASL and everyone I know is going to have to learn it and that's it.'

Kat was relieved to find out that this was not the case. At age forty-five, after struggling with hearing aids for nearly fifteen years, Kat was informed that she had become a candidate¹² for a cochlear implant and underwent surgery for her first implant. The surgery for her first implant took place after what she considered to be long period of deafness, although medically she was not “deaf” enough to qualifying as a candidate for a cochlear implant. Below, she explains her struggle in accepting this delineation of candidacy criteria:

I was deaf for a long time, or profoundly hard-of-hearing, or whatever you call it. It was like I heard too well, but since I couldn't hear anything, I thought that was kind of silly. I think if people have that much trouble – I mean the insurance companies – and I couldn't afford it. I was really happy when I found out I was a candidate to get one of these [pointing to cochlear implant].

¹² According to The American Food and Drug Administration, among other candidacy criteria: Current guidelines permit cochlear implantation in persons age 2 years and older with severe-to-profound deafness (i.e., pure tone average thresholds of 70 dB HL or greater) and no discernable communication benefit from a hearing aids. (fda.gov, 2009)

She explained that for many years, even with her hearing aids, she had difficulty understanding speech. She feels that in her situation, candidacy criteria were too strict and that she could have benefited from an implant much earlier.

Like I said, hearing aids didn't work for me. So, I – I really wish they'd have gotten me implants earlier because in my case the hearing aids weren't doing it. But for whatever reason they have this rule of what you're supposed to be able to hear and not hear.

She cited the following example from an experience at her audiologist's office as evidence that long before becoming a candidate for a cochlear implant, she could not access speech:

You go in there, and there is this person talking and you're in a sound proof booth and you repeat, and it's – it used to be – I was like, 'No, don't make me go in there.' Because, it's not that I thought I would do well, but then you realize how bad you were. It would be this person saying, 'mad, sad, glad...' and they all sounded the same. And then there were certain words that actually sounded dirty. So they would just ask me to say whatever I heard. So sometimes I'd say like a word and I'd go, 'I know it's not right.' And I could see the audiologist in the back cracking up. But you know, they sounded like that.

When Kat finally became a candidate for an implant, she was overjoyed with her decision to undergo the surgery; however, immediately following the surgery she was less sure. She explains an adverse reaction to the surgery:

What happened was, for whatever reason, I have a tendency to bleed a lot. And what happened was when I woke up, literally it felt like I had a jug of gin in my head and tinnitus too. I mean just painful. I mean I was in so much pain I was

screaming. I've never done that with any of my other surgeries. I was just like, 'So much pain.' It was like pain in the ear. It was just horrible.

The doctor prescribed pain medication and predicted that the tinnitus would, in due course, diminish. They warned her that there remained a small chance that it would not and that she would have to learn to live with it. In fact, within twenty-four hours the tinnitus did dissipate; at the same time other symptoms were emerging.

My head ballooned out to here [holding hand approximately six-inches from her face] I kid you not, and it was this red [pointing to a red bottle cap] and full of blood. What happened was I bled too much inside and I literally wanted to use the bathroom and it scared me when I saw myself. I looked like an "Outer Limits" person. This swollen head was just, you know, monstrous. And then the blood all came into my face. And I was like totally freaking out.

The doctors explained to Kat that the reactions that she was having to the implant had been seen before in very rare cases, but that they had checked to determine that the device was working and she should have no trouble with it after the swelling subsided. After waiting approximately a month, until the swelling lessened, she made an appointment for the activation of her cochlear implant.

In the following excerpt, Kat describes the moment her cochlear implant was activated:

And then, um, when they turned it on, it literally felt like someone inside my brain was going 'tick, tick, tick' [tapping fingers on table]. It didn't feel like sound. It felt like fingers. And then Donna, who's the audiologist, started talking to me, and I was like – and it sounded like – it's so hard to describe, somebody,

you know, in a submarine. And then she said, 'What day is it?' and I knew what she said but I didn't know why I knew it. It sounds really weird. It's like, I didn't really hear the words, but I knew what the words were. And what it was – it was like my brain was forming the pattern, but it didn't in any way, shape, or form sound like words.

Kat left the audiology appointment ecstatic that she had heard those four words: “What day is it?” Later, as she became accustomed to interpreting the sensation of sound through her cochlear implant, she began understanding increasingly more language. Kat said that people often ask what it sounds like to hear through an implant. She explains:

I don't know because I don't know what they sound like. I mean I remember what things sound like and I think a lot of it your brain makes things – makes patterns and makes things work. And it reminds – it brings back whatever brain memory there was of sound and works with it.

As Kat became accustomed to listening with her implant, she explained that, early on, one of the biggest challenges she encountered was difficulty in discerning the voices of different speakers.

I started understanding people but like your voice and my husband's and the cat, everyone would sound like [imitating cat's meow]. You know, like Minnie Mouse, you know. And then slowly things calmed down and everything got back to normal.

She explained that because of her specific hearing loss, which makes it difficult to hear mid frequency sounds, it was particularly difficult to hear people, male or female, whose pitch is within a certain mid-range.

Actually, it was a friend of my husband's, who we've lost touch with, and for whatever reason his voice hit everything I couldn't hear. It was horrible. He knew I was hard of hearing, and he tried, you know. He'd say, 'Hi, how you doing?' you know and blah blah blah. And I'd be like, 'I have no idea what you're saying.' And Michael would be like 'How've you been? We've been really good.' I would just run away from him because I couldn't catch a word. For whatever reason, some people's voices are particularly hard.

Kat further explained that speakers with flat intonation patterns, such as those of her adult nephew, in the following example, are particularly difficult to understand.

He just has a very difficult voice to hear – and it's because he has a – he doesn't have a lot of inflection in his voice. You know a lot of people do great with low tones but I'm not one of them. He has a low voice and kind of an even [gesture: a flat pattern], and he's kind of a quiet guy anyway. And, um, when I was going – when I was losing my hearing he was literally unintelligible [gesture: mouth movements as in speech]. I just couldn't understand him.

Kat illuminated this point by attempting to describe the sound input she receives when listening to speakers with difficult pitch ranges and intonation patterns.

It's if they hit that area in the middle registers and they don't go up and down, then it's like all of the consonants are dropping out so it's like 'ah-ee-oo.' I don't know what that means, but I understand nothing.

Hoping to receive even more auditory benefit, at age forty-nine, Kat underwent surgery for a second cochlear implant, on her right ear. She explained that she had great and nearly immediate success with her second cochlear implant and had “very little

reaction to the operation.” She attributed the success with the second implant to the fact that she had lost hearing in her right ear much later than she did in her left, and furthermore, she did not have the post-operative complications with the second implant that she had with the first.

Kat explained that the greatest benefit of having a second implant is that her brain now works, as she describes it, “in stereo,” which helps her to localize sound. While her sound localization abilities are not perfect, she admits, they are much better with two implants than with one.

It’s weird because my brain makes it work in stereo, but they [pointing to cochlear implants] actually don’t. They’re trying to get them to work in stereo but they don’t really do that. And I’m okay about locating sound, too, much better. I mean it’s still a quadrant. It’s like, you know, I look exactly where it’s coming from but I can’t tell if it’s from the back or the front or whatever.

Kat demonstrated this idea in the following story:

One of the funniest things that happened was – see that, that British sort of pottery? [pointing] In my old house it was in the dining room and my daughter was about 18-months and she just got – she was missing or something and I heard her laughing and heard crashing and she crawled around or whatever – moved around. I couldn’t find her, but I could hear this crash, crash, crash – something breaking. So I ran all over the house, upstairs, downstairs, to the basement, because we had a basement in the house, and I kept running out. I’m looking towards the living room and I never turned around. What it was, was she had gotten that cabinet open and she was smashing things. And all this

stuff just flies everywhere. So, when I finally found her I was horrified. I was like, 'Don't move,' because there was sharp stuff all over so I was like I picked her up and I was shaking the debris off her. And then she had broken all this stuff that was from England. It's okay, it was just stuff but she was just right behind me, like two-feet and I kept hearing it, but I couldn't – I never turned. I never thought of that one corner. So I wouldn't have that with two. It's better because I hear so much better.

It is these types of limitations, such as sound localization, that remind Kat that even with a cochlear implant, she is still a deaf person; and that she will never again be a hearing person.

So they go, 'Oh, you're fixed!' And I go, 'No, I'm not.' I do really well, I mean, amazingly well. I mean, I'm amazed I do as well as I do, but I'm not. You know, there are situations I have trouble with. You know, noisy rooms, if you're behind me, you know, I'm going to have to ask you to repeat yourself, whatever. But, they get very fascinated because you have computer chips in your head, you know, 'Wow, like refrigerator magnets?' [gesture: pulling the speech processor off and putting it back in place].

Kat explained that the function of cochlear implants is a hard concept for others to grasp. Specifically, that when she takes them off she becomes fully deaf. This places an extra burden of consideration and responsibility on her family.

It's frustrating when I take these off because I am – I hear nothing. And with a four-and-a-half-year-old, um, at night, if she gets up in the middle of the night and wanders around and says the house is on fire, and I hear nothing. I am out.

I don't hear anything. And so [my husband] has to deal, to be fair with him, he has to deal with a lot more than a person with an average hearing person. He gets stuck with all that night stuff.

Kat explained in the following passage that even her four-year-old daughter had to learn what it means for her mother to be deaf and have cochlear implants.

And now when [my daughter] gets on the bed I hear her. And she pretends she's not there. She freezes like, 'I'm not here. I'm going to pretend I'm a statue on your bed.' She kind of gets the fact that I need these [pointing to implant]. She'll bring them to me in the morning because I'll say, 'I don't have them in...' and she'll be [gesture: mouth movements as in speech] and I'm like, 'I don't understand what you're saying, hold on.' And so she's pretty good. Sometimes she gets snappy and then I'll put them in and say, 'Okay, what?' and then she'll yell at me. And I'll go, 'Don't yell at me, you know I can't hear and that's why I couldn't hear you.' And then she's like grudgingly, 'Okay, sorry.' You know but she's kind of grown up. You know, kids kind of adapt to whatever you say normal is. So in a way she is really easy, because she knows from day one that I take these off [gesture: removing implants], I don't hear. I put these on [gesture: putting on implants], I hear. So, she's easier. With my husband, it was a process.

Although Kat felt that people generally did not understand cochlear implants, the modern technology provided an opening for talking about deafness with friends, acquaintances, and even strangers. This was in stark contrast to the experience she felt with wearing hearing aids and the stigma that is associated with them. She explained:

Cochlear implants, because it's high tech, is very interesting. I think that gives you more of a conversation that people feel comfortable with because they're more comfortable with technology. With hearing aids, there's this terrible old person bias. Which I feel bad enough for old people too, since I'm pretty much almost there. But, um, so if you're a younger person with hearing aids, it's just really - and the problem too is compounded because the marketing is to hide them as much as possible. They're flesh colored, they fit in your ear; no one will be able to tell. Well, come on, if you're hard-of-hearing they're going to be able to tell. You know, it's better, make them bright red. Make them look like Bluetooth technology. And that's a lot of it, it's like the attitude has to change so it's not like, 'I'm so embarrassed. I can't hear you.'

In fact, the recognition of hearing loss is a focal issue for Kat. During the interview, she said, "I would like more attention to hearing loss. I would like not to be invisible." As such, she works determinedly with members of her support group to create awareness about deafness and one of their missions is to advocate for acceptance of hearing loss. She explains the role of the group in realizing this mission below:

We try to tell people, to get them to quit saying, 'I'm sorry, I didn't hear that.' I'm not saying, be like mean, but you can just say, 'I have a hearing loss, I have trouble, could you look at me.' But quit apologizing like you're doing something wrong, because it's not like I wasn't paying attention to you. You know, so it's - it's that transition. It took me years and years. And now I look back and go, 'What an idiot!' but at the time it was just really, really difficult and meeting assertive people in the group really helps.

Several years after being invited to an Association for Late-Deafened Adults (ALDA) group by her sign language instructor, Kat became one of seven members who branched out to create a local Hearing Loss Association of America (HLAA) chapter. She explained that of the seven, there were three couples, in which the wives were deaf or hard-of-hearing and the husbands were hearing, and there was one single hard-of-hearing woman. All of the members use hearing technologies and continue to rely on oral communication.

We were all pretty deaf. Now we're all – one of the four initial women still wears hearing aids but the rest of us wear – have cochlear implants. And we're all oral people.

She explains that while HLAA continues to be a predominately oral group, the face of the group is changing, in that that younger members are beginning to join her local chapter as well as at the national level. Below, Kat explains her stance on the importance of educating younger generations about deafness, disability rights, self-advocacy and acceptance.

And we're getting younger people joining and I think that's nice just to have a whole cross section of people. Because, um, it just gets 'em thinking young and stuff. So I feel good about the future for hearing loss because I think, unfortunately, there's going to be more people with hearing loss because of the iphone, ipods and stuff, but I also think it's good if younger people start accepting it as like a – it is a disability or more of a health issue than just something that needs to be dealt with and aren't embarrassed to deal with it or whatever. Audiologists were telling me they couldn't get high school students to

wear hearing aids, you know. So, that's really bad for their education and socialization and stuff.

Even within her own family, Kat has been an advocate for the acceptance and visibility of hearing loss. This was demonstrated through the following story, which she shares about her father:

Also, what's really strange, my dad has age onset hearing loss because he's eighty-eight and he's had trouble hearing, especially in one ear, for the last, gosh, probably fifteen years. So he knows I belong to these support groups. I talk about hearing loss all the time. I've written articles, he's read them, blah blah blah. Well, about three visits ago, so I'm guessing six years ago – five, six years ago – he came to visit and you know, he stays for a few weeks. He's getting ready to go and he gets this phone call from a friend in Argentina and she says, 'Did he get his aparato?', which means "little thing, technical thing," 'checked out?' And I said, "What are you talking about?" You know, he had gotten all the presents people wanted and stuff. And she said, "You know, his hearing aid. He was supposed to get it checked out because I don't think it works right." And I said, "Dad wears a hearing aid?" and she said, "Yeah, he was supposed to get it fixed when he was there." Well, my dad hadn't told me he wore one. He was hiding it in his luggage. After all this stuff, I said, 'Dad! I gave you all these lectures about why it's important to accept your hearing loss and,' and you know. So the last two times I've actually taken him in to a really good hearing aid audiologist that I know of and he's gotten really in depth testing and they got him a new hearing aid and he wears it and he's doing much better.

He's acknowledging the whole thing and everything. But you know, that's what I mean. He didn't want to appear to be old and I'm like, 'I'm in my 40's,' or whatever at the time and I'm going, 'I'm wearing, like, stuff.' So it was really weird.

Kat reiterated that she “just can't say enough about support groups.” The groups have provided her not only with information and emotional support, but also a social network through which friendships have developed. She has, furthermore, channeled opportunities, which might not have otherwise developed, including being a regular contributor to the groups' newsletter.

I mean I've met some of my best friends and they are people I would have never met otherwise. But I like them because I like them. I don't like them because of hearing loss, because there are lots of them I don't like. And they're not my friends. They're a big part of my life – a couple of my best girlfriends, definitely. I've done a lot of stuff that I – I don't think I ever would have gotten into writing as much as I did. I write articles for the newsletter and they liked them and so I kept going. I don't get paid but I kept going. It just made it a bigger life.

Another benefit of the group, according to Kat, is that members are able to come together, both face-to-face and through message boards, to both commiserate and celebrate shared experiences that family and friends who have not endured a loss of hearing could likely not relate to. Through exchanging stories, she explains, it demystifies shared experiences and bonds the members together as a community.

Through sharing stories and experiences with other late-deafened adults, Kat has learned to laugh about her deafness. She is now aware that what has happened to her has

happened to many other late deafened adults in one way or another and she no longer views the events as a series of personal attacks. Instead, she comes together with other HLAA members and they “get a kick out of each other’s stories,” such as the story she narrates below:

We post mistakes that we made, misunderstandings. I did one, which I forgot now, but this one man posted one, which I thought was hilarious. He went to Chinese food and it was really loud, it was dim sum and those places are loud, and the person had an accent, which Asian accents are hard, and she asked something that he thought meant ‘white or fried’ and so he said, ‘fried,’ meaning fried rice. So his plate came and he goes to taste it and he catches fire. This thing was so hot that he started sweating and, and he was just, his eyeballs almost fell out. She had said, ‘The heat is from one to five.’ He said ‘five.’ When he said, ‘fried,’ because she’s Chinese, she understood ‘five,’ so that’s what she gave him. So, basically it was like a giant jalapeno or habanero or whatever it was and he was just like crying.

In reflecting on her personal journey of becoming a late-deafened adult, Kat realizes that facing hearing loss has made her a stronger person, and more appreciative of what she has.

I guess in a sense I’ve learned that – not to take anything for granted. And not assume that something won’t happen, because it might. I mean, I don’t worry about it. I don’t sit around all day going, “The house is going to fall on me” or whatever. But in a way it’s like, stuff is gonna happen so you better learn to be flexible and bounce back because you’re going to have to. Because nobody likes

when it happens to them, but it does. So I'm more resilient than I would have thought. I hope, I mean, I hope that's one thing I teach [my daughter]. And it's not what happens to you. It's how you deal with it, is more important that what happens to you.

Deafness is not the only challenge that Kat has faced in her life. At the age of thirty, she was diagnosed with breast cancer, which she described as, "minor and treatable," but nonetheless life altering, in hindsight. Kat compares her experience with cancer to that of becoming deaf and examines the outcome of both experiences in the following quote:

With deafness, I wouldn't wish it on anyone you know because going through it is horrible, but then afterwards its like you get something out of it. I'm not going to equate it to getting cancer because that's all negative, basically. But the one thing they told me when I was first diagnosed with cancer was, 'This will change your life.' She said, 'You won't realize how, for a few years, but it will.' And within three or four years I had gotten divorced, sold the house, changed jobs, started my own business and – it wasn't like I got up one morning and – but what happens is when you face very big health issues, at some point they highlight things that work and don't work in your life. And you know, cancer did that in one way but then hearing loss made me – because I was just totally work oriented. I was like work, work, deadlines, deadlines. And the fact is, it got me out of being that kind of person. It got me out of being – out of just being about that. And now sure, yeah, I work but I like writing, I like doing different things. And I think it kind of forced the issue of being a bigger person.

As with deafness, one of Kat's greatest concerns after being diagnosed with cancer was the fear of losing her identity. Kat explained she did not want to be seen as anything other than herself. Below she describes her concern about being seen first and foremost by her disability:

One of my big worries, besides, you know, 'I don't want to die,' was, um, I didn't want to be the girl with cancer. You know, and I wanted to be myself, who had cancer, as opposed to the cancer person. And I think with hearing loss that's what the big challenge was, I'm myself who has hearing loss or I'm deaf, but I'm myself first. You know, and it's like, being Latino, which I am. Or, being a mom. You know, it is what it is. It's just part of my life. And it's made my life harder but I've gotten a lot out of it.

Kat, though, does not wish to downplay the significance of cancer or deafness in her life. In fact, Kat feels these experiences have possibly improved her life. She explained that she is now able to see people for who they are and appreciate their differences rather than seeing people for their disabilities. She believes that her own challenges have made her a more open and accepting person, particularly toward individuals with different abilities. She explained:

I mean this is going to sound like I'm contradicting everything I just talked about, but I think it's made me more sensitive to other people. Um, I think I'm more, I don't want to say a better person because it's like, "I'm sure a nice person." I'm not. But I think I am nicer than I would have been. And I think I look at life a lot differently than I would have.

When asked to expand on this idea, Kat explained:

I don't – I'm certainly a lot more sympathetic about people's – whether they are limitations or just, um, different needs – I'm a lot more open about that. I also will go up to disabled people and talk to them. I used to be one of those people who was like, 'I'm not sure.' And some people are hard to understand because they have a speech impediment and I actually force myself to talk to those kind of people and I will be honest and I will say, 'I'm having trouble understanding you, but I'm trying, did you just say blah blah?' You know, that kind of stuff. Which, I would have never done before this, because you know I'm not going to not look at them. I'm glad I got hearing loss if it led to that because I think that's a better way to be in the world. There are people who don't have patience, or tolerance for differences of any sort.

Overall, Kat now appreciates the lessons she has learned through the experiences she has had becoming a late-deafened adult and cancer survivor.

You get a little less freaked out by everyday stuff. And you realize, 'Well, I'm basically healthy.' You know, it's okay. It's going to be fine. And whatever comes I'll be able to eventually handle it. And I think that that's a nice kind of thing to have. You know, a friend of mine said it. She said, 'Nobody likes to have happen to them what gives you the lesson, but the lesson is kinda nice.'

Kat hopes to use the lessons she has learned about her own deafness to make a difference in the lives of other late-deafened adults. She hopes that through her work with the hearing loss support group, she will effectively instill a sense of acceptance and confidence in people struggling with hearing loss. She specifically would like to disseminate the following advice to other late-deafened adults:

If I had a message, it would be: 'This is what you are and make the best of it. And if someone is mean to you, it's their problem. It's on them, not you, as long as you do the best you can with whatever you have. And then if people can't deal with that, that's their problem.' People who get a disability later in life are just as good as they were before. They're just different, you know? Seeing people marginalized is a shame. It's a loss of a lot of talent. It's bad for them and it's bad for society because you're losing all this brainpower and ability and stuff. So, I'd want people to be more assertive.

Emerging Themes: Kat

1. Kat is a native of Argentina and moved to America at the age of nine. Her primary mode of communication is spoken English.
2. Kat was an executive at a major television network before losing her hearing. She now runs a small business out of her home through which she does consulting work for the television industry.
3. Kat is currently married to her second husband, whom she knew as a friend and colleague prior to losing her hearing. They adopted a daughter together from China.
4. Kat was diagnosed with a rare "cookie-bite" hearing loss and was told she would eventually go deaf, to the extent of not being able to understand spoken language.
5. Kat is a self-described type-A personality who thought that if she worked hard enough she could prevent her deafness.
6. Kat initially experienced emotions of anger, depression and frustration about her hearing loss.

7. Initially, Kat took people's lack of ability to make accommodations for her for communication as a personal attack.
8. Kat has a lot of respect for the signing deaf culture community but does not feel that she can become a part of it because she was not socialized into it an early enough age.
9. Kat wore hearing aids for approximately fifteen years; however, she never liked them and never got used to wearing them.
10. As soon as she became an eligible candidate (i.e. her hearing loss was profound), Kat underwent surgery for a cochlear implant on her left ear.
11. Kat had a serious infection after her first cochlear implant surgery.
12. Kat was able to understand some speech immediately after the activation of her first cochlear implant, although she could not express how she understood it because it did not sound like words.
13. Kat received a second cochlear implant on her right ear nearly five years later. She has experienced great success with it and it has greatly improved her ability to localize sound.
14. Kat is a leader in her local support groups for people with hearing loss. She also writes articles for the groups' newsletter to advocate for people with hearing loss. She credits the support groups for helping her positively adjust to deafness.
15. Kat prefers to be called "deaf," as opposed to "hard-of-hearing." She feels that not only is it a more appropriate label, but it facilitates others' understanding of how to interact with her.

16. In addition to being a late deafened adult, Kat is also a cancer survivor. She believes that deafness has had a more positive influence on her life than cancer.

Participant Four: Liz

Liz is a 60-year-old female with profound deafness; she has a cochlear implant in her right ear. She is fluent in American Sign Language and has a family history of deafness, including her mother who was deaf-oral and her brother who attended a residential school for the deaf and was fluent in sign language.

Liz was interviewed in her office on two separate occasions. The first meeting lasted for seventy-five minutes. The second, which was scheduled for longer, was interrupted after twenty minutes due to a work emergency. A total of ninety-five minutes of data was collected from interviews with this participant.

Liz was diagnosed with hearing loss at age eighteen. Her hearing progressively declined for twenty-five years, until she became profoundly deaf in both ears, which she estimates happened in her right ear by age twenty-nine and her left ear by the age of forty-five.

The conversation with Liz began by deciding on a communication modality. Liz opted to use her voice, but because she was concerned that her “deaf voice” rendered her speech unintelligible, she ultimately decided to use sim-com. Any discrepancies in speech and signs are noted in the transcription.

Liz grew up in a family with a deaf mother, hearing father, older hearing sister and younger deaf brother. She explained that her mother learned how to speak at Clarke School for the Deaf – a well-established school for the deaf in New England that has a strong oral tradition. Her brother, who signed only and did not speak, attended a school for the deaf in California that promoted sign language and deaf culture. When asked about family dynamics, Liz explained:

So I pretty much grew up being a CODA, which is a child of a deaf adult. Um, interpreting for them, being responsible for things my mother didn't hear; or, at the park where kids would make fun of my brother [sign: beat up] Pow! I was a little Tom-girl. So I grew up pretty much as an advocate. You know, someone who will always be there. You know, typical CODA.

Liz believed that her mother was always ashamed of her own hearing loss and as such did not have any deaf friends and lived in the hearing world to the best of her ability. Liz described a story that her mother had shared with her about her childhood experiences that served as the impetus of her mother's attitude about her own deafness. Liz recounted the story as follows:

And back then – let me tell you a little bit about her parents who happened to be wealthy and they owned a house. Well, the people in the neighborhood didn't feel that deaf people should own a house because they were deaf and dumb. So they would come by the streets and throw rocks at the window – my mother was born in 1928 so I would say in the 30's – and so my grandfather wanted a better life for my mother and his kids. He has three children – no four. Two were deaf – three were deaf, and my mother was probably hard of hearing, and the baby was hearing. So, they ended up going to Boston to go to Clarke school so my mother could learn to speak, to have a better life so she wouldn't be discriminated. So, she already had that history of being – what's that called [sign: put- down] persecuted.

Liz's own hearing loss was first detected when she was eighteen-years-old, after an accident playing football with her brother. Liz was taken to the hospital for a broken nose

and was subsequently diagnosed with a severe hearing loss. She explains in the following quote how her hearing loss was exposed:

I broke my nose, then I actually found out I had a severe hearing loss. And how that came about, they put a sheet over my head and they were fixing my nose and I kept pulling the sheeting thing down going, 'What? What?' I had been lipreading, unaware that I was becoming a lipreader.

Liz suspects that she began losing her hearing long before it was diagnosed, but that it had not been detected because her father was in the Navy and therefore her family moved a lot. Essentially, she was never at one school long enough for her hearing loss to be identified. She does, though, remember being asked by one teacher to stay after class to discuss her possible hearing loss. Liz denied it, "Nope, not me. Nope."

Looking back, Liz suspects that she struggled through her last years of high school because of her hearing loss, but had subconsciously developed coping mechanisms. She explains this in the following narrative:

In school I noticed that when we had to read our books and chapters, I would count the kids and I'd know what chapter that I was supposed to read. Now this was totally, um – I was unaware that I was doing this. You know, it was a tool of survival. When I was going to be called upon and I didn't know, I was totally lost, I would do something out of the ordinary to get kicked out of the class, you know to be out in the hall. And that was my coping mechanism until I was busted when I busted my nose.

Liz was fitted for her first hearing aid after the football incident. At the time, she explained, her family could afford only one hearing aid, although, she would have benefited

from two. She used the unilateral hearing aid to get through college but she described it as a struggle; “I’m sure I would have been a much better student if I could hear, you know?”

While Liz did utilize disability services that were available on her college campus to assist in accessing course lectures, she did not take full advantage of their services because she would have been embarrassed to draw any attention to her hearing loss. In fact, Liz constantly strived to conceal her hearing loss in college. As she put it, “I was not about to have a signer in college.” She also made an earnest effort to hide her hearing aid, of which she was extremely self-conscious. As she explains in the following quote, her endeavors of concealment were not always successful.

If someone got too close to me, I would whistle. You know, or if something went wrong with my hearing aid I would whistle and it was a constant form of embarrassment and hiding it.

Both in and outside of the classroom, as Liz’s hearing levels were progressively declining, she struggled to accept her hearing loss, and certainly did not want to admit it to others, let alone herself. To avoid the consequences of disclosing her hearing loss, Liz explained that she did a lot of “bluffing.” She provides the following examples of feigning hearing, which ultimately brought about disadvantageous consequences:

Somebody would call – a guy would call, and I’d made a date. I wouldn’t know who it was. I wouldn’t know what time. You know, just – it’s really serious stuff. You know, and um, sometimes I would make dental appointments and show up on the wrong day.

Liz explained that denying her hearing loss led to more than mere inconveniences, which began to take a serious toll on her psyche. Liz explains below the conscious efforts she made to conceal her diminishing hearing:

You know, it was constant disappointment. It was always being in check with, 'What can I do? What can I not hear?' I would go to parties, they were drinking, I would never drink because if I drank I wouldn't be able to understand. If I smoked pot – you know, this was the 60's – if I did that I wouldn't be in control and I wouldn't be able to understand; therefore, I wouldn't be able to hear and they wouldn't like me or they wouldn't accept me because of my loss. So I was a hard-of-hearing girl in a hearing society, trying to fit in.

Although her mother had been managing her own hearing loss for her entire life, straining to overcome it enough to fit into the hearing world, she was not a promising means for supporting her daughter to relieve the pressure she felt as a result of her own hearing loss. She explains as follows:

And unfortunately my mother didn't – she didn't pick up on it. Didn't notice it. She did not see it happening. I was totally alone with how to cope with this.

In fact, deafness and hearing loss were not discussed in Liz's family. While she suspected that her parents grieved her hearing loss, it was never explicitly mentioned. She depicted her family's reaction to her hearing loss as follows:

I don't think my father ever accepted it because he never learned to sign. I think that – well, I'm daddy's girl – you know. I was daddy's girl—you know. And I think he felt bad. My mother felt bad because she passed this gene onto me.

The negative impression Liz had of deafness from a young age is reportedly what led to the denial of her own hearing loss, rooted in the underlying forces of the relationship between her hearing father and deaf mother and brother. Furthermore, Liz explained that, because of the adverse relationships her deaf mother and brother had with her father and sister due to their deafness, she was increasingly concerned, as her hearing levels decreased, of losing the affection she had come to know from her father. Thus, Liz was reluctant to acknowledge her own hearing loss.

My father would get frustrated with my mom. And my father would get angry with my brother because he couldn't speak. He would 'ahh, ooooh' [mocking vocal patterns of a nonverbal deaf person] you know, shout out. And my brother would – my dad would hit him. And so, the psychology of that was so impounded in me that I didn't want to be deaf. I didn't want to have a hearing loss. Because deep down inside I think I felt that my father wouldn't love me. You know, he was mean to my brother, he was mean to my mother, he was going to end up being mean to me. So I totally denied it. Totally. You know, I grew up watching the dynamics of my father never really accepting my mother. My older sister, who was hearing, put my mom down. You know, so those dynamics were there and it was such a huge factor for me in accepting my hearing loss so slowly. That's probably why I never even mentioned it, because somewhere in the back of my mind, in my soul, I did not want to lose my hearing.

In fact, rather than admitting her hearing loss, Liz preferred to let people presume that she had less than desirable personality traits. She relates an incident that occurred when she was working in a retail store during her college years:

One time somebody came up to me and said, 'Boy are you stuck-up.' And I said, 'What do you mean?' and she said, 'I was calling you from behind and you just walked off.' And I said, 'Oh I'm so sorry I was in a hurry and I only had ten minutes for my break and I had to get going. I'm so sorry. Please don't take that wrong.' And people were accusing me of being snotty or stuck-up or rude, you know, aloof, and it was all related to my hearing loss.

In spite of her limitations, Liz successfully graduated from college and soon thereafter began working for a prestigious technology company. By the time she was twenty-five-years old she was experiencing financial success and as she describes it, "everything was my oyster." A short time later, she met the man of her dreams and got married; and within two years she became pregnant. Liz was on top of the world and had everything she ever wanted.

However, during her pregnancy, at age twenty-nine, due to her changing hormones, she believes, she started experience symptoms of Meneire's Disease. It was during this time, she explained, that she started waking up at night to "horrible tinnitus and horrible dizzy spells." She was, in fact, diagnosed with Meneire's Disease, which would, in time, render her progressively more and more hard-of-hearing. In fact, it was during one of these attacks that Liz became profoundly deaf in her right ear. She explains this particular attack as follows:

And then one morning I woke up and I fell out of bed with the vertigo. I couldn't hear at all in my right ear. So with that, I switched my hearing aid over to my other side and progressed you know, doing what I was doing.

A short time after being diagnosed with Meniere's and losing the hearing in her right ear, Liz's son was born and was soon after diagnosed as hard-of-hearing. Liz expressed that because of her own hearing loss she felt more prepared to comprehend and meet his needs as a person with hearing loss. She explains as follows:

And then my son was born and he was born hard-of-hearing. And sometimes I think that this process of being late deafened or losing my hearing progressively, helped me understand better what my son would be going through, himself, because he was hard-of-hearing.

