

Cultural Themes Across Generations: Exploring Changes in Lived Experiences of Six
Deaf Individuals

A DISSERTATION
SUBMITTED TO THE FACULTY OF THE GRADUATE SCHOOL OF THE
UNIVERSITY OF MINNESOTA
BY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF EDUCATION

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December, 2010

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Abstract

Historically, hearing people have held positions of power and influence in many areas of society affecting Deaf people, yet they often know little about the life experiences of Deaf people, or how Deaf people feel about decisions made on their behalf.

Understanding the lived experiences of Deaf or hard of hearing people is important for developing effective educational models for teaching Deaf children and creating a more inclusive society. This qualitative study collected and examined life story narratives from six Deaf people, ages 18-77. The life story narratives provided examples of Deaf community values that have remained consistent, even as the day-to-day lives of Deaf people have changed dramatically over the last 60 years. Significant themes emerged, including education for Deaf children, American Sign Language, cultural awareness and acceptance, and the importance of listening to Deaf people. Recommendations for educational administrators, based on the research findings, are listed.

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CHAPTER ONE

Introduction

The life experiences of Deaf people have been influenced by historical and societal events. These influences can be recognized in Deaf life stories. Deaf people have faced many challenges, some more overt than others, and all demonstrating a decidedly anti-cultural view of Deaf people. Threats to the culture almost always are grounded in a medical/pathological view of deafness (Lane, Hoffmeister & Bahan 1996; Branson & Miller, 2002; Parasnis, 2002).

Until relatively recently, very little of the published research on Deaf people came from Deaf people themselves, in their own voices, and from their own perspectives (Van Cleve, 1993). According to Lane (1999) “In America, there is no place for deaf people where decisions about deaf lives are being made” (p. 204). Sacks opens his book *Seeing Voices* with the statement “We are remarkably ignorant about deafness” (p.1). It is difficult for hearing people to easily understand the nature of Deaf Culture and the experiences and beliefs of Deaf people without first understanding the context in which Deaf Culture developed and the issues faced by Deaf people.

For hearing people, the term *deaf* signifies something missing or lost, a deficit, a disability. *Deaf*, for those who are Deaf, means something entirely different. “Deaf refers to a member of a linguistic and cultural minority with distinctive mores, attitudes, and values and a distinctive physical constitution” (Lane, 2002). For the purposes of this study, Deaf Culture is defined as a common life experience that includes values, customs and norms, and most importantly, a language--American Sign Language.

Background of the Study

Historically, the American Deaf Culture has been challenged in many ways by the actions and attitudes of the dominant culture. “It is not unreasonable to say that people who are deaf have been effectively colonized by the dominant culture which never consciously questions its capacity to hear.” (Stone, 2002, p. 172) Linguistic and cultural colonization can be perceived in the education system, where the dominant culture forces its language and values onto the minority culture (Ladd, 2007). Much of the documented history of Deaf people has been written by hearing people and focused on issues that have standing and importance in the hearing world (Lane 1999). These issues tend to fall under the broad category of pathology, defining the amount of hearing loss, the “handicap” of deafness, the communication and speech problems, and how to remedy these difficulties. Lane, Hoffmeister and Bahan identify two elements of the “hearing agenda.” The first is to mitigate a disability, and the second is to eradicate the DEAF-WORLD (1996, 2008). Titles of typical research on Deaf people often include negative descriptors such as problems, pathology, deficiencies, and delays. Lane studied 350 journal articles and books on psychology of the deaf and took note of every word or phrase used to describe characteristics of Deaf people. After combining like words and phrases, a list of over 60 descriptors was generated. All descriptors were negative, including opposing descriptors such as aggressive and submissive. “In general, Deaf people are characterized as socially isolated, intellectually weak, behaviorally impulsive, and emotionally immature” (Lane, 1999, p. 349).

It could be argued there existed no genuine, documented cultural history of Deaf

people and the Deaf community until the recognition of American Sign Language (ASL) as a true and natural language in the mid-1960s (Jankowski, 1997; Armstrong & Karchmer 2009). In Stokoe's groundbreaking ASL research, he applied universal linguistic principles to the grammar and structure of signed language and found ASL satisfied the principles of a true and natural language (Valli, Lucas & Mulrooney 2005; Armstrong & Karchmer 2009). Once this "discovery" was revealed, the nature of the group of people knitted together by the common bond of a shared Deaf experience changed. It became clear that this group was much more complex than simply a group of people sharing a physiological characteristic. With the research on language, the world began to recognize what Deaf people had long intuitively understood: that their "in-group" was, in fact, a culture.

Bahan, in the book *A Journey into the DEAF-WORLD* (1996), coined the phrase "DEAF-WORLD" to describe this group of individuals united by similar life experience. Bahan recognizes Lane--the first hearing person to respectfully describe the values of the DEAF-WORLD--as an ambassador to and from the hearing world.

Ninety percent of deaf children are born to hearing parents (Schien & Delk, 1974; Mitchell & Karchmer 2004). It could be argued, that these Deaf children, at birth, are immediately relegated to a sort of Deaf Diaspora. Easy exposure to people like themselves and their natural language becomes less likely as medical solutions are imposed and schools attempt to integrate solitary Deaf children into the hearing mainstream. "The emergence of diaspora means that deaf and hard of hearing identities increasingly involve indirect and convoluted, often tension-filled journeys toward

exploration” (Leigh 2009, p. 171). Many post-Stokoe Deaf writers have written with common voice about the early experiences of Deaf children. There are significant differences between the experiences of Deaf children of Deaf parents and those of Deaf children of hearing parents (Lane, Hoffmeister & Bahan, 1996; Padden & Humphries 1999; Sheridan, 2001). Their personal experiences, together with the experiences of many other Deaf collaborators reveal fascinating similarities in the lived experiences of Deaf children and how they make their way into the DEAF-WORLD.

These colorful narratives illuminate the ways in which Deaf children are supported or inhibited in their development--in communication, identity, self-esteem, and education--and how, despite their differences in early development and educational choices, many will find their way to the DEAF-WORLD. Deaf children have various education and sign language acquisition experiences, but almost all eventually are exposed to ASL and the DEAF-WORLD. The result is remarkably similar; most choose to identify with this cultural group. (Bahan 1992; Lane, 1984; Padden & Humphries 1999, 2005; Oliva 2004).

Statement of the Problem

Little is known about the lived experiences of Deaf people, their perspectives about Deaf identity and inclusion in American Deaf Culture and the historical and societal challenges to American Deaf Culture.

Purpose of the Study

The purpose of this study was to identify historical and societal challenges to American Deaf Culture and describe perspectives on identity and inclusion in an evolving American Deaf Culture, through the voices of Deaf people in ASL. The study explored, through generationally varied life stories, common life experiences and personal perspectives on Deaf Cultural values, beliefs, norms and history through ASL story in Deaf narrative.

This knowledge can be applied to better understand the American Deaf community as a cultural and linguistic minority, to recognize the remarkable ability of ASL to build story and transmit culture, and to acknowledge the historical resilience of the American Deaf Culture in spite of efforts to control, “fix,” and even annihilate its members (Branson & Miller, 2002; Lane, Hoffmeister & Bahan, 1996).

Additionally, this study sought to support the claim that Deaf people have a world-view different from hearing people, theirs is a visually based interaction, and they view the world from a “different center” (Lane, 1999).