While on the one hand, her own hearing loss prepared her to parent a child with hearing loss, on the other hand, she was acutely aware of the challenges her son would be confronted with throughout his life. Liz later disclosed that she had a certain sense of guilt about her son's hearing loss and did not want to continue to pass her genes on to other, future children. She explains her decision to not have more children as follows:

My son was born hard of hearing and I never had any more children because of that. I did not want my children to have to go through what I went through.

After the birth of her son, Liz fell quickly from what she described as being "on top of the world." With her persistent decrease of hearing levels, Liz faced increasing challenges, including a demotion at work. She explains the setback in the following quote:

I eventually lost my job, they felt – because I was in marketing, going out for sales and so forth, that I would be a liability to the company. And this is long

before the American Disability Act, so ADA was not in effect. And so that was a huge blow for me. Huge blow. And so with that I took a lesser job troubleshooting and going to different sites, still with [the same company]. I was teaching like the secretaries how to do word processing and so forth, and at that time I had my baby as well and so it was really tough to focus on my grief of losing hearing.

Ultimately, Liz was let go from her job altogether, and soon her marriage began to fall apart. She explains how her marriage deteriorated as her hearing levels progressively declined:

He became embarrassed when we were at social functions and maybe I wouldn't understand and he would be embarrassed. He would come in and maybe try to change the topic. He would never tell anybody that I had lost my hearing. And you know, neither did I because I was not there yet. So umm, I ended up staying home and he ended up going out more and more alone. And then, you know, the frustration, the blame, because my son was hard of hearing. I got blamed for that. It's all my fault.

Ultimately the constant reminder from her husband of what she considered to be her inadequacies became unbearable and, consequently, her marriage ended in divorce.

And then a little later I started having difficult, um, difficulty with my husband because he was so used to just being able to talk with me. We ended up, oh about five years later, agreeing to separate and eventually divorcing. Because he was always mad at me. He would talk to me from another room and then he would come in and say, 'I asked you for a beer you didn't hear me.' And so

again, it was like being stabbed. How I call it, it was like cutting off your arm, letting it heal, cutting your arm off, letting it heal. It was a slow progressive death, you know?

Going from having everything she ever wanted to losing it all, Liz described the following eight years as her “bleakest dark spiral to nowhere.” In fact, she confessed that, “had it not been for my son, I probably would have taken my own life. And I’m very serious about that.” She continued:

It was so raw and emotional. I didn’t have any fight. I gave up. You know, there was no fight. That fight came later. The fight came with the cycle of grief. You don’t have any fight. You’re grieving. You try to come to terms and you rationalize with yourself and you know – and you beat yourself up so badly, but eventually, hopefully as you start getting healthier you begin to get mad and you kind of find ways to fight back.

After becoming unemployed and a single mother, Liz was able to support her son and herself by collecting disability, which she explained was barely enough to survive. She took advantage of the silver lining in her otherwise ominous situation, however, by staying home with her son to work assiduously on his spoken language development and listening skills.

Then, soon after her divorce, Liz’s life took another unforeseen turn. Her brother died from type-1 diabetes, and left his three children to live with her. Two of the children were deaf and one was hearing. Now, in addition to her own son who was hard-of-hearing, Liz was suddenly raising four children, ages: six, five, four and two. Although her life had been turned upside down, she explains that there was a hidden blessing in having her

brother's children, in that she was able to put the issue of her own hearing loss on hold and instead focus her energies into raising the children. She professed that: "The kids saved me."

While she was raising the children, which she now claims as her own, she avoided dealing with her hearing loss, and to some extent, her life. Over a ten year period, which she today reflects on as her "black years," Liz sought out isolation and her life revolved solely around her children and her home. She explains this period of isolation and emotional turmoil in the following quote:

You know, if I was going to be in a situation where I wouldn't understand, I would avoid it. I didn't go to parties. It was more of sheltering. And, you know, I mean, today I look back and there were missing years. Missing years for me with a lot of pain. I didn't have a boyfriend for ten years maybe – and that's a long time. For ten, maybe even longer, years, I was isolated. I had a beautiful garden because that's all I could do. But I had those kids. I did not socialize. I did not date. They were, like I say, my black years. And had it not been for my kids, zip [gesture: slicing her throat].

Then one day, on what started out to be a typical day of running errands and grocery shopping with the children, Liz happened upon a meeting that would be a pivotal moment in her life. She describes the occurrence as follows:

And one day we happened to go to the grocery store and shopping and everything and I'm in the shopping line, um, check out line and this woman is behind me talking to me and of course I didn't hear her. And then she tapped me and I turned around and she said, 'Honey, are you deaf? Do you have a

hearing loss?’ and I just lost it. I just broke down crying. And she said, ‘Oh my goodness, oh my goodness.’ You know, and she said, ‘Come have coffee with me.’ So we went for coffee and the kids had ice cream and she said there was an agency called DCARA, Deaf Counseling Advocacy and Referral Agency. And I said, ‘Well, I know about DCARA. My mother is on the board.’ And I said, ‘But I’m not deaf.’ And that was a turning point. She looked at me kind of funny and she said, ‘You’re not?’ And I said, ‘No, I just can’t hear.’

After the serendipitous meeting, the woman from the grocery store arranged an appointment for Liz at the DCARA office. She depicted the meeting as follows:

We were supposed to meet for an hour appointment. We talked for maybe about twenty minutes and she was a little impatient. She goes [waving arms], ‘Okay, okay. That’s enough.’ She said, ‘I know your mother. I know you can sign. You’re going to come work for me – tomorrow. You’re going to volunteer for me tomorrow while the kids are in school. You’ll be excellent to teach my late deafened and hard-of-hearing people some basic sign language.’

Liz accepted the offer and began volunteering at the center for a couple of hours each day. Her efforts eventually led to a full time job that lasted for nearly two decades; and, in addition to teaching sign language, she eventually became a counselor for late deafened adults and held various workshops for people with hearing loss.

And I stayed there for eighteen years, becoming a counselor for people who are late deafened. And through my journey with that, you know, my hearing loss continued to get worse and worse to the point where I could barely hear anything.

As Liz was becoming progressively more deaf, she began to connect more with other late deafened adults who she came in contact with through her work. Eventually, she and others started a local chapter of the Association of Late Deafened Adults, and began hosting social events. Liz described these events as a “life changing celebrations of life.” Through her local chapter, and eventually the national conference, she witnessed late deafened adults coming together, with an ease of being themselves that she explains she had not seen when there is a constant pressure for late deafened adults to perform. She described her involvement in the support group for late deafened adults below:

When I started working for DCARA people would sporadically come in and we ended up forming a chapter. I was one of the first leaders to start that and ended up becoming the regional director and that final journey [sign: process]. But just to start a little gathering of people it was such a strong family. But when I started to get into the ALDA group I started to have parties at my house once a month, if not, you know, more. And getting people together, it's just – I mean it was just a celebration of life. As much as I could, and I'm still like that, you know. And then we had the ALDA convention so it was like, 'Okay let's go.' I mean I have goose bumps talking about it. Going to a convention where you see 300-400 people signing, writing, reading lips where whatever worked, worked. And if you didn't understand, it was okay. It was a place where it didn't matter who you were; we're going to communicate one way or another. And they had captioning and they had signers and they had karaoke. It was just excellent. They had a lot of workshops and at that time it

was excellent. It was just perfect for someone who was just losing their hearing. It gave people hope. That's the best way I can describe it.

Liz went on to further compare the shared sense of purpose that she felt in hearing loss support group, to the plight of black Americans during the black civil rights movement.

It was unity. You know, unity. It helped me understand the black civil rights revolution. I could identify with the discrimination. I could identify with everything that they had gone through, because it was the same. It just happened to be hearing loss. We were discriminated against, we were put down. It's the same kind of war that we get to face.

Liz explained that as she became involved in working with other late deafened adults and became active in ALDA, she slowly became less withdrawn and more sociable. She met an audiologist who she dated for six and a half years. According to Liz, "it was a typical codependent relationship where a hearing man wanted to fix a deaf girl." She describes below his empathetic remarks regarding her hearing loss, which she interpreted as condescension:

I remember one day I was in the kitchen and my audiologist boyfriend was at the table and I just kept hearing something and finally I said, 'Honey, what's that sound?' And the look on his face, I'll never forget it. It was just a look of pity. He said, 'Oh, honey, you know that's the coffee pot next to you.'

Liz remembers that it was precisely this moment that she realized she could not identify the sound of the gurgling coffee pot next to her that she grasped the severity of her hearing loss. She described her reaction to the realization that her hearing levels had dropped to profound:

You know it just hit me. I just went in my bedroom and cried. You know, I could no longer hear – I could no longer identify sounds. Or I'd be sitting in the kitchen or standing making dinner and the phone would ring and the kids would come running before I could identify what the sound was. You know, that was just a lot of hard stuff.

Although there were admittedly numerous negative aspects of their relationship, Liz credited her audiologist boyfriend as being instrumental in her getting a cochlear implant and being supportive of her throughout the process of implantation. Liz underwent surgery for a cochlear implant on her right ear, a process with she likened to the religious experience of being “born again.” As she explained it:

With my implant, the day after they programmed me and hooked me up, I was a different person. My personality came back. I was no longer afraid or scared to do a lot of different things. It just gave me a salvation.

When asked to recall the activation of her implant, she described her “journey of sounds” in great detail, as follows:

And oh, it was amazing being turned on – well programmed – and walking outside. It was a rainy day and I got into the car and my boyfriend who was an audiologist was there and he turned the music on and I could – it was like country western – and I could hear the violin. Well I haven't heard the violin in a long time. And the windshield wipers were tch, tch, tch [gesture: the motion of windshield wipers], and even walking on the gravel. You know, it was just mind blowing. I went to the bathroom and the first thing I heard was fan going on. I never knew a fan was there. And flushing the – well actually peeing. But

going to the bathroom, I thought, 'God, I'll never be able to pee in a public bathroom again.' It was just a journey of sounds, you know babbling brooks and oh my God, you know learning about things. Hearing a bird in a tree and looking up and, 'What's that?' and then identifying robins and little different kinds of birds. It's been a heck of a journey.

Liz received her cochlear implant in 1993 at age forty-three, when the technology was relatively new. She boasts that she was one of the first recipients of the, at that time, ground-breaking technology. Yet, when Liz received her cochlear implant the technology was tremendously controversial within the deaf community, which saw the device as robbing them of future members and likened it to genocide. Liz, however, was supported by her boss, “a prominent radical figure in the deaf community,” who warned the staff that if anyone discriminated against her for getting a cochlear implant they would be fired.

Although she had the support of her supervisor at work, she faced discrimination, alone, outside of her workplace. Particularly, at her children's school for the deaf, where the culture of the program was firmly against cochlear implants. According to Liz, this really resonated when one of her children came home from school and pointed to her implant saying, “You know, you're not supposed to do that.” Liz explains her response to the curriculum that she felt was prejudicing her children against her:

I ended up going to that school and actually getting the curriculum removed. Because they were teaching my children that what I did for myself was wrong. And that changed. I was glad to be part of that movement of change.

For a time, Liz functioned well with a hearing aid in her left ear and a cochlear implant in her right ear. However two years after her implant, while on a commuter train, she suddenly lost all hearing in her left ear, rendering her hearing aid useless.

I was coming home on the subway and when you go underground you kind of get this suction sound. And I thought – well, if it goes up high pitch – sometimes the batteries will turn off – so I thought my batteries were, you know, off and so I was fiddling with my – and I thought [sign: give up]. It was the day before Thanksgiving. So I got home and I changed the batteries and put it back on and it was the same. And I thought, ‘Oh, maybe something’s wrong with my hearing aid.’ You know. I was just trying to make excuses, instead of – and then it just kind of hit me [sign: ‘evidence’], ‘Oh my God, it could be my hearing!’ And it just went like that, just “blip” and I was deaf. Deaf.

Liz explained, though, that it was not an easy or automatic transition to being able to access sound through her cochlear implant alone, without the added benefit of hearing sound through a hearing aid on her left ear.

But the sound of when I first got my implant and my hearing aid it was analog and digital and my brain crossed over beautifully. I had heard what I had heard and then with the implant it just blended. And when this was gone [sign: totally deaf (on left side)], it was like I, um, lost my crutch. And I had to learn to hear all over again with the implant. It took me about maybe six months to a year.

She explained the process of learning to hear solely through her implant as follows:

Implants are not perfect; it's digital sound. You know your brain – it's just amazing. It's like having a pair of glasses, I take my glasses off and you're blurry and then I put them on and I can see you. You know, it's the same way with an implant. Once you put it on, your brain hears that sound and it makes that imprint. And the next time you hear it, it becomes clearer and clearer and clearer. That's how it works. But, it is digital. But, it's not like speech, naturally, you know. You have like a digital firing to it.

When asked if, considering the success of her first implant, she had thought about getting a second implant, in her left ear, Liz said, 'Oh sure.' But she then began to describe the imminent hair cell implant technology and that her preference would be to wait for the new technology. "I want to wait. They are doing the hair cell implants. Implanting the ear. And I want to wait and do that. It's something above and beyond having an implant." In the meantime, Liz is using her unilateral cochlear implant to access spoken language, environmental sounds, and even music.

Currently, Liz explained, she is dating a musician, who is also deaf and they spend a lot of time "doing band stuff." She talked about her ability to enjoy music with the cochlear implant, explaining that new music is difficult for her because she can't hear the words, but she does enjoy old music because she already knows the words. Liz suspects that she also cannot distinguish the words of the more familiar music, but that her brain fills in what it misses auditorily, from memory. She explains: "Music I used to hear, I can identify it, but – and then somewhere in – my brain puts everything together."

When asked to expand on her dating-life, Liz explains that her boyfriend was a friend of her brother's and so she has known him for many years, since she was a hearing

child. She confided that when she was a teenager her brother had warned him, “Nope. That’s my sister. Leave her alone.” And so he did. Furthermore, Liz hesitantly admitted:

And, you know, I wouldn’t have anything to do with a deaf man. You know, this is just a part of my thing, but deaf men were never good enough for me. You know, that’s kind of hard to say and very discriminative too.

Today, Liz is happy to be in a relationship with a deaf man, which she describes as, “different from dating a hearing man who wants to fix you and help you and, you know, pity you.” She said their shared use of sign language makes him, “a fit that feels like home.”

Liz went on to say that she now feels very connected to deaf culture and deaf pride and that she, furthermore, has “a deaf soul” and proudly identifies herself as a deaf woman.

My movement in the deaf culture, because I do have deaf children. They are in deaf school. You know, I’ve had the opportunity to play a big role for my children in a deaf environment. Absolutely, I have a deaf soul. You know, my mother was deaf, my brother was deaf; so, that’s part of who I am today. I fought it for a long time. And I think that once I just opened my heart and say, probably the first time when I told somebody, ‘I am a deaf woman – that can hear.’ That was a turning point for me. You know, I finally identified myself as a deaf person.

It took a long time, though, to accept herself as a deaf woman. Until recently, Liz never referred to herself as deaf, only that she “couldn’t hear” or “wore a hearing aid.” While Liz is now comfortable with her deaf identity and denies any sort of impairment, when asked about being characterized as deaf earlier on in her hearing loss, she responded as follows:

Absolutely. Well, now. Before, hell no! Before it was the worst label. I could never identify with that. I was hard-of-hearing, or I had a hearing impairment, different things. I just can't hear, you know. But I'm not impaired, you know. I'm deaf. And truly, I don't think I accepted myself until I was 43 years old. To the point where I could say, 'I am a deaf woman, but I can hear with my implant, I can read lips, I can sign, I can do whatever is available to communicate with.' And still, I will have people – you know they'll be talking to me at parties, they'll meet me, and they'll say, 'Oh, your voice is different. Are you from, you know, Boston, or Europe, or whatever?' And I say, 'No, the reason I speak different is because it's the way I heard for so long and my speech began to change.' And sometimes I'll say that and they'll just back off, 'Oh, excuse me.' And they'll walk away. You know, as if I give a care [sign: fuck off]. Now at this time and age I can say, 'Fine. I have better things to do and I can make friends who want to be a friend of mine.' Well, I couldn't do that before when I was younger. I think it's the age, the identity of being different, and um, just trying to fit in.

Since coming to terms with her deaf identity, Liz claims that her quality of life has drastically improved and that she is now a much happier person.

You know, there was not really a lot of joy about life until my 40's and 50's; and now I'm 60, so I rejoice. But it was a long time getting there, yeah.

In fact, the once isolated Liz has emerged as a social butterfly, and after many years of being a leader in the LDA community and hosting numerous social events, she now yearns to venture out and explore other aspects of life. Liz explains that being involved in the LDA community helped her to come to terms with her identity as a deaf woman, and in

turn, she was able to help many more people. However, recently that passion has subsided. Liz proclaimed that now, as she has come to fully accept herself and have the confidence to completely be herself, she is ready to pass that torch on to someone else in exchange for new experiences.

It's less now. I have, um, I have evolved to the point where I don't need to have a lot of parties all the time. But it's – the passion has subsided, and it could be age, too. You know I fought for a long, long, long time and now I just want to enjoy my life. You know so there's change. I'm happy. There's nothing that I regret.

Although her interests have shifted slightly, Liz's passion for the well-being of the late deafened adults is unwavering. In fact, she believes strongly that there needs to be more information available to support late deafened adults and healthcare professions who work with late deafened adults. Case in point, Liz reasoned that she was left without adequate resources early on in her hearing loss journey; and furthermore, she contended that through her work at DCARA, she was aware of several late deafened adults who committed suicide because their hearing loss felt entirely overwhelming. She adamantly believes those lives could have been saved had the proper resources been in place.

A point I want to make is there was not help for me. There was nowhere to turn. My doctor didn't give me any advice, um, they didn't know – they couldn't explain. I thought I was dying when I had my first Meniere's attack and they just sent me home. You know, 'Just deal, there's nothing we can do.' That is wrong. It's wrong and I think there has to be better communication for someone who is losing their hearing. There has to be therapy for someone who

is grieving. There could be a lot of lives saved. You know, during the course of working as a counselor, less than five people in the whole course, but you know that five people is too much.

When asked, specifically, how she believes health care providers could better serve late deafened adult clients she replied as follows:

They need to be able to say to a person that has hearing loss, 'This is a resource.' You know, I know that Kaiser does now, but before there were no resources. Um, they sent me to a hearing aid dealer and they didn't have resources. I mean sure you can get fitted but what do you do for the inside? What do you do for the soul? What do you do for the mind? You know, you need to reach out to someone, and you need to understand grief and life is changing and what you can do and how you can cope, survival signs, you know, survival tools. You know, how to speak to someone and how to learn to overcome the label of having a hearing loss: it is okay; and today it is a lot better than what it was twenty years ago. Thanks to Marlee Matlin who brought all the – Child of a Lesser God¹³; it changed a lot of people's perception of "deaf." We no longer have "deaf and dumb" we just have deaf culture. And so that is different.

Liz concluded her interview with the following advice to other late deafened adults:

You know, there's been rejection. Um, there's been – it's life changing, it's a life changing situation. You are no longer the person that you used to be. Your

¹³ **Children of a Lesser God** was a 1986 movie adaptation of Mark Medoff's Tony Award-winning stage play of the same name. The movie starred Marlee Matlin, who won an Oscar for her performance, and William Hurt. The story centered on the relationship between a hearing speech teacher and a deaf custodian and is credited for not only being the first feature film to cast a deaf actress, but also for being groundbreaking in exposing deaf culture to hearing audiences.

family turns on you, your husband, your work, and people reject you. That's something that you need to be prepared for. Changing your life. Allowing people to come into your life that are the same, like you and that understand. It's just a fine line of losing who you are. Get books. Get social. Internet. If you're hurting, get therapy, talk to someone. Understand that it is a loss and that you need support. Go to ALDA, go to HLAA, you know. There are hearing dogs. I'm on the internet if people ever want to talk to me, I'll open myself up wholly for them. I just wish there were more – information. You know I think we need more books. We need a lot of awareness. Thank God for the internet you know, it's truly – there were no books at the library for me.

Emerging Themes: Liz

1. Liz was diagnosed with severe hearing loss at age 18. She became profoundly deaf in her right ear at age 29 and profoundly deaf in her left ear at age 45.
2. Liz has a family history of deafness including her mother, who is deaf-oral, and her brother, who is a fluent ASL signer.
3. Liz used one hearing aid, which she received at age eighteen, because her parents could not afford two. She wore the hearing aid, first on her right ear and later on her left, for approximately twenty-seven years.
4. Liz lost her job because of the presumed burden her hearing loss caused to the company.
5. Liz's hearing loss was a strain on her marriage, which consequently ended in divorce.

6. Liz raised her hard-of-hearing son, as well as her brother's children, two of whom are deaf and one is hearing.
7. Liz denied her hearing loss and avoided the label "deaf" for many years.
8. Liz had strong beliefs about discrimination against deaf people because of the dynamics of the relationships between her father and mother and brother. She furthermore worried that she would lose the affection of her father if she became deaf.
9. Liz received her first cochlear implant at age 43 in her right ear. She continued to wear her hearing aid in her left ear until it was no longer effective, approximately two years later.
10. Liz was one of the first people to receive a cochlear implant.
11. Liz challenged discrimination from the deaf community regarding her cochlear implant and successfully advocated for discriminatory curriculum to be eliminated at her children's school for the deaf.
12. Liz is considering getting a second implant but is first waiting to see how hair cell implant technology progresses.
13. Liz worked as a counselor in a deaf advocacy agency for fifteen years after a chance encounter in a grocery store.
14. Today, Liz embraces her deafness and acknowledges that she has a deaf soul.
15. Liz is involved in deaf culture, which she largely credits to her children being in deaf schools.
16. Liz was involved in the late deafened community for at least ten years. She served on the board of ALDA and hosted numerous social events.

Participant Five: Max

Max is a 54-year-old male with profound deafness. He is currently a Zen Priest living, training and working at a Zen center in a major west coast metropolitan area. Max began experiencing symptoms of Meniere's¹⁴ disease and subsequent hearing loss at age twenty-nine. At that time, he became functionally deaf for two years before regaining some hearing. Enough hearing returned so that for the next twenty-five years he was able to function as a hard-of-hearing individual. However, he was warned that he might again lose his hearing, and two years before our interviews Max became profoundly, and permanently, deaf in both ears.

Max's primary mode of communication is American Sign Language (ASL), which is supplemented through written notes and more technologically advanced forms of written communication, such as email and text messaging. Because Max is a self-proclaimed "lousy signer," he was not confident that he could fully express his experience as a late deafened adult through sign language. Consequently, we conducted our interview using a messaging program on a computer. We met three times for approximately two-hours per interview session. A total of three-hundred and forty minutes of data was collected during the interviews with Max.

Our interview began with the topic of his childhood. Max described a relatively typical childhood with his mother and three older siblings. He is unaware of any family history of deafness other than a cousin on his mother's side of the family from an unrelated

¹⁴ **Ménière's disease** /meɪn'ʒeərz/[1] is a disorder of the inner ear that can affect hearing and balance to varying degrees. It is characterized by episodes of vertigo, low-pitched tinnitus, and hearing loss. The hearing loss is fluctuating rather than permanent, meaning that it comes and goes, alternating between ears for some time, then becomes permanent with no return to normal function.

cause. Max is unsure about his father's side of the family and assumes that this is where the Meniere's disease may have come from.

At the beginning of our interview, Max explained that even as a child, from the time he could remember, he had always contemplated questions of existentiality and sought answers about the meaning of life. Left to his own devices as a "latch key" kid, he described the many opportunities he had to "find his way." His search included exploring a plethora of religions. He summarized his experience "religion shopping" as follows:

I was looking, always looking. I actually lived in that commune for part of my high school tenure. I followed some odd religions like Guru Maharaji, Transcendental Meditation, I studied Vedic with a Hindu group, Hatha Yoga – as a religion, and the Living Room Christian of Isla Vista. And not so odd religions: Judaism, Catholicism – to keep a girlfriend – and Pure Land, and non-Zen Buddhism.

Max eventually came to Zen Buddhism and found that, as he explained, "it just clicked." He began formally practicing at age thirty-seven; and by age forty-four, Max decided to commit to moving into a full-time work/study program at a Buddhist Zen center. He has now been an ordained priest for approximately six years; however he is waiting to complete his final semester of training, called "Shuso," in which he will be asked to be the head student, give talks and take oral exams with other priests from the United States, as well as Japan. This training program is currently delayed by at least a year due to his hearing loss because, as he explains, the Zen center is very hearing centered. Specifically, Max's Shuso is on hold because of the intimacy of word-play and difficulty of interpretation involved with the process. Thus, Max's training is at a stand-still, with all

parties involved being unsure how to accommodate his hearing loss to keep him moving through the program.

Max's hearing loss began approximately fifteen years before he moved to the Zen center, beginning in fall of 1986, at age twenty-nine, with what Max thought to be the flu.

I thought I was clogging up. I went deaf on one side and then the other side in less than an hour later. And I was dizzy. After the flu started getting better, and the hearing did not, and I went to the hospital.

Initially, doctors were skeptical of Max's asserted hearing loss, especially because the loss was in both ears, citing that "sudden bi-lateral nerve deafness was almost unheard of."

Oh, that was a tough time! The doctor I went to was an ex-military doctor. Because of the bilateral loss, he sort of pressed me to 'fess up.' He asked, 'What's your game? Are you malingering?' It was quite shocking. But that's who my HMO gave me.

Eventually, Max's doctor prescribed a battery of tests that confirmed severe hearing loss. Ultimately, the doctor apologized for suggesting that Max had been malingering.

A brainstem test cleared that up. I had what the doctor labeled "severe deafness" and I started a regimen of injections, but I can't remember what it was.

The injections made a scarcely noticeable difference in Max's hearing levels. After the treatments, doctors informed him that whatever hearing did not return within two weeks of the injections would never return. Max described this information as a burden that was "dumped on him." Left with more questions than answers from the medical community, Max eventually began researching the topic on his own. He described the process as

follows:

I then bought a two-year subscription to Medline network, to try and get answers the doctors won't give. They really balk at saying, 'I don't know.' My studies implied that earlier treatment may have helped more. That made me kind of angry back then, but I'd all but forgotten it until now. Because he thought I was faking, he didn't do any blood tests for a week.

Max's severe hearing loss, which could be described as the inability to hear sounds as loud as an alarm clock, busy traffic or kitchen blender (i.e, a loss of 70-90 dB), left him feeling lonely. That is until he met a woman who he ultimately married.

It was sheer luck that I met my second wife and sort of had a network there. But I did not get much into the deaf network because of it. Oh, we did take [ASL] classes together. Two, I think. And we loved to sign in places where we were supposed to not talk, like the movies, or in a crowd of people. But I didn't use sign as a tool to communicate with other deaf people.

In fact, any attempt to explore deaf culture was met by resistance from the medical community as well as networks of friends and family. Max interpreted comments such as, "If you don't practice speech therapy you'll end up in the deaf community," as warnings from the medical community about the importance of maintaining his hearing identity.

Although doctors had advised him otherwise, eighteen-months after going deaf, Max slowly began regaining his hearing, to the level moderate hearing loss, which Max described as, "severely hard-of-hearing." He explained the occurrence as follows:

Eighteen months was just long enough to feel deaf, then it came back, and over the course of the next couple of years, I learned to hear again, although high-

pitched sounds were totally gone.

When asked to describe his feeling about regaining his hearing, he explained that he had neither relief to regain his hearing nor grief for the loss of his deafness:

Strangely, no, there was no relief. It was very gradual. And I suppose it just meant another transitioning. Hmm, maybe I was getting a little deaf minded. I think if I had lost my hearing for a longer time, I might have felt a loss of deafness, but I just did not get connected, or changed enough for that.

Max explained that in transitioning into life as hard-of-hearing, he realized it felt surprisingly different than anything he'd experienced as either a hearing person or a deaf person.

I flowed into hard-of-hearing life, which is considerably different than either hearing or deaf. I didn't like hard-of-hearing. It has no culture of its own. I would be neither deaf nor hearing. So, I became as hearing as I could. No aversion to deaf culture, I just did not know that most deaf people can actually hear a little.

With nearly half of his hearing back, Max was able to function at an acceptable level with bilateral hearing aids for more than twenty years. Although, admittedly, he wore them off and on, not quite able to gauge how much benefit he was receiving from them. When asked about his experience with the technology, he explained:

My audiologist said I could take them or leave them, based on my audiogram. The hearing aids did not seem to help much, if at all. Maybe they helped for a while. It just seemed after a couple years, they were not doing the job. So I got a new pair after retesting, from a different place. But it still didn't feel like they

were helping. I finally realized that I was not hearing voices better, not even sound in the purest sense, but I was receiving input in the form of organized static. Now, of course, I cannot hear static.

Max was left with the decision of whether or not the benefit that he was receiving from hearing aids was worth the effort of wearing them.

I actually, at that point, used them on and off for another couple of years. Then it must have been getting worse, because that static was now only a tap on the ears to let me know something was making a sound.

After spending nearly ten years in the Zen center, and more than twenty years functioning as a hard-of-hearing person, in 2006, Max began suffering classic Meniere's attacks, entailing bouts of tinnitus and vertigo. Max explained that at the time, his biggest concern were "balance attacks," which he characterized by his constant falling over with any sudden movements or changes in lighting. He stated that these attacks were so bad in the beginning that he paid little attention to the concomitant hearing loss.

Eventually it let up. I got over the severe attacks, and had a deaf right ear. The hearing aids no longer served. I lost the hearing in one ear, this time, and it did not come back. It took about a year to go away. Meanwhile the other ear was a little worse and in 2009, the other ear started to go, and the attack was bad enough that it was considered possible Meningitis. Right first, then the left in 2009. After that, it was an alternating worsening of the ears.

Max explained that after losing his hearing, he continued to identify as a hard-of-hearing person although some would consider the same hearing level to be deaf. He confided that as his residual hearing gradually faded, fear and uncertainty began to set in.

It's this latest development, the profound loss that has been most difficult. I think I was battling fear more than depression but I recall panicking when it first happened. Fortunately, I've had some great support, and opportunity to stay at the Zen center despite the change.

To cope with his fear of deafness, Max admittedly developed a certain level of denial about his hearing loss: "I kind of entered a period of unintentionally faking my way through." But as time passed, Max realized that this task was becoming increasingly arduous.

Every month I noticed that the Dharma talks were getting harder to understand, even with lip reading. We use bells, gongs and clackers for everything. And it was a constant reminder, month by month, that it was getting worse. One by one, the various noise-makers became silent. The last to go was the taiko drum, and the big densho temple bell, but I can still feel those when I get close to them. I realized I was faking a lot. Pretending I understood stuff. I would back up study lectures with the reading assignments and such.

As Max's hearing levels plummeted, so did his sense of well-being. With this realization, Max decided that it was time to take action. His first step was to sign up for a sign language class and begin connecting with the deaf world.

Things got bad. I was really depressed and anxious. What was I going to do? I was alone in the crowd, jostling elbow to elbow. Totally alone, even among friends and family. It was when I started taking ASL classes and talking with deaf people that I began to formulate ideas and gain understanding.

It was one unassuming question that initiated a paradigm shift for Max about

deafness and set him on a path of an identity revolution. He explains:

And I had a real paradigm shift when one doctor who lost his hearing asked why they called it 'losing your hearing' instead of 'gaining deafness.' This idea blew me away, and when I realized that this was a one-way street, I started considering this idea. It was a real life-saver, and arrested a downward trend I was stuck on.

Max explained that after nearly six months of complete silence, he had one lingering problem: hearing people seemed to be inept at effectively communicating with him. He elucidated, "I almost went nuts!" and further exemplified:

I would go into a food place and place an order, explaining I was deaf, and they would have to write back to me, or point or such. They instead shouted or exaggerated lip-syncing or just started talking back. Multiply this by hundreds. It was exasperating!

He explained that it was on the advice of a friend that he re-evaluated his communication methods, which became a "real game-changer" in his everyday interactions with others, albeit contrary to his perceived status as a late deafened person.

A deaf friend, wise beyond years, picked up on it, and unlike everyone who was screaming, 'Speech therapy! Cochlear implants!' he just said, 'Have you tried not talking?' He challenged me to a weekend of no-voice. It was a great relief to stop trying, and then I tried a week, then two, then a month, then off. I have not regretted it. September will be two years.