Rationale

“We are remarkably ignorant about deafness” (Sacks, 1990, p.1). The world of Deaf people is invisible to most hearing people. Understanding people who experience the world visually is foreign to most hearing people. Deaf people are often thought of as imperfect hearing people and significant effort is expended to fix them (Lane, Hoffmeister, & Bahan 1996; Padden & Humphries 2005). This study seeks to listen to Deaf people as they share and reflect on their life experiences. In the listening, it is

hoped to learn about Deaf people. In the learning, it is hoped to gain valuable insights for parents, educators and others who interact with Deaf people. Deaf education has been and still is fraught with controversy. Decisions on methods and perceptions of a method's effectiveness often do not include any voice from Deaf people (Lane, Hoffmeister & Bahan, 1996, Baynton, 1996). Hearing people have long held the power to make decisions for Deaf people in education, in the workplace, and in the family. What do Deaf people think Deaf children and adults need and want? Listening to the experiences and perceptions of Deaf people can inform hearing educators, policy makers, and parents about the values and needs of Deaf children from those who were once Deaf children.

Deaf people themselves can also benefit from this study. Systematic oppression can breed feelings of isolation, inferiority and separation (Leigh, 2009). As life experiences are shared and compared, new confidence and self-worth can result from a profound in-group identity.

Technology, including Internet, email, and video capability has increased interaction between hearing people and Deaf people, and allowed Deaf people easy access to hearing culture in ways that were previously unavailable. Laws such as the Americans With Disabilities Act (1990) and Section 504 of the Rehabilitation Act of 1973 have mandated equal access for Deaf people in employment, education and in many aspects of American society. While numerous technological and societal advances have been made, the Deaf community remains fundamentally invisible. This study seeks to

support the notion that Deaf people have a unique culture and way of experiencing and interacting with the world.

Research Questions

The following research questions guided this study:

1. How have the lived experiences of Deaf people changed over the last 60 years?
2. What are the common cultural themes found in stories of lived experiences of Deaf people?
3. What are the Deaf participants' personal perspectives on their life experiences and Deaf Cultural values, beliefs, norms, and history?

Significance of the Study

Data gleaned from this study contributes to the body of knowledge of the Deaf community. Listening to stories of Deaf peoples' lives is important in several ways.

First, when the dominant language in a society is spoken English, stories of Deaf people whose language is American Sign Language are often overlooked. These stories can provide insight into other ways to understand the world. In practice, understanding other world-views can promote more effective interactions and trust. Their stories can illustrate commonalities that Deaf people face as well as unique and individual differences. To understand the variety of ASL stories found in Deaf narratives is a benefit to those seeking to learn ASL and work with Deaf people (Nicodemus, 2003).

Second, Deaf adults were once Deaf children. Their educational experiences and perspectives are valuable and can guide (predominately hearing) educators and

administrators in making appropriate policy and classroom decisions for Deaf children. Deaf adults often have higher expectations for Deaf children than their hearing teachers do. Policy decisions based on input from Deaf adults can also inform teacher education programs, to better prepare both general education and deaf education teachers.

Finally, listening to Deaf people is important to Deaf people themselves. The body of knowledge about the varied life experiences of Deaf people can reveal a shared heritage and create bonds of shared life experiences. Increased confidence may come from learning another Deaf person's story, Deaf role models may emerge, and Deaf children may be inspired to achieve more than they thought was possible for them.

Assumptions

I have been a certified Sign Language Interpreter for over twenty years. I did not have Deaf family members and I did not really know any Deaf people before I took my first sign language class, a community education class. It was not an ASL class, per se, nor was it a Signed English class, as not enough was known about either to label the class or profess to be in one camp or the other. The teacher was a hearing sign language interpreter who tried to introduce us to the way deaf people actually signed. In spirit, it was an ASL class without knowing so. I was hooked. It was like nothing I had experienced before, language in the air, full of meaning, colorful story and a new and fascinating way of seeing the world.

I pursued Interpreter education and became a certified sign language interpreter. My interpreter education program, guided by excellent instructors, Deaf and hearing, was deeply connected to the community and culture of Deaf people. I learned with the

support, careful guidance and admonishment of the Deaf community. I feel fortunate to have learned my craft essentially in the embrace of the Deaf community.

Much of what I write about in this dissertation begins from direct experience and observation. What has drawn me to pursue specific research in the Deaf community is the curiosity, love and fascination I have for the language and culture of Deaf people - combined with twenty-plus years of learning about, thinking about, wondering about the scope of cultural connectedness in the Deaf community. My professional and personal association with Deaf people has reaped an untold number of epiphanies, some small and some enormous, that color my perspective on the world, on the nature and the value of language, and the worth of each unique individual, as well as some shocking truths about power, control, oppression, fear and failure.

I wanted to learn how the challenges of the majority culture have affected Deaf peoples' lives, historically and currently, and how Deaf people themselves feel about these challenges and changes to Deaf Culture. I wanted to explore and understand the stories of Deaf people in the context of a changing cultural world. I wanted to learn this through the natural language of Deaf people, ASL, and through the natural storytelling tradition of the Deaf community.

Limitations

While this study sought to find common experiences among the participants, it is important to recognize that the study involved only six participants. Few definitive statements could be made that might apply to the entire Deaf Community. However, the

stories in total, in combination with other life stories of Deaf people by other researchers can contribute to a larger understanding of the Deaf experience, in all its variety.

Important to note is the fact that the participants are all Deaf, but the researcher is hearing. Although the researcher has been involved in the Deaf community for over twenty years, fluent in ASL, and generally well respected in the field, it must be recognized that some responses may be tempered because the researcher is a hearing person.

Finally, the comments and stories of the six participants represent a snapshot in time. Their stories might look different five or ten years from now, and their opinions as well might evolve over time. What is presented herein is the composite information provided by these participants on eighteen different days, offering a view of their world from their perspective on these days.

Nature of the Study

Life stories are organic. They represent both the action or event and the reflection or perception about the action or event. “Life stories are particularly revealing because they not only tell us something about the individual, but they also reflect the presuppositions of the expected beliefs and behaviors of an entire community” (Nicodemus, 2003, p.3). They can change over time, revealing additional insight or revisions to memory. They can demonstrate specific narrative structures or types. They can be funny, poignant, painful or uplifting. They can make or argue a point, illustrate a cultural theme, create rapport or alienate an audience.

In this study, life stories were gathered from six Deaf participants, and analyzed for common themes. The decision on precisely what and how much to share was left up to the participant. It was assumed that the choice of stories to share indicated a level of personal significance. As other participants told similar stories, the relevance of that particular story subject stood out as a common theme in this study.

Organization of the Remainder of the Study

In chapter two, historical information provided a context to understanding influences critical to the development of Deaf Culture. Famously, the American Deaf Culture “creation story” was presented. The first Deaf school was established. American Sign Language developed. Later, controversies in educational methods and power struggles impacted how Deaf children were schooled. Conflict over language eroded trust and effort to “correct” deafness breed suspicion and hostility. From this background, the stage was set to better understand the life stories of the study participants through the lens of historical and societal influences.

Chapter three describes the methodology used in the study and provides the rationale for choosing a particular approach. Processes for gathering and analyzing data are described. Human subject protocols are explained and copies of documents are included in the appendices.

In chapter four, results of the interviews are shared. Many original stories are found here and like stories are grouped by theme. A picture of both variety and commonality in experience emerges. Stories are evaluated and illustrative examples are highlighted.

Chapter five evaluates and provides commentary on the results. Particular findings guide conclusions and recommendations found in this chapter.

Definitions of Terms

ASL: American Sign Language, a true, natural and native language of many Deaf people in North America

“Culture is a set of learned behaviors of a group of people who have their own language, values, rules of behavior, and traditions” (Padden, 2002).

Deaf: A cultural identity and a level of hearing loss: 1. “d” eaf = an audiological measure, 2. “D” eaf = Culturally Deaf – use of ASL and self identified as member of cultural group (Woodward, 1972).

Deafened: Hearing loss acquired later in life

DEAF-WORLD: The group of individuals united by similar life experience (Bahan, 1995, Lane, Hoffmeister & Bahan, 1996)

Hard of Hearing: Hearing loss without Deaf Cultural identity, often characterized by the use of amplification, speech and residual hearing.

CHAPTER TWO

Literature Review

Introduction

It is difficult for hearing people to easily understand the nature of Deaf Culture and the experiences and beliefs of Deaf people without first understanding the context in which Deaf Culture developed and the issues faced by Deaf people. This chapter will provide background and context through which to better understand the stories and opinions of the study participants.

History

The American Deaf community's history reads like an epic. Until the early nineteenth century, most Deaf people in the United States were isolated in hearing communities and families (Van Cleve, 1989, 1993). There were a few exceptions, places where Deaf families flourished in communities with a high prevalence of deafness (Groce, 2001), but most Deaf people until the early 1800s did not have significant or consistent interaction with other Deaf people.

Until the early 1800s, Deaf children, by and large, did not receive the benefit of education. Communication between Deaf and hearing people was raw and rudimentary, consisting of a combination of home-signs and gestures. The lucky Deaf person stayed on the farm, learning and doing basic chores, without meaningful communication; the unlucky Deaf person was institutionalized.

Deaf Education Arrives

The birth of organized education for Deaf students in the United States is recognized as the American Deaf Culture creation story (Bahan 1996; Padden 2002). It

has been told and retold in Deaf Clubs and Schools and is well known among most Deaf people in the United States (Baynton, Gannon & Lindquist Bergey, 2007; Lang 2003, Gannon 1981; Oliva, 2004).

In the early 1800s, Mason Cogswell, a wealthy Connecticut businessman, was concerned about education for his daughter, Alice, who was Deaf. He hired young Episcopal priest Thomas Hopkins Gallaudet to learn state-of-the-art European deaf education methods, then return home to establish a school for the Deaf (Valentine, 1993). Cogswell and Gallaudet assumed that the preferred location for such a school would be England, where wealthy American families routinely sent their children, hearing and some Deaf, to be educated in well-established residential schools.

Gallaudet made his way to England and attempted to enter the famous Braidwood Schools for the Deaf. The Braidwood Schools employed a strictly oral method, and the Braidwood family held its methods in rigorous secrecy. To earn access to the Braidwood method, Gallaudet was asked to apprentice to them for an inordinately long period of time with little compensation. He passed on the offer, not because he had any particular disagreement about method, but because he was concerned about returning to the Cogswells as early as possible.

Gallaudet went to France, where he was well-received by Abbe Sicard and his protégée, Laurent Clerc (Ree, 1999). He simultaneously studied the manual methods of Sicard and learned French Sign Language (Baynton, 1996). Realizing he needed help to create a Deaf school, Gallaudet convinced Clerc to return to the United States with him to establish the first school for the Deaf in America. Famously, the sea voyage across the

Atlantic took 52 days during which Clerc tutored Gallaudet on French and French Sign Language, and Gallaudet reciprocated by teaching Clerc English (Gannon 1981; Moore & Levitan, 2008). After a fund-raising tour and U.S. legislative approval, the American Asylum for the Deaf in Hartford, Connecticut, opened in 1817 with a handful of students in attendance (Lane, 1984).

Beginnings of a Deaf Culture

American Deaf culture emerged when Deaf people first had the opportunity to form communities, co-occurring with the establishment of schools for the Deaf. Deaf children, sent then to residential schools for the Deaf, found themselves, for the first time, with children and adults like themselves.

Visual Communication

Once Deaf students found themselves in communities with other Deaf students and with Deaf teachers, their individual systems of visual communication, consisting of home signs and gestures, contributed to developing a natural language of signs – American Sign Language (ASL). ASL has its roots in French sign language (Ree, 1999; Moore & Levitan, 2008) with contributions from a variety of home-sign dialects and gestures, including the more established dialects of the few communities with large numbers of Deaf members, such as those found on Martha's Vinyard (Groce 1985). Over the years, ASL developed naturally and became standardized through its use in the schools and in communities of Deaf people.

Language Acquisition

Language acquisition research has discovered the brain's language center in Deaf children functions visually to support visual language development. Sacks, in "*Seeing Voices: A Journey into the World of the Deaf*" describes this phenomenon as a "reallocation" of auditory language centers of the brain to visual processing (p 103). In Deaf children's brains, the language domain becomes operationally visual and develops in typical ways, paralleling spoken-language development in hearing children. Some research indicates first signs may appear earlier than first words in both hearing and Deaf children, perhaps because the language production can be seen (hands vs. voice), or because signing is physiologically easier than speaking (Ree, 1999). Language milestones for Deaf children using ASL tend to match developmental milestones for hearing children using spoken language (Ree, 1999; Moores, 2010).

Deaf children who are exposed early to an incomplete visual language are able, to some extent, to create the appropriate grammar and structure. For example, if they are exposed to a manually coded English system, presented to them in the linear fashion of spoken English, they manage to create spatial grammars that are in line with ASL rules and structures.

...Human beings have a biological capacity for language that involves an internal set of norms. Children construct the grammar of the language they are acquiring on the basis of these internal norms. This is called the 'nativization hypothesis', because the children are using their native ability to construct grammars, to

‘nativize’ the incomplete information they receive (Lane, Hoffmeister & Bahan, 1996, p. 49).

Deaf children are able to acquire language naturally because of an innate ability in the brain’s language center that simply follows a visual path rather than an auditory one. In this way, the child’s biological adaptations allow for the acquisition of their natural and native language—the visual language of signs.

Because the mind has adapted to process language visually, Deaf people will perceive the world via the context of their visual language. In other words, Deaf people have a “different center” (Padden & Humphries, 1999; Lane, 1999) from which they interpret the world and their experiences. This supports the highly contextual nature of the Deaf community, and its role as a cultural vehicle.

Belugi and Klima’s research on Deaf stroke victims discerned how left-hemisphere damage impacts language or spatial areas of the brain. Their results show that damage to the spatial areas of the brain (but not to the language center) does not affect a stroke victim’s ability to use space linguistically, and that damage to the language centers of the brain does not affect the ability to use space non-linguistically. This is key to understanding the role of the language centers in the brain and how they can adapt to visual-spatial language development and use. (Klima & Belugi, 1979; Poizner, Klima, & Belugi, 1995).

“The deaf children who do best in school, mainstream or residential, are—note it well—the fortunate 10% percent who learn ASL as a native language from their deaf parents” (Lane, 1999, p. 138). Moores (2010) reviews research and reports that Deaf

children of Deaf parents were found to be superior to Deaf children of hearing parents in reading, math, written language, maturity, sociability, vocabulary, and overall academic achievement, while Deaf children of hearing parents were superior in speech (p. 28).