According to Max, the results were significant and immediate; people treated him differently. When asked if he thought people understood "deaf" better if he did not use his

voice, Max clarified:

When I started voice-off, people and things just fell into place more often. Voice is a heard thing, and people think if a deaf person speaks, they are somehow receiving the same kind of feedback a hearing person is, when they hear their own voices.

He went on:

People stopped shouting and stopped treating me as a hard-of-hearing. But I felt guilty about that, too, because I thought I was still hard-of-hearing, even after I was out of the hard-of-hearing zone completely. Naturally, I was passing through the LDA [late deafened adult] phase at that time, but the 'D' in LDA did not seem legal, you know what I mean?

Regardless of the guilt that Max felt about passing as deaf, when he had not yet come to terms with the identification, being non-vocal served another purpose for him: by not using his voice at all, he no longer had to confront the consequences of his incipient “deaf voice.”

Speech therapy or not, one forgets over time. When you cannot hear your own voice, the pitch changes, the accent and any number of things begin to creep in. You can tell by the look on people's faces; especially those who have known you for a long time. I had one relative freak when I visited after many years and had developed a bit of a deaf accent – and that was during my hard-of-hearing years!

Not everyone is sympathetic to Max's conviction to remain silent. He recalled a recent encounter:

Last week I was hit with a person that was pressuring me to speak and read lips. It was so forceful and rude, and from an intelligent, college-educated person too! Basically, she asked me a question, and I signaled that I was deaf, grabbed paper and pen, and introduced myself. She started fingerspelling; however quite poorly. So we jotted notes. I was Com-syncing a bit to help. Big mistake! She said, 'Will you just please speak to me?' I said, in notes, that I do not speak. She said, 'You're moving your lips, and making some sound, just do it louder,' etcetera – that's me paraphrasing. And so it went. She became very opinionated, and I came to realize that for some unknown reason, it was her goal to enlighten the deaf about how it's better to speak.

Max said that he walked away from the woman feeling “devalued and unaccepted” and that he wished he had had the opportunity to make clear the concept of “Audism” to her.

Later I realized that folks have their opinions, but gee, would anyone ever suggest that a gay person act more straight and they'll go farther in their career, or that a black person act whiter and they'll please more people? I still cannot understand this attitude.

The meeting, as Max recounted, was reminiscent of many other encounters that he has experienced throughout his deafness. He explains that what he once believed to be a personal attack, he has now accepted as people's naivety that should not be taken to heart.

Early on in my deafness I felt rejection and unacceptance, even abandonment by some. Later, as I understand and embrace deafness, it's more often a feeling of pity for their ignorance, or even anger if I was feeling

impatient.

It is possible, however, that as Max has begun to embrace deafness and move forward in silence, such interpersonal experiences have created a shift in his personality. He explained that prior to losing his hearing, he had always been an extrovert, "I have a history of talking a bit too much. I used to be the class clown;" but deafness, he claims, "has me flipping between wallflower and social center." His willingness and ability to interact in social situations, he suggests, is highly dependent upon the group with whom he is interacting. If he is in the presence of signers, he explains, he tends to be much more social. He illustrates in the following example the difficulty of interacting with hearing people who don't sign.

I think the first time I had the serious experience of that was at one of our ordination parties. We have people become official Zennies or priests, and as such there is a party. This usually has a lot of visitors present. So, a few of my friends, and all these strangers. Lots of people I have not had the chance to "coach" yet. They would say stupid stuff, yell even. They tell me I need to learn to lip read! So, even now, around strangers, I guess I'm "off." Now that I think about it, my social life is pretty much restricted to sign language classes, deaf groups, and of course the Zen center.

Even in the comfort of the Zen center, which Max describes as very sound oriented, he is able to participate very little. He explains that he has "gone to great pains to educate people and it has paid off somewhat." His friends at the Zen center have now learned to fingerspell in order to relay information; however, other than what is immediate and easily accessible most of his communication takes place through written notes.

Max explained that communicating through written notes feels exceedingly elementary. He is no longer able to bond with his conversation partners through “small talk, jokes, puns and spontaneous reactions to things.” He explained that most of his interactions on a day-to-day basis stick to practical matters.

Max reflected for a moment on what it was that made communication with hearing people so difficult for him. He eventually came to the following conclusions:

Not being able to hear myself anymore? Seems too simple. No knowing what was coming out? Warmer. Not being on equal communications with others? Probably! It rings true. They get to hear fast and heartfelt communication. I get some scribbles that are nowhere near the talking speed or depth. Nor do I get the feeling that voice imparts. I could give them my heart, and they give me notes!

It is for similar reasons that Max rarely interacts with old hearing friends outside of the center, other than through technology, “I see them only in pictures and emails.” In the past he has made attempts to meet friends who knew him when he was hearing, but the results were not favorable.

This was a very close friend. Actually, I looked up three. The first one had died several years ago. That's how isolated I was getting. The second was just too freaked out to meet with me. My Facebook page makes no secret about my deafness, and this guy was not going run out of excuses. The third one was probably the best friend, or one of, that I had, as it did not make a difference. But the one time was all slow notes, and the coffee chats could not really be done with the hyper-laughter, puns and jokes the way we used to enjoy. It was a

bummer, you know? Our emails are of much higher quality.

In fact, Max describes some of his most positive interactions as being with other students in his sign language classes. He describes these interactions as encouraging and motivating. "This was encouraging, because this showed me that if I stick it out and get better, I can have some good connections with fellow signers, hearing and deaf!" He is confident that through sign language he will again have the opportunity to have deep and meaningful interactions with people.

Signing is deep. Deeper than voice in some ways. When it is two-way, it is connected, whether the conversation was adversarial, intimate, professional or whatever.... the tone and the rules are established when the conversation begins, and we started to talk. The tone would establish feelings of anger or intimacy or sarcasm, or any number of other moods. Notes and emails lack that. ASL does not.

Max suspects that hearing people will always "freak out" when they realize he cannot hear. He claims this happens regularly when, for example, someone stops to ask for directions. He claims that when he gestures that he is deaf and pulls out a pen and pad, they appear eager to end the interaction.

This, he purports, doesn't just happen with hearing people, but also with deaf people. While he had suspected that culturally deaf people would be more sympathetic to his situation, it turns out they too appear uncomfortable in their interactions with him. He describes the following meeting with a deaf individual at a movie theater:

I went to a movie last week, and was carrying my captioner. And a guy waved at me asking if I was deaf. I signed 'deaf,' and before I could explain, 'LDA-sign

poorly, deaf,' he was whipping out ASL much faster than I could understand. After explaining, I sort of felt sad that I am so far from fluency. I almost felt like a poser of some sort. But what else can I be, if I cannot hear even my own shouts, let alone talking? He sort of shined me on when I could not keep up the ASL. I've been at this long enough to read body language pretty good, and suddenly he was in a hurry. You know how it is? Deafies¹⁵ usually stop and chat for a good spell when meeting. It was rather a traumatic event for me that was slow-burning, rather than sudden, know what I mean?

Although Max described the experience of perceived rejection from the culturally deaf individual as somewhat traumatic, it has not stifled his desire to be around deaf people and to learn the language and the culture.

The deafies are great to be around for the feeling of finding my way. Oh, it's a challenge. I get nervous, and I do have a long way to go to better understanding and acquiring the culture. But it's also a means to an end. It's where I expect to be. There is a scary adventure in it – much like a scary ride or a haunted house. We scream and kick and then say, 'Let's go again!'

Max expressed some grief of not belonging or feeling quite welcome in either the hearing or the deaf world. It is through interactions with deaf people, that Max has come to realize that learning ASL is going to be key to his integration into deaf culture, and therefore a sense of belonging. Although he admits he has his work cut out for him in acquiring the language, Max isn't new to ASL. He explains:

I was dating a girl in junior high, and she dragged me to a silent weekend and I

¹⁵ "Deafie" is a label generally marking in-group membership of culturally deaf individuals.

learned some then, not a whole lot, but I was amazed at how effective immersion in ASL is.

Max became interested in ASL again in the early 80's and took some ASL classes through adult education, being primarily motivated by the opportunity to meet people; and when Max became deaf, he immediately enrolled in evening sign language classes.

However, it was while reflecting back the effectiveness of the language immersion experience he had had much earlier in life that decided to spend a summer at Gallaudet University, studying sign language, and being immersed in deaf culture. When asked about his experience at Gallaudet, and specifically if he felt comfortable in a culturally deaf environment, Max beamed, stating:

Oh boy, was I! I didn't want to leave! Everything was deaf oriented! No talking on campus allowed! At All! The staff, teachers, fellow students, all signed. Lots of deaf folks that made me feel "in place." We had group get-togethers, and ate at the café together. It was special.

He explained that while there weren't many deaf people in his ASL classes to socialize with, a group of deaf signers eventually sought him out.

They came barging into the dorm living room where me and the hearies were staying, the deafies were in the dorm next door, and signed "Okay, we heard there is a deaf guy here." They picked my brain and we talked for hours. Hooked up later around campus so I was sharing my time with them and my hearing classmates.

Max's interaction with the culturally deaf group proved to be much more positive than his previous experiences. Below he explains the communication accommodations that were

extended to him:

It was good; because even though my sign was even worse then, there was an awareness, it seemed, that ASL skills there varied. They adjusted for me, and the others. Still pressing it to the limit though. But it was a quick adjustment in that we seemed to know the speed to use after a short time. That was so cool, because you feel peer connection that way.

While at Gallaudet, Max felt that the social experiences he had with other deaf people were enormously important because, “they had some of the answers I was, and am still looking for.” The interactions furthermore provided a sense of “finding my way.”

Overall, Max described a positive and inspiring social connection with the deaf peers he met at Gallaudet; and although at times he was still met with the attitude of, “come back when you can sign better” he never doubted his potential to fit in.

Theirs [attitude] was better than my fellow late deafened adults. Oddly, the deafs are the ones that keep telling me to persevere, learn ASL, keep in touch. But still I get cut out of purely [culturally] deaf situations at this time in my skill.

Instead of rejection from deaf people, as he had on some level expected, pessimistic attitudes about joining deaf culture were, surprisingly to Max, expressed by hearing people and by other late deafened adults. He described one such instance:

My friend sat me down, he was a leader in the late deafened group, and straight out said that I could never be completely [culturally] deaf, my ASL would never be that fluent, nor could I get the ethnic experience of the truly deaf. That was like a slap to me.

Max came to find out that he had little in common with the other late deafened adults he was meeting, in both philosophy and practice.

The late deafened adults I was meeting were oral, had lots of hearing aids, and only signed a little. And most of them seemed to crusade to prevent the late deafened from joining the ranks of the [culturally] deaf world.

In fact, Max suggested that the group he went to would more properly be described as a late hard-of-hearing group; and that is not what he was looking for. He explained:

I have decades of hard-of-hearing to remind me what it's like to be between cultures. I'm burned out being in-between. I had high hopes for LDA groups, but we were more of a sub-hearing culture than a deaf one.

Max explained that the late deafened support group that he attended was very oral and relied on speech, lip reading, notes, and then ASL, “in that order.” He admitted that those forms of communication were fine until his hearing loss progressed to a certain level, and then he needed sign language.

You see, I was always in a state where at least every couple of months, my hearing was just a tad worse. So I was intent on ASL. I guess I was preparing for total deafness. I was burrowing deeply in the questions that must be asked at some point in this journey. I am not a born leader, and I wanted answers. It was getting to the point where I was going to have to be the decision maker.

Max expressed uneasiness about accepting the stern warning of other late deafened adults, or taking the advice of anyone else, for that matter. According to the principles of Max's spiritual practice, he needed to make a decision for himself, but he also realized that in order to do so, he needed to gather sufficient information on which to base his decision.

That's hard to do, because if I'm stuck in a place where I'm following advice and I should not be, then I'm leaking rebellion. If I am trying to lead myself, and I have insufficient information or experience, then I fail, or get lost, and go back to following. The cycle repeats.

In order to gauge whether or not joining the signing deaf community was even an available option to him, Max read copious amount of literature about hearing loss and consulted with numerous people in the deaf and hard-of-hearing communities; however, although he persevered in collecting information, it soon stopped being new, and stopped giving him new ideas. Instead, he was repeatedly hearing the same two, opposing perspectives.

I was still not sure how much I could choose. Was there some criterion for all this? Sort of, but nothing everyone agreed upon. Almost six months after profound, four months after voice off, I began to realize, after lots of study and communication, that there is an "alone element" to all this. Sort of like the Democrats and the Republicans. Each side feels strongly – and even has their own set of facts.

Realizing there was no one easy or right answer, Max decided it was time for him to make an informed and independent decision about how he planned to move forward in his life with deafness.

This is where the personal responsibility has come in. At some point, you notice that there are conflicting ideas and viewpoints. Let's face it - most of us grew up trusting those in authority over us. I keep noticing that thread through most of it – that it's going to be up to me to make and choose what's going to happen. The decisions will have to be mine. I must allow that, and stop asking, "What do

I do?" and start asking, "What are my options?" And this means creating new options, and tailoring existing ones to fit my unique needs.

Through his soul searching, Max has come to terms with the idea of living his life as a culturally deaf individual, abiding by the customs and rules established through deaf culture, as a legitimate option.

I have just recently begun to accept that this is a valid choice. A deafened person can choose to be big 'D' deaf. But the same characteristics apply to everyone; that the deaf have ASL as their primary language. It's a little "cart before the horse," but it seems it cannot be any other way for the deafened. It probably could, actually. Maybe it's my situation.

Max confessed that, "it's a scary thing," but he feels that, based on his physiological limitations and social needs, joining the signing, culturally deaf community is the only choice to fulfill his needs. According to Max, it came down to being "a common sense choice when [he] had no hearing left." He elaborates in the following passage:

What else could I choose? I could be oral deaf, and read lips. But I know that will only take me part of the way. We only get one life. I do not want to give in to "impaired" and live a half-life. I also know I cannot be ethnically deaf. I do not want to be what I'm not. But I do want to shoot for the maximum. I read and talk to small 'd's and they have no trouble with it. Neither did I when I could hear some.

When asked if Max had ever considered getting cochlear implants he likened it to giving up on a deaf cultural identity:

Actually, as hearing aids became useless, I did look into cochlear implants. I

would not be considered a candidate until my hearing stopped changing so much. Eventually, it did. By then it became a sort of balancing act choosing to embrace not only the deaf community, but deaf culture as well were weighing heavily. Sure, many born-deaf were giving them a try, but not without cultural and personal consequences. So, I put it off, until I had a chance to explore and experience my deafness more fully.

After a moment of hesitation, Max added the following caveat:

Oh, and I suppose I might consider cochlear implants if my life situation demanded it. Maybe if I could not get work or make sign work on a level that got me in to deaf culture. I hope it does not come to that, and that if I ever do get them, it would be because it was okay and sort of just fit.

Max acknowledged that his decision to acculturate into deaf culture is “uncharted in so many ways;” however, Max is still confident that he has made the most practical choice to meet his needs. Furthermore, he realizes that for him, there is no turning back now that the decision has been made.

This is big, really big. It's dropping one culture, and picking up another. Even those who have gone before - well, in their own story, and the choices and scenarios are so varied. What makes it have teeth is that I have no choice in the matter. I did gobs of adventure sports and dangerous things, as well as careers and hobbies that did not work out, but it was fun trying. With this, all the challenge is there - but I feel like I can't go back now. There is no changing my mind.

Although Max's primary reason for transitioning into a new culture is arguably his inability

to connect with people through speech and language, ironically, one of his biggest fears now in this new path is that his lack of sign language skills will impede him from being fully able to form an attachment to the culturally deaf community.

I thought I'd not have to soul search anymore. Not so. But, you know, I'm impatient. If I pay attention, it is slowly taking shape. I feel downright anxious sometimes. While this path is working, there is not room for changing the rules much. What if I cannot succeed enough to get my needs for connection and identity fulfilled?

At the same time, Max knows that giving up is also not a viable choice.

I cannot quit this like a job that is not working out, or a class that is too difficult. I have no choice, so I move into deaf culture as much as I can, but there is resistance from me, others, deafies, hearies, etc. That resistance hurts! Especially when deafs call me hard-of-hearing.

Being referred to as hard-of-hearing, at this stage in his deafness is particularly painful for Max, who confided that after years of being hard-of-hearing, he was happy to now be deaf because it gave him an identity that being hard-of-hearing did not. He explained that now that he is fully deaf, he no longer feels he has to keep a foot in both the hearing and the deaf worlds; instead he can now proceed fully into deafness.

I have a cup that says, "What?" on the side and below that it says, "www.deafandlovingit.com." I think it was the web address that dug the deepest. It exposed the feelings I was having: the relief, almost joy, that I could now pursue the path properly. I was really enjoying deaf compared to hard-of-hearing.

In fact, not only is Max happy to be deaf, but he has furthermore developed a sense of pride in his deafness, specifically in the severity of his hearing loss. He explains:

On the message boards and in chat rooms, it's easy to see the almost competition that goes on with comparing levels of deafness. Well, in person, it's another matter; when [culturally] deaf and [orally] deaf alike find out that I am in the small percentage of profound, and that I do not know ASL well, it's a kind of, "You got the creds kid, come back when your ASL is better." There is a respect there that kind of makes me squirm. It's back to that deserving thing. It's so odd. But here I am, grew up hearing, and now I have a deafness that some envy! It seems wrong. Of course this is all in a small back of my mind thing.

Max suspects that the opposition he encounters from others regarding his decision to join deaf culture results from their lack of understanding. He said that his motives for dropping hearing culture and picking up deaf culture are simple and straightforward. He explained:

It's not that I have this obsession to belonging to only the [culturally] deaf community, as opposed to another deaf grouping, it is that it feels I have no other choice.

While his hearing friends cannot understand the joy that Max has found in deafness, his culturally deaf friends are unable to understand the grief that is associated with the loss of his hearing, especially as it coincides with his eagerness to join deaf culture.

You see, my culturally deaf friends cannot relate to my pain at transitioning. To them, deafness is normal and unique, and joyful. And I do experience that sometimes. It's the transition that is hurting a bit. My [Buddhist] training is

golden for this time in my life.

Max was fortunate in that the temple provided a safe place for him to come to terms with his deafness and seek out answers without feeling pressure to make absolute decisions; however, that does not mean he was sheltered from emotions stemming from his hearing loss.

Well, being Buddhist does not eliminate the feelings and stresses. It just gives me a workable practice to navigate it. So, looking at those feelings that are there - if I were not a Buddhist, I might be casting about for support on a deeper level. I feel a sadness - so I sit with it. I invite it in for a cup of tea. After a short while, it just leaves, rather quickly too, if I do not make a big fuss about it. The trick is to allow it its full life. Do this daily, and it gets routine, and often the experience is still there - the sadness, anger, depression, etc., but has few stuck times where it balls up and does a lot of damage. It's not foolproof, and I've had some hairy times.

Max disclosed that he now suffers from anxiety as a result of his deafness.

I never had a panic attack before this happened. It caught me off guard. But after introducing it to Zen Practice, it lays kind of low. Hope that makes sense? We fully engage - but we are able to see these things "unexaggerated" if we keep to center.

His practice empowers him, though. Max is able to manage the anxiety attacks through his spiritual practice. Furthermore, through his practice, he explains, he is able to more deeply and fully understand his experiences, which enables him to better manage various difficulties and situations as they arise.

Our practice helps us to reveal and strengthen what's there - but at the same time I can point to specific impetus that triggered change. Was it the practice? Or the situation? In Zen, we would say the practice, because all events and substance have their definition in our perceptive minds. The practice does give me guidance in that regard. Patience with people, peace of mind, stress reduction are all gifts of practice that have helped me get this rolling. Sure, I've been greatly disturbed and distressed at times but my practice buoys me.

Sooner than later, Max will be leaving the Zen center and finding his own way in the “outside world.” He recognizes that he has some fear and insecurity about leaving the sheltered environment of the Zen center.

I'm past middle age, and deaf, and not knowing ASL enough to fit in with hearing or deaf. It's very scary and very depressing at the same time. But these are feelings, and I carry them lightly in the sense that I do not feel immobilized or suicidal or anything like that. Perhaps because I'm in a safe and supportive place right now, while this is going on. But it will end some day.

He is particularly concerned about leaving the physically safe environment of the Zen center, and fears the dangers of the outside world for deaf people.

Sound was input. We could listen and do something else at the same time. It was safe. I've been nearly killed twice; once by an ambulance, the other a fire truck. One even swerved and just grazed my jacket. It was on the heels of one of my friends here getting hit by a turning vehicle. How would I survive without this safety net?

However, according to Max, Zen Buddhism emphasizes personal responsibility in all

matters, spiritual and mundane. As a deaf individual, he feels an extra burden of responsibility in the Zen center that has been exceptionally challenging. He explains:

You see, everything from the morning wake up bell, meals, chants, the call to the Zendo, etcetera are all sound based. This is so we can put aside watches, and the American way of scheduling the life out of things. Now, I've had to take up clocks and alarms, and often must be tapped on the shoulder to end meditation. No chants anymore, and I miss the positive effect of that.

Max envisions a temple that is designed to accommodate a deaf congregation, where deaf people could come together and practice without restrictions.

I am alone here, and it's not very practical. I participate very little. Oh, I have a bed-shaker, and flashing lights¹⁶ in my room and I use a watch for the other stuff - and I'm late a lot too! But it could all be redesigned for a Deaf congregation using lights and other means.

The challenge that faces Max as he goes about his daily activities at the Zen center has also highlighted a need.

Soon, I will rise to a level transition where I will need to seek out a more productive way to assist with this transition. As I said before, the Zen community is very sound-oriented, and I participate very little; but being here for now is good, because I cannot really sign that well yet either. I'm a bit protected here, as yet. You have caught me at a time where I'm in the middle of whatever steps I'm going through to reach the "acceptance" phase.

According to Max, there is currently only one deaf Zen center in the world, "and it's

¹⁶ Alerting devices are a type of assistive listening device that connect to alarms, doorbells and telephones to alert people with hearing loss to events in their environment.

not in the United States, but in Asia somewhere. We need one!" Eventually Max hopes to meet that need by opening a deaf Zen center in the United States. He explains:

We've worked for ten years to make me a priest - it's still a path I want to follow, and I'd like to eventually see a deaf temple. I envision a place where we can practice with light signals, visual cues, and Dharma talks in ASL. But after this place, and before that one - I must cultivate my signing and deaf identification, to get more of these stories. Deafies like stories!

Max thinks there will be something particularly special about giving Dharma talks in ASL: "It's like art. The of idea of giving a Dharma talk in the beauty of sign language is awesome!" He and his leaders have spoken extensively about opening a deaf Zen center, and he claims, "They would like this to happen sooner, rather than later." However, he claims they easily underestimate the time he needs to prepare for such an endeavor. At this point, he plans to possibly start with a deaf "sitting group" and gradually build from there.

When asked if, as a Zen priest in training, and considering the need for a deaf Zen center, he believed that he was meant to be on this path, or in other words if he was put on this path by some spiritual force greater than himself, to become deaf and open a deaf Zen center, Max explained the following tenet of Buddhism:

I think I would have to say that "meant" is no longer a way to look at things. That must sound funny from a clergyman, but it's part of our practice to take things as is. "Meant" implies a force other than ourselves. And while that's true - that the world, the universe, is a force - it's still just what it is. This tells none of the joy - because we can then call all things "mundane" or all things "holy." I look to the future lightly. Things change, so it helps to grip lightly, ready to

move with the change. But that still leaves room for the possibility of a deaf Zen center.

It is the same philosophy that has aided in Max's acceptance of his deafness.

This has allowed me to run with this deafness. I cannot change it - so why not find out why the deafies like it so much, and join them? Then carry that into a deaf Zen practice?

In his course of becoming culturally deaf, Max is making assenting changes in his life; one being that he is beginning to advocate for his needs as a deaf person. As Max is becoming more comfortable with his deafness he is beginning to take ownership of it. He explained how he is now ensuring his needs are met:

Now, I'm starting to say, "Hey, I need captioning; the law says I get a flashing smoke alarm; I need an interpreter." I am only – I'm just now beginning to ask for these things. So when does it really ever begin? The deaf are fighting for this stuff all the time. For me it's a game-changer.

He also believes that he is beginning to change physically, as an evolutionary function to help him avoid dangerous situations.

Slowly, my eyes are learning to scan better. A person scratching their nose across the room catches my attention.

Max's subconscious mind is becoming deaf too, he claims, as evidenced by his dreams, which are now in sign language. He explains that rather than dreaming in words, as he used to, he is now beginning to dream in signs and concepts, which he depicts as something that is difficult to wrap his mind around. He recalled the following, recent dream:

The dream was on a grassy hill, and I was reading a newspaper to someone, but it was in ASL! Don't even ask what that looked like. The dream did not say. Weird, huh? I was sharing with a girl I knew, with who – we drifted apart when deafness kind of killed the talking together – but I was signing the news to her.

Max's closing remarks of the interview, which he thought best expressed and summarized his experience of becoming a late deafened adult and hoped would facilitate understanding of his experiences, consisted of the following profound statement:

I do not confess this much to people, that I think the longer I am deaf, the more unhappy I would be with being hearing again. It's too strange for some folks to grasp and I cannot fault them, because as I reflect I know that I felt the same way, before I understood. I had to go deaf to get it.

Emerging Themes: Max

1. Max is a Zen priest who lives in a Zen center. He spent 10 years at the center as hard-of-hearing, one as severely deaf, and two as profoundly deaf.
2. Max spent two years being severely deaf, regained some hearing, spent 25 years being hard of hearing and now is profoundly deaf and his hearing will never return.
3. His progress in his priesthood training has been delayed due to his hearing loss.
4. Max feels that because of his profound deafness, he has no choice but to join the culturally deaf, signing community.
5. Max has not used his voice in over a year and a half.

6. Max relies primarily on sign language and notes for communication.
7. Max realizes that in order to fully be part of deaf culture his sign language skills need to improve.
8. Max prefers communication with people who know sign language; he feels that notes prevent a personal and emotional connection.
9. Max is interested in one day opening a Zen Buddhist center for the deaf. Currently there is only one in the world – in Asia.
10. Max feels a sense of pride in his audiological level of deafness.
11. Max has been seeking answers to questions of culture and identity.
12. He describes his current situation as “dropping one culture and picking up another.”
13. Max struggles to be self-reliant in an atmosphere that is primarily sound-based.
14. Max suffers from anxiety as a result of his hearing loss but is able to cope with it through his practice of Buddhism.
15. Max feels that he is not able to connect with his hearing friends anymore because of the language barrier, likewise he is not able communicate with culturally deaf people because of the sign language barrier. He is also not comfortable with late deafened adults because they have different beliefs and values.
16. He feels his current communicative interactions lack both depth and emotion.
17. Max believes that he is changing emotionally, physically, and sub-consciously

into a deaf person.

18. The longer Max is deaf, the less happy he thinks he would be being hearing again.

Participant Six: Meg

Meg is a 33-year-old woman with profound bilateral deafness, and currently uses bilateral cochlear implants. Interviews were conducted over two meetings for a total of five hours. Although Meg is fluent in American Sign Language, the majority of the interview was conducted in spoken English, except when ASL provided cultural or visual nuances that could not easily be expressed in English.

Meg has no family history of deafness.

The interview began with a description of Meg's transition into deafness, which happened in her senior year of high school, as a result of Spinal Meningitis. According to Meg, her hearing loss began with what she thought was the flu. "I just had a really, really bad headache and was nauseated," she said. "I was having a hard time keeping my food down." After sleeping all day, and despite her illness, she made plans to meet friends that evening.

One of my friends called and told me that the guy I liked wanted to meet me that night and if I was able to get away, that we could meet at the park. So I told my mom I was feeling better, and she made me eat a whole bowl of top ramen and keep it down for one hour, and then she let me go. So that night, I walked down to the park and met them. By then it was after curfew, so the cops pulled up.

Meg said that she had been very athletic in high school, but when her friends all ran away, she felt weak and was not able to keep up. Her friends left her behind, and she was questioned by police officers. She remembers walking alone back to her friend's house that

night, but has no memory of the events that followed until the following day, when her brother was carrying her to his car.

What had happened between the time I fell asleep and being carried out by my brother, my friend said I was vomiting in my sleep and she couldn't wake me up. And she kept shaking me and I wouldn't wake up. So instead of calling my parents she called my brother. My brother carried me out to his car, put me in the passenger seat and put a seat belt on me. And then he drove me home...and that was on a Saturday, so (it was) probably Sunday when he brought me home. And he had to help me walk into the house, and laid me on the couch.

When Meg's parents arrived home later that afternoon, she asked to be taken to a doctor because she had never before experienced such an excruciating headache. Believing that Meg had the flu, her mother told her to wait and see how she felt on Monday; since Meg didn't have health insurance, her mother did not want to have to pay for an unnecessary weekend visit to the emergency clinic.

Meg continued to sleep throughout the day on Sunday. She described waking up from a "scary nightmare," which was actually the first sign of visual and auditory problems to come.

It was dark, so I must have slept all day. And I had one of those grandfather clocks in my living room and I was confused because it was dark so I looked over to see what time it was, and at that point, the clock split in two and there were two clocks. So I was seeing double. It was two and sometimes it was three. So there were two or three of everything and everything was spinning. So I was really scared so I yelled for my mom really loud. And then I realized that I

couldn't hear myself say 'mom' so then I screamed louder. Nothing. And then all of the sudden she was hovering over me, saying something. I saw her mouth moving but I didn't hear anything. And I just started yelling, 'I can't hear anything! I can't hear anything!' So she ran out of the room and got my dad, and my dad came and picked me up off the couch and put me in the car. And by that time they put a bowl in the car because I was throwing up so much. And on the way to the hospital I was throwing up blood. And then I don't remember what happened. How I got there. But I woke up and I was in a room.

The next time Meg woke up, she was in a different hospital room and her mother was sitting next to her, crying. She went back to sleep. When she woke up again, her brother was also in the room, crying. At this point in the interview, thinking back to the fear she saw in her mother and brother's faces and remembering the fear she felt as a result, Meg began to cry.

[crying] So, I woke up and I said, 'Why is everybody crying?' And I could hear. There was like fifty-percent in my right and my left ear was completely deaf so I could hear myself talking a little bit. I said, 'Why is everybody crying?' and my brother jumped up and said, 'She's awake!' I guess I had slept for two weeks. I was in a coma. The doctors were saying to my family that they didn't think I was going to wake up. The night before I woke up they had the preacher come in and read my last rites.

Meg's mother explained to her that she had meningitis but because of her hearing loss and continued dizziness, she did not understand her diagnosis. "I thought my mom

said tonsillitis and I said, 'I didn't know tonsillitis could get so bad.'" Her mother told her not to worry and to go back to sleep.

I ended up sleeping for four more days. I don't know if I was in a coma or just sleeping. And then I woke up again, and my room was filled with balloons and flowers and cards. I guess everyone in my high school sent me balloons and flowers. Even the boring hospital picture...someone had covered it with a poster of Johnny Depp.

Meg believed that the thoughtful gifts and visits from her friends helped her recover, but she continued to have problems with her vision, balance and hearing.

When I woke up I was cross-eyed for about four months....and I felt like every doctor that we talked to couldn't give us an answer. I was asking, 'is my vision going to get better?' because I was seeing double. I couldn't see, couldn't hear, and couldn't walk. I had vertigo. My balance was so bad.

Several weeks after being released from the hospital, Meg met with an audiologist, who told her that her hearing could potentially get better, but that it would likely never get worse. He fitted her with a hearing aid for her right ear, but said her left ear was "too deaf" to receive benefit from amplification.

And that worked for about three weeks. And then one night, I went to bed and I was listening to the radio. Then I went to sleep and I woke up in the morning and thought someone turned the radio off. So, I tried to turn it back on and it wouldn't work. I thought the radio was broken. And then I was talking with my dad to tell him my radio was broken and the strange thing was that all of the environmental sounds that I would have heard if I hadn't lost my hearing, I was

still hearing, like phantom sounds, so when my dad spoke to me I thought I was hearing him. I didn't know I wasn't hearing him. And it wasn't until a day or two later that my mom approached me and she said, 'I don't think you're hearing me.' And I said, 'Yeah I am.' So she said, 'Close your eyes.' And then she tapped me. She said, 'What did I say?' I said, 'Nothing.' and she started crying.

Meg admitted that, at this point her journey, she had not yet acknowledged that she had advanced from hard-of-hearing to deaf, to the point where she was no longer able to access spoken language. She remembered thinking her mom was probably being “emotional” and “overly dramatic” and had most likely whispered whatever it was she had said.

I didn't believe it, because the doctor said it couldn't get worse. It wasn't until that night that my friend called me on the phone and my brother said, 'It's for you.' and he handed me the phone and I said, 'There's no one on there.' And then I realized, 'Oh, maybe she's not being dramatic.'