Perhaps ... the basis of the higher achievement of deaf children of Deaf parents over deaf children of normally hearing parents [is that] the former provide[s] their children with directly applicable, immediately relevant coping skills. ...

Additionally, of course, the Deaf parent generally communicates more effectively with the deaf child than would a normally hearing parent.... The 'everydayness' of deafness for these children contrasts sharply with the 'otherness' of deafness for deaf children of hearing parents (Schein, 1997, p. 123).

American Sign Language

The establishment of schools for the Deaf in the early 1800s created social and educational opportunities for Deaf children and adults to share, for the first time, their common lived experiences through a visual language (Baynton, Gannon & Lindquist Bergey, 2007; Gannon 1981). These shared language experiences helped develop ASL as a rich language, used for inclusive and comprehensive communication. Although ASL displayed an intricate structure, complete with its own grammatical system and a vast amount of generative possibility, it would be 150 years before it received recognition as a true language (Maher, 1996).

American Sign Language became the fundamental building block to a culture rich in visual acuity and representation, shared lived experiences, values, norms and behaviors. As a tool of cultural transmission, ASL uses vivid linguistic elements to pass

on the trials and tribulations as well as successes and fame of the Deaf community from one generation to another.

When it was necessary for ASL and Deaf Culture to “go underground” as a result of oppressive forces in education and American society, the Deaf people nurtured it, kept it healthy, and continued to cherish ASL as the true and “god-given language of the deaf.” (Veditz, 1913.)

Not until 1965 did Stokoe, then a young English professor at Gallaudet College, observe that ASL was much more complex than previously thought by scholars and linguists—even by Deaf people themselves (Armstrong & Karchmer, 2009). He applied general linguistic principles to ASL and theorized, for the first time, that ASL had all the elements of a true language. While his findings were controversial at the time, they sparked enormous growth in the field of sign language research and ASL has become recognized as a full, true, and natural language. Stokoe's groundbreaking research on the structure and legitimacy of American Sign Language ushered in a new era of pride and legitimacy for the community of Deaf people. (Maher 1996).

Storytelling

Deaf communities in the United States share the bond of individual cultural histories grounded in story. Theirs is a storytelling culture. History, values, behaviors, folktales, instructional stories, jokes and humor are all passed from generation to generation richly through story, shared in their cherished signed languages. Because the structure of American Sign Language lends itself so vividly to the art of story, it has become a functional tool for the deaf community to preserve history and memory and to

pass on the values and shared beliefs of their culture. As in many cultures, Deaf Culture has a strong “oral” tradition. That is, stories of the culture are passed live from elders to younger members. Deaf children who are born to Deaf parents may also pass along the stories and composite elements of the culture to other Deaf people who were born to hearing parents and lacked immediate and natural access to the culture. Within the culture are found creation stories, heyday stories, challenge to the culture stories, survival stories, and future or utopia stories, as well as highly contextual jokes and poetry (Lane, Hoffmeister & Bahan, 1996). Many of these literary genres are thought to be universals in other Deaf Cultures as well (Breivik, 2005). Padden and Humphries (1999) present evidence of creation stories from their experience visiting Deaf clubs in France.

During formal events, recognized experts tell stories; proud and elaborate retelling of stories about famous Deaf people and events take place, with the storyteller a prominent and recognized member of Deaf Culture. Most of the audience will be familiar with the stories, but look to the ritual retelling for the feeling of cultural pride, group cohesiveness, validation and pure entertainment it offers. Many individual Deaf people will be recognized in these stories by name, securing their place in the oral tradition and historical record and providing role models for younger Deaf people (Mottez, 1993). Signing style in formal events reflects the significance of the setting—larger, more formal and elaborate signs, great detail and honor exhibited in the telling of a cherished history (Padden & Humphries, 1999).

At informal events, many storytellers might tell many stories simultaneously, in small groups around the room. Some stories will be delightful retellings of personal

experiences or famous jokes, well known to many. Others may be new stories, highly contextual, personal or general, with themes of challenge, victory or survival. Adults may spend significant time with Deaf children, inquiring about the childrens' experiences in the Deaf community and the hearing world, school, social events, and family, and providing stories of their experiences in return, to pass on common experiences and to provide support and instruction in how to operate in the world.

Life Stories

Nicodemus (2003) explored the notion of common sense themes found in the life stories of Deaf people. These themes are based on common experiences of Deaf people, including “communicating with hearing people, the abilities of Deaf people, being a minority in a hearing world, and a universal search for a Deaf identity” (p.13). She suggested five tenets of common sense found in Deaf life story narrative: 1. Hearing people don't understand Deaf people, 2. Deaf people often have delayed exposure to ASL, 3. Deaf people struggle to find their identity, 4. People are individuals whether they are Deaf or hearing, 5. The Deaf community has two worlds, two languages, and two cultures (Nicodemus, 2003).

Deaf Cultural Values

Some identified values of American Deaf Culture include American Sign Language, self-identity, storytelling and folklore, residential schools, Deaf children, visual environments, eye contact, group cohesiveness, time for communication, Deaf role models, and equipment/technology (Bienvenue & Colonomos, 1980; Padden and Humphries 1999). These values support a life of self-determination and independence as

well as traditions and behaviors that help form a cohesive cultural group. These values are specifically geared to a people who interact with the world in a visual way. This list should not be construed as exhaustive because culture is in a constantly evolving state. (Bienvenue & Colonomos, 1980; Humphries & Padden, 1999; Lane, Hoffmeister & Bahan 1996; Saks, 1990).

Challenges to the Culture

Deaf people have faced many challenges, some more overt than others, that demonstrate a decidedly anti-cultural view of Deaf people. Threats to the culture almost always are grounded in a medical/pathological view of deafness (Lane, Hoffmeister and Bahan 1996). A comparison of medical-pathological and cultural perspectives of deaf people helps to understand these threats and their effects.

Those who hold a medical-pathological view believe that people who are deaf have something wrong that needs to be fixed, that they have behaviors and beliefs that are deviant, that they need help and helpers, and that communication problems are theirs alone. Those who hold a cultural view of deaf people believe that people who are deaf are different, not deviant; that they share a common language and culture, that they relate to the world visually and that communication problems reside in society (Lane, 1999; Branson and Miller, 2002; Parasnis, 2002; Erting and Kuntze, 2008).

Most challenges to Deaf Culture originate from a medical-pathological frame of reference, whether the challenge occurred over a hundred years ago or yesterday (Lane, Hoffmeister and Bahan 1996; Branson and Miller, 2002; Parasnis, 2002).

Challenges often target Deaf children first, in schools. In this setting, powers of influence and decision-making have long been held by hearing people who operationalize a medical-pathological view of Deaf people by banning sign language, and removing Deaf role models such as teachers, staff, and administrators (Ladd, 2007).

Oral vs. Manual

One of the first challenges to the newly emerging culture of Deaf people was the effort of hearing teachers of Deaf students to lobby for a ban on using sign language to teach Deaf children. Noted social eugenicist, Alexander Graham Bell, was not in favor of schools for the Deaf, and supported proposed legislation to prohibit Deaf people from marrying other Deaf people (Baynton, 1996; Lane, 1984; 1999; Padden & Humphries, 2005; Sacks, 1990; Winefield, 1987). Hearing teachers supported oral-only methods for teaching Deaf students, and their efforts succeeded at the 1880 National Conference of Teachers of the Deaf in Milan, Italy (Parasnis, 2002; Ree, 1999). Deaf teachers were denied full membership and any voting privileges, and had to meet separately from the larger body. Since Deaf teachers were excluded, the motion to declare oralism the one, true, and right method for the educating Deaf children passed easily, and oralism became the predominant method for nearly 100 years (Ree, 1999; Branson & Miller 2002; Van Cleve & Crouch 1989). In 1867, ASL was used in all 26 schools for the Deaf; by 1907, ASL had disappeared from all of the 139 schools for the Deaf (Lane, 1999).

So strong did faith in oralism become that even the profoundly deaf spent virtually all their time at school learning to make sounds and read lips. Whole classes would sit in a ring waiting for their turn to say a word, waiting while the

teacher spent time with each individual until satisfied with his or her pronunciation. As they waited, they were forced to sit on their hands so they could not sign and were even forbidden from signing in the playground (Branson & Miller, 2002, p. 209).

While forced “underground,” ASL did not die (Van Cleve & Crouch, 1989; Baynton, 1996). It became an even more cherished element of Deaf Culture. ASL was used in homes, in residential school dorms (but not pervasively in the classrooms), and wherever Deaf people gathered (Gannon, 1981; Padden & Humphries, 1999). Still, ASL was considered inferior to spoken English, and only students who were labeled “oral failures” used it publicly.

Total Communication

By the mid 1960s, it became clear that for Deaf students, the oral-only method was a dismal failure, with average academic performance of Deaf students far below that of their hearing peers (Baynton, 1996). Couple these findings with the surge in research on ASL and its viability as a true and natural language, and many educators began to reconsider manual communication. Recognizing that very few Deaf students become oral successes and most need additional visual input helped spark efforts to re-introduce at least some form of manual/visual communication in the schools. The era of Total Communication began.

Total Communication was less a method and more a theory in which educators were encouraged to use any and all methods that would benefit Deaf students (Sheetz, 2001). While Total Communication included amplification, speech therapy, speech

reading, writing, pictures, and signing; in practice it was commonly believed to mean speaking and signing at the same time, or simultaneous communication—“SimCom” (Lane, 1999). Teachers attempted to use spoken English and some form of sign language simultaneously. Research by Johnson, Liddell and Erting found that the spoken and signed outputs by teachers using SimCom were not equivalent (Johnson, Liddell & Erting, 1989; Tevenal and Villanueva, 2009). Total Communication/SimCom also proved to be ineffective for most Deaf students, as it did not provide students with access to a complete language in either English or American Sign Language. Research by Tevenal and Villanueva compared the message understood by hearing and deaf participants when information was presented using SimCom, and found that the “comprehensible inputs received by d/Deaf and hard of hearing participants on the one hand and hearing participants on the other are not equal” (pp. 284-285). Interestingly, Deaf and hard of hearing participants believed that they understood much more than they actually did. Hearing participants as a group achieved 74.29% accuracy, while the hard of hearing group scored 29.17% and the Deaf group scored 28.12% (Tevenal and Villanueva, 2009, p. 277).

Manually Coded English

The door opened for signing to re-enter the schools, but not wide enough to include ASL. Some believed that Deaf students who could not master spoken or written English needed to be able to see the structure of English visually. Because the stigma of ASL had not yet been ameliorated by the discovery that it was a true and natural language, and because most teachers of Deaf students were not fluent in ASL, researchers

such as Bornstein, Gustason, Wampler and Anthony developed signing systems for use in the classrooms.

In the early 1970s several Manually Coded English (MCE) systems were developed, including Anthony's Seeing Essential English (SEE1), Gustason's Signing Exact English (SEE2), and Wampler's Linguistics of Visual English (LOVE). To make every element of English visual, many signs were invented or initialized for words or parts of words that did not have ASL signs. It was not that ASL could not represent these English words, but ASL conveyed them in a manner consistent with a visual-spatial conceptually oriented language. For example, MCE systems have several initialized signs for the English variants of the 'TO-BE' verbs, while ASL has one basic sign, glossed 'TRUE,' which can be easily understood in a variety of contexts. Another example is the use of prefixes and suffixes. MCE systems have a series of invented signs for -ment, -ness, -ed, -ing and other suffixes (Sheetz, 2001). In ASL these are unnecessary because the original base sign, in context, is sufficient for understanding the concept. Another common adaptation in MCE is to initialize signs in order to indicate a specific English word. The original ASL handshape is discarded for a handshape representing a letter of the alphabet that begins the English word. Again, ASL does not need such a distinction as the signs represent concepts, not English words. Finally, in some MCE systems, there is a one-word, one-sign rule. The developers of these systems determined one sign for all of the versions of a specific homonym category. For example, the English word "RUN" has multiple meanings, but one sign was chosen to represent all meanings. The sign for the physical act of running—'moving fast by foot'—

was selected and would be used in all situations in which the word RUN appeared. Thus, if someone wanted to express that their nose was RUNNING—in the MCE signed sentence, it would look like their nose was literally RUNNING—‘moving fast by foot!’ Deaf adults who are fluent in English may be able to recognize this usage in context, and in the form of a cross linguistic pun; young Deaf children may not have the linguistic competence to make that connection.

Many Deaf people supported the introduction of Manually Coded English systems, in part because they were still under the influence of a lifetime of being told that ASL was an inferior communication tool to English, and because MCE provided a way to return some form of visual communication to the schools (Jankowski 1997).

It is important to recognize that Manually Coded English systems are not languages themselves, but representations of languages (Sheetz, 2001; Lane, Hoffmeister & Bahan, 1988; Baynton, 1996). They are systems by which one can see the English language when one cannot hear it. Other systems that represent languages include Morse Code and Braille. Manually Coded English systems represent something already known. Belugi explains the difficulty in processing MCE:

Deaf people have reported to us that while they can process each item as it appears, they find it difficult to process the message content as a whole when all the information is expressed in the sign stream as sequential elements (in Sacks, 1990, p. 113).

Sacks adds:

These difficulties, which do not diminish with use, are due to fundamental neurological limitations – in particular, of short-term memory and cognitive processing. None of these difficulties occur with ASL which with its spatial devices is perfectly adapted to a visual mode, and can be easily signed and understood at high speed (Sacks 1990, p. 113).

This is, essentially, what Deaf children are being asked to do when a Manually Coded English system is substituted for a natural language. MCE systems proved to be helpful for people who lost their hearing after learning English, but less successful for those who were Deaf from birth or before acquiring language. The combination of Total Communication/SimCom and MCE boiled down to an environment in which the teacher mostly spoke, and added some MCE signs, but not consistently, rendering an incomplete message. It is quite cumbersome to sign every prefix and suffix of each word, as well as every article and specifically initialized signs, at the same time and with the same cadence as the corresponding speech. Some equate it with trying to simultaneously speak one language and write another. Consequently, Deaf students educated with MCE often lack a competent language model in either the manual or oral mode (Johnson, Liddell and Erting, 1989; Tevenal & Villanueva, 2009).

While the use of some kind of signing has become routine in many schools, there is still a reluctance to embrace the use of ASL, often because the teachers of Deaf students, who are predominantly hearing, are not skilled enough in ASL to use it effectively (Cerney, 2007).