Meg returned to her audiologist, who then diagnosed her with profound bilateral hearing loss. Although Meg recalled seeing other specialists about her hearing, she never fully understood her prognosis.

I never really thought about my hearing loss as a permanent thing. My dad took me all over the place...to all these hospitals and ear specialists, looking for someone who could fix it. That was really frustrating for me, because he took me to all those hospitals and I had all these MRIs and CAT scans and things. It was frustrating, because all these doctors would be talking with my dad, but I had no idea what anybody was saying.

When asked about her emotions regarding her diagnosis of profound deafness, Meg described a complex situation in which she was conditioned to ignore her hearing loss, as well as the grief and emotions that accompanied it.

I was feeling frustrated, unsure about my future and confused. In the meantime, my dad was taking me out of town to all these hospitals and he sexually abused me. He told me not to tell my mom because they'd get a divorce and it would be my fault. So, I didn't want to go to my doctor's appointments. I didn't want to deal with my hearing loss at all because it meant being alone with my dad. Also, my mom was really dysfunctional too, and I felt like I was always taking care of her. Like my mom was crying, saying 'I can't believe you're deaf' and I had to comfort her and put on a strong front and show her that it would be okay. So I never got to experience the grieving for myself. I did have emotions, but I just hid them. There were times when I would cry myself to sleep but I couldn't let anyone know. I was depressed, but I was raised to not feel sorry for myself. So, I just kind of ignored it. I didn't go to counseling or anything. I just tried to pretend like everything was okay and I was okay.

In one of the appointments that Meg went to with her father, she was presented with the options of getting a cochlear implant. As part of the decision process, Meg was asked to watch a series of informational videos and then was introduced to a girl, approximately her age, with a cochlear implant.

I met her and she was just a couple of years younger than me, but she was just so socially awkward. I just didn't want to do it. And the technology at that time was not that good, so they didn't think the results would be that good. It was

kind of a gamble. So I just decided against it. Plus, I could still speechread pretty good in a quiet room with my hearing aids.

By this time, Meg had been prescribed bilateral, behind-the-ear (BTE) hearing aids, which were much bigger and stronger than the smaller, in-canal hearing aid she was originally given for her right ear.

I remember getting my hearing aids and putting them on and turning the speaker in my house all the way up, and then it was just noise. And I remember taking them both off and throwing them across the room. I was mad because I couldn't hear the stereo. I wasn't getting any speech awareness. Everything sounded like noise. I didn't like wearing hearing aids. It just sounded like noise, but it did help with speechreading.

At school, Meg initially felt uncomfortable exposing her hearing aids. She was especially self-conscious of them after a date told her that they were not acceptable.

In the very beginning, I was embarrassed to wear them. I covered them up with my hair. But after some time passed, I started to accept it and wear them. And then I went to prom with a hearing guy, and he asked me to take my hearing aids off for the pictures. I did it, but I felt rejected.

Meg returned to school after missing nearly a semester of classes. She talked about the changes she encountered after returning to school as a deaf person; the first of which happened on her first bus ride back to school.

They put me on a short bus and I had to ride to school with other kids who had severe disabilities. And they were like poking me and petting and drooling on me on the bus. I felt humiliated, like the school thought I was like 'those' people.

The high school Meg attended prior to losing her hearing happened to have a deaf education program, in which she was able to enroll.

I was already in a school that had a deaf program. It was a tiny program with like four people...and two of those people had just moved to the United States. So once I lost my hearing I entered that program.

Prior to meeting the other students in the deaf program, Meg had never met another deaf person and she quickly realized she did not fit in with them. She had grown up hearing, with English as a first language, and the deaf people in the program were nothing like her. Her classmates, who were born deaf – several of whom were born outside of the United States – were “odd” and had not mastered the English language to her standards.

I had never met or heard of anyone else like me. The other deaf people were not like me. They weren't academically where I was, or socially where I was. They used broken English and I was a really smart girl. School came easy for me. I was an honors student. And so I didn't feel like I could connect. I looked down on them a little bit because of their bad English.

Meg also realized, though, upon her return to school, that she no longer felt comfortable in social interactions with her hearing classmates.

But then I didn't fit in with the hearing people anymore because I couldn't follow a conversation; I was fine, one-on-one, with the hearing people. So I'd find myself in a group of hearing people and everyone one was talking, and I'd find myself off to the side.

Feeling like there was no longer a group in school with which she could connect, Meg became isolated and depressed.

I would say for sure I felt, like, depressed a lot at school...like an outcast. But I never let anyone know. I just kept it all in. I was feeling isolated, and that caused depression. Not having anyone who really understood what I was going through, I felt like I couldn't be me.

Meg was determined to make the most of her senior year in high school. She realized, though, that in order to access the curriculum, she needed to learn sign language, which added an extra demand to her school workload. Meg learned Signed Exact English (SEE), which, rather than being a full-fledged language on its own--like ASL--is a visual form of English, which is performed on the hands. It maintains the same grammar and syntax as spoken English.

I had to work harder to get the same kinds of grades I used to get in school. I had to go in after school to learn sign. I had interpreters in my mainstream classes, but I didn't understand what they were saying. It was really hard to learn sign language...so I learned SEE first, because I already knew English.

To compound her academic challenges, Meg noticed that her teachers treated her differently after she became deaf. She described the attitude of one teacher toward her as “hostile.”

He didn't want me in his class. He had a rule that you had to be in your seat and have your book open when the bell rang or you would get a tardy, and after so many tardies you would lose credit for the class. And this was in the days before clocks were all synced. So he tried to give me an 'F' when I actually had an 'A' in the class. I told him it wasn't fair because I couldn't hear the bell. So I went and talked to the principal and the teacher had to change my grade to a 'C' but said

for the last quarter of the school year he wanted me out of his class. That rejection made me feel mad. The more people told me I couldn't do things, the more I wanted to do them. The principal said he needed to give me a chance, so then the teacher started playing a game where whoever raised their hand first and gave the answer got a credit and I couldn't participate. But it was his way of giving me an 'F,' so when I complained again he said he wanted me out of his class. And the office changed my schedule, but I went to that class anyway and said I had a right to be there. So he told me he wanted me to leave or he would call security. So I said go ahead. So he called security.

Although Meg asserted her right to be in that class, she also acknowledged that following lectures and conversations in class was extremely challenging, and that her hearing loss had changed how she participated in school.

I became a little bit more shy. I was very outspoken before that in class. I felt embarrassed to participate. My voice hadn't changed, but I felt like I wasn't always following the dialogue. So, I felt like I might say something that's not really what they were talking about or somebody already said, so I'd just be quiet.

Meg had difficult encounters with other teachers, too, who although seemingly did not have bad intentions, discriminated against her, discouraged her, and made her feel less than equal to her peers. She provided the following example:

I had taken a typing class after losing my hearing. The teacher told me I had to sit in a separate class away from my classmates because I was different. So I had to sit in a class all by myself to do my work. And when I confronted her and

told her I wanted to sit with my classmates, and she said 'aren't you cute?' and flipped my hair back.

Reaching the realization that others viewed her as less capable than she was before she lost her hearing, Meg became determined to prove her value.

I was never good enough after I became deaf; I just wasn't accepted fully for who I was anymore. I was always a good student, but I didn't feel like anyone acknowledged me unless I proved myself. That's why I buried myself in my studies. That way, I could get recognition for being smart. I was trying to counterbalance the negative...like I wasn't as good anymore now that I was deaf, and it became an obsession for me that I would be good at school to prove my value.

The worst change that Meg experienced in her last year of high school, was the loss of her friends and social connections that she had as a hearing person.

I had a lot of friends who said we were still friends but slowly they became different towards me. All kinds of friends talked about how they were going to learn sign language and they were still trying to invite me to their things and carrying on like normal but I just remember going and feeling like a total outsider, not being able to follow along with anyone's conversation. I slowly stopped getting invited and included in things.

Meg even lost her closest childhood friend.

My best friend learned how to fingerspell and a little bit of sign, and then after a couple of months had gone by, she asked me to come over because she needed to talk to me. So I went over and she told me that we couldn't be friends

anymore, because we didn't have anything in common anymore. She said, 'You're different now.'

Meg said that although this rejection hurt, she had been raised not to feel sorry for herself. She shrugged it off, and made sincere efforts to find new friends. She described one short-lived friendship that gave her hope she could have the social connection she craved.

There was one girl that I was friends with after I became deaf, we were best friends over spring break. But when school started again, she acted like she didn't know me or want to be friends with me. So that was another rejection for me.

Meg no longer had girlfriends she could connect with, and because of this, she started spending her time with boys. She found it easier to be connected with boys than with girls, and before long she was “just hanging out with all boys.” She admitted, though, that her standards at the time were low so that she “clung to whatever.”

I spent more time with boys than girls for sure. I became promiscuous. It was easier to hang out with boys sexually, than to try to socially interact with girlfriends who were rejecting you because of your hearing loss. I didn't really need to like talk to connect with boys. I thought it was more like being sexual was easier...rather than trying to have a conversation with somebody.

By graduation, Meg had started spending time exclusively with one of her male classmates. That summer, he proposed.

I wanted to go to Gallaudet to learn, because I had heard all about it and I heard there were smart deaf people there, which was a new concept to me. I found out that [Vocational Rehabilitation] would pay for college and I thought,

'Why not go to Gallaudet?' I applied and I got accepted, and then my boyfriend proposed. And he told me that I need to think about how I'm going to support myself if I move across the country.

Meg agreed to stay and marry him, with the promise that he would work to support her while she went to a local college. Looking back, she regretted that decision, and claimed that she missed major signs that she was getting into a controlling and abusive relationship.

Soon after marriage, Meg's husband began to use her hearing loss as a means to berate and humiliate her in front of family and friends.

We would go places with my family or our friends and he would say, 'Come sit on my lap' so I would sit on his lap and then he would voice, 'Get the fuck off me' and 'holy shit! It feels like she weighs two tons' or other derogatory comments and everyone would start laughing and I'd say, 'What did you just say?' and he wouldn't tell me.

Meg's husband also criticized her for her "deaf voice" and inability to pronounce unfamiliar words. Over time, that led to insecurity about speaking in public.

He said "it sounds like I talk through my nose" and that I am whiney. It was very hurtful, because I had no control over what my voice sounds like. If I learned a word and did not know how to say it – because I couldn't hear, and pronounced it wrong – he would make fun of me. 'Oh my God, you just said it wrong. You sound so dumb! I can't believe you're in college.' His little comments about my voice and my speech made me feel self-conscious and not want to use my voice around other people. I was scared they would think the same thing.

In addition, Meg said her husband became easily frustrated and quick-tempered when communication difficulties arose. As a result, all attempts to communicate, on his part, eventually ceased.

He would say, 'Never mind. Just forget it.' So at night he would get home from work and I would want to talk about my day and hear about his day and he would tell me he was too tired to talk. He just wanted to have sex. I felt like that's all I was good for. I felt like a piece of meat. He he used me for sex but wouldn't talk to me.

Having been convinced by her husband to go to a local school, Meg enrolled at a west coast college that had a well-known deaf program. After arriving at her new school, however, she realized there were “issues fitting in” with her deaf classmates. Although she had been signing for several months now, she did not sign “like a deaf person.” Meg used Signed Exact English (SEE), which she later learned was polarizing in the deaf community.

I had never met a smart deaf person before. I was blown away. My very first day, there were eight deaf students in my first class. It was a geography class and like a quarter of the class was deaf and they were all sitting together and I couldn't follow their conversation...and I could just tell they were smart. They tried to include me, and it was always like the same thing: they'd asked me my name, and as soon as I responded they said, 'oh you're oral,' or 'you're mainstreamed,' because my signing sucked.

Although she wasn't yet comfortable with the deaf students, she also was not comfortable with the hearing students, or exposing her own deafness to them.

I was taking this Women's Studies class, and there were a couple of other deaf people and they chatted a lot in sign language. I couldn't focus on the class, so I didn't sit with them. I sat away from them a little bit, and I would try to speechread what the teacher said, and only watch the interpreter occasionally. And there was a really cute guy in class and he sat next to me, and then when it came time to do group work he would look at me like he needed a partner. But I was too embarrassed to tell him that I was deaf and need to use the interpreter, so I never sat by him again. I didn't want to fail at communicating with him; didn't want to put myself in a position where I might fail to communicate because it was embarrassing.

After spending some time positioning herself in such a way that she could avoid deaf and hearing classmates, Meg finally began to feel more comfortable in the deaf community after a chance encounter with one deaf person who helped her improve her ASL skills.

I had to go set up a mailbox, because so many deaf people get notes that there was a copy room and mailboxes for the deaf students. So I went to set up my mailbox and the guy working in the mail room signed so fast that I had no idea what he said, but he slowed down for me and we wrote notes to get it done. And then I had to go next door to set up computer access in the lab, and the guy in the lab signed even faster than the guy in the mail room. He didn't understand me and I didn't understand him. So after trying for a few minutes, he signed [sign: broken communication] 'Go learn sign and come back when you're ready.'

Leaving the computer lab, discouraged and in tears, and still without an account for computer access, Meg happened to see the man she had just met in the mailroom. He calmed her down and offered to help her learn ASL.

He was like, 'I'm going to help you. Come see me every day and we'll practice sign.' And so I did, and after a few weeks he said 'You need to turn off your voice, because that's hindering your ability to pick up ASL. If you can turn off your voice for two weeks I'll buy you lunch.' And he said he was going to ask people to make sure I did it. So I stuck it out and did it and noticed how much easier it was to sign when I didn't voice.

Once she gave up her voice and was better able to connect with the language, it took her about a year to be comfortable enough with ASL that Meg could carry on “decent” conversations.

And that's when I started to feel more comfortable, and also I think I started to feel more accepted by deaf people. People stopped calling me 'think-hearing.' I started to get invited to deaf events and things, and was even invited to join the deaf sorority...but my husband said 'no.'

The more time Meg spent with deaf people, the more she realized she had found her place, and that she no longer enjoyed being around hearing people.

I started to feel like there was a place I belonged, and there was a support system I didn't know existed. I found that I had a lot more fun with deaf people. With hearing people if they were talking and laughing I felt a sense of paranoia that they were talking and laughing about me. And anytime I would go around

a group of hearing people, I felt a sense of dread. I just didn't want to be there.

When I was with deaf people, I always felt at ease – happy and peaceful.

Furthermore, now that she had experienced barrier-free communication through ASL, she realized how much more difficult and frustrating communication was with hearing people.

I pretended I heard things I didn't all the time. People are talking a mile a minute, and I would just kind of nod my head like I understand. I can only ask, 'What?' so many times – maybe three or four times – and then I feel hearing people reach their threshold. I just have to nod after that and pretend I understand. I'm like the monkey in the movie Madagascar: 'just smile and wave, smile and wave.'

As communication became increasingly easier with deaf people, Meg reached a point where it became burdensome even to be around her own family.

I wanted to be with deaf people all the time. There was a time when we would go up to visit our family and I used to really enjoy that, but after I became involved in the deaf community, I didn't even want to see my family anymore; I didn't give a crap. And there was even one time for Thanksgiving my mom invited us, and I said no because nobody signs.

Furthermore, her family did not support her emerging deaf identity.

One time I went back home to visit my family for the weekend, and I went out to dinner with my dad. Dad was talking to me but I was signing at the same time as talking. He said to me, 'Can you please not sign in public? That's embarrassing.' I was really hurt by that – super hurt by that. It was part of who I was becoming, part of my new identity. But I knew it wouldn't be accepted in

my family. I felt like I had to conform to what they wanted to be. I was being rejected. They didn't approve of who I was.

At school, as Meg became increasingly connected to the deaf community, she began to crave a deeper connection with her new deaf friends. As a result, she began spending a lot more time at school, usually late into the night.

I would stay at school as late as I possibly could, because I was getting that human connection that I needed for sure. So the longer I was in college, the more I wanted to be around deaf people.

One of the friends that Meg began spending time with was a classmate in her deaf theater class.

We were studying "Children of a Lesser God" and they picked me to be Marlee Matlin and this cute deaf guy – who was super smart – was my husband from the movie. So my relationship with this guy in college was just a friendship, but we started going out together after school and spending every minute together. And we would talk all night. I think it was the first time I had just a conversation with a guy that wasn't sexual or anything like that. I couldn't have those kinds of conversations with my husband – not even close – because of the language barrier.

Through this friendship with her classmate, Meg was able to relate to a man in a way she never had previously experienced. Furthermore, cast as husband and wife in the class production of "Children of a Lesser God," they were forced to examine critical elements of the play, including the relationship between a deaf woman and a hearing man. This, according to Meg, was the catalyst for questioning her own marriage.

There were a lot of conversations in the class about, like, an interracial marriage; not really interracial, but deaf and hearing. It was this major internal struggle from that point on in my marriage. I knew I would be happier with a deaf guy, but I had this internal struggle that my family wouldn't approve. It was just a different level of comfort.

In fact, Meg could not let go of the idea that she would be more comfortable in a relationship with a deaf man.

When I started hanging out with deaf people more, I felt like I wanted to be with a deaf man more. It made me start questioning if my marriage was the right decision. I started to feel, for the first time, that I regretted getting married. 'Why am I married to a hearing guy? He doesn't understand me like these people understand me!'

As a result, Meg began to feel divided between the person she was at home –around her hearing husband and his hearing friends – and the person she was at school, around her deaf friends and classmates.

So when I was at school, I felt like I was one person and at home I was someone else. At home I was only around hearing people, and I tried to fit in; I would speak all the time and not sign. I would lip-read the best I could, but I got left out of conversations.

Meg felt pressure at home to follow conversations that she could not hear, and was criticized when she failed to understand. In particular, she often felt left out of jokes.

All jokes were, like, secondhand jokes. One time my ex and some friends were sitting around talking and laughing like always, and I asked 'What's so funny?'

He told me, and I only laughed a little. He said 'You had to be there.' And I was like 'I was there.' And he goes, 'Not really.' It was like he was saying 'You're not really part of us, because you're not really here; you're broken.'

Meg explained that when she was at school, the ease of communication made her feel more relaxed than she was at home, where it was a constant challenge to connect. Meg was happier, and felt more like her true self when she was around her deaf friends, using ASL.

So, at home I was sitting in the corner not laughing with everyone else...it was just this constant gloom. I was not happy. I would go to bed early. When I was at school, I was like the 'me' that I was before I lost my hearing, only speaking a different language. I could relax. I was never paranoid what people were talking about. I never felt left out. I didn't feel different. I didn't feel lacking in anyway. I could just be me.

After graduating from college, Meg began graduate school to become a teacher of the deaf. Although she was recruited by a top university, she declined their offer because their program focused on oral education of deaf children. Meg explained that "by this point in my life I felt strongly about the benefits of ASL." So, she continued her studies at the same school from which she received her undergraduate degree. Halfway through her program, Meg's husband informed her that they were returning to their hometown, where her contact with the deaf community was extremely limited.

In the last year of her graduate program, she accepted a job teaching deaf children at a school in her hometown, where she was the only deaf employee. The only reprieve from

the social isolation she felt in her small town was seeing her deaf friends when she arrived on campus for her evening classes.

I would go three times a week after working all day. It was a three hour trip each way and I can just remember feeling like I couldn't wait to get there...and I never wanted to go home. It was so hard to leave.

Limited exposure to the deaf community began to take its toll, and by the time Meg finished graduate school, and after a year at her job, she realized she was “sick of being around hearing people all the time.” She decided to leave her job and her husband.

I waited until he was at work one day and I packed up as much as I could and I drove. I had no idea where I was going. I just saw friends and kind of ‘house hopped’ all summer.

Meg described feeling free to forge a deaf identity that entire summer. She spent her time socializing with only deaf friends, and dating only deaf men. By fall, Meg was offered a teaching position at a deaf school.

I interviewed and realized every last person on campus signed, and I was like, ‘this is where I want to be!’ So, I took a job down there and started working, and it was like the best thing that ever happened to me. I was so happy. I stopped wearing my hearing aids.

Several months after starting her new job, Meg’s husband contacted her to sign divorce papers; she met him, eager to sign. However, as she reached for the pen, her husband stopped her and questioned her intentions. She explained to him as follows:

I found my community. I know where I belong. I know where I’m happy and what I want. And I can’t live in a hearing world and be left out all the time, and

not be able to have conversations and feel isolated. I can't do it anymore. I need to be happy.

Her husband, now saying he understood her needs, promised to change for the sake of her happiness. And although he had once proclaimed “I didn’t know sign language when you met me,” he also agreed to learn ASL and socialize with her deaf friends. Despite feeling “happier than she ever had been in her life” when she was immersed in the deaf community (and not needing return to the hearing world at night), Meg naively agreed to give him another chance.

For a short time, her husband followed through with his promises. Within a few years, however, with the birth of their first daughter, he stopped signing altogether. He also became selective about which deaf friends they would socialize with, based on their ability to speak and lip-read. Eventually, he completely reverted to his previous attitude about her deafness and her involvement in the deaf community.

So I started to feel like I was stuck in between again; I wasn't getting to be deaf at home, and I could only be deaf at work. After my daughter was born, I think he started to be more jealous of my deaf friends. He started always making comments like if I said, 'I wish you would talk to me more.' He'd say, 'Oh, like your deaf friends?' Or if I'd say something like, 'You don't understand how I feel.' 'You mean like your deaf friends understand?' He made me feel guilty for connecting with these people. He didn't like the deaf people I was hanging out with, and over time, he was isolating me from the deaf community.

With the birth of their second daughter, Meg agreed to take time off from her job – her only form of connection to the deaf community – in order to stay home with her

children. Without deaf relationships that allowed for her to freely communicate and be herself, Meg began to feel hopeless.

After my second daughter was born, he told me he wanted me to quit my job. I agreed to stay home for two years, and I got really depressed because I wasn't seeing deaf people. I didn't have any connections, and I felt lonely and isolated. I became extremely depressed and was probably suicidal. I felt like I almost got out, and then I dropped the ball. I felt like 'now I have two children and I can't leave because he's the father of my children.'

Over time, she came to realize that she would never be happy in her marriage because her husband wanted her to be something that she was not: hearing. Unable to fulfill the social roles of a hearing wife, Meg felt that he only valued her for sex.

I wanted to leave him because he didn't respect the fact that I was a deaf person. He didn't respect my language and he didn't respect my identity choice. He wanted me to assimilate. As the marriage went on I felt like I was just there for his sexual needs because we didn't have that deeper connection that came through communication. He didn't want to talk. He just wanted to have sex.

Although Meg had no intention of giving up her deaf identity and assimilating into the hearing world, when her children were born she began wearing hearing aids again, to better hear their cries. Months later, one of her hearing aids broke.

I went in to get it fixed, and the audiologist told me that insurance wouldn't cover hearing aids...but it will cover cochlear implants. So, I started talking with other deaf people who had cochlear implants, and I realized it was more accepted in deaf culture than it was a long time ago.

Meg was warned that the surgery was a gamble, because she had been deaf for close to a decade. It was uncertain how much benefit she could receive from a cochlear implant, after being deaf for so long. Conversely, because Meg had very little residual hearing and no speech perception with hearing aids, she had “nothing to lose by getting the implant.” She decided to get the surgery, and got a cochlear implanted on her right ear.

Although she was fully prepared to “just take it out” if it didn’t work, Meg had impressive results.

The same day I got hooked up they put me in the booth – probably fifteen minutes after turning all the channels on – and I scored eighty percent on the sentence level. I went back two weeks later for a remap, and I was at one hundred percent! I was talking on the phone and everything.

Her re-orientation to sound began almost immediately. She quickly began to re-familiarize herself with sounds that are generally taken for granted, as well as sounds that she had long forgotten.

The night that I got my cochlear implant turned on, I couldn’t believe how many sounds I had forgotten about – I was just literally fascinated by all these little sounds. The first thing I noticed when I got home was when I tried to cook something. I put butter or oil in the pan and I could hear it crackling and I could hear the flame. Then I opened a can of Dr. Pepper and I heard the ‘click, pop, fizz’ I totally forgot about the fizz sound. I poured it into a cup slowly and then I poured it down the sink and opened another can and poured it. And I ended up opening the whole six-pack and pouring it into cups to hear the fizz.

For weeks Meg was intently focused on discovering forgotten sounds, and was relentless in identifying everything she heard.

I heard a fly buzz and couldn't figure out what the sound was. And I kept hearing it, and it would get louder and softer, and louder and softer. I was looking around trying to figure it out. And it got louder again, and then I saw a fly and I was like, 'Holy crap, I can hear a fly!' I called my husband at work and he said 'Is this important? I'm in a meeting?' and I said, 'YES!' So he went out in the hall and I said, 'I can hear a fly!' He was so mad at me.

She was so pleased with the benefit from her cochlear implant, that two years later she underwent surgery to get a second implant on her left ear, which was equally successful.

Meg said that cochlear implants did not take away from her positive deaf identity, but added to it. By getting cochlear implants, she regained part of her hearing identity, and had the option of accessing sound and spoken language. She explained that there are times when she chooses to use her cochlear implants to hear, and times when she chooses to turn them off and be deaf.

I didn't feel like it took away from me being deaf at all, but it gave me some of my hearing back. It gave me my hearing identity back if that's what I chose. It gave me more freedom to be where I want to be. I wear them selectively. I'm deaf when I want to be and I'm hearing when I want to be. I feel like I'm truly bilingual and bicultural.

Although Meg receives excellent benefits from her cochlear implants, she still feels most comfortable and relaxed when they are turned off and she is using ASL.

When I'm around my deaf friends I turn them off. I just want to be one of them. I have no need to care about sound when I'm with them. If I had a long day at work I take them off. My kids sign; so, they know when mommy is tired, they have to sign for the night. It is definitely more work to hear than it is to sign. At the end of the day, when I want to relax and have a conversation, it is definitely ASL; without a doubt!

While cochlear implants are more accepted in the deaf community than they previously have been, Meg believed her attitude about cochlear implants and her awareness of deaf cultural customs enabled her continued association with the community after she got implants. She has “implant rules” that she follows when spending time with her deaf friends:

When you're a member of deaf community, there are certain things you don't do in front of deaf people. I don't talk on the phone in front of my deaf friends. I wouldn't speak my order to a waitress. I would point to the menu like everyone else. I think it's like deaf people view it that if you speak or talk on phone when no one else is, they think you're trying to act like you're better than them. So I don't use my cochlear implant when I'm with other deaf people. Only because I don't want to lose that connection and make them feel like I'm superior to them in any way – because I'm not.

With hearing family and friends, Meg was made to feel more accepted and included after getting implants. Her husband was particularly pleased about her implants, which gave her hope that if she could hear, they could have a better marriage.

The cochlear implants had a significant “downside” as well. Meg noticed that hearing people would speak of her “pre-surgery” deafness in a very back-handed way.

The worst part was that they had the nerve to talk about it after I got my implant...that I was so much more valuable now and they never understood how I could be seen as someone of value before I got my implants. There was a time he had a friend come over to the house after I got my implants, and his friend said, ‘It is so nice to be able to have a conversation with you. I always wondered how [your husband] could be married to a deaf girl and be happy.’

In fact, hearing people did not understand why she would voluntarily choose to be deaf, now that she had the option of hearing.

People just don’t understand deafness in general. If I tell people I don’t wear my cochlear implants full time people always say, ‘Why on earth would you want to be deaf?’ Like it’s the most terrible thing in the world to not be able to hear. They don’t understand that there is a whole other side to deafness that they don’t know about.

Her husband did not understand that deafness was a permanent part of her identity, and cochlear implants did not change her desire to continue being involved in the deaf community.

He also thought that I should leave the deaf community once I got my cochlear implant; he said I didn’t have a need to be with deaf people anymore.

Meg claimed that hearing people don’t understand that even though cochlear implants help significantly, they are not a perfect technology; and they do not “cure” deafness. With her

new implants, she said that she often felt pressured to “hear” ... even in situations where it wasn’t necessarily possible.

I remember going to one of my husband’s work events, and I couldn’t hear anyone. He said, ‘Why are you so antisocial?’ and he told me that I need to learn to speechread better. My ex thought that because I could hear him in private, that I should be able to hear in groups or in bars. He didn’t understand that I’m still deaf, no matter what.

She has experienced similar misconceptions about her hearing capabilities in the workplace. Meg explained that she has a particularly difficult time in meetings where people tend to talk at the same time. She also has more difficulty understanding people with accents, as well as when she is feeling anxious or tense. There’s an “ideal level” of sound where she can hear and understand, but finding that level is not always possible.

At work meetings, I still like to have an interpreter...and people act like I don’t need one. The school district doesn’t understand why I request an interpreter when I have cochlear implants. They don’t know why they have to pay for it...they just don’t get it. I still miss things or don’t know who said what so I look at the interpreter. It is so much easier to watch sign and understand.

Although she had cochlear implants and was able to hear speech enough to communicate effectively with hearing people, Meg came to realize that deafness was now part of her core identity, and she wanted to be more immersed in the deaf community. When the opportunity presented itself, Meg filed for divorce.

I realized that even though I had the cochlear implants, there was a fundamental need that I had that could not be met by a hearing guy. I needed more of a 'deaf life' in my personal life. So I found out he was having an affair and I was happy I had an excuse to file for divorce. And I felt like my family would approve because it was his fault.

After divorcing her husband, Meg avoided “burdensome” social interactions with hearing people.

I avoid situations where I'm going to have to be around a bunch of hearing people. I guess I just got to the point where I don't even want to deal with it, because I don't care to give it the effort. I know it's going to take too much work. I spent so many years putting all the effort into the communication while everyone else just sat back and did nothing and now I don't care to be around those people that are going to make me put in all the effort.

Today, Meg's closest friends are deaf.

Most of my friends are deaf. It is a different level of connection; it almost feels like a big family. We have gatherings for holidays, and we get all of our kids together. All of the things we would do with our families where we would be left out, we do it together, like a second holiday where we are more included. I think this is true of deaf culture. The closeness is there. Since I've become part of deaf culture I can travel anywhere in the United States and have a place to stay for free. That's the cool thing about being deaf: there is always someone somewhere. There is always someone that is going to take care of you. Deaf

people have this bond with each other that is super cool. It isn't like that with hearing people.

After years of considering the advantages of having a relationship with a deaf man, Meg met one at a work conference. In fact, one of the initial attractions for Meg was his deep involvement in the deaf community.

I was at a conference for teachers of the deaf and I met a deaf guy. He told me he worked at Gallaudet. I thought he was so cute and so smart and so involved in the deaf community. I thought he was the best thing since sliced bread. We started off just being friends, and I sent him an email a week later. It started with a few lines back and forth and turned into long emails back and forth. We wanted to know everything about each other.

Soon their relationship escalated from emails to videophone conversations and then traveling to visit each other. Meg met his friends, and felt an ease being with him in social situations – a connection that she never felt with her hearing husband.

He asked me if he could fly me to DC to visit him. So I went back there and he introduced me to all of his friends, deaf friends, and we had the best time. Everyone was very welcoming. I knew a few of his friends from college already who had moved back to DC. It was awesome to be at a deaf event with a guy and not have to interpret for him and have him interpret for me. We could go our separate ways in the crowd and talk to whoever we wanted to and come back together whenever we wanted to.

After four years and many cross-country visits, Meg married him. She contrasted her first marriage, with a hearing man, to her current marriage, with a deaf man in the following passage:

It's different, this relationship. I can't even begin to compare the two. The two of us – anytime we go anywhere, a restaurant, or, wherever we go, we are always the last two left. Our connection is on such a deeper level, because we actually have conversations and communicate and share our stories. We get passionate about the same things, like educating deaf kids. We are passionate about ASL. We make jokes by using ASL idioms and playing on words in sign. We enjoy playing with language together.

Meg elaborated on their common interests and shared passion for educating deaf children.

We have the same passions. Actually, I find that deaf people, in general, have a passion for deaf youth and sharing and passing down the language, culture and deaf values. Deaf people highly value education of our children, because deaf children are almost like deaf community children.

In fact, Meg feels that deafness is misunderstood in the educational system. One of her passions as a teacher lies in promoting awareness about the social and cultural needs of deaf children.

People at work don't understand the social needs of deaf students. Deaf kids need to be together. They need community. People don't understand that. People don't understand deaf education is different than special education. Deaf kids need interaction. They need community, not inclusion. They get isolated and shut down when they are mainstreamed in a hearing program.

They would probably grow up depressed and who knows what. And I know that feeling because I know what it's like to have signing professors, and I know how much better it is when I have a teacher I can directly communicate with. Part of my goal as a teacher is to help people understand the unique needs of deaf kids and deaf people in general, and the beauty and value of our language because it's huge!