Language ability, expressed in writing, reading and communication deteriorated for Deaf students during this first generation of mainstreaming, and could not be effectively remediated, because students were not receiving consistent or accessible language modeling in either ASL or English (Johnson, Liddell & Erting, 1989; Tevenal and Villanueva, 2009).

Speech Therapy

Speech and language have historically been confused and, as a result, the two words have been used interchangeably (Haualand, 2008; H. D. L. Bauman, 2008). The goal of education for Deaf students, then, was to restore language to the languageless in the form of speech (Lane 2002). Speech therapy was used rigorously in oral programs in conjunction with the use of hearing aids, residual hearing and speech reading to achieve intelligible speech.

In schools, a vast amount of time was spent fixing and adjusting hearing aids and ear molds with most of the rest of the time spent on speech therapy. Education often lagged far behind....The central focus of the school was on its ability through science and technology to produce hearing and speaking students.

Academic matters were secondary (Branson & Miller, 2002, p. 205).

Students were drilled for hours on speech sounds, at the expense of content-based learning in the schools (Lane, Hoffmeister & Bahan 1996; Baynton, Gannon & Lindquist Bergey 2007). In many oral schools, achieving the correct answer included the ability to speak the correct answer. Graduations at oral schools were marked by a demonstration of a student's ability to speak, rather than their ability to learn.

In the view of the DEAF-WORLD, to be subjected to extensive speech therapy and remedial work is in itself a very disabling experience. Of course, being able to speak is a convenience, but to members of the DEAF-WORLD that is all it is – and it is much more a convenience for the hearing than the Deaf (Lane, Hoffmeister & Bahan 1996, p. 216).

Many Deaf people see value in some level of speech therapy (Baynton, Gannon & Lindquist Bergey 2007), but most find the quantity and intensity tantamount to child abuse (Gannon, 1981). “It is estimated that a congenitally, profoundly deaf person has, at most, a 5% chance of developing intelligible speech” (Moore & Levitan, 2008, p. 209).

Mainstreaming

Public Law 94-142, commonly known as the *Equal Education for All Handicapped Children Act* or *The Mainstreaming Act*, was enacted in 1975 as a response to concerns that children with disabilities were receiving inferior and isolating educations (Karchmer & Mitchell, 2003; Scheetz, 2001; Lane, Hoffmeister & Bahan, 1996). Most were sent to special schools where students with disabilities had a wide range of abilities and most, whether they were high or low functioning, did not receive a fair and appropriate education. Deaf children, who typically had been sent to the state residential schools, were included in this population (Lane, 1999).

Residential schools for the Deaf have long been considered by the Deaf community to be the places where culture is learned, shared and passed on from older students to younger ones (Gannon 1981; Padden & Humphries 1999; Baynton, Gannon & Lindquist Bergey 2007). Since only about 10% of Deaf people are born to Deaf parents

(Schein & Delk, 1974), Deaf Culture is generally not transmitted through the family of origin. The residential school is where Deaf children were exposed to Deaf role models—teachers, staff and older students who helped them understand Deaf culture and how to live as a Deaf person in a hearing world (Lane, Hoffmeister & Bahan 1996). When it came time for a Deaf child to go off to school, he or she would automatically go the state residential school for the Deaf, and begin the enculturation process there.

With the passage of PL 94-142 (in recent years renamed IDEA), many of the students at the state schools for the Deaf would return to their home schools, presumably with the aid of *qualified* sign language interpreters and itinerant teachers of the Deaf.

The goal of PL 94-142 contains the mantra-like phrase *Least-Restrictive Environment* (LRE), which means that the student's education or ability to participate fully should not be restricted by educational placement and they should enjoy the same experiences and opportunities that all children do. For students with disabilities, conventional wisdom of the time meant placement back in their home schools.

The flaw in this logic is that access to natural communication in the educational and social setting for Deaf children was grossly underestimated (Cerney, 2007). It was felt that if the school simply provided an interpreter, then equal access was achieved (Bahan, 1986). In reality, the public school, for many Deaf students, became the *most* restrictive environment (Lane, Hoffmeister & Bahan, 1996; Lane, 1996). Often, a Deaf student was the only Deaf student in his/her class, his/her school, or even the entire district (Oliva, 2004). "In 1990, almost three-fourths of all deaf school children in the United States...attended classes in an integrated setting" (Van Cleve, 2007). In 2003,

53% of schools serving deaf and hard of hearing students had only one student and 80% had less than four Deaf or hard of hearing students (Dolman, 2010). Thus, the circle of people with whom Deaf students could communicate freely and easily was often less than one person. Oliva (2004) employs the words *solitary* and *solitaire* to describe those who experience the loneliness and isolation of the mainstream setting, but who are “a single gem, set alone”(p. ix). The first generation of mainstreamed Deaf students had to suffer through the effects of severe isolation, unskilled first-generation interpreters, teachers of the Deaf who knew no sign language, lack of appropriate language modeling, and virtually no opportunity to engage in the social, cultural, or athletic life of their mainstreamed school (Holcomb, 2002; Lane, Hoffmeister & Bahan, 1996).

Conversely, in the residential schools, Deaf children are able to socialize with other Deaf children, teachers and staff, communicating unfettered by barriers found in the public schools. They can choose their friends, like and dislike other children based on more than their level of hearing. They help each other with the concepts taught in classrooms and look to the Deaf staff and older Deaf students as role models (Holcomb, 2002). They can be involved in virtually any extra-curricular activity in which they are interested and capable. Deaf students in a school for the Deaf can aspire to play the lead in a theatrical event, be captain of the debate team, play a different sport each season, and see adult role models on a daily basis (Holcomb, 2002; Gannon, 1981; Baynton, Gannon & Lindquist Bergey, 2007). All of this is, on a practical level, virtually impossible in a mainstream setting.

As Deaf students drifted back into the public schools, without residential schools to guide their entrée to the Deaf community, they often would not find their way into the Deaf community until adulthood (Padden & Humphries, 1999).

Teachers of the Deaf

After the 1880 Milan proscription of signs in the education of the Deaf, the number of Deaf teachers dropped dramatically. In 1870, Deaf teachers represented over 40% of all teachers of Deaf students, by 1960 that percentage had dropped to less than 12%, mostly in manual trade programs (Lane, 1984; Jankowski, 1997). At Gallaudet College in 1891, a negotiated agreement was reached between Bell and Gallaudet. A training program for teachers of the Deaf could be established at Gallaudet College, but Deaf students would be categorically denied admission (Branson & Miller, 2002).

In 1975, when PL94-142 was implemented, a most education programs training teachers for Deaf and hard of hearing students were still operating on the oral-only philosophy, and most required little or no course work in manual communication (Commission on Education of the Deaf, 1988). In mainstream education, it was rare to find a teacher of the Deaf who possessed any signing skill, and certainly not fluency in American Sign Language. As pedagogy began to change, and manual communication was beginning to find acceptance in the curriculums, it was difficult for veteran teachers to quickly gain language fluency in ASL. Few opportunities were available to provide legitimate language instruction and the time required for an adult to learn a new language is significant. Cerney (2007) found that co-workers perceived teachers of the Deaf as severely deficient in signing skills, knowledge of the Deaf community and how to work

with an interpreter, and that these deficiencies negatively affected their Deaf students (p. 146).