Meg has made it her personal mission to provide a sense of community for her deaf students.

I take it on a personal level for my students to succeed; it's very personal for me. Sometimes I almost feel for them, like I can't wait for them to get involved and make them a part of something. Usually it takes some time before they get that sense of belonging, and they 'get' that they belong to a community that is different from their families...where they often feel left out. So I take it personally and feel personally rewarded when they 'get' that they are part of a community.

To Meg, the most positive aspect of becoming deaf is the bond she has made with deaf community.

The best thing about becoming deaf, is the community and the language. It's like a discovery of a whole world out there that I didn't even know existed! Really, I will tell you: it was a major blessing to become deaf. The community and the sense of closeness within the deaf community is something that you would never get in the hearing community. The sense of connection you get

from shared language and shared experience and triumphs is something you don't get in the hearing community.

Meg concluded her interview with the following advice and observations about her experience of becoming a deaf adult later in life, in hopes that it would inspire others who are adjusting to hearing loss.

In hindsight, I would do things differently. I would have learned to be an independent deaf woman from the get go, and value myself. I spent so many years – I lost so many opportunities, so many smiles and laughs – trying to fit in with hearing people, and not change who I was after become deaf; trying to stay the same person. At the end of the day you're not the same person. You're a different person. I have a lot of regrets, because if I had just accepted the fact that I was a deaf person and walked away from all those hearing people from the get go, I would have had this feeling of acceptance of who I am and this feeling of happiness much sooner. I hope that other 'late deafened' adults can learn sign and find a community and a place they belong.

Emerging Themes: Meg

1. Meg became deaf during her senior year of high school as a result of spinal meningitis.
2. Due to issues within her family, Meg was never afforded the opportunity to grieve her deafness.
3. Meg returned to her high school, which had a program for deaf and hard-of-hearing students, but she did not fit in with those students. At the same time, she no longer

fit in with hearing students.

4. Meg eventually lost all of her childhood friends after becoming deaf.
5. Meg felt socially isolated and craved connection, which she found through sexual relationships with men.
6. Meg learned ASL and discovered a deaf identity when she went to a college with a well-known deaf program. She became involved in the deaf community.
7. Meg married a hearing man and felt split between his hearing world and her deaf world.
8. Meg did not feel included in social interactions with her husband and his hearing friends.
9. Meg craved full-time immersion in the deaf world and desired to be married to a deaf man, but at the same time feared disappointing her family.
10. Meg's first marriage lacked the deep emotional connection that comes through communication. She felt valuable to him only for his sexual needs.
11. Meg eventually got cochlear implants, which she said made her feel bilingual and bicultural.
12. Even after getting implants, Meg feels most confident and comfortable communicating in ASL. She finds hearing to be much more exhausting.
13. Meg felt her cochlear implants did not jeopardize her position in the deaf community because of her attitude and knowledge of social rules.
14. Meg's husband did not understand or support her desire to be part of the deaf world.
15. After many years of being in an unhappy marriage, Meg viewed her husband's

infidelity as an excuse to divorce him, which allowed her to follow a deaf path.

16. Meg became a teacher of the deaf and is passionate about deaf education and wants to pass down the value of the language and culture to deaf children.

17. Meg is now happily married to a deaf man, with whom she is able to have a deeper connection.

18. Meg's social life is primarily in the deaf community with culturally deaf friends.

Participant Seven: Nell

Nell is a 54-year-old woman with severe hearing loss. She was born with normal hearing and continued to have normal hearing until her early 40's. Currently, she has bilateral hearing aids and uses both spoken English and American Sign Language for communication. She has no family history of hearing loss.

The interview with Nell took place in her work office and lasted for approximately two hours. She used a combination of American Sign Language and spoken English throughout the interview.

At age 41, Nell was married and had two young children. The first indication that she was having difficulty with her hearing came in the form of a complaint from a neighbor that she wasn't attending to her son: "I guess he was being mischievous. He was right behind me but I didn't hear him." Nell's inability to hear and correct her son's misbehavior caused tension between Nell and her husband, as well, who thought that she was neglecting their son.

My husband thought I wasn't focusing and not listening to him so he wasn't happy about that. I didn't understand why he was upset. I was trying my best. This was before we knew anything.

It didn't occur to Nell that her difficulties could be a result of hearing loss until one day when she was in the car with her husband and children and she was the only one who could not hear a loud noise coming from the car.

We were all driving in the car and the air-conditioning broke or something. It was making this really bad noise, it was really loud. And I was the only one who didn't hear it. They were just looking at me like, 'How can you not hear that?'

After the incident with the air conditioning, Nell and her husband began to suspect that she might have hearing loss. He urged her to make an appointment to get her hearing tested.

He suggested I go to the doctor, so I went to an audiologist and she confirmed that I had hearing loss. The audiologist said that I had a mild hearing loss. So if zero is no hearing then I had 45-decibel hearing loss. So that was the first time that I knew, but it must've been happening before and we didn't realize.

Nell said that she was honestly surprised by the diagnosis because she never knew, until that point, that she was missing anything that was happening around her.

Nell's audiologist did not express any expectations that her hearing loss would get better or that it could get worse. "She just tested me and that's what they found and so they gave me hearing aids." Nell received early technology hearing aids, but was less than happy with the benefit she received from them.

I got analog hearing aids and they were fine for a while but, eww, they were awful because they just exaggerated the sounds. And if I put my fork – or if I just laid it down on the plate, it was like a bomb went off. It was awful. It hurt. I hated it.

Although her hearing aids caused discomfort, she was able to use them to access spoken language for nearly a year before her hearing levels dropped dramatically over night. Nell described the sudden decline in hearing, which now classified her as having severe hearing loss, as "a trip."

It continued on at the same level for, you know, a while, and then just one night I woke up in the morning and I lost forty decibels all at one time. And it was like

the sound was stretched and it was like being in one of those funny houses in the circus where you know you have the mirror and it stretches your shape. That's how the sound was. It was stretching the sound. And it was scary, you know, I just didn't know what was happening.

The doctors, who were not convinced that Nell had permanent deafness, tried unsuccessfully to treat her sudden hearing loss. "We went to the doctor and I got medicine – they thought maybe I was sick, but nothing helped."

When asked if she considered herself to be deaf once her hearing declined to the level of severe hearing loss, she answered as follows:

Yeah, because I can't hear speech. I can hear the sounds but I can't understand what I'm hearing. If I'm reading your lips I can understand what you're saying one-on-one. If there were two people here, and the three of us talking, then it's a mess. There's just too much sound in the room and it's bouncing all over the place and it's hard for me to understand it. And then you're both talking at the same time and I'm just going back and forth and going – [shaking head] I mean, I've lost it.

In fact, when Nell's hearing reached its lowest thresholds, without access to spoken language, she met the candidacy criteria for a cochlear implant. She explained in the following passage why she opted to not get an implant:

At the beginning, I wanted one but I've had a few surgeries and since I know my body – for some reason, is allergic to everything. So I'm – I get allergic to the stitches, the tape. I'm allergic to everything. I have gotten infections each time.

And it's too close to my brain. That's scary for me. It's not worth it. And now I'm happy I made that decision because I'm happy with who I am right now.

Instead of getting a cochlear implant, Nell advanced to digital, behind-the-ear, hearing aids that were bigger and more technologically advanced than her previous analog hearing aids.

When my hearing got worse I graduated to the digital hearing aid and that's so much better because they adjust to filter what is noise and what is speech instead of just making everything louder. I enjoyed those better. That's what I still have right now, actually.

Nell was initially frightened by her sudden deafness. She described her progress of emotions as those of the “typical stages” of grieving. “I guess I was grieving the loss of my hearing life.”

It was scary. I just didn't know what was happening. I was crying when it happened. I knew it would change everything. Hearing loss changes who you are. I was depressed. I was very depressed.

Although she was grieving the loss of her hearing and scared about how deafness would affect her future, Nell had the support of her husband to help her through the difficult time. She also had her children to consider. Nell realized early in her journey the importance of providing a role model for her children of how to confidently manage adversity. This was particularly important because each of Nell's children had their own struggles, including learning disabilities. Through the support of her husband and the standards that she modeled for her children, Nell gained strength through the grieving process.

I was definitely going through a grieving thing. I didn't know kind of what was going on and kind of getting to that, 'Oh my gosh, I'm going to be deaf and what does that mean?' and getting to that – and I was also worried about how it would affect my relationship with my husband. But, I mean, he's been amazing. He's been with me just all the way through. And I have my daughter and my son and each one has their issues and I thought I need to be strong for them because they're going to be looking at me about how I manage my issue because you know they have to learn to handle what they are going through and I had to be their role model for that, and it was tough.

The first evidence of major change to Nell's life was to her social life. Soon after becoming deaf, Nell stopped receiving invitations to social gatherings from one of her closest groups of friends. Nell confessed that the changes to her social life, that were brought about by deafness, significantly contributed to her depression.

Before, I had friends through my daughter, her friends' parents. And we would go out, go to restaurants, get together, and then they recognized, maybe before me, they recognized that I couldn't understand the conversation. I was missing a lot of information in the conversation and so they just started not including me in the invitations.

When Nell confronted her friends about not being included, they acknowledged that they had purposefully avoided her in social gatherings, because it was too problematic for them to engage with her in a group setting, but agreed to spend time with her one-on-one, where conversations could be better managed. Nell felt hurt and rejected.

And they said that they were willing to go out with me one-on-one but not as a group. I mean, they said that. And I guess I was – I appreciated that they wanted to still go out with me, but you know to not include me in the group, you know. I just felt really depressed. I mean, why not invite me and let me decide if I feel comfortable enough to be around the group?

Nell said that she did not purposefully initiate withdrawal from social situations. In fact, she did not realize how much she was missing in social settings and did not understand why she was no longer being included.

I just didn't understand why they didn't include me. But I guess I couldn't join in on the conversations. I just felt it was hard for me to add things to the conversation so I was happy to sit and just watch and just try to add whenever I could. But maybe I was adding the wrong things. I mean sometimes that happens, that my husband will tell me, 'We're not discussing that.' And at least he was saying it, but maybe the others weren't telling me and I didn't know.

Furthermore, Nell felt that her friends did not understand deafness and could not relate to her once she became deaf. Prior to learning ASL, people assumed that because she was now deaf, she had immediate knowledge of the language of the culturally deaf community.

And they also thought that when you become deaf that you are fluent in sign language, that it's automatic. And you know, I said, 'No, I don't understand signing.' And I remember there was one woman, we went out for lunch and this group of four women and she said, 'Oh I know signing.' And she started to sign, and at that time I hadn't started signing I didn't learn yet and I said, 'Well, I

don't know signing.' And she said 'It's okay, it's okay. I know signing.' And still she continued to sign and everyone stopped to watch me and I said, 'Well, I'm sorry but I don't know signing.' And they just couldn't understand that. They were disappointed in me and that was the last time we ever went out together. That was it.

Nell expressed frustration with her friends' assumptions about her deafness, and although she was not emotionally prepared to tell them at the time, she wanted them to know the following:

There's such a wide variety of deafness. There are deaf people who grew up oral, there are people who grew up in deaf schools and sign, there are people who became deaf, and there are people who will never admit they're deaf. Don't assume [deaf] people are all the same. Don't assume when you see someone with a hearing aid 'Oh they sign,' most don't.

Even at home, with her supportive family, Nell felt misunderstood and excluded. She explained that people, including her family, didn't realize that because she was present, it did not mean she followed, or was even aware, of the conversations that were taking place around her.

It was hard. I mean, it's hard for everybody, because as my hearing got worse I just – it was really hard to join the conversation so I would just sit and then I would withdraw because I couldn't join. I didn't know what they were saying and they wouldn't know that I didn't understand. And so they would see me looking and they would think I understood the conversation. They didn't realize I couldn't. And it would only be later that I would ask a question and they'd be

looking at me strange and they'd say, 'We discussed that.' And I'd say, 'Well, I didn't know.'

Thus, Nell believes that deafness, because it is an invisible disability, is particularly difficult for others to understand. "It isn't like a broken leg you can see." Furthermore, she reasoned that the consequences of having an invisible disability, like deafness, are magnified for late deafened adults who tend to have normal voices and therefore speak without exposing their disability.

Well, my experience is that hearing people don't understand, especially when you lost your hearing later in life. Just because I'm speaking normally doesn't mean I'm hearing. When I speak people think I can hear, even people who know I'm deaf. People forget that I'm not hearing. They forget because I'm talking and it's normal. I'm talking fast, I'm having a conversation, maybe I understand because I'm reading lips really well that day, and then they forget that I can't hear. They start talking to me a mile a minute or they chew food or look away or you name it. People just forget. So that's what's hard.

Nell's inability to communicate was one of the most negative outcomes of her hearing loss.

I can't stress enough how important communication is. It's just to have that cut off, or impacted, you know. It's just such a big deal. You have to prepare yourself for how you're going to communicate.

In fact, without access to spoken language, Nell decided she should learn sign language. Never having met a deaf person before, her only connection to deafness was through her audiologist, who discouraged her from learning sign language.

He was afraid – he told me he was afraid of deaf people and he did not support me learning signing. And I would go to him – he was a good audiologist, I mean the hearing aids helped me, but he said to me, ‘You don’t want to become like they are.’ And I said, ‘What do you mean? Who is ‘they?’” And, you know, I was just amazed. I was so upset I thought he needed to learn about deaf culture. And he says, ‘Oh no, I’m the enemy.’ And I just didn’t understand why he thought that. I mean, they’re his clients. I just didn’t get that.

Nell, though, became increasingly motivated to learn sign language and adopt a deaf identity when she met a confident, signing deaf woman who changed her perspective about deafness and, therefore, about herself.

I had met a deaf woman and she was amazing. She was talking and signing at the same time. She was a businesswoman and she was lecturing, she was selling equipment. And she was so proud of herself. And I thought – you know, this is the first businesswoman who was deaf that I had ever met and I was just surprised to see her. And I thought, ‘I want to be like her.’ And for the first time I thought that I’m going to be okay, because she’s okay. And so I just wanted to do whatever she was doing and she was signing so I wanted to sign.

By learning sign language, Nell was confident that she would be able to communicate and participate in social events without barriers. Soon after meeting the deaf businesswoman, she registered for an ASL course at her local community college.

And so I just started taking classes because I felt like I need to know sign language. I wanted to be able to go to lectures or whatever. I didn’t want to just

depend on equipment. I wanted to be able to converse with people and socialize.

Nell had hoped that her family and friends would support her decision to learn sign language and ideally would also learn to sign. Unfortunately, her friends did not understand her desire to learn sign language and were concerned they would lose her to the deaf world. Instead, they encouraged her to get a cochlear implant.

Most of my friends, friends that are new in the past ten years, they didn't accept me and they don't accept signing. And they felt like why don't I just get a cochlear implant or why don't I just try to stay with hearing people and when I try to explain that the signing helps me understand, they just don't accept that. They don't seem to realize what I need to understand, to communicate better. It's like a philosophy for them but it's a need for me. So I've lost friends.

Her family, on the other hand, did make some effort to learn to sign language but not enough so that she could be included in conversations.

My husband tried to learn signing. It's hard because he travels a lot but he goes with me to a lot of deaf events and he took one class in signing. They all know fingerspelling. But my husband and my son both know some signs so that helps. It's not enough for conversation but it helps.

As Nell became more comfortable with sign language and began accepting deafness as a permanent attribute in her life, she realized she could no longer do the job she had trained to do. Prior to having her children, Nell had earned a master's degree in business administration from a prestigious university. Once she had children, though, she postponed her professional ambitions to volunteer as an assistant in her children's school. Now that

she had become functionally deaf, she could neither work in the classroom nor pursue her business career, which left her uncertain about her future.

You know, I thought, 'What kind of work am I going to do?' And I felt frustrated.

I didn't know what kind of work I could do. I didn't even know how to present my hearing loss in an interview for work. I didn't know what to do. I was just lost. I was frustrated.

Nell reached a juncture at which she was determined to find a new path and make positive decisions about how she would live her life as a deafened person. After months of depression and insecurity about her professional life, she began making strides in building a new career, which she deemed to be more appropriate for a deaf person.

So I went to the department of rehabilitation. I decided to just see how I could manage it so they told me to go back to school and get some other type of degree, even though I had my MBA, and maybe teach deaf and hard-of-hearing.

And I knew that I loved math so I thought maybe I'd teach math.

In addition to going back to school, Nell also began volunteering at a school for the deaf, which was her first exposure to the deaf community. The opportunity to work with deaf people enhanced her studies of sign language and deaf culture.

I love to volunteer for things. So I was volunteering at the deaf school and at the same time I was taking classes in math and I was taking signing classes and deaf culture classes. It was so special for me to be able to use what I was learning in my classes. I always tell young people that you must volunteer for things because you never know how that will help you. And it's really fun.

In fact, Nell had aligned herself to be in perfect position for a job offer. One day, she was in the library with her sign language tutor and she said, "You're always helping me; let me help you today, whatever you need." As it turned out, her tutor had an important upcoming interview and Nell, considering her business background, was the perfect person to help her prepare for the interview.

So I was teaching her and we were doing role playing and so we are doing this in the library and I'm teaching her how to role play and so we're working and I'm laughing and I'm helping her and she's feeling better and then she left. And my tutor is deaf so I'm signing at the same time. So she leaves. But what I didn't know was that there was a man who was watching. And when she left, he came up. And he said, 'Are you a teacher?' And I said, 'No, that was my tutor, but I was helping her today.' And he said, 'I saw you signing and I heard you laughing and I am from the biotechnology department and we need a bridge for biotechnology with the deaf school. Can you tell me about yourself?'

Nell shared her background and qualifications during the opportune encounter and was soon offered, what turned out to be, "a perfect job."

So I told him how I was learning the math again and told him about my background and that I was taking sign language classes and volunteering at the deaf school so I had contacts there. And it all just came together and so they hired me. And so I became the deaf community liaison for the biotechnology program. And it was wonderful. I did it for a year and a half. It was wonderful. So then I was volunteering and I was working and I was taking the sign language classes and I was so excited to see my life coming together.

Once her professional life was on track and Nell began moving forward in a deaf life, she realized she needed to reestablish her social life. Although she was cognizant that she was different from culturally deaf people, she began attending deaf events in order to make connections and learn more about deafness and deaf culture.

I learned a lot about deafness in my deaf culture class. I started going to deaf events and I think because I never tried to act like I'm something I wasn't – so the more I went, the more people saw me, the more I was accepted. And I would bring things up. I'm sure no one expected me to bring up cochlear implants at deaf club meetings, but I would bring it up but I would adapt it to what they were talking about and then that was acceptable to them, and so they were fine. I haven't gone to deaf events lately. I had to miss – there was always some conflict. I do want to go back to them. It's just a matter of getting to know people. Everyone is people. No matter where you go, it's not like people are going to be different anywhere else. Everyone is the same.

Asked if she related to deaf culture, Nell said, “not so much,” but she does have a deep appreciation to the deaf community. She explained her position in deaf culture as follows:

I'm very grateful to the deaf community for accepting me. I've heard other horror stories from late deafened adults that they didn't feel accepted by the deaf community, because maybe they didn't sign or – but I didn't have that problem. I felt welcomed. It's a two way street. You have to be willing to communicate with them. So I learned sign and I learned to communicate. I would go to deaf events, but I will never be 'big D' deaf. I didn't grow up having

their experiences. I didn't go to deaf schools or have a deaf family. So I feel welcome in the community but I will never be 'big D' deaf.

Although she accepts that she will never be a qualified member of the culturally deaf community, Nell feels that through interacting with the group, she learned a valuable lesson about accepting herself and living her life as a deafened adult for herself, and what works best for her, rather than for the satisfaction of others.

Honestly, I feel that other groups can learn a lot from deaf culture. And I've adapted a lot of what I've learned from deaf culture to being late deafened. I mean they don't try to be something they are not. Late deafened adults are trying to lipread and wear all the equipment, trying to please everybody, but you're never going to succeed. You're never going to be like everybody else.

Still seeking a connection with a group in which she could identify, Nell joined a support community for late deafened adults. She took comfort in the use of sign language within the group. Other late deafened adults understood and accommodated her communication style and ability. There was no judgment about her sign language skills or her inability to hear and no impatience if she needed people to slow down or repeat themselves.

And when I joined ALDA a lot of people were signing. I noticed that people had two different languages that they could use to be understood and to understand people. And it was just fascinating. So I wanted to be part of that. They accept me for who I am. I feel supported. My signing has improved. It's not's perfect. I miss a lot. But it's okay, you know, they see I'm trying my best and it's okay, they slow down or whatever.

Although Nell continued to socialize and make friends in the culturally deaf community, after attending an ALDA event, she immediately felt that she belonged to the group in a way she had seen that culturally deaf people bond together. Before long she became actively involved in the organization.

I volunteered and it helped me so much. I was asked to run for regional director. I mean it was just amazing that each thing helped me in another place and I was just making more and more different friends of different kinds. And it didn't matter if they identified as deaf or hearing or hard-of-hearing or late deafened, it didn't matter. They were all nice people and they accepted me. It was wonderful because I just joined a whole new family, and they just accepted me. I really enjoyed it.

When asked about which label she used to describe herself, now that she had made connections in both the deaf and the late deafened communities, she provided the following narrative, which highlights the advantages of using 'deaf.'

It was funny. I went to buy some running shoes. And this young guy sits down, and I figure he looks like college age, and he's not going to get it so I said, 'look—' he goes 'blah blah blah' talking really fast. I said, 'hold on a sec, I'm really hard-of-hearing so you're going to have to talk really slow.' He goes, 'Okay, blah blah blah blah,' talking really fast again. I said, 'No, wait. You don't understand. I am super, really hard-of-hearing. You have to speak slowly.' He goes, 'Oh, okay' and then blah blah blah really fast again. And I said, 'This is not going to work. I'm deaf.' He goes, 'Oh, do you know sign?' I said, 'Yes, do you?' He goes, 'Yeah.' And so we signed the rest of the time and it was perfect. Oh my

God. It was too funny. So I tend to just say I'm deaf now. Because even if they just sort of sign it slows down their speaking.

Nell does not find the label “deafened” to be advantageous, but does clarify, when speaking to culturally deaf people, that she did not grow up deaf, but that she became deaf later in life, thereby signifying an out-of-group status that indicates cultural differences.

I've tried a few times to say I'm deafened and people don't seem to understand that either. When you're signing and use the word “late” it's 'late' [sign; tardy] or 'late' [sign: later], [laughing]. I used to say deafened and then I thought, 'Oh forget it. I'm deaf.' You know, 'What is deafened, you know?' I just say, 'deaf' if I have to fill out a paper for the government and they want to know what I am. Or if I'm with some deaf people and they want to know what I am I might go [sign: profound loss of hearing] because that will explain to them I wasn't born deaf and I didn't go to deaf school so they understand my background. It just makes more common sense for them.

Nell found it important to clarify to culturally deaf people that she learned sign language later in life, as a second language, because as a non-native signer who has not mastered the language, she misses a lot of information in ASL. Likewise, as a late deafened adult who does not have access to spoken English, she misses a lot of information in verbal interactions, which she cannot hear.

I miss information no matter which way I communicate, even with signing, I miss things. My receptive is not one-hundred percent, so I miss. I'm always missing something and its so frustrating because I feel like I'm a smart person but I just can't participate fully no matter what.

Because she misses key pieces of information regardless of which language she uses, she believes she is perceived as less intelligent than she actually is.

People just think that I don't get it, that I just don't understand, and I can't participate fully. I miss things. So I make wrong decisions sometimes and people think I just don't get it. We had a staff meeting and I missed something important, so I was eager about setting up some workshops and I didn't realize an important point and I shouldn't have been excited because of that point. And other people were looking at me like something was wrong. I think they felt sorry for me. I mean they are nice. But I'm such a smart person and that was such a simple thing not to get.

Because of Nell's communication limitations, she often resorts to e-mail and other electronic communication methods, which she feels are disadvantageous because they take away from the intimacy of conversation and create a disconnect in social connections.

How I communicate is the biggest change that came with hearing loss. That's the worst. That's the saddest part is losing the ability to communicate fully with people – that I'm not going to understand fully. I can't communicate fully. I have to rely on email; I'm always emailing. The late deafened world seems to communicate by email but it's not personal, you know. It loses something and I wish I could have that deeper meaning that comes in direct conversation.

Nell finds sign language to be easier than spoken language for communication and prefers to socialize with people who can use ASL to interact with her. However, because her hearing friends don't know sign language, she tends to socialize with deaf and deafened people.

Well, at this point, I would go with deaf because I don't understand the conversation with hearing people. You know, if hearing people were able to sign or had a way to communicate with me then I wouldn't mind. It wouldn't matter. But most hearing people don't sign and most of the time I get left out of conversation and so I'm just sitting there.

When Nell is forced to join interactions in which she is the only deaf person, she now advocates for her need in order to be included in the conversation. She provided the following example of a conversation with her husband and his friends, in which she made her needs known so that she could participate.

I went to a BBQ with my husband and there were a lot of people there and – if I know there is a person there that signs I tend to drift toward that person, hearing or not, but there was nobody. So, at one point my husband was talking to three people and they were like in this huddle. And I couldn't understand a single thing they were saying so I just said, 'Excuse me, you know what guys?' – because I couldn't even break into the huddle – and I said, um, 'I'm having a really hard time understanding you guys, or even anyone else here, so, um, if you all wouldn't mind standing in a line over in that corner in the kitchen in a line and face me, I would really be able to join the conversation.' And they said, 'Oh sure no problem.' So we all went over there and I was able to chat with them for forty-five minutes, but it's exhausting. It's really super exhausting.

In fact, as Nell has become more comfortable with her deafness, she has become accustomed to advocating for herself by telling people that she is deaf and what her

communication needs are. “I’ll tell them. I’ll tell everybody, now. It doesn’t matter if I’m in a restaurant or a store – I say, ‘I’m deaf.’”

People just take it for granted when you go someplace and order lunch. For me, I have to prepare myself – what I think they’re going to ask me. I have my order prepared for the server and then they’ll ask something and I’ll – ‘Ugh, I thought I explained everything.’ So I’ll say it again. You know, just things you take for granted. Think of every possible question they could ask you, prepare yourself and then they ask you something different.

When asked is she ever regretted the decision not to get a cochlear implant, due to her communication difficulties, she explained as follows:

I’m proud of who I am and the choices I’ve made in life. I’m glad I didn’t let an audiologist limit my choices. I did what I feel comfortable with.

In fact, she explained that she likes to wear her hearing aids. She doesn’t think that she would be as happy with the sounds through a cochlear implant.

I like to hear the noise. It’s just that some of the noise is strange. Like my voice is strange. You know, everything is kind of weird. That’s also the reason I’m not that excited about getting the cochlear implant because I’m a perfectionist, I want everything the way it is supposed to sound. And I don’t want it sounding metallic and weird. I want it to sound like how it’s supposed to sound.

She explained that even with a hearing aid, the sound she hears does not sound natural and sometimes she takes them off at home “because it’s quiet. it’s peaceful, it’s nice.” However, she fears that if she takes them off for too long she will get used to not wearing them and

will not want to wear them anymore. So she forces herself to wear them as much as possible.

Right now it feels like I'm hearing through a machine. I hear double. From what I remember from when I used to watch Star Trek and they'd have some mechanical thing "take me to your leader" [imitating a robot in voice and gesture] that's how you sound. That's how you sound, that's how my voice – I'm hearing my voice double. And it sounds like it's in an echo – like I'm talking through a tube. That's what it sounds like so it's very strange.

Nell's primary concern about her hearing loss, at the time of the interview, was the fear she felt for her safety. She furthermore expressed uneasiness with the lack of attention given to deaf people's safety, in general. She finds public service and access for deaf people to be critically lacking.

I have a fear of dying because people don't care. The subway here has no fire alarms that are flashing and they're refusing to put them in. There's no access to the local announcements. And they don't care. And they are refusing to communicate with me to find a solution. And I've been sitting on the accessibility task force for two and a half years and they still refuse to do anything. Nothing. They haven't spent one dollar on the deaf and hard of hearing community for accessible communication. And now it's my problem because I will die if there's a disaster. And I'm there. And that's scary to me.

In fact, Nell recommends that all late deafened adults advocate to have their needs met.

I would just emphasize that anyone who loses their hearing [should] advocate, because you feel better about yourself, you feel like you have some control of your life by doing that and just working with others.

She concluded the interview with the following additional advice to other late deafened adults.

It's not the end of the world. It may change your life. There's nothing you can do to change it. You can't change your life but you can change your perception of yourself. You can change your environment. Most important, know that you are not alone. There are many, many people with hearing loss. They shouldn't be afraid of hearing loss. Change happens. And there are a lot of famous people with hearing loss. And they think that when they have hearing loss they can't do anything, that they need to quit their job, they can't work for whatever reason, they need to lose their friends, or they can't drive or whatever, but that isn't true. We've had two presidents of the United States with hearing loss: Clinton and Reagan. We've had singers, we've had football players, we've had baseball players, wrestlers. We've had so many famous people with hearing loss. There is no reason to sit at home and not have a communication link with your friends, family or neighbors. So that's the most important thing – to not be alone or isolated.

Emerging Themes: Nell

1. At age 41 Nell was diagnosed with mild hearing loss, from an unknown cause. At age 42, overnight, her hearing loss advanced to severe. She has no family history

of hearing loss.

2. Nell was surprised by her diagnosis because she hadn't realized how much she'd been missing.
3. Nell considers herself deaf because although she still hears sounds, she is unable to hear speech. She prefers the label deaf, as opposed to hard-of-hearing or deafened, because it most accurately reflects her hearing level and identity and helps people understand how to communicate with her.
4. Nell was depressed about her hearing loss and uncertain about her future but wanted to set an example for children of how to face adversity.
5. Nell made changes in her life including: returning to school to earn a degree in education, volunteering at a deaf school, and studying sign language.
6. Nell had difficulty maintaining social connections with hearing friends because she could not follow conversations. She stopped getting invited to group events with her circle of friends.
7. Nell thinks people don't understand hearing loss and expect that she either automatically knows sign language or that she can hear things she cannot hear.
8. Nell doesn't want a cochlear implant because she is afraid of the consequences of the surgery that is so close to her brain. She doesn't feel the need for cochlear implants because she is happy with herself as she is.
9. She wears digital hearing aids and enjoys hearing sounds but, although they aid in speechreading, they do not help her comprehend spoken language.
10. Friends did not understand her desire to learn sign language and encouraged her to get cochlear implants.

11. Nell's audiologist discouraged her from learning sign language and adopting a deaf identity.
12. Her husband and children have learned some signs and fingerspelling but not enough for conversations.
13. A lot of her communication is limited to emails, which lack depth.
14. Because Nell is a non-native speaker, she misses information in sign language, as well as in spoken language.
15. Nell finds sign language to be less taxing than spoken language and prefers to interact socially with people who sign.
16. Nell believes that people think she doesn't understand things because she isn't smart, instead of understanding that she misses information she can't hear.
17. Nell attended deaf events and learned about accepting herself as a deaf person and not making decisions about her deafness in order to please other people.
18. Nell joined ALDA and found a place where she felt at home and accepted regardless of her sign language proficiency.
19. Although Nell still struggles to communicate because she cannot hear spoken English and is not fully fluent in ASL, she does not doubt her decision not to get cochlear implants.
20. Nell has learned to advocate for herself to get her communication needs met.
21. Nell fears for her safety and is appalled by the public's general lack of concern for deaf people. She encouraged other late deafened adults to advocate for their rights for safety and access.

CHAPTER SIX

DESCRIPTION OF THEMES

After analysis of data from each late deafened adult in the current study, the major themes emerged and were compared here. As was demonstrated in the previous chapter, each late deafened adult's lived experience of becoming deafened was unique because of their history, context and background; and yet, there were similarities in the descriptions of the experience. Themes from all of the interviews were strengthened when they were confirmed in subsequent interviews, with differences within their experiences adding depth and breadth to the themes. Identification of emerging themes and examination of common and contradictory meaning units across narratives are presented in this chapter. The resulting structure provides a framework for understanding the experience of late deafened adults.

Fifteen emergent themes were abstracted and clustered together under broader, super-ordinate themes or dimensions of the lived experience of late deafened adults. The dimensions include: (1) transformation of self, (2) social interaction, (3) interaction with technology, and (4) deaf advocacy. The four dimensions of the lived experience that have emerged from analysis of the current data are highlighted below in table 6.1.