With apologies to Maslow, “if the only tool you have is a hammer, everything looks like a nail” applies to Deaf education after the passage of PL-94-142. Local school districts, used to serving only hard of hearing students, now had to serve Deaf students who used ASL. Most teachers in Deaf education, trained in oral-only methodologies, predictably, found the oral method to be their preferred method of instruction. Schools wrote individual education plans (IEPs) for Deaf students that looked a great deal like the IEPs for hard of hearing students. School districts had a tool for teaching hard of hearing students, but they did not have such a tool for Deaf students.

Lane (1999) suggests that Deaf Education today is hearing-teacher-centered, not Deaf-student-centered. The language of instruction is that of the hearing teacher, the expected language of student response is also that of the hearing teacher, and Deaf students see few Deaf role models that suggest possible life choices for them. It is the values, themes, and world-view of the hearing teacher that permeates the classroom (p. 179-80).

In 1988, the Commission on Education of the Deaf submitted a report on the state of Deaf Education and offered 52 recommendations. Recommendation #15 states: “The Department of Education should take positive action to encourage practices under the Bilingual Education Act that seek to enhance the quality of education received by limited-English-proficiency children whose native (primary) language is American Sign Language” (Bowe, 1991). No action was ever taken on this recommendation.

Furthermore, it was not in the best financial interest of school districts to allow Deaf students to transfer to the state residential school, as the cost of attendance and transportation must be borne by the home school district. However, in some cases, a student was allowed to transfer to the residential school, but typically only after repeated failure. By the time the student failed enough to be allowed to attend the residential school, he or she was delayed in language acquisition and behind in age appropriate content learning as well.

Yet even in the residential schools, not all teachers were fluent signers, nor was signing always allowed in classrooms. However, the necessary environment rich in language and culture was found in the community of Deaf students, in the dorms, on the playground, in the cafeteria, on the sports fields.

Interpreters

If teachers of Deaf children, who were predominantly hearing, could not serve as a language model for Deaf children in mainstream situations, then who could? In the mid 1970's, it was thought that a sign language interpreter could be a language model, facilitate all communication in the classroom, and function as a tutor and classroom aide (Fleetwood, 2000).

The conventional wisdom held that if an interpreter was placed in any situation in education at any level the result would be equal education for Deaf students. Experience proved differently. There are many flaws in this logic.

In the 1970s, research on ASL as a language was relatively new and still quite controversial. A textbook on ASL that included significant linguistic information had not

yet been published (Baker & Cokely, 1980). Sign language instruction focused on vocabulary only, some ASL, some MCE. The first interpreter education programs were 6-week intensive summer programs, and many of the first students were Children of Deaf Adults (CODAs). Other students entered interpreting programs with no signing skills. Language fluency cannot be achieved in six weeks. Still, after graduating from short training programs, interpreting students typically found work in the public schools.

It was believed that the least skilled signers/interpreters could be placed in primary and elementary grades, because vocabulary is basic. It was thought an interpreter would not need a rich lexicon to work with young Deaf children. This proved disastrous for young Deaf children, whose brains are 'ripe' for learning language, and need consistent and competent language models (Johnson, Liddell & Erting, 1989; Tevenal & Villanueva, 2009).

The process of interpreting in a school setting is complex. To interpret, one must be fluent in both languages and be able to quickly assess a message for its meaning, drop the original linguistic form of the source language, retain the meaning and reconstruct the message in the proper linguistic form of the target language, while simultaneously listening to the next idea. Processing time is necessary and the interpreter is always just a bit behind the speaker (Frishberg, 1990). Functionally, this means the Deaf student is waiting for information the hearing students are receiving spontaneously. It may only be seconds of processing time, but the result is that Deaf students cannot answer a question immediately, or add timely comments to a discussion. Further, an interpreter must fully understand the original message to provide a competent interpretation, so he or she must

be a cross-disciplinary as well as a multi-level educational expert (Frishberg, 1990; Fleetwood, 2000).

In mainstream classes, the Deaf student may have only one person with whom he or she can communicate—the interpreter (Baynton 1996). Virtually all communication with teachers and other children in mainstreamed classes happens through an interpreter. This can lead to co-dependency, complicated by the unique power relationship between interpreter and student (Lane, 1999).

Finally, the task of learning through *mediated instruction* (Marschark & Hauser, 2008)—receiving instruction secondarily through a sign language interpreter—is complex and requires multi-tasking abilities to take in the instructor, the interpreter, visual aids and other multimodal information simultaneously. “Thus, while there is evidence that concurrent, multimodal information processing is advantageous for learning, multimedia classrooms functionally require consecutive processing by Deaf students, alternating their attention between instructors/interpreters and visual materials, a situation known to impede learning” (Cerney, 2007; Marschark & Hauser, 2008, p. 9).

Medical Intervention

While attempts have always been made to cure deafness, including early attempts by pouring hot oil into the ears, or ‘bleeding’ the deafness out of a victim, and later, taking Deaf people on harrowing airplane rides to restore hearing (Baynton, Gannon & Lindquist Bergey 2007), more recent attempts at medical intervention have also caused great controversy in the Deaf community.

Hearing Aids and Amplification Devices

In the 20th century, much effort was focused on remediating the auditory effects of hearing loss, and deaf people used hearing aids of all kinds. In the first half of the century, schools provided amplification systems for young children that consisted of an enormous box strapped to their chest with big curly wires going to hearing aids placed in the ears (Sheridan, 2001). This often so stigmatized a student that he or she would refuse to use hearing aids at all, regardless of whether they were helpful or not. In the latter half of the century hearing aids became smaller, from a hearing aid attached to a small box that looked like a transistor radio to behind-the-ear varieties, an ear mold in the ear with a tube connected to the amplification element (Baynton, Gannon & Lindquist Bergey, 2007). These hearing aids amplified all sound, not just the sounds a person cannot hear well. The sound of a slamming door or a fire engine could inflict severe pain on the wearer. Now, in-the-ear aids are common, can hardly be seen, and, with the assistance of modern digital technology, achieve much better sound quality.

Hearing aids are expensive, costing into the thousands of dollars, and usually not covered by medical insurance. Many Deaf people, after 12 or more years of mandatory educational use of hearing aids, choose to discard them, or only wear them infrequently, when they are in the company of hearing people or to alert them to environmental sounds.

Cochlear Implants

More recently, a cultural challenge and controversy has arisen around a surgical procedure to place cochlear implants in Deaf people. From a medical-pathological perspective, the cochlear implant is a miracle (Weisberg & Aronson, 2000). It has the

potential to restore a useful *sense* of hearing (not hearing itself) to people with correctable kinds of damage to their functional hearing. It is most controversial in its application for infants and young children (Baynton, Gannon & Lindquist Bergey, 2007).

For many Deaf people, this procedure strips Deaf children of their right to determine their cultural identity (Leigh, 2009). It represents the rejection of the Deaf community by the hearing, and is perceived by some to be an effort to annihilate Deaf people—a Deaf holocaust (Lane, 1984, 1999). Others are more moderate in their stance, believing a cochlear implant can be appropriate for some Deaf people such as those who were deafened in later life, those whose first language is English and those who simply choose to identify with the hearing world (Leigh, 2009). But for young Deaf children, who have no choice, and from whom ASL will then likely be withheld, it is a deep concern for the Deaf community.