Table 6.1 Summary of Themes of the Social World of Late Deafened Adults

Super-Ordinate Themes	Recurrent Emerging Themes	Examples
Transformation of Self	LDAs in the current study experienced: • Conscious decision-making regarding disclosing deafness to others. • An altered perception of self by others. • An altered personal identity. • An altered cultural identity and decision-making regarding cultural affiliations.	• “I just never told anyone.” • “I feel stupid now.” • “It’s like people think you’re really stupid.” • “I just feel like I don’t even know what my personality is anymore.” • “I found out I didn’t belong in the hearing world, but then I definitely didn’t belong in the deaf world...” • “I must cultivate my signing and deaf identification.”
Social Interaction	LDAs in the current study experienced: • Feeling that others were unwilling or unable to make basic accommodations for communication. • Periods of social isolation. • Difficulty participating in social interaction. • Feeling most comfortable interacting within the group with which they identify.	• “People don’t get what they need to do to make it shared responsibility.” • “Why do you keep having to remind people? Why can’t they remember?” • “I created a safe little, like, bubble.” • “I slowly stopped getting invited and included in things.” • “Because a lot of what people want is to get together with a bunch of people they feel comfortable with...”

Table 6.1 Continued

Interaction with Technology	LDAs in the current study experienced: • Stigma associated with technology. • The role of technology in personal and cultural identity development. • Dis/satisfaction regarding technology.	• “It was a constant form of embarrassment.” • “I’m happy with who I am right now. I didn’t want to just depend on equipment.” • “I didn’t feel [cochlear implants] took away from me being deaf at all.” • “I was a different person. My personality came back.” • “If it works, great, if it doesn’t work, then I will know and I will just totally learn ASL.”
Deaf Advocacy	LDAs in the current study experienced: • Learning to advocate for their personal needs. • Involvement in deaf and/or late deafened community groups. • Believing that acquired deafness is ignored/misunderstood and feel a sense of purpose in educating others about deafness. • Advocating for the needs of themselves and others and fighting for equal rights of deaf people.	• “People just don’t understand deafness in general.” • “People don’t understand the needs of deaf kids.” • “Now, I’m starting to say, ‘Hey, I need captioning; the law says I get a flashing smoke alarm; I need an interpreter.’” • “I was glad to be part of the movement of change.” • “I’ve been sitting on the accessibility task force for two and a half years” • “So I got involved with the union working on deaf issues.”

The four super-ordinate themes that emerged in the narratives of seven late deafened adults are highlighted in the following, thereby capturing the essence of the experience of the participants in the current study.

Transformation of Self

Transformation of self was a recurring theme in the narratives of all seven late deafened adults in the current study. Participants unanimously described changes in their identities in the following ways: (a) altered perceptions of self by others, (b) altered perception of self by self, and (c) a loss of cultural identity, which might or might not be replaced by a cochlear implant. Management of personal identity was achieved by making mindful decisions regarding whether or not to disclose deafness to others, while management of cultural identity required complex decision-making regarding relationships, group affiliation and involvement.

(a) Altered perceptions of self by others

Within the super-ordinate theme of identity, a common dimension of the experience of late deafened adults that emerged from the data was that the perception of self by others played an integral part in the management of identity. The participants in the current study believed others perceived them differently after becoming deaf, specifically, they believed others considered them to be lacking in intelligence, graciousness, and overall acceptability.

Late deafened adults in this study universally felt they were viewed as less intelligent, especially in social interactions, after becoming deaf. Liz explained, “I was never good enough after I became deaf. I just wasn’t accepted fully for who I was anymore.” Participants explained it as follows: “I feel stupid now. I know I’m not stupid but I feel stupid in conversations. I feel boring a lot of times because I don’t participate. I just sit there.” (Jo) “I’m a smart person but I can’t participate fully no matter what.” (Nell) “It’s like people think you’re really stupid and you want to walk around saying, ‘I’m not stupid I just

have trouble hearing.’ But it makes you seem really lost and out of it.” (Kat) “I miss things, so I make wrong decisions sometimes and people just look at me like I don’t get it.” (Nell) “I think just not being able to participate in conversations makes me feel stupid.” (Jo) “People tend to talk over your head or just think you’re slow.” (Nell) “They think I’m stupid.” One participant confidently said that any negative views held by others must stem from her hearing loss: “They didn’t like me because I couldn’t hear.” (Kat).

A shift in the way others view participants in this study after they became deaf was particularly evident to Jay when he realized he was being treated differently when he used sign language in public spaces, as opposed to using his voice. As he described it, “[people] would talk to me like I wasn’t as smart when I wasn’t voicing. You know, they’d talk to me like I was five years old. When I voiced, people talked to me like I was older, more intelligent.” Highlighting deafness in public spaces was also an embarrassment to others. Meg was asked by a family member to not sign in public because of the negative attention it created. “He said to me, ‘Can you please not sign in public? That’s embarrassing.’”

Max, who opts to not use his voice for speech, supported the idea that deafness is less than desirable by recounting an encounter with a woman who wanted him to use his voice to communicate with her. He explained that the situation in which she attempted to persuade him of the ease and benefit of talking, left him feeling “devalued and unaccepted.” He characterized the experience as discriminatory and equated it to discrimination of gays and blacks. He proposed the following categorization of the interaction: “Would anyone ever suggest that a gay person act more straight and they’ll go farther in their career, or that a black person act whiter and they’ll please more people?”

Late deafened adults in this study also expressed that others perceived them as being discourteous. In one instance this was expressed as defensiveness: “You get defensive so you come off defensive to other people.” (Kat) Often, however, perceptions of late deafened adults were depicted as arrogance. As Liz explained, “people were accusing me of being snotty or stuck up or rude, you know, aloof, and it was all related to my hearing loss.” Kat illustrated a situation in which she was confronted by a customer who accused her of being “stuck up” when she failed to hear her call for assistance. This experience was confirmed by Jo who explained: “I think before people thought I was ignoring them, or I was stuck up, or I was a bitch, you know, because I didn’t hear them.” “I’m sure I ignored people a lot of times just because I didn’t hear them.” (Jo)

The mistaken perception of late deafened adults as being rude was not exclusive to hearing people who didn’t understand deafness. Kat shared a story of her culturally deaf sign language instructor who accused her of being rude for looking at the interpreter rather than at her: “She yelled at me and said, ‘It’s really rude to not look at me.’ And, I understand for deaf people it’s rude to look at the interpreter because they aren’t supposed to be there, but I can’t do what you’re asking me to do, you know, because then I’ll be lost.”

Most deafened participants in this study believed that their speech and language abilities influenced others’ perspectives of their intelligence. Jo explained that she was wary of pronouncing words that she had not heard before as a hearing person. She provided the following example: “I don’t know how to pronounce certain things that are going on in the news, like Alk--al--ki--yada [pronouncing ‘Al Qaeda’], or whatever. You know, I read it but I’ve never heard it pronounced.” Reactions to other participants about their speech tended to be in regards to their acquired “deaf voice.” Late deafened adults in

the current study were aware that, “When you cannot hear your own voice, the pitch changes, the accent and any number of things begin to creep in.” (Max) In fact, during her interview, Liz was so concerned about her “deaf voice” that she decided to use sign language (and sim-com) throughout the interview for fear she should would not be understood. Furthermore, Meg described being ridiculed by her husband for not knowing how to pronounce certain words. In addition to making comments about her “nasal” and “whiney” voice, he said, “Oh my God, you just said it wrong. You sound so dumb – I can’t believe you’re in college.”

While some participants recounted careless comments that were made about their speech, such as: “Oh, your voice is different. Are you from, you know, Boston, or Europe, or whatever?” (Liz), others described people’s reactions as less subtle. One late deafened adult explained: “You can tell by the look on people’s faces, especially those who have known you for a long time.” (Max).

(b) Altered personality

The results of this investigation suggest that late deafened adults in the current study experienced a change of personal identity after becoming deaf. Participants described losing a sense of themselves, particularly in regards to their sense of humor, which could no longer be expressed, as well as their inability to engage in small talk and enjoy social interactions. Jo explained that, “You can’t just be yourself when you can’t hear.” Meg collaborated: “All jokes were like second hand jokes.” Jo, who prior to losing her hearing had enjoyed engaging in playful exchanges with friends and colleagues, went on to say: “You never have that kind of banter anymore.” As a result, she explained, “I just even feel like I don’t even know what my personality is anymore.” This was experienced by

other participants as well: “I lost some of my sense of self. What I thought I was, I wasn’t, anymore.” (Kat) “I became a little bit more shy. I was very outspoken before...” (Meg) and, “I think that that’s the part that’s the hardest is you lose your sense of fun.” (Kat).

Participants who chose to engage socially within the culturally deaf community also expressed difficulty maintaining their personality. Humor, particularly, was reported as not carrying over well into sign language and deaf culture. “I’ve never done a good job at adapting my humor to make it match deaf culture.” (Jay).

The changes that late deafened adults described in their personalities were not all losses. In fact, as Kat described it, deafness “made a bigger life.” Hearing loss was also described as making participants more compassionate, in that hearing loss “forced the issue of being a bigger person.” Participants’ experience with acquired deafness promoted openness to other people’s differences and limitations. Kat admitted that, “I think I am nicer than I would have been and I think I look at life a lot differently than I would have.” Participants agreed that deafness also inspired them to be amenable to new experiences, which was described as, “I’ve done a lot of stuff that I – I don’t think I ever would have gotten into.” (Kat).

Late deafened adults in this study described a process of coming to view themselves as deaf individuals. Unlike culturally deaf individuals who proudly call themselves ‘deaf,’ most late deafened adults in this study took years to accept that label and preferred to use labels such as ‘hearing impaired,’ or ‘hard-of-hearing,’ or to avoid labels altogether by simply stating, “I can’t hear.” Max identified as “hard-of-hearing” long after his hearing loss had advanced to profound deafness: “I thought I was still hard-of-hearing, even after I was out of the hard-of-hearing zone completely.” Liz, who now claims to have a

“deaf soul”, acknowledged that at one point, “[deaf] was the worst label. I could never identify with that.” Other participants described “deaf” to be a more powerful label in getting their communication needs met. “People just don’t get hard-of-hearing. They get ‘deaf.’” (Kat). Similarly, Nell, after repeatedly identifying herself as “hard-of-hearing,” finally said, “This is not going to work. I’m deaf.” After which her communication partners better understood her communication needs.

In fact, participants described accepting a ‘deaf’ label to be a powerful turning point in their lives as they began to see themselves as deaf. Kat explained, “Actually, the big change for me was actually saying ‘deaf’ instead of ‘hard-of-hearing.’ Deafness is taken more seriously than hard-of-hearing; there’s a seriousness to saying, ‘I’m deaf. End of story.’ So for me, using that word was very liberating.” Liz revealed that deaf is now who she is. She explained: “I fought it for a long time. And I think that once I just opened my heart and say, probably the first time when I told somebody, ‘I am a deaf woman – that can hear [with cochlear implants.]’ That was a turning point for me. You know, I finally identified myself as a deaf person.”

(c) Conscious decisions regarding disclosing deafness to others

The decisions late deafened adults made about disclosing their deafness played an integral role in the management of identity for all of the participants in this study. While all participants made conscious decisions about whether or not to put their deafness on view in public, it appeared that different choices were made for different reasons.

For some, the decision to not disclose their deafness was clearly based on negative preconceptions and ideologies about hearing loss. These participants, who relied on oral communication, admitted to concealing hearing loss in conversations by feigning hearing

much of what they could not hear. One participant revealed, “When I’m in conversations and people are talking and they laugh, I just laugh along. I pretend I know what everyone is saying.” (Nell) “I pretend I hear things I don’t all the time. People are talking a mile a minute and I would just kind of nod my head like I understand.” (Meg). Another participant echoed this sentiment by describing work meetings in which, “They didn’t know. I faked it all day. I just never told anyone.” (Kat). Meg shared an experience in which she didn’t want to admit to a hearing classmate that she was deaf: “I was too embarrassed to tell him that I was deaf and need to use the interpreter.”

There was stress involved in concealing hearing loss in social interaction. It was described by Jo in the following way: “I’m afraid to say anything because I’m afraid someone will ask me a question about what I said and I won’t be able to hear, so I just kind of sit there.” Liz, who also concealed her hearing loss in an attempt to fit into hearing society, described the experiences as “a constant disappointment.”

While some participants aimed to avoid situations in which their deafness could be discovered, others found it advantageous to highlight their deafness in public spaces, thereby making their communication needs known. “I’ll tell them. It doesn’t matter if I’m in a restaurant or a store – I say, ‘I’m deaf.’” (Jay). He preferred that people understand he is deaf, and rely on written notes, gesture or sign language to support spoken language.

The two participants who did not use assistive listening technology agreed that deafness is easier for others to understand if they do not speak. Jay explained, “Sometimes it’s easier if I don’t voice because when I voice, people assume I’m hearing.” For that reason he typically does not use his voice in public. He stated, “I found out in some situations for me I didn’t want to voice. I would just write to let people know that I was deaf, or gesture.”

For this participant, facilitating understanding that he is deaf helped to facilitate interaction. Max, who had chosen to relinquish spoken language altogether, agreed that when he stopped using his voice, thereby highlighting his deafness, “people and things just fell into place more often.” According to these participants, by making their deafness known, they were better able to facilitate conversation with people who then, “stopped shouting and stopped treating me as a hard-of-hearing.” (Max). Although he had not used his voice for spoken language in nearly two years, Max added the caveat that, “In situations where there’s an emergency, clearly I’m going to use my voice to make sure that I’m understood.”

(d) A loss of hearing identity and decisions regarding new cultural affiliation

A loss of cultural identity was expressed by all participants in this study as an inability to relate to hearing culture through social interaction. With a loss of their hearing identity, late deafened adults were left without group affiliation. All participants expressed that they no longer felt connected to the hearing world; yet, they also realized that they were not part of the deaf world. As Jo described it, “I really could tell that I wasn’t functioning well in the hearing world. I didn’t feel like I really belonged in the hearing world, but then I definitely didn’t belong in the deaf world so ... I felt so alone.”

Late deafened adults believed that assimilating into deaf culture would be difficult for logistical reasons, particularly because they themselves, as well as their family and friends, lacked sufficient sign language skills. Jo explained, “The problem was everyone I knew, my family, was hearing. It would have been a really hard thing for me.” Late deafened adults in this study also acknowledged that it would be difficult to relate to the deaf community because of their different viewpoints and life experiences, and therefore,

they could never belong to the group. It was expressed as follows: "I think because we come from such completely different views, different viewpoints, to us we lost something, to them, um, they feel defined." (Kat). "There's a shared sense of sensibility that I don't share and I would feel a little odd." (Kat) "I go to deaf events but I will never be big 'D' deaf. I didn't grow up with their experiences." Late deafened adults generally agreed that being socialized as a hearing person from birth through adulthood would make it difficult to adopt deaf culture. "My feeling is we were born into a hearing world and so it would mean starting over, much later in life to go into deaf culture and trying to catch up." Jo, who explained, "I can't see deafness as anything but a disability," also said she felt ashamed and embarrassed by her deafness.

For some late deafened adults, living between cultures was unacceptable and so they decided to immerse themselves into deaf culture. Two of the participants, who identified strongly with deafness, went to Gallaudet University, the center of American deaf culture, to socialize with other deaf people. Jay described a positive experience in which he made several deaf friends, but realized that while he was no longer hearing, he also did not fit and was not fully accepted into deaf culture. He suspected that a lack of shared experiences with culturally deaf people made him ineligible for group membership. He observed, "I was still like an outsider at Gallaudet."

Max, who sought group membership at Gallaudet similarly realized he did not fit into deaf culture, as of yet, but left after his summer visit with a renewed hope that with perseverance, he could eventually join deaf culture. He stated, "I must cultivate my signing and deaf identification." He does understand it won't be an easy transition. "I get nervous and I do have a long way to go to better understanding and acquiring the culture," but he

admitted, "It is that it feels I have no other choice." In fact, this participant was warned by others that his attempts to join deaf culture were futile, that he would never be fully accepted into the culture, that his ASL would never be fluent enough, and that he could never truly experience the ethnicity of deafness. He admitted, "That was like a slap to me." However, instead of being discouraged by this advice, he likened it to politics, "Sort of like the Democrats and the Republicans. Each side feels strongly – and even has their own set of facts." He said, "I cannot change [my deafness] - so why not find out why the deafies like it so much, and join them? It's not that I have this obsession to belonging to only the [culturally] deaf community, as opposed to other deaf groupings, it's that I feel I have no other choice."

Most participants in the current study identified with other late deafened adults and found a community and culture within support groups for late deafened adults. However, within these groups the culture varies. Of the two primary support groups for late deafened adults, Hearing Loss Association of American (HLAA) tends to be more oral with a focus on assistive listening technology, while the other, Association of Late Deafened Adults (ALDA), uses sign language and has a philosophy of "whatever works" for communication. Participants in this study felt comfortable in one or the other group, but rarely did they interact in both.

Other participants did identify with culturally deaf people. In fact, for Meg, who attended deaf college programs, it was turning off her voice and improving her sign language skills that made her finally feel a part of deaf culture, which had previously derogatorily called her "think-hearing" and "oral." "And that's when I started to feel more comfortable and also I think I started to feel more accepted by deaf people." "The longer I

was in college the more I wanted to be around deaf people.” “It was part of who I was becoming, part of my new identity.” “I found my community. I know where I belong. I know where I’m happy and what I want. I can’t live in a hearing world and be left out all the time.” In fact, in hindsight, the best part of becoming deaf, for this participant is the community and the language. “It’s like a discovery of a whole new world out there that I didn’t even know existed.”

Social Interaction

Another reoccurring theme in the narratives of late deafened adults in the current study was the difficulty participants experienced in social interactions. Late deafened adults described their experiences in social interactions as (a) an inability to fully participate in communication, (b) an inability of others to make the necessary accommodations to communicate with them, (c) social isolation as a result of communication difficulties, and (d) comfort of communication within the social group with which they identify.

(a) Late deafened adults expressed difficulty participating in social interactions

Late deafened adults agreed that being cut off from communication was the most difficult aspect of their hearing loss: “The saddest part is losing the ability to communicate fully with people – that I’m not going to understand fully.” As one participant illustrated, “I don’t feel like I can communicate. When you can’t hear you can’t participate in conversation.” She also pointed out that her communication options are even more limited because she does not use sign language. As she explained, “I don’t have an interpreter with me all the time, I don’t know sign language and I don’t feel I can do all those things because

I can't communicate the way [Marlee Matlin] does" (Jo). Other participants verified that "with hearing people it's impossible for me to read lips and I really can't follow – it's not possible for me to communicate." (Jay). "It was really hard to join the conversation so I would just sit and then I would withdrawal because I couldn't join." (Nell).

To compound matters, late deafened adult in this study believed that, because deafness is an invisible disability, hearing people tended to forget they were deaf. "People forget that I'm not hearing. They forget because I'm talking normal. They start talking to me a mile a minute or they chew food or look away or you name it. People just forget." (Nell).

Communicating with deaf people was described as equally challenging. When attempting to interact with deaf people in groups, Jay explained, "I find it hard for me to maintain concentration with the signing and the tracking conversation and as time goes on the more and more I'm falling behind, stepping back from the conversation." Similarly, Meg, after trying unsuccessfully to communicate with a signing deaf person, was made known that she wasn't welcome for interaction until her sign language skills improved. "He said [sign: broken communication], go learn sign and come back when you're ready."

Some late deafened adults realized that ASL could be an important tool for communication. As Jay explained it, "For me [being cut off from interaction] was more like a kick in the butt that said this isn't going to work. I needed some kind of visual language to be able to connect with people." Although all participants took sign language classes at some point after their diagnosis, several quickly dismissed the idea of using sign language because they didn't know anyone who signed. Participants echoed similar concerns. Jay said, "I wasn't connected with anyone who knew sign language so my skills never improved." Another claims that he did seek out deaf people with whom he could practice

basic signs, but that his sign language really flourished when he began working with deaf people on a daily basis. “And that’s where my language skills for sign language really improved.” One late deafened adult, who continued to learn and use sign language, lost hearing friends who did not support her decision. “Signing helps me understand, they just don’t accept that. It’s like a philosophy for them, but it’s a need for me.”

In fact, late deafened adults who used ASL in this study realized that mastery of ASL was the key to being welcomed into social interactions in the deaf community. Participants who continued to use sign language for interaction with the deaf community felt more welcomed there as their sign language skills improved. “And that’s when I started to feel more comfortable and also I think I started to feel more accepted by deaf people. And people stopped calling me ‘think-hearing’.” Another participant shared a similar experience interacting with culturally deaf people, “I felt welcomed. It’s a two way street. You have to be willing to communicate with them. So I learned sign and I learned to communicate.” (Nell).

All participants described experiences of heightened levels of exhaustion and frustration in communication interactions. Kat explained, “You get tired. And everything feels like a wall. It was like life was too much work.” Another described her attempts to be constantly alert in social interactions as disappointing: “You know, it was constant disappointment. It was always being in check with, ‘What can I do? What can I not hear?’” Some participants who signed found sign language to be less taxing than spoken language. Meg explained: “It is so much easier to watch sign and understand...It is definitely more work to hear than it is to sign. At the end of the day when I want to relax and have a conversation it is definitely ASL, without a doubt.”

(b) Late deafened adults felt that others were unable to make the necessary accommodations to communicate with them.

Frustration levels were increased for participants in the present study when hearing people are unable to make basic accommodations to communicate with them. Late deafened adults in this study described elevated levels of frustration at other people's inability to make basic adaptations to communicate with them. Frustration was placed on people being "narrow-minded" and "set in their ways." As Jay explained, "[Hearing people] don't get what they need to do to make it a shared responsibility. They either will make no adjustment or they will over exaggerate things and make it feel like it's a burden to communicate with me." Max corroborated this notion with the following example, "I would go into a food place and order, explaining I was deaf, and they would have to write back to me, or point or such. They instead shouted or exaggerated lip-syncing or just started talking back. Multiply this by hundreds. It was exasperating!"

Other participants expressed exasperation when, after explaining basic communication strategies to hearing people, no strategies were employed to facilitate successful interactions. Jo described an experience with a supervisor who didn't know how to communicate with her. She said, "I told him, 'I can't hear you when you talk like that' I mean, he knows I'm deaf but then he'll whisper." Another participant explained, "When people would forget to look at me I always thought they were doing it on purpose. Why do you keep having to remind people? Why can't they remember?" (Kat).

Even when late deafened participants all took precautions to ensure successful communication, they felt the full burden of responsibility was often still placed on them. Jay explained that although he had a sign on his desk that said, "please make eye contact," and

had pen and paper easily accessible for communication, he had situations in which customers were unable to adjust their communication method to make themselves understood. He provided the following example, "I was like, 'I'm sorry, what did you say?' 'I want three books of stamps [quickly].' I said, 'Okay, you want stamps. How many books do you want?' 'Three books of stamps [quickly].' I said, 'Can you show me by fingers?' He couldn't do it. He refused to show me by fingers how many books of stamps he wanted. He wouldn't write it down. Nothing." Max, expressed similar frustration when, after offering a pen and paper for communication with an acquaintance, he was pressured to use his voice. He described her insistence in the interaction as follows, "'Will you just please speak to me?' I said in notes that I do not speak. She said, 'You're moving your lips, and making some sound, just do it louder.'" This participant felt that rather than respecting his language choices, his acquaintance wanted him to communicate in a way that would be more beneficial to her.

Another late deafened adult, Meg, summarized her feelings about carrying the full burden for successful communication as follows: "I spent so many years putting all the effort into the communication while everyone else just sat back and did nothing and now I don't care to be around [hearing] people that are going to make me put in all the effort." Participants in this study also felt that hearing people were less than tolerant of late deafened adults' requests for clarifications: "I can only ask 'What?' so many times – maybe three or four times – and then I feel like hearing people reach their threshold." (Meg).

However, lack of shared responsibility in interactional opportunities was not limited to hearing people. Late deafened adults all described similar experiences with signing deaf people. One participant relayed the following example: "I went to a movie last week and

was carrying my captioner. And a guy waved at me asking if I was deaf. I signed 'deaf,' and before I could explain, 'LDA-sign poorly, deaf,' he was whipping out ASL much faster than I could understand. He sort of shined me on when I could not keep up the ASL." (Max).

(c) Late deafened adults experienced periods of isolation.

As a result of communication difficulties in social interaction, participants all described periods of withdrawal and social isolation. "I created my safe little, like, bubble." (Kat). Participants said it was easier to be alone than to "put myself in a position where I might fail to communicate because it's embarrassing." (Meg). All participants described spending a significant amount of their time alone after they lost their hearing. One participant thought that by being alone he was, "playing it safe by not taking chances with interpersonal connections with others." (Jay). As a result, he explained, "I was very isolated from the world. That was hard." Other participants explained: "I don't really talk to that many people and I think that's where you just don't feel like you belong anywhere." (Jo). "I'm just going to read books and watch movies with captioning and that's it." (Kat).

Late deafened adults in this study were no longer interested in joining social events, at least for a time. Deafened participants started to feel as if, "I don't want to go to new places. I don't want to go to parties." Participants described their isolation in the following ways: "I dropped back and back and back. And I stopped talking and stopped wanting people to talk to me and then I didn't know how to deal with anything." (Kat). "I participate very little." (Jo). "You know, if I was going to be in a situation where I wouldn't understand, I would avoid it. I didn't go to parties. It was more of a sheltering... I did not socialize. I did not date." (Liz). Even when late deafened adults did make an effort to be socially active,

they often still felt alone. One participant described the feeling as, “I was alone in the crowd, jostling elbow to elbow. Totally alone, even among friends and family.”

For some late deafened adults, social isolation was not by choice, but rather they were ostracized by their friends. Participants explained that they were no longer invited to social events that they had been a part of when they were hearing. “I had a lot of friends who said we were still friends but slowly they became different towards me. I slowly stopped getting invited and included in things.” (Nell). Another said, “I was missing a lot of information in the conversation and so they just started not including me in the invitations.” (Meg). Both of these late deafened adults confronted their friends and were told, “you’re different now,” (Nell) “we don’t have anything in common anymore” (Meg) and that conversations were too difficult to manage.

Even within social interactions, late deafened adults often felt isolated. At times, their friends, family and spouses become what were described as “hearing dogs.” Kat explained how this left her feeling alone even in the middle of an interaction: “You’re the person standing next to the person who talks. So the other people start going, “So, how’s she doing?” and you’re standing right there.” Late deafened adults furthermore explained that they were felt insignificant in conversations, in that if they missed information and said, “Well, what did they say?” the reply was, “Oh, never mind. It was stupid.” (Kat). One participant furthermore described humor, at her expense, because she could not follow the interaction: “Everyone would start laughing and I’d say, ‘What did you just say?’ and he wouldn’t tell me.” (Meg.). In a similar example, when Meg didn’t hear jokes that everyone was laughing at, her husband would say, “You had to be there,” to which she would say, “I was there,” and he would say, “Not really.”

Being cut off from trivial interactions was described as devastating. “Just making those little connections in everyday life. To me that’s what makes life worth living.” “It’s just to have [communication] cut off, or impacted, you know. It’s just such a big deal.” (Jo).

(d) Late deafened adults experienced involvement in deaf and/or late deafened community groups

The value of support groups was another common theme that emerged from the data in the current study. Participants described support groups in terms of the social and emotional benefit they provided. Jo said group membership “really helped me to accept [hearing loss] and start telling people about it.” Specifically by, “allowing people to come into your life that are the same, like you, and that understand.” Liz felt so strongly about her experience with other late deafened adults that she compared the shared sense of purpose that she felt in the support groups to the plight of black Americans during the black civil rights movement. “It was unity. You know, unity... It’s the same kind of war that we get to face.” She felt that late deafened adults, like members of the black community, faced discrimination, but as a community they gained strength through numbers.

Participants valued the social support they received from other late deafened adults in adjusting to their deafness. Because the support that late deafened adults received from hearing loss support groups was a factor in their own self-acceptance and overall well-being, late deafened adults who initially joined the communities looking for support for themselves, in turn became champions for other late deafened adults. Liz, who eventually became a regional director of ALDA, described starting arranging social events: “But just to start a little gathering of people it was such a strong family. But when I started to get into the ALDA group I started to have parties at my house once a month, if not, you know,

more.” In fact, several of the participants in this study expressed that as they became more involved in working with other late deafened adults and became more active in support groups, they slowly became, “less withdrawn and more sociable.”

Late deafened adults also joined culturally deaf events: “I started going to deaf events and I think because I never tried to act like I’m something I wasn’t – so the more I went, the more people saw me, the more I was accepted.” (Nell). Through interacting with the signing deaf community, late deafened adults were able to learn about deaf issues from a cultural perspective. “I’m sure no one expected me to bring up cochlear implants at deaf club meetings.” While most participants at one time interacted in the culturally deaf community, only one is currently immersed in the culture, while a second is striving for immersion.

(e) Late deafened adults felt most comfortable interacting within the group with which they identified.

Most participants in the current study indicated that they prefer to interact socially with those with whom they can easily communicate. Jay expressed that, “It didn’t matter if they identified as deaf or hearing or hard-of-hearing or late deafened.” He explained, “I’m most comfortable with hearing people because I’ve had the same experiences, but finding a group of hearing people who are comfortable communicating with me is hard” and, “If hearing people were able to sign or had a way to communicate with me I would go with them. But most hearing people don’t sign.” Participants, described the joy and ease of communicating with other late deafened adults. The ease of communication, however, was described as not necessarily stemming from easy communication in itself, but was due to a shared understanding of each other’s basic needs for effective communication. “You know,

people are just communicating. You see all these people who are writing, talking, signing, gesturing. You know their philosophy of 'whatever works' and it's such a comforting feeling. You're just trying to express yourself. And so it was really comfortable for me." Another participant said of other late deafened adults, "[my signing] is not perfect. But It's okay, you know, they see I'm trying my best and it's okay. They slow down or whatever." (Nell).

Participants experienced a feeling of relief when they were first introduced to events for late deafened adults through social support groups. Participants explained: "because a lot of what people want to get together with a bunch of people that they feel comfortable with and end up building social bonds." (Nell). "I mean I've met some of my best friends and they are people I would have never met otherwise." (Kat). "Just knowing that everyone knows, it takes so much anxiety off. Even though we're still talking, we don't sign, everyone understands and makes an effort to speak loudly or clearly because they know. So there isn't that awkwardness or embarrassment that goes with it." (Jo). "It was a place where it didn't matter who you were; we're going to communicate one way or another...You're in a barrier free communication environment and it's nice for me to just be able to sit back and relax and not have to work to communicate." (Jay).

In fact, regardless of communication mode, late deafened adults reported a significant reduction in their level of stress when communicating with other late deafened adults. Jay remarked that the environment was less stressful to him, as a non-native signer, because, unlike his experiences with culturally deaf people, his sign language skills were adequate for communication with other late deafened adult. "It was easier to communicate because I didn't have to worry about signing well." He attributed the reduction of stress to

the fact you “don’t have to worry about saying, ‘what?’ or ‘I don’t understand.’ So it makes it really comfortable. The pressure of feeling insignificant because I’m not understanding a conversation or I’m missing a joke. Things like that. I’m part of the conversation all the time. It’s just a wonderful feeling.” (Jay).

Most participants in the current study did not feel connected or at ease in social interactions with culturally deaf people. Kat explained, “ I think I was afraid of deaf people, not because they were deaf, but because I just thought I wasn’t going to fit in.” Jay, who is fluent in sign language and connected to the deaf community, explained his uneasiness with deaf culture, “I never felt connected to deaf culture, but I felt like – okay, more I would say I developed a rapport... more one-on-one with a person was fine, or a few people. But from then and still now, I’m not a part of deaf culture. I’ve never felt comfortable partly related to my language skills. ASL is not my first language. Part of it is related to my experiences which are very different.” Another participant explained: “I would go to deaf events, but I will never be big ‘D’ deaf. I didn’t grow up having their experiences. I didn’t go to deaf schools or have a deaf family. So I feel welcome in the community but I will never be big ‘D’ deaf.” (Nell).

Late deafened adults also expressed having felt superior to deaf people, before becoming deaf themselves. Liz, who had deaf family members, said, “I wouldn’t have anything to do with a deaf man. You know, this is just part of my thing, but deaf men were never good enough for me.” Another participant said, “I heard there were smart deaf people [at Gallaudet], which was a new concept to me. I had never met a smart deaf person before. I was blown away.” (Meg). She admitted to having previously judged deaf people for their poor English skills: “They used broken English. I looked down on them a little bit

because of their bad English.” They also expressed a general uneasiness and inability to connect with culturally deaf people: “I think I was kind of afraid of deaf people, not because they were deaf, but because I just thought I wasn’t going to fit in.”, “[deaf culture] makes me feel uncomfortable in a way.” (Kat).

In contrast, Meg, who said, “I just wanted to be around deaf people all the time. I didn’t fit in with hearing people anymore because I couldn’t follow a conversation,” found that she much more enjoyed being with culturally deaf people. “With hearing people if they were talking and laughing I felt sense of paranoia that they were talking and laughing about me. And anytime I would go around a group of hearing people I felt a sense of dread.” With deaf people, this participant felt a closeness and a sense of community that she had never experienced as a hearing person. “It is a different level of connection. The community, the sense of closeness within the deaf community is something that you would never get in the hearing community. The sense of connection you get from shared language and shared experience and triumphs is something you don’t get in the hearing community.”

Max, who also understood the benefits of community that comes with being part of deaf culture, knew that improving his sign language skills was the key to acceptance into that community. He is currently studying American Sign Language and described some of his most positive interaction being with other students in his sign language classes. He related to others who were also trying to learn and understand the language and culture of the deaf community and described these interactions as encouraging and motivating, “This was encouraging, because this showed me that if I stick it out and get better, I can have some good connections with fellow signers, hearing and deaf!” He hoped that through sign language he would eventually have the opportunity to have the deep and meaningful

interactions with people that he had lost with his hearing.

Interaction with Technology

The intersection between technology and the social world of late deafened adults was a universally reoccurring theme in participants' narratives. All but one wore hearing aids at some point in time during their journey to becoming late deafened adults, until they were no longer effective. The only participant who did not wear hearing aids could not have benefited from them because he advanced from being hearing to profoundly deaf immediately, as a consequence of surgery. Of the seven participants in this study, two had bilateral cochlear implants, two had unilateral cochlear implants and wore a hearing aid in the other ear, one had bilateral hearing aids, one had a non-functioning auditory brain stem implant, and one did not use any assistive listening technology.

(a) Late deafened adults experienced stigmatization regarding assistive listening technology.

Late deafened adults in this study expressed feeling embarrassed about their use of hearing technology. This was particularly true of hearing aids, which were described as having a "terrible old person bias." This, according to Kat, makes it especially difficult for young people who wear hearing aids. This was made clear to Meg when her date asked her to remove her hearing aids for a picture. This problem is compounded, "because marketing is to hide them as much as possible." (Kat). Three female participants in the current study supported this notion by indicating that they, indeed, constantly attempted to conceal their hearing aids with their hair. Jo explained, "I always have my hair long so I never show anyone my hearing aids." Unfortunately, the re-amplification of sound through the microphone of hearing aids often causes feedback, or a squelching sound, rendering

attempts to hide them futile. “If someone got too close to me, I would whistle,” Jo explained, which was “a constant form of embarrassment.” Jo recounted an event, in which she allowed her companion, who mistook the feedback from her hearing aid as his car alarm, to believe that there was something wrong with the alarm rather than admitting that she was wearing hearing aids.

The idea that cochlear implants were less stigmatized than hearing aids in hearing culture was expressed in the narratives of late deafened adults in the current study. It was suggested that the reason cochlear implants are more accepted is “because it’s high tech” and therefore “very interesting.” (Kat). She explained that, “I think that gives you more of a conversation that people feel comfortable with because they’re more comfortable with technology.” She described people’s reaction to her implants as, “very fascinated because you have computer chips in your head, you know, ‘Wow, like refrigerator magnets?’”

While there is stigmatization of hearing aids in the hearing culture, the same could be said of cochlear implants in deaf culture. One participant in this study, Liz, who may be considered to be a part of deaf culture due to her native signing skills and family connection in the deaf world, faced discrimination from the deaf community for getting a cochlear implant. Specifically, the curriculum at the deaf school her children attended discriminated against cochlear implants: “They were teaching my children that what I did for myself was wrong.” Another participant, Meg, who became fully immersed in the culturally deaf community after becoming deaf, determined that cochlear implants are more accepted by culturally deaf people than they once were. She still avoided stigmatization in the deaf world by following certain, unspoken rules about using her implant to access spoken language: “When I’m with my deaf friends I turn them off. When

you're a member of the deaf community there are just certain things you don't do in front of deaf people."

(b) Technology played an integral role in the personal and cultural identity development of late deafened adults.

Implant technology was described as influential in shaping the personal and cultural identity of late deafened adults in the current study, either negatively or positively. The decision whether or not to get a cochlear implant was found to be rooted in issues of identity. Furthermore, after undergoing surgery for implantation, the success or failure of the technology impacted personal identity and cultural affiliation. This, however, did not appear to be the case for hearing aids. All of the participants in the current study who could benefit, regardless of their personal identification and cultural affiliation, wore hearing aids at some point during their hearing loss journey.

For some late deafened adults, the decision of whether or not to get a cochlear implant was rooted in issues of culture and identity. Max explained that "choosing to embrace not only the deaf community, but deaf culture, as well" was his primary motivation for deciding against getting an implant. This participant felt that a cochlear implant would impede his ability to join deaf culture. He felt that implantation would have been akin to, "giving up on deafness." Nell also chose not to get a cochlear implant, partially because she feared negative consequences of a surgery so close to her brain, but also said, "I'm happy with who I am right now. I didn't want to just depend on equipment."

For Meg, who had adopted a culturally deaf identity prior to getting an implant but had a hearing husband and children, found that cochlear implants, restored her hearing identity, without taking away her deaf identity. "I didn't feel like it took away from me

being deaf at all, but it gave me some of my hearing back. I wear them selectively. I'm deaf when I want to be and hearing when I want to be. I feel like I'm truly bilingual and bicultural."

For Jo, though, who had spent a decade denying her hearing loss and rejecting a deaf identity, deciding to get a cochlear implant forced her to accept her deafness. Prior to deciding to get a cochlear implant, she had not wanted to admit that she had a profound and irreversible hearing loss that made her a candidate for an implant. She explained, "Before the implant I never wanted to get an implant. It signified to me that I was totally deaf."

For other participants, it was not the decision to get an implant, but the success or failure of the technology that affected their deaf identity development. For Jay, the failure of technology, if not Divine intervention, played an important role in putting him on the path to embracing a deaf identity. He explained, "I'm not really religious but I felt that [the fact that] the implant didn't work was like God's way of saying, 'You're deaf.' So I was supposed to move towards being deaf and not think about being hearing." Kat, who had success with bilateral cochlear implants, disclosed that if cochlear implants would not have worked for her, she would have felt that she had no choice but to join the signing deaf community. She said, "Well, this is it. If this works, great, if it doesn't work, then I will know and I will just totally learn ASL. I'm just going to have to learn it and that's it. I will just do immersion ASL and everyone I know is going to have to learn it and that's it."

For participants who had success with their cochlear implant, their hearing identity was restored. For Liz, who had maintained a hearing identity to that point, this was favorable: "I was a different person. My personality came back. I was no longer afraid or

scared to do a lot of different things. It just gave me a salvation.” Meg, on the other hand, who had a positive deaf identity, was insulted when people expressed their appreciation of her cochlear implant, thereby rejecting her deaf identity: “The worst part was they had the nerve to talk about it after I got my implant that I was so much more valuable now.”

(c) Late deafened adults encountered unfulfilled expectations of technology

Unfulfilled expectations of technology was another theme that was expressed by late deafened adults in the current study. Of the five participants who underwent surgical implantation for assistive listening devices, four receiving cochlear implants (Jo, Kat, Liz, Meg) and one receiving an auditory brainstem implant (Jay); two late deafened adults in this study did not benefit from the implant technology. In different ways, both of these late deafened adults had unfulfilled expectations from technology that was meant to restore their sense of hearing. Jay viewed the technology failure as a sign that provided him with clear direction, “So I was supposed to move towards being deaf and not think about being hearing.” “That the ABI didn’t work, it changed my path. The ABI not working was really a plus for me.”

Jo, on the other hand, who, also experienced technology failure, was less certain about the direction of her future. She explained, “I got the implant and it hasn’t been working well for some reason. I’ve had hardly any progress...the sound quality has remained really, really bad.” She described it as “birds squawking.” The lack of success with her implant and the constant squawking in her ear, which she further described as, “Mickey Mouse in a deep, deep well,” has led to feelings of frustration and hopelessness: “I feel like I’ve reached that point in my mid 30’s when I was rock bottom and I feel like in the last year I’ve gone through that again.” After trying numerous Eastern and European remedies

to cure her deafness, this participant viewed the technology failure as “just one more thing [that did not work].”

Liz described having great success with her cochlear implant when she used it in juxtaposition with a hearing aid; however, when her hearing loss progressed to the point that she no longer received benefit from the hearing aid, she had unfulfilled expectations about how the implant would work without the support of the hearing aid. She did not anticipate the significant amount of time it would take for her to learn to access sound through her cochlear implant, as it had been nearly automatic when she used it with her hearing aid. She explained, “And I had to learn to hear all over again with the implant. It took me about maybe six months to a year.” Furthermore, now that she is not using her hearing aid, she explained that she was not prepared for how different speech would sound through a cochlear implant. She explained that “it’s not like speech, naturally, you know. You have like a digital firing to it.” Although she is, for the most part, happy with her implant, she explained that instead of getting a second cochlear implant, she will wait for advancement of hair cell implant technology, which she explains as “something above and beyond having a [cochlear] implant.”

Late deafened adults also described feeling that other people had unrealistic expectations about how cochlear implants work and put unrealistic expectations on users’ ability to function with implants. Kat explained that people assume that cochlear implants have cured her of deafness and make comments such as, “Oh, you’re fixed!” Leaving her to explain that, “No, I’m not. I do really well, I mean, amazingly well. I mean, I’m amazed I do as well as I do, but I’m not.” She emphasizes that when she takes her sound processor off, she hears nothing. Jo agreed that people have idealistic expectations of cochlear implants in

the following quote: “I think when people see these stories of, ‘Oh, she put on this implant and she can hear again’ and they think everything is great and you’re cured. I feel like it is so misunderstood.” Similarly, Meg, who finds it easier to watch interpreters at work meetings than to hear conversations, had to defend her need for interpreters to her employer. “People act like I don’t need one. The school doesn’t understand why I request an interpreter when I have cochlear implants. They don’t understand I still miss things or don’t know who said what.”

Deaf Advocacy

All of the late deafened adults in the current study shared a common concern. They felt that deafness, particularly acquired deafness, is misunderstood and inadequately represented. The participants universally wanted more visibility of acquired deafness and more resources available for late deafened adults. Late deafened adults in this study became involved in advocacy and support roles in the late deafened adult community, as well as in the deaf community as a whole. They believed that with the right resources, late deafened adults are as fully capable after becoming deaf as they were before and want to share this message with other late deafened adults and with healthcare professionals who serve them.

(a) Late deafened adults felt that acquired deafness is misunderstood and underrepresented.

Misapprehensions about deafness, particularly acquired deafness, were described by all participants in this study as occurring in social, familial, educational and professional environments. The lack of awareness that late deafened adults in the current study encountered was described as, “People just don’t understand. They just don’t get it.” (Jay).

“People just don’t understand deafness in general.” (Meg). Specifically, family members were said to “underestimate the significance of hearing loss” (Kat). Kat explained, “I think they thought it was just this thing where they’d have to talk a little louder or, you know, be a little more careful; but I don’t think they really got it.”

Family members were furthermore portrayed as being insensitive to the emotional impact of acquired deafness. Meg explained that her parents’ selfishness after her diagnosis prevented her from being able to face the emotions pertaining to her hearing loss, “So, I never got to experience the grieving for myself. I did have emotions, but I just hid them.” For other participants, family members failing to recognize the grief that late deafened adult experienced with the loss of their hearing was a common theme. Kat explained it as follows: “I don’t think they got how freaked out I was.” “I don’t think they understand what it feels like to be that isolated and that worried all the time.” In the case of Jo, the apparent obliviousness of her family regarding the emotions surrounding her hearing loss caused a substantial strain in their relationship. She described her parents’ failure to recognize her hearing loss as, “It’s like they forget that there’s this problem. They don’t even ask about it.”

Misconceptions about deafness and the needs of late deafened adults were also described as occurring in work and education settings. In most cases, the ignorance of others about deafness, in general, and acquired deafness, specifically, was described as resulting in nothing more than mild frustrations. This was exemplified by Jay, who recounted that when he asked his college professor where he might find a certain book, he was warned, “I’m not sure you can find that in Braille.” This participant expressed frustration over the professor’s inability to distinguish between the needs of deaf people from those of blind people. Another participant, Meg, was asked to complete her

assignments separate from her peers because she was different. “So I had to sit in a class all by myself to do my work.” In another example, Jay depicted an event in which his employer gave him hearing test, even after he explained that, “I’m fully deaf, I hear nothing.” During the test this participant failed to respond to even the loudest beep; afterwards the employer, still apparently not understanding profound deafness, suggested the machine was broken.

In some cases, though, the ignorance of others was more than a mild irritation, and instead deeply affected the lives of participants in this study and their ability to do their work. Meg, for example, described rules that were imposed by her teacher that were discriminatory towards deaf people and resulted in her failing the class. She was given multiple tardies because her book wasn’t open when the bell rang, “I told him it wasn’t fair because I couldn’t hear the bell. So I went and talked to the principal.” The teacher then implemented “a game where whoever raised their hand first and gave the answer got a credit and I couldn’t participate.”

Other participants described similar experiences in the work place. Jo had a supervisor who whispered when communicating with her despite the numerous attempts she had made to remind him of her hearing loss. She said, “I mean, he knows I’m deaf but then he’ll whisper.” In another example, Kat, after pleading with her superiors, to no avail, to make accommodations so that she could successfully fulfill her duties, ultimately decided to seek support from her company’s human resources department. Although they were knowledgeable about the guidelines of the Americans with Disabilities Act, they were less than helpful in implementation of the guidelines, such as providing the appropriate accommodations that would facilitate her ability to do her job. Sadly, Liz was let go from

her job, prior to the Americans with Disabilities Act, because her supervisors deemed her to be high risk because of her hearing loss.

Participants explained that the lack of understanding of their experiences was not limited to hearing people, but that culturally deaf people, too, and in some cases, other late deafened adults failed to understand the circumstance of adults with acquired deafness. Max explained that while his hearing friends cannot understand the joy he has found in deafness and his eagerness to join deaf culture, his culturally deaf friends are unable to understand the grief that is associated with the loss of his hearing, “You see, my culturally deaf friends cannot relate to my pain at transitioning. To them, deafness is normal and unique, and joyful.” He furthermore described late deafened people who warned him that he could never be fully accepted by the culturally deaf community; and hearing people who pressured him to continue to use his voice and maintain a hearing identity and who did not understand his decision, as a late deafened adult, to become a member of the signing deaf community. He explained, “I was hit with a person who was pressuring me to speak and read lips. It was so forceful and rude.” He went on to compare this woman’s intolerance of his decision to live as a culturally deaf man with the ignorance and prejudice that is enacted upon discriminated minorities: “Would anyone ever suggest that a gay person act more straight and they’ll go farther in their career, or that a black person act whiter and they’ll please more people?”

Participants believed that acquired deafness is “ignored” and “misunderstood” partially because it’s an invisible disability. “It isn’t like a broken leg you can see.” “Well, my experience is that hearing people don’t understand, especially when you lost your hearing later in life. Just because I’m speaking normally doesn’t mean I’m hearing.” (Nell).

Participants in this study, furthermore, emphasized the role of the media in perpetuating misconstructions of the social world of late deafened adults. Jo criticized the misrepresentation of her experience as a result of the pervasiveness of deaf celebrities, such as Marlee Matlin and Heather Whitestone, in the media, which she believes creates a false expectation that all deaf people are either fluent in sign language or get a cochlear implant and can immediately and miraculously hear. Nell confirmed this assertion: “And they thought that when you become deaf that you are fluent in sign language, that it’s automatic. Don’t assume when you see someone with a hearing aid, ‘Oh they sign,’ most don’t. “

Furthermore, Jo believed that media failed to convey the challenging aspects of hearing loss that late deafened adults experience, which in contrast to media portrayals of well-adjusted deaf people, was described by one participant as “really, really challenging and really, really devastating.” (Jo). In fact, all participants in the current study described the transition to deafness in terms of isolation: “I dropped back and back and back” (Kat), “I created my own little safe bubble” (Liz), “I became promiscuous. It was easier to hang out with boys sexually than to try to socially interact with girlfriends who were rejecting you because of your hearing loss” (Meg), “I stopped doing things” (Jay). They also referred to loneliness: “I felt totally alone” (Jo), “I’m alone in a crowd, jostling elbow to elbow. Totally alone, even among my friends and family”(Max). Another theme was denial: “I thought if I work hard enough, I can hear; I never really thought about my hearing loss as a permanent thing,” (Jo) “I kind of entered a period of unintentionally faking my way through” (Max), “for the next ten years I was just in denial” (Jo). Some participants even entertained suicidal

thoughts: “I thought I would rather be dead than deaf” (Jo), “had it not been for my kids, zip [gesture: slicing her throat.]” (Liz).

While movies like “Children of a Lesser God,” starring Marlee Matlin, brought deaf culture to the forefront of American culture, consequently changing perceptions about deafness and advancing understanding and acceptance of the signing deaf community, participants in the current study felt that no such revolution has occurred for acquired deafness. Participants in this study find their deafness to be a distinct and unique experience that has not yet been accurately portrayed in the media, and therefore, remains misunderstood. As a result, late deafened adults in this study admitted they commonly needed, “on a daily basis,” to educate people about acquired deafness and to advocate for the needs all late deafened adults.

(b) Late deafened adults advocated for the needs of the deafened community.

As a result, the participants in this study unanimously described a nascent sense of purpose and responsibility to educate others about hearing loss and acquired deafness. Jay maintained that his need to educate people about deafness continues on a daily basis and that what he finds particularly challenging is that he is only able to educate one individual at a time, “when the entire world needs to be educated about deafness.” Participants described education of others as being accomplished through self-advocacy.

As part of educating others, all participants in the current study described self-advocacy efforts as they related to hearing loss. For example, Nell, rather than falling behind and withdrawing from conversations, has started to say, “I’m having a really hard time understanding you guys...if you all wouldn’t mind standing in a line over in that corner...” Max explained, “Now, I’m starting to say, ‘Hey, I need captioning; the law says I

get a flashing smoke alarm; I need an interpreter.” Jay exhibited similar efforts of activism by explaining his rights, per federal law, as a person with a disability upon being denied interpreting services. In another example of direct action, Kat, in an attempt to promote her needs in the work place, sent out an email to her coworkers informing them of her hearing loss and requesting support for communication. Similarly, Meg advocated for her needs in to be met in school and sought council with the principal when they were not.

Advocacy efforts, however, went beyond meeting personal needs. Some late deafened adults in the current study also resolved to advocate for the rights of the deaf community as a whole. Liz advocated for acceptance of cochlear implants and after successfully championing the removal of biased curriculum from her children’s deaf school, was “glad to be part of that movement of change.” Jay described activism in the workplace when he campaigned, through the union, for all deaf employees who, previous to his efforts, were not getting equal access and opportunities for advancement. Through this experience, this particular participant came to realize that he had begun to identify with discrimination against deaf people and, as a deafened person, needed to stand up for himself and all other deaf employees. Believing that “people don’t understand the needs of deaf kids,” Meg took a personal role in advocating for the social and emotional needs of deaf children in the academic setting.

Late deafened adults in this study felt that advocacy served as an important coping mechanism. Nell explained, “You feel better about yourself, you feel like you have some control over your life by doing that,” Max described advocacy as a “fight or flight” response for survival of injustices that you’ve never experienced before. In fact, while participants acknowledged that, “The [culturally] deaf are fighting for this stuff all the time” (Max),

advocacy for the needs of self and others was described as “a game-changer” that was intertwined with personal and cultural identity development. As late deafened adults became more comfortable with disclosing their deafness, they began to advocate for their personal needs. One participant explained becoming involved in advocacy efforts as follows: “Really it was like opening my eyes and starting my deaf identity, I guess” (Jay).

(c) Late deafened adults are aware of a lack of resources and are involved in increasing public service

The results of this study indicated that the level of resources, social services, and support that participants received played an integral part in their adjustment to deafness. Jay and Meg described positive experiences with deaf support services, including a vocational rehabilitation counselor who helped them find jobs that were better suited for them as a deaf people, and provided resources to return to college; however, other participants said that they were not provided with resources after being diagnosed with deafness or progressive hearing loss. The following quote by Liz represents a common theme among participants: “I just wish there were more – information. You know I think we need more books. We need a lot of awareness.” Liz further described feeling that because there were no resources, “there was nowhere to turn.” In fact, a lack of accommodations at school led to unfulfilled ambitions and regrets for Jo, who, prior to her diagnosis, had planned to earn a doctoral degree, but explained, “I didn’t know you could get a note-taker and all that. It was just too hard. I think that’s one thing I really regret.”

Participants in the current study unanimously pointed to a lack of support by the healthcare professionals who they encountered throughout their diagnosis and treatment. Participants described a need for professionals who work with late deafened

adults to grasp the impact their diagnosis has on their social world. Kat summarizes the majority experience: “They just sent me home.” Liz rhetorically asked, “I mean sure you can get fitted [for hearing aids] but what do you do for the inside? What do you do for the soul? What do you do for the mind?” Participants in this study called for more resources to be available to late deafened adults to address: “how you can cope, survival signs, you know, survival tools” (Liz).

Other participants found that advice given by health care professionals regarding the use of speech and language was naïve and discriminatory. Nell reported, “He was afraid – he told me he was afraid of deaf people and he did not support me learning signing. He said to me, ‘You don’t want to become like they are.’” Max shared a similar experience: “My doctor even said, ‘If you do not practice speech therapy, you’ll end up in the deaf community!’ Like it was a warning or something.”

Participants in the current study unanimously conveyed that because there was a lack of resources and reliable information available to them during their hearing loss journey, they, in turn, were compelled to increase awareness of acquired deafness and make resources available for late deafened adults. Liz explained, “You need to be able to say to people, ‘this is a resource...before there were no resources.’” In fact, increasing public awareness about the realities of acquired deafness and supporting others with hearing loss was a universal theme in the current data. Several participants described writing about their experiences with hearing loss, which, while cathartic, was also meant to provide support and information for others to better understand acquired deafness. Participants documented their experiences with deafness in blogs (Max), personal journals (Jo), and

newsletter articles (Kat); some participants also considered turning their writings into books to help other late deafened adults feel less alone in their hearing loss journeys.

Late deafened adults in the current study also supported others with hearing loss through their career choices and community service. Four participants worked professionally with people with hearing loss. Jay, in particular, used his experience with acquired deafness to counsel and educate families who were affected by hearing loss. As he explained, “I really identified with that because I had lost something – I had lost my hearing.” Meg, who is a teacher of the deaf, has “a passion for sharing and passing down the language and culture and deaf values.” She has taken it as a personal responsibility to provide students with a sense of community so that they do not become depressed and isolated. Furthermore, Nell, who became involved in community service out of her fears for the safety of the deaf community, said, “They haven’t spent one dollar on the deaf and hard-of-hearing community for accessible communication. And now it’s my problem because I will die if there’s a disaster.” This participant has held a seat on the accessibility task force in her community for two and a half years in hopes to come to a solution, which would provide equal access to deaf people in case of emergencies.

CHAPTER SEVEN

DISCUSSION AND IMPLICATIONS

1. Overview of Study and Summary of Findings

Interpretive, or hermeneutic, phenomenology was used to form a description of the lived experience of adults with acquired deafness by answering the primary question, “What is the social and cultural experience of becoming profoundly deaf as an adult?” The phenomenological method of exploration of the social world of late deafened adults and the phenomenon of acquired deafness for seven late deafened adults was accomplished without attempting to prove a hypothesis (Creswell, 2006). Instead, the intent of this study was for late deafened adults to share their perceptions and experiences of becoming profoundly deaf and then analyze those statements to form an overall essence of what was experienced.

Data was collected for a period of one year through multiple semi-structured formal interviews, which were video recorded and then transcribed. The transcripts were analyzed using interpretive phenomenology analysis method. Data analysis progressed as themes were uncovered and experiences within those themes were compared and contrasted. Analysis of the results focused on themes discovered and overall cohesive understanding of the experience of the phenomenon.

Each participant’s experience with hearing loss was meaningful and complex. Four dimensions, or superordinate themes, of the lived experience of late deafened adults emerged from the current data. They included: Transformation of Self, Social Interaction,

Interaction with Technology, and Deaf Advocacy. Although each participant's experience of acquired deafness was unique because of their history, context and background; for each participant, their experience with these themes was integral to their entire experience of becoming deaf and was found to define the essence of the experience of acquired deafness. Similarities and differences from which the dimensions of the experience emerged added depth and breadth to the understanding of the experience of late deafened adults.

Although the essence of the experience of late deafened adults in this study was examined and interpreted here in four superordinate themes, it must be acknowledged that all of these themes overlap and are interrelated. In other words, the themes are divided into artificial distinctions, which in the experience of the late deafened adults do not really exist. These themes, while discussed separately here, cannot really be separated from one another in understanding the life experience of late deafened adults. A brief description of the themes that defined the experience of late deafened adults in this study is as follows:

Transformation of Self. A certain loss of identity was universally expressed by participants in the current study, some of whom saw their new emerging identity positively, while others viewed it more negatively. Changes were expressed in both personal and cultural identity. Late deafened adults were found to make conscious decisions regarding whether or not to disclose their deafness to others in specific settings, which they believed affected to how they were perceived by others. Late deafened adults, in general, felt that others perceived them less favorably after they became deaf. Furthermore, they believed that they no longer had the personality that they did as hearing people, or at least that they could no longer express their personality, particularly through

humor and interaction. Late deafened adults also expressed a shift in cultural identity and made careful and conscious decisions about their place in different cultural group affiliations.

Social Interaction. All late deafened adults in the current study described experiencing difficulty in social interactions due to their inability to fully participate in communication. This appeared to be true in interactions with both hearing and signing deaf people, as they could no longer access spoken language to communicate with hearing people and didn't have the sign language skills necessary to engage with culturally deaf people. Attempts at social interaction were described by the participants as tiring and frustrating due to the need to be constantly alert. To compound matters, late deafened adults in the current study felt that others were unable to make basic accommodations to communicate with them. They expressed frustration that the burden of communication was placed fully on them and not made a shared responsibility. As a result of the communication difficulties in social interaction, late deafened adults in this study all experienced periods of social withdrawal and isolation, resulting in lost connections to others.

Most participants indicated that they felt most comfortable interacting with other late deafened adults, who had shared experiences and understood shared communication needs. While most reported that they did not feel completely comfortable interacting with culturally deaf people due to different background experiences and language barriers, for one participant, who strived to identify as culturally deaf, this type of interaction was most meaningful.

Interaction with Technology. Late deafened adults in the current study expressed feeling a negative bias towards technology and, therefore, female participants, particularly, made a constant effort to hide their hearing aids with their hair. There appears to be an exception to the bias in the case of cochlear implants, which participants thought were “fascinating” and “high tech.” The decision regarding technology and its subsequent use to assist in listening played a role in both personal and cultural identity development for late deafened adults in this study. This was particularly the case for the decision of whether or not to get a cochlear implant. Those who wished to maintain their hearing identity tended to want implants, although one participant who was admittedly in denial of her hearing loss did not want implants because they signified deafness as a permanent situation. Another participant chose not to get cochlear implants because he wanted to join the signing deaf community and feared social exclusion if he were to get an implant.

Unfulfilled and unrealistic expectations regarding technology were a reality for participants in this study. One participant viewed the failure of his implant technology as a sign to move forward with a deaf life. Another participant agreed that if her implant had failed she, too, would have joined the deaf community. However, for another participant, unrealized expectations regarding the success of her cochlear implant caused emotional distress due to the increased difficulty of maintaining a hearing identity. Participants in this study furthermore felt that others had unrealistic expectations of their ability to hear with implants, mistakenly believing that they were “cured” of deafness. While participants who had success with their technology understood that they were still deaf and had not been cured, they did credit cochlear implants for restoring their personality and giving them “salvation.”

Advocacy. All of the late deafened adults in the current study described feeling that deafness, particularly acquired deafness, is misunderstood and underrepresented, if not ignored, and wanted more visibility and resources for themselves and, subsequently, in some cases, other late deafened adults. The transformation of self and interaction with others led the late deafened adults in the current study to become more aware of their own needs, and subsequently, to their realization of their needs not being met. Insensitivity and misconceptions about acquired deafness were attributed to hearing people within the context of family, work, school, with strangers, as well as to other deaf people. Participants believed acquired deafness is misunderstood in part due to the misconstructions of the invisible disability that are perpetuated by the media. Furthermore, the lack of resources available to late deafened adults, particularly through health care professionals, has inspired late deafened adults in this study to educate people about deafness, advocate for the needs of themselves and, in some cases, others. What makes this subset of participants unique is they all also go as far as fighting for equal rights of deaf people. Late deafened adults in this study have contributed to the deaf community through service in their careers and in outreach roles and support groups, as well as through writing and documenting their experiences to share with others.

2. Interpretation of Findings

a. Relationship of Findings to Goffman's Theory of Stigma

The lived experience of late deafened adults cannot be fully understood without interpreting it in relation to the wider socio-political and historical contexts that have shaped the American deaf community. This section explores the relationship between the

superordinate themes of acquired deafness that were revealed in this study and their relationship to our previous understanding of the deaf community. The linking of the dimensions from the current research to a bigger picture is a method of heuristic interpretation that ascertains the relationship between this study and the context of the world in which we live, thereby expanding and enhancing our knowledge of late deafened adults.

Late deafened adults find themselves situated in a vulnerable position as a result of hundreds of years of social and political oppression of deaf people. Whether or not they are cognizant of the historical persecution of the deaf community, participants in this study were confronted by the enduring stigmatization of deaf people.

For late deafened adults in this study, stigmatization was apparent when their social identity did not meet society's normative expectations. This was particularly evident during social interaction. Evidence of stigmatization was apparent in the narratives of late deafened adults who described being treated differently after becoming deaf. Specifically, they believed that others considered them to be lacking in intellect, etiquette, approachability, and over all acceptability after becoming deaf. Strauss et al. (1984) has previously described this generalization of negative attributes onto specific disabilities as providing rationalization for prejudice and fear.

The most common and deeply affective judgment of late deafened adults reported by participants in this study pertained to their perceived lack of intelligence (e.g., Nell: "People just think that I don't get it; Jay: "They'd talk to me like I was five years old;" Kat: "It's like people think you're really stupid;" etc.) Indeed, the quality of deaf people's minds has been brought into question for centuries and throughout history mental deficits have

been mapped onto deafness (Tellings and Tijsseling, 2005; Strauss et al., 1984). The idea that late deafened adults in this study felt less acceptable, in general, and less intelligent, specifically, is supported by the theory of stigmatization and the idea that mental deficits, as has been the case historically (Roots, 1999), continue to be mapped onto deafness.

Late deafened adults in this study were also stigmatized for not being able to fulfill the role requirements of social interaction. Whether they continued social interaction with hearing family, friends and colleagues or attempted to establish associations within the signing deaf community, their inability to successfully communicate was negatively valued and thus, they were generally deemed illegitimate interaction partners and considered disruptive to social interactions. Once the participants in this study were considered by others to lack the skills for social interaction or proved to be a threat to the interaction in any way, they then had the full responsibility to facilitate successful communication and thereby prove their value in social interaction. Therefore, as stated in the results, late deafened adults in the current study unanimously expressed frustration with having the full burden of responsibility to facilitate successful interaction (e.g., Jay: “[People] don’t get what they need to do to make it a shared responsibility,” Jo: “He knows I’m deaf but then he’ll whisper,” Meg: “I spent so many years putting all the effort into the communication while everyone else just sat back and did nothing,” Jay: “[They] make it feel like it’s a burden to communicate with me,” etc.) Participants provided various examples of interactions in which the conversation partner was unwilling to contribute to the success of the conversation, or in some cases, even continue the conversation once a threat to the interaction was ascertained.

This result can best be explained in relations to stigma theory, which states that individuals who are believed to lack the skills to carry on an interaction and are viewed as a threat to the interaction are beyond the protection of social norms (Elliot, et al., 1982; Zeigler, Altman, & Scott, 1982). Once late deafened adults in this study were judged to not be able to meet the communicative expectations of their conversation partners, either because they could not hear the conversation or they did not have the signing skills to contribute equally to the interaction, their conversation partners had no social obligation to commit to the success of the interaction.

Because their perceived discrediting attributes prevented late deafened adults from being protected by the social norms of interaction, communication was depicted as *exhausting, frustrating, and disappointing*. As a result, late deafened adults in this study, as well as in previous studies (e.g., Hull, 1992), found it easier to withdraw from communication than to face the embarrassment of frequently misunderstanding conversations or responding inappropriately. All participants described periods of isolation in order to avoid this stigmatization in social interaction. The withdrawal and social isolation of late deafened adults can therefore be understood through the social constructs of stigmatization. Late deafened adults, without the protection of social norms during interaction, manage their stigmatizing condition by limiting social interactions and, therefore, opportunities to be discovered as illegitimate conversation partners. Late deafened adults in this study furthermore managed their stigmatizing condition through concealment, a principle dimension of stigma, described by Jones, et al., (1984). Deafness, being an invisible disability, is only noticeable when one attempts to communicate. Therefore, late deafened adults in this study were able to manage

stigmatization of their hearing loss, which offered reprieve from the dominant culture's values and beliefs about deafness. Participants described carefully weighing the costs and benefits of disclosing their deafness in various circumstances. When late deafened adults decided that information regarding their deafness would be received negatively they attempted to pass as hearing by "faking it" in conversations that they could not hear. (e.g., Jo: "I had been sitting there and just going along with it and was like 'oh ha-ha' just laughing when everyone else did, I was too embarrassed to say, 'well, actually I'm deaf,' after half an hour of faking it and pretending I heard everything." Kat: "They didn't know... I faked it all day... I faked it... I just never told anyone." Nell: "I pretend I know what everyone is saying," etc.) Thus, the management of hearing loss became critical to participants in this study, which according to Goffman's stigmatization theory is representative of people with invisible disabilities. As has been the case historically, and is documented in the Justinian code of A.D. 526, the results of this study confirm that concealment of deafness, or "faking it," continues to be advantageous for late deafened adults in managing their stigmatizing condition. Therefore, social context, embedded with stigmatization, prevented disclosure of deafness by late deafened adults in this study.

While generally concealment served a purpose for participants in managing stigmatization, at other times they found it beneficial to make their deafness known. This seemed to be particularly true when their conversation partner was required to adhere to social norms of interaction, despite their acknowledgement of a stigmatizing condition, due to their specific role in the interaction. For example, late deafened adults found it beneficial to disclose their deafness to food service workers, who, because of their professional role in the interaction have an interest in ensuring successful communication. Therefore, in

such interactions, late deafened adults are protected from the consequences of stigmatization, making concealment less necessary than in less defined social interactions.

Results of this study suggest that hearing technology is also stigmatized. All participants who could receive benefit wore hearing aids until their hearing loss progressed to the point that they could no longer benefit from the amplification of the devices. Participants, especially female participants, described feeling embarrassed by their hearing aids and attempted to conceal them with their hair. (e.g., Jo: "I always have my hair long so I never show anyone my hearing aids," Meg: "I was embarrassed to wear them... I covered them up with my hair," etc.) This depiction of the experience supports and is supported by a theory put forth by Jones, et al., (1984), that stigma relates to the aesthetic quality of the stigmatized person, or the extent to which a condition affects the appearance of the person. Hearing aids, in effect, provided visual access to knowledge about a deaf person's disability that might not otherwise be apparent. While participants in this study described feeling that hearing aids were stigmatized because of "an old person bias," it may more accurately be attributed to the fact that the hearing aids pointed to the presence of their stigmatized disability and created an aesthetic quality that was damaging to their identity.

Interestingly, participants in this study generally reported feeling that cochlear implants were less stigmatized than hearing aids in the hearing world. Participants suggested that this is because cochlear implants are "high tech" and, therefore, more interesting. However, to the novice observer, hearing aids and cochlear implants, depending on the type, are very similar in size and appearance. It is, therefore, more likely that participants who wore cochlear implant components were less stigmatized than those

who wore hearing aids because with the more advanced technology they were better able to function in hearing society, thereby minimizing other stigmatizing characteristics of deafness. Because late deafened adults who benefited from cochlear implant technology were better able to fulfill their role requirements in social interaction, they were less stigmatized for being deaf. This, again, relates to concealability and the idea that the better a person with a stigmatizing condition can manage their disability, the more they will be accepted by “normals” (Goffman, 1963; Jones, et al., 1984).

Conversely, late deafened adults who had cochlear implants and socialized in the culturally deaf world faced stigmatization by deaf native signers, who, as the majoritized minority of the deaf community have defined themselves as the “normals” of deafness. Late deafened adults in this study described cognizance of the stigma that was associated with cochlear implants in the deaf community. One described managing the stigmatizing condition of having a cochlear implant, and therefore being able to perceive sound and communicate orally, by following the social norms of the culturally deaf community and thereby not highlighting her difference. (e.g., Meg: “When you’re a member of deaf community, there are certain things you don’t do in front of deaf people. I don’t talk on the phone in front of my deaf friends. I wouldn’t speak my order to a waitress,” etc.) This prevented her from being marked as having an attribute that was different from the group and minimized the consequences of the stigmatizing difference.

Max, who considered getting a cochlear implant, suggested that although the technology is becoming more accepted by the deaf community, as a late deafened adult who was motivated to be part of deaf culture, he did not feel it would be acceptable because “choosing to embrace not only the deaf community, but deaf culture as well, were weighing

heavily.” He suggested that cochlear implants were more acceptable for those already accepted in deaf culture (e.g., “Sure, many born-deaf were giving them a try, but not without cultural and personal consequences,”) and that as a late deafened adult striving for acculturation into the signing deaf community, it was not an option for him.

In summary, the experiences of late deafened adults can be more broadly understood through stigma theory, which provides a framework for the social construction of deafness resulting from the historical and socio-political position of the community. Experiences of late deafened adults in this study including conscious decision-making regarding disclosing deafness to others, altered perception of self by others, feeling that others are unwilling or unable to make basic accommodations for communication, periods of withdrawal and social isolation, and stigmatization of technology, can be better understood in relation to Goffman’s theory of stigma. Therefore, the idea of what it means to be deafened is a cultural phenomenon that is socially constructed, further supporting the idea that the experience of late deafened adults should be interpreted through a social and cultural description of the experience.

b. Relationship of Findings to Theories of Identity Development

This section links the themes and dimensions of the lived experience of late deafened adults to the principles of cultural identity development. This linking, called heuristic interpretations, serves to expand and enhance our understanding of the social world of late deafened adults.

The late deafened adults in this study, who had been born and socialized in hearing culture, evolved from hearing to deafened individuals. For the most part, participants, who had been deaf between 2-31 years, came to recognize change as a necessary part of

adjustment. Participants underwent a process of learning a new language and foreign cultural practices that were similar to those described by Kim (2008), who described the adaptive experiences and identity transformation of individuals who are born into one culture and then relocate to a new one for an extended amount of time.

Simultaneously, as late deafened adults became acculturated to the deaf world, they underwent a process of deculturation from the hearing world. According to Kim (2008), during acculturation and deculturation an underlying psychological evolution of progresses from outwardly expressive behaviors to deeper lived changes in fundamental values. For late deafened adults in this study, this was apparent as their values and ideals of what it meant to be deaf shifted to varying degrees. Participants who had achieved self-acceptance and self-definition as a deafened person learned to reject the dominant hearing cultures ideals of deafness.

A progression of deaf identity development was evident in the narrative of all late deafened adults in this study. Although each participant had a different experience with acquired deafness, all narratives followed the same general patterns of identity development. Participants represented varying perceptions of deafness and advancement of deaf identity development.

The identity development of participants in this study was compared to three models of minority identity development, including Cross's Black Identity Model (1971), Cass's Gay Identity Model (1979), and Glickman's Deaf Identity Model (1993). These models were judged to be the most relevant and influential models of minority group identity development.

Results of this study suggest that there are seven stages of identity development that the late deafened adults in this study experienced; however, not all participants in this study experienced each stage in the same way, or achieved each stage of development. The seven stages of identity development that were identified as occurring for late deafened adults in this study that can be defined by the previously mentioned models of minority identity development. However, as seen in table 7.1, no one model of identity development describes all of the experiences of late deafened adults as they progress from hearing to deaf people.

Table 7.1 Stages of Deafened ID development¹⁷

LDA Stages	Described by:		
	Glickman, 1993	Cross, 1971	Cass, 1979
1	Culturally Hearing – Deaf individuals reference of normality is through dominant hearing culture	Pre-Encounter – Individual identifies with white people and culture while rejecting black people	<i>Not described</i>
2	Culturally Marginal – Deaf people find themselves fitting between deaf and hearing world, but not being comfortable in either	<i>Not described</i>	Identity Confusion – Individuals question their sexual orientation Identity Comparison – Individuals feel isolated as the difference between self and non-homosexual others become apparent
3	Immersion – A period where people immerse themselves in the deaf world and identify positively with deaf people	Encounter – An experience leads the individual to begin rejecting identification with whites and seeking identification with blacks	Identity Tolerance – Individuals seek other homosexuals in order to lessen isolation. However, individuals in this stage still maintain two identities: a public heterosexual identity and a private homosexual identity.

¹⁷ Although the seven stages of identity development that were revealed in the results of this study are listed here in sequential order, they did not necessarily move sequentially from one stage of development to the next, because, according to McCarn and Fassinger (1996), “Changing life situations always hold anew the possibility of rejections” (p. 115).¹⁷

Table 7.1 continued

4	<i>Not described</i>	Immersion-Emersion – Individual identifies everything of value with blackness and abhors everything symbolized as white	Identity Acceptance – Individuals have increased contact with the homosexual subculture and make selective disclosures, but continue to use passing strategies in the dominant culture. Identity Pride – Everything homosexual is seen as important while everything heterosexual is devalued
5	Bicultural – Deaf people who have achieved this stage feel a sense of comfort in both deaf and hearing settings and have become skilled in negotiating cultural differences.	Internalization – Individual incorporates a positive black identity	Identity Synthesis – Individuals have integrated identity and come to see themselves as people having many sides of their character, only one part of which is related to homosexuality
6	<i>Not described</i>	Internalization-Commitment – Individual maintains a positive black identity in spite of societal oppression, and is committed to action that will benefit the minority community	<i>Not described</i>

STAGE 1. This stage of identity development has been previously described by Glickman (1993) as “culturally hearing” and Cross (1971) as the “pre-encounter” stage. There is no corresponding stage in Cass’s (1979) model. At this stage, late deafened adults in this study referenced normalcy through dominant hearing culture’s ideals, and therefore understood deafness to be an undesirable abnormality. In fact, deafness is not ingrained into the core identity of people who became deaf as adults (David & Trehub, 1989).

All seven participants described passing through this stage of deaf identity development. Late deafened adults, upon becoming deaf or learning that they would soon become deaf, held the stigmatized dominant culture’s ideal of deafness. As such, the experience of late deafened adults in this initial stage of development coincides with the

social constructs of stigma that were described in the previous section of this chapter and includes occurrences of denial, depression, helplessness, anxiety, frustration and embarrassment, concealment, social withdrawal, and altered perception of themselves.

STAGE 2. All late deafened adults in this study described periods of isolation resulting from the differences between themselves and their previous hearing lives. During this stage of development they no longer felt that they fit in the hearing world, but also did not feel a part of the deaf world. This stage, described by Glickman (1993) as “culturally marginal” and by Cass (1979) as two stages, “identity confusion” and “identity comparison,” was evidenced by all seven participants in this study.

During this stage of development late deafened adults in this study questioned their sense of self, which is a culmination of an individual’s sense of personal skills, capabilities, needs, preferences, values, beliefs, aspirations and dreams (Norton, 2000; Woolley, 1987). Late deafened adults in this study were no longer able to do everything they could as hearing people. Some lost their jobs and had to find new careers (e.g., Jay, Liz). They also described their personalities as changing in this stage, in that they were no longer the intelligent, quick-witted people they once were (e.g., Jo, Jay, Kat), and they no longer felt at place in social interactions in the hearing world because they lost their ability to participate in spoken English conversations. (e.g., Max: “I’m burned out being in-between,” Meg: “But then I didn’t fit in with the hearing people anymore because I couldn’t follow a conversation,” etc.)

Furthermore, all late deafened adults took classes in which they explored the deaf community and the use of sign language at this stage of deaf identity development. For most participants this was a positive experience. However, for all participants it

highlighted the differences between themselves and the signing, culturally deaf community and themselves. (e.g., Jo: “It makes me feel uncomfortable in a way,” Kat: The other deaf people were not like me; I just thought I wasn’t going to fit in,” Max: “I almost felt like a poser of some sort,” etc.) They realized they did not yet fit in with deaf culture and even with other late deafened adults who sign. This was largely due to their lack of sign language skills, but also, according to participants, cultural differences and differences in experiences.

While late deafened adults struggled with their personal and cultural identities and future possibilities in this stage of identity development, they became depressed (Liz, Kat) and even suicidal (Jo) at the differences. As a result, they minimized the differences of themselves with hearing world and with the deaf world by withdrawing from social interaction. (e.g., Jay: “It’s easier to be alone. I stopped doing things – and so in my alone time I would say, ‘Oh I love to read’”, etc.) This stage of identity development can be tied to negative emotions, social isolation and withdrawal, and overall diminished quality of life.

STAGE 3. After a period of social isolation, all seven late deafened adults in this study sought out interactions with other deaf and deafened people. This stage of identity development is described by all three identity development models examined in this study. Glickman (1993) labels this the “immersion” stage, Cross (1971) the “encounter” stage, and Cass, (1979), the “identity tolerance” and the “identity acceptance” stages.

Identity transformation, from hearing to deaf, occurred when participants began to interact with other deaf or deafened individuals. For five participants in this study (Jay, Jo, Liz, Nell, Kat) identity development, through interactions with other deafened people, occurred in the context of support groups for late deafened adults. Three late deafened

adults in this study (Jay, Meg, Max) developed interactions within the culturally deaf community.

Through positive interactions with other deaf and deafened individuals, late deafened adults in this study were able to, to varying extents, dismiss the negative stereotypes and dominant cultural values of deafness and adopt a more positive understanding of what it means to be deaf. This shift required access to information on deafness in the real world, based on a model of difference rather than deficit.

Furthermore, in order to achieve a deaf or deafened cultural identity, late deafened adults recognized qualities of sameness in other deaf and deafened individuals and acknowledged that they belonged to that group. Identity, therefore, was primarily drawn from membership in social groups and through “ongoing interactions with other persons” (He, 2006: 7) as well as through qualities of sameness in relation to a person’s connection to others and to a particular group of people (Tajifel, 1981: 255).

Participants in this stage of deaf identity development described meeting other deafened individuals who inspired them to embrace their deafness and realize their potential. Nell, for example, met a powerful deaf businesswoman, who served as an inspiration for who she wanted to become. Similarly, as Jay met professional, college educated deafened adults, he realized that he, too, could go to college and have a career.

Significantly, late deafened adults in this study who rejected the dominant hearing culture’s ideals of deafness and embraced a deaf or deafened identity found a sense of liberation and expressed increased contentment with their circumstances, while those who chose to not re-categorize their stigmatized condition expressed more difficulty coping with their status in society.

Disclosing deafness, a stigmatized disability, required a weighing of the cost and benefit of disclosure. As participants began having increased contact with other late deafened adults or with the culturally deaf community, they continued to use “passing” strategies in the dominant culture. This is likely the stage of deaf identity development that Jo achieved, as evidenced by her statement, “I still do that,” after talking about hiding her deafness during a nearly two-hour-long interaction. Researchers have described a similar process of “coming out” for gays and lesbians (Cass, 1979; Rosario, et al., 2001).

STAGE 4. This stage of identity development, “immersion-emersion” (Cross, 1971), “identity pride” (Cass, 1979), occurs when individuals come to see everything relating to the minority culture as important, while everything that symbolizes the majority culture is devalued. This stage of deaf identity development was not described by Glickman (1993); however, two of the seven participants in this study (Meg, Max) attained this level of deaf identity development. It is possible that Jay was also at this level of development when he decided to attend Gallaudet University to be immersed with sign language and deaf culture.

Meg, at one point in her deaf identity development, demonstrated being in this stage when she only wanted to be around deaf people, only wanted to date deaf men, no longer enjoyed visiting her hearing family because they didn’t sign, and even turned down invitations for family holidays in lieu of spending them with her deaf “family.” Likewise, Max, who was likely still in this stage of identity development at the time of the interview, made decisions about his deafness and how he presents himself based on his devaluation of hearing culture. Although he was not yet proficient in sign language, he gave up using oral language completely and chose not to get a cochlear implant because they signified a hearing identity. Interestingly, at this stage of deaf identity development, Max compared his

deaf identity to that of other minority groups, including blacks and gays (e.g., “Would anyone ever suggest that a gay person act more straight and they’ll go farther in their career, or that a black person act whiter and they’ll please more people?”) Although Max was not fully immersed in deaf culture, he was clear that his goal was to reach that point, as his sign language skills progressed. In addition to finishing his Zen training, this was a primary ambition in his life. Indeed, one of Max’s favorite possessions is a mug that reads, “Deaf and loving it.”

STAGE 5. Four of the seven late deafened adults in this study (Jay, Liz, Meg and Nell) had developed an integrated identity that allowed them to comfortably negotiate their deafened identities in various social contexts. This stage described in Glickman’s deaf identity development as “bicultural,” is the stage in which deaf people feel a sense of comfort in both deaf and hearing settings and have become skilled at negotiating the difference. Similar stages were defined as “internalization” and “identity synthesis” by Cross (1971) and Cass (1979), respectively.

At this stage of development, although participants have found a group with which they primarily interact socially, they are comfortable interacting in deaf, deafened, and hearing environments. At this stage of identity development, participants’ identity as a deafened person is solidified regardless of the social context. Meg, for example, who was most comfortable with culturally deaf people and communicating with native signers, used cochlear implant technology to also interact with hearing people, including her children.

Jay, on the other hand, who, after exploring deaf immersion and realizing that he doesn’t fit in deaf culture, still had many signing deaf friends. He embraced a positive deafened identity, and while he felt most comfortable interacting with people who he could

easily communicate with (i.e. deafened or hearing non-native signers), he described a certain level of comfort interacting with deafened, hearing and culturally deaf people. Liz and Nell also both used sign language and spoken language to interact socially with hearing, culturally deaf, and deafened people.

STAGE 6. All seven late deafened adults in this study reached the final stage of identity development in some capacity. It was described in Cross's black identity model (1971) as the level of identity development in which individuals maintain a black (i.e. minority) identity despite societal oppression, and are committed to action that will benefit the minority culture. This level of development was described by neither Cass (1979) nor Glickman (1993).

Late deafened adults unanimously described feeling that deafness, particularly acquired deafness, was not understood. As they developed a sense of acceptance and empowerment regarding their deafness, through community membership, late deafened adults in this study began to advocate for themselves, their personal needs, and subsequently, in some cases, the needs of other deaf people, in various contexts. In addition to advocating for their needs as deafened people (e.g., "you have to look at me when you talk to me."), most of the participants in this study felt a sense and purpose as they engaged in acts of public service to educate others about deafness and to make resources available to other late deafened adults. Late deafened adults served on committees within the community (Liz, Nell), became involved in unions and fought for equal rights of deaf people in the work place (Jay), published articles in newsletters for late deafened adults (Kat), and blogged and journaled in order to share their experiences with other late deafened adults (Max, Jo).

Late deafened adults in this study also contributed to the deaf community through their career choices. Meg became a teacher so that she could champion the social, emotional, and cultural needs of deaf children; while Jay became a counselor to work with families affected by hearing loss because he related to their loss and, having developed a positive deaf identity, he wanted to help other people do the same. Similarly, Max's career ambitions were to open a Buddhist Zen center for the deaf community.

As seen in this section, the six stages of identity development of late deafened adults described here can provide a social and cultural context for the themes that were uncovered in chapter 6 of this study. As late deafened adults advanced in their deaf or deafened identity development and became exposed to models of deafness in the real world, their ideas about deafness shifted and, therefore, the negative emotions, concealment, social withdrawal and isolation generally decreased. As progression continued, late deafened adults in this study made decisions about social connections and the use of listening technology based on their deaf identification. Most came to realize that they could continue to have meaningful and fulfilling lives and wanted others to be aware of that potential.

The three models of identity development described earlier share common stages, but not all stages were described in all models. No one model of identity development describes all of the stages of late deafened adults in this study; however, each stage of identity development of late deafened adults in this study could be described using the stages of three models.

Results of this study suggest that the current model of deaf identity development is insufficient to describe the experience of late deafened adults. Glickman's model of deaf

identity development, which includes the deaf identity development of late deafened adults, cannot fully represent the stages of identity development of the participants in this study. However, the stages of identity development documented here, but that are not described in Glickman's model, can be accounted for using stages described in Cross's (1971) Black Identity Model and Cass's (1979) Gay Identity Model.

Specifically, Glickman's model of deaf identity development does not address two stages of identity development experienced by late deafened adults in this study. These stages, which have been defined by Cross (1971) as "immersion-emersion" and "internalization-commitment," proved to be central to the experience of some late deafened adults in this study.

c. Relationship of Findings to Existing Literature on Late Deafened Adult

As in previous studies, late deafened adults in this study experienced negative emotions (Aguayo & Cody, 2001; Barlow, 2007; Ringdahl & Grimby, 2000; Hogan, 1999), damaged relationships and social networks (Aguayo & Cody, 2001; Barlow, 2007; Hogan, 1999), withdrawal and social isolation (Aguayo & Cody, 2001; Heine & Browning, 2007; Hogan, 1999; Ringdahl & Grimby, 2000), reduced confidence and self-esteem (Heine & Browning, 2002; Hogan, 1999), overall diminished quality of life (Ringdahl and Grimby, 2000; Hein & Browning, 2002), and unsatisfactory contact with healthcare professionals. The description of the lived experience of acquired deafness revealed dimensions that can be supported by and can enhance the existing literature.

However, previous studies, which were conducted outside of the United States, were written from a pathological perspective and failed to take into consideration the social world of late deafened adults, specifically how it is impacted by the cultural, historical and

political factors that shape the American deaf community. This study expands the current research by examining the experience of late deafened through the lens of a cultural model in order to generate new understanding and de-medicalize acquired deafness. Specifically, by examining the psychosocial phenomenon of acquired deafness including dual issues of identity and stigmatization, this study answers the question of “why” that previous research has neglected to ask.

For instance, during the process of deculturation individuals experience extreme lows (Kim, 2008). In fact, the emotional aspects of adjustment to hearing loss that were expressed by participants in this study, for example, *depression, helplessness, anxiety, frustration* and *embarrassment*, were consistent with the findings in existing literature (i.e., Aguayo & Coady, 2001; Barlow, et al., 2007 Ringdahl and Grimby, 2000). This study, unlike previous studies, did not directly examine emotions of hearing loss as a broad theme in itself, but rather, as an attempt to better understand the social world of late deafened adults as well as the underlying origin of these emotions. The emotions expressed by late deafened adults in this study are common during the process of deculturation (Kim, 2008).

During the early stages of deaf identity development, participants in this study, who still held the dominant culture view of deafness, felt that they were inferior, less intelligent, lacking in personality and sense of humor. They found it easier to withdrawal socially and isolate themselves, rather than to face the stigmatization of their condition. Furthermore, according to stigma theory, late deafened adults were no longer protected by social norms. As a result, participants in this study lost connections with hearing friends who, without the social obligation to accommodate communication, seemed to find it easier to cut off relationships than to facilitate interaction.

However, unlike previous research, the current study found that as deaf identity developed and progressed and participants' ideas of deafness shifted, most participants adopted a positive self-concept. This was largely attributed to group solidarity and membership as they adopted deafened and culturally deaf identities. According to Phinney (1990), the most significant factor in developing a positive cultural identity, which, in turn, indicates a positive self-concept, is related to "the extent to which people have come to an understanding and acceptance of their ethnicity" (508). As discussed in chapter 2, *ethnicity*, as understood in this study, relates to membership in a group that shares a common history and culture, with the most important characteristic of said group being a belief in their very existence as a group (Waters, 1990). With new social connections for deafened adults in this study came increased self-esteem and overall quality of life.

Additionally, late deafened adults in this study felt that their psychosocial needs were largely ignored by the medical field (e.g. "He just gave me hearing aids and sent me away," (Kat), "You fixed my ears what about my soul?" (Liz). This supports findings from previous research that has criticized health care professionals for failing to address the needs of deafened adults (Luey, 1980; Aguayo and Coady, 2001; Hogan, 2001), for lacking knowledge and sensitivity regarding this population (Barlow, et. Al, 2007), and for failing to understand the complex psychosocial consequences of acquired deafness (Barlow, 2007; Coady, 2001).

Specifically, participants in this study felt that medical professionals failed to take into consideration the social and cultural aspects of deafness. Two participants (Max, Nell) were cautioned by medical professionals against learning sign language and warned to maintain their hearing identity through spoken language in order to maintain their status

in the hearing world. Consequently, depending on whether the medical or cultural model of deafness is assumed, the outcomes for a deafened person's emerging identity and conflicting ideals can be strongly affected.

In summary, this study confirms previous research findings that late deafened adults experience negative emotions, withdrawal and isolation, damaged relationships and social networks, and reduced confidence and self-esteem. However, this study goes beyond previous research by providing a social and cultural model of understanding for these experiences through the dual theories of stigma and identity development. Furthermore, this study, unlike previous studies, suggests a progression of development in which, through group membership and sense of belonging, late deafened adults build a positive sense of self, which in turn builds confidence, self-esteem and overall quality of life. Health care professionals, as in previous studies, were found to have ignored the psychosocial aspects of deafness. Furthermore, this study found that health care professionals are lacking information regarding the cultural aspects of deafness, which can be damaging to the development of a positive identity and self-concept of late deafened adults.

3. Implications

In this study of the experience of becoming a late deafened adult, the participants viewed deafness as central to their lives and integrated this into the experience. The participants' experience with transformation of self, social interaction, interaction with technology and advocacy all are integral to their entire experience of acquired deafness.

The study of late deafened adults is a significant contribution to the body of knowledge of the deaf community. Late deafened adults, who are the largest segment of the deaf population, are the least represented group in deaf-related research. Furthermore, late

deafened adults have been defined in the literature from a strictly medicalized perspective. In contrast, this study initiated a shift to a social and cultural perspective of late deafened adults and described how late deafened adults adapt to their particular life circumstances given their changing social worlds.

The participants in this study shared their feelings, fears, triumphs and uncertainties about the future. By using hermeneutic phenomenology and interpreting the compiled stories of the participants through a more comprehensive scope of the social structures in which we live, it was evident that the psycho-social dimensions of acquired deafness was not embedded within each individual but were established and maintained through external social structures and dominant hearing culture values. Therefore, this study demonstrated how cultural, historical, and political processes of the deaf community influence the experience of late deafened adults in the social world, as a function of their values and beliefs, which are rooted in stigmatization and oppression.

The information gained in this phenomenological research study is important in gaining general public awareness about late deafened adults. Particularly, it provides information about the experience of late deafened adults to others who feel like they are alone and the first to navigate the cultural and linguistic obstacles that accompany acquired deafness. Furthermore, the results of this study should be used to inform healthcare practitioners and policy makers about their interactions with late deafened adults, which should not just focus on the ear, but should take into account their transformation of identity. Late deafened adults should be encouraged and supported in exploring cultural affiliations and their position in deaf and hearing communities. In addition, this study benefits deaf studies scholars and researchers in understanding the social positioning of

late deafened adults in the deaf community and should enhance their awareness of the social world of late deafened adults.

4. Limitations and Suggestions for Future Research

The contribution of this study to the larger body of literature on the topic of deafness will also be determined by future studies that arise from it. The richness of data obtained in this study can provide a foundation for formulating research tools that are based on the reality of late deafened adults, rather than the perception of the experience from health care providers' vantage points. The results suggest the appropriateness of a categorization of late deafened adults, moving strictly from a medical paradigm, to a socio-cultural understanding of the phenomenon that takes into account all of the dimensions of the experience of becoming profoundly deaf.

One of the limitations of this study was the small number of participants. Further research should be conducted with more late deafened adults, and especially should include participants with different ethnic, religious, racial and socio-economic backgrounds. All of these factors affect experience, and exploration of different backgrounds would strengthen the description of the lived experience of people with acquired deafness. Furthermore, by integrating understanding of late deafened adults from cultures outside of the United States where there is an absence of a strong deaf culture identity, we can more deeply understand the role of stigma, history and socio-political practices in the identity development of late deafened adults.

Another limitation of this study was that all descriptions of the experience of acquired deafness were reflective. A longitudinal case study of a recently diagnosed late

deafened adult that follows an individual through the process of hearing loss, decision about the use of technology, identity transformation and adjustment would be beneficial to show how perceptions of the experience change over time.

Lastly, the evolution of the culturally deaf community, along with the value of ASL and deafness that have been identified in the current study as characteristics that are shared by late deafened adults demonstrates the difficulty of differentiating between deaf and Deaf in the case of late deafened adults. Research should be conducted to develop an updated model of deaf identity that takes into account the changes in the deaf community and the diversity of late deafened adults. The deaf community, like all cultural and ethnic groups, is evolving and according to Padden and Humphries (2005) is now more fluid than ever as culturally deaf people are becoming increasingly immersed in the hearing world, possibly eliminating some of the criteria that was established by Glickman (1993) in his deaf identity model. Future research should determine how late deafened adults fit into the changing boundaries of what it means to be a culturally deaf individual and a member of the deaf community.

5. Concluding Personal Reflections

The participants in this phenomenological study opened their hearts and souls and shared stories of both sad and happy times that provided rich, colorful data about their experiences of acquired deafness. The time I spent with each participant was personally rewarding and throughout the process of writing this dissertation, each time I read a transcript or reread data analysis I relived the interview and felt the pain, emotions, joys and uncertainties of each participant fresh in my memory.

I became interested in this research topic after communicating with a late deafened friend about his experiences with sudden sensorineural hearing loss. Through him, I was first introduced to a group of late deafened adults at an ALDA convention. I arrived at the ALDA convention as an eager researcher, ready to learn about this scantily known subculture of the deaf community. I had my notepad and video camera in hand, ready, as a linguistic anthropologist, to capture “rare footage” of an “unknown people.”

Instead, when I arrived at the convention, I met my peers. I met people who had grown up with the same experiences as me, who drank the same kind of beer as me, told the same kind of jokes as me, but, who admittedly, were probably better karaoke singers than me. Although I knew intellectually that acquired deafness could happen to anyone, it wasn't until I met a room full of people who were neither “rare” nor “unknown” that I was hit by the impact of this reality. Acquired deafness can affect anyone at any time. It could happen to me. It could happen to you. Hence, this study provided a model of understanding that can become relevant to any person.

I have been fortunate, throughout the years of conducting this research, to be included in the deafened community, despite my hearing status, and have been invited to, and attended, various workshops, conferences, community events, a wedding, and sadly, a funeral. I continue to be inspired by the happy and fulfilled lives that many late deafened adults live. I can now confidently say, losing your hearing is not necessarily life-shattering. In fact, it can be an extremely positive experience than can open your eyes to a whole new world.

APPENDIX

Interview Guide

1. Where were you born? Tell me about your family.
2. What is a favorite memory from your childhood?
3. What age did you lose your hearing?
4. How did you lose your hearing?
5. What was your thought process when you were told you were going to lose your hearing/
that you had lost your hearing?
6. Thinking back to your first realization that you were deaf, what do you remember or
recall? Can you describe your emotions at that time?
7. When you first lost your hearing, do you remember a particularly stressful period?
8. If there was one striking memory of realizing you could no longer hear, what would it
be?
9. Was there an impact on family relationships and social life?
10. How did your family, friends, etc. take the news of your hearing loss? How did their
reactions make you feel?
11. Think of one memory you have of telling family or friends that you had lost/would lose
your hearing tell me about it.
12. Was there an impact on your employment? (What was your job before you lost your
hearing? Were you still able to effectively do your job? What kind of job do you do now?
What challenges do you face in the work place?)
13. What contact did you have with health and social care professionals and/or support
groups? What role did they play in the decisions you made, paths you took?

14. What words do you use to describe yourself (i.e. deaf, deafened, hard-of-hearing, etc.)
Are there certain labels that you are more or less comfortable with?
15. Did you learn sign language? Tell me about the process of deciding to learn sign language / to continue using oral language over sign language.
16. Is there one main memory of a communication obstacle that stands out for you?
17. What was the hardest thing to get used to as a deafened person? Can you tell me about some of the obstacles you have overcome? Are there any that you feel are still in the way?
18. What have been your deepest fears or insecurities about becoming deaf? (How have these changed over time?)
19. What has been the most positive affect becoming deaf has had on your life?
20. How would you say becoming deaf has influenced you?
21. If there was one thing you would say about being a late deafened adult what would it be?
22. Do you have any advice for other late deafened adults?

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