It should be noted while there are many successful and miraculous results to be achieved from a cochlear implant, there are other circumstances the general public may not be aware of. First, it is not real hearing. It is an implant with a receiver that sends a signal to the auditory center of the brain, which the implanted person must learn to decode as sound (Schein, 1997). A formerly hearing person must learn to ‘hear’ all over again. Most find it well worth the effort (Leigh, 2009). Second, the surgical procedure destroys any residual hearing a person may have had to begin with, so if for some reason, the implant is not successful, the patient is deafer than before. Third, for children, there are issues of activity and implants; contact sports may be problematic, it cannot be worn in water, and of course, when the receiver is not worn, the child is still Deaf. The device

also works as a result of a magnet implanted in the brain, thus a person with a cochlear implant cannot undergo any type of MRI scan without surgically removing the magnet first. Finally, for some, the implant just does not work. It may cause migraine headaches, persistent infections, or for some reason need to be re-programmed more often than is necessary and may even need to be surgically removed (Jankowski, 1997; Lane, 1999).

Most often, when a family makes the decision to implant a child, they also, by virtue of professional medical advice (as opposed to socio-cultural advice), make the parallel decision to disallow sign language (Chute & Nevins, 2008; Branson & Miller 2002).

Children who have used sign communication for longer periods of time and get a cochlear implant pose a particular challenge to the speech and hearing professionals with whom they work. As the child continues to use sign for communication and academic purposes, the professional who is accustomed to the immediate visual feedback possible in sign may rely on this modality and not provide enough auditory or spoken support (Chute & Nevins, 2008, p. 133).

The cochlear implant debate becomes a modern version of the oral or manual debate (Branson & Miller 2002). The result is implanted Deaf people who can pass for hearing people in some situations, but are robbed of their choice in cultural identity and language (Jankowski, 1997).

Technology

One of the greatest impacts on the lives of Deaf people is the rapid growth of technology. Technology now allows Deaf people to have flashing signals in their homes, indicating everything from a telephone ring, to a doorbell, to a fire alarm, to a baby crying. Televisions with built in closed captioning bring popular culture as well as world news to Deaf people (Baynton, Gannon & Lindquist Bergey, 2007). TTY (teletype, or text telephone) machines were new, exciting and novel to Deaf people in the 1960s, providing telecommunication access for the first time (Gannon, 1981). Now TTYs are seldom used, much like pay phones in an age of cell phones. Deaf people use pagers, hand held text messaging devices, email, web cams and videophones (Leigh 2009). These tools and devices provide spontaneous, easy access to information that, prior to the electronic age, was difficult for Deaf people to obtain. Technology has provided entrée to the hearing world that was previously impossible for Deaf people. Information can be searched for and retrieved on-line without having to speak awkwardly or write notes to a hearing person. Chat rooms, games, shopping, search engines, email have all improved access to the larger world and provided an opportunity to interact with and engage in the mainstream culture to an extent never possible before. It has yet to be determined how these technological advances will impact solidarity and membership in Deaf Culture.

Problem Statement

Little is known about the lived experiences of Deaf people, their perspectives about Deaf identity and inclusion in American Deaf Culture and the historical societal challenges to American Deaf Culture.

Purpose of the Study

The purpose of this study is to identify historical and societal challenges to American Deaf Culture and describe perspectives on identity and inclusion in an evolving American Deaf Culture, through the voices of Deaf people in ASL. The study will explore, through generationally varied life stories, common life experiences and personal perspectives on Deaf Cultural values, beliefs, norms and history through ASL.

This knowledge can be applied to better understand the Deaf community as a cultural and linguistic minority, to recognize the remarkable ability of ASL to build story and transmit culture, and to acknowledge the historical resilience of the American Deaf Culture in spite of efforts to control, “fix,” and even annihilate its members (Branson & Miller, 2002; Lane, Hoffmeister & Bahan, 1996).

Research Questions

The following research questions guide this study:

1. How have the lived experiences of Deaf people changed over the last 60 years?
2. What are the common cultural themes found in stories of lived experiences of Deaf people?

3. What are the Deaf participants personal perspectives on their life experiences and Deaf Cultural values, beliefs, norms and history?

Summary

This chapter has explored and documented the history of and challenges to the Deaf community particularly in the areas of language, education and technology. This background provides a grand narrative of common Deaf experiences through which to gain insight and perspective for understanding and interpreting study participants' stories.

CHAPTER THREE

Methodology

Qualitative research explores individual and group experiences through ethnographies, grounded theory, case studies, phenomenological research and narrative research (Creswell, 2003). This study relied most heavily on narrative inquiry, with elements of ethnography and phenomenology as a foundation.

The American educator John Dewey once wrote that the ultimate aim of research is the study of human experience. This is a particular aim of narrative research.

Narrative tells about past actions and how we understand them. Narrative research is the method of drawing out the truth and meaning behind the experience (Lang, 2007, p. 149).

Clandinin and Connelly (2000) look to Dewey's theory of experience as a starting point with which to examine the art of narrative inquiry. Dewey's framework of situation, continuity, and interaction has informed the work of Clandinin and Connelly, who have posited a similar framework with their own language: "personal and social (interaction), past, present and future (continuity), and the notion of space (situation)" (p. 50).

Historically, research on Deaf people has been largely confined to institutions and elements in their lives that were established and operated by cultural outsiders, hearing people. These institutions include (but are not limited to) education, social services, medicine and audiology, fields that foster the notion that deafness is a pathology needing remedy (Marschark 2003). This type of research has predominantly been authored by hearing people with little knowledge of Deaf Culture (Lane 1984, 1992, 1996; Jankowski

1997; Padden & Humphries 1999; Sacks 1990).

Because most research on Deaf people has focused on what they *lack*, rather than what they possess, the research approaches have tended toward the medical/pathological in affect and attitude, and often completely overlook the rich and valuable positive life experiences of Deaf people (Lane, 1984; Sacks, 1990; Lane, Hoffmeister & Bahan, 1996; Maller 2003; Marschark 2003). This study adopted a cultural view of the world of Deaf people, focusing on the characteristics of the Deaf community that contribute to building and maintaining a rich culture and language. This viewpoint helps identify elements of participant narratives that give voice to specific and common phenomena found in the Deaf community. This “essence of human experience” (Creswell, p. 15), shared by many Deaf people, illustrates specific yet similar lived experiences.

“Formalists begin inquiry in theory, whereas narrative inquirers tend to begin with experiences as expressed in lived and told stories” (Clandinin & Connelly, p. 40).

This qualitative study collected individual stories in original voices. Phenomenological theory was used to study perceived threats to the Deaf community and how cultural values, norms, behaviors, beliefs, and history are transmitted through ASL story. Some elements of ethnography were applied, particularly observation and interpretive skills that Geertz (1973) describes as “thick description.” The Deaf community collectively, and Deaf people individually operate in a highly contextual environment, that is, by layers of cultural meaning embedded in behaviors, norms, and values; it is within these layers of deep meaning that the members of this world share and understand specific and unique elements of the Deaf community (Baker & Cokely, 1980;

Gannon, 1981; Padden, 2002; Padden & Humphries, 1988, 2005; Lane, Hoffmeister & Bahan, 1996; Baynton, Gannon & Bergey, 2002). Participants' lived experiences, the study's predominant feature, was conveyed through narrative inquiry. Information was gathered from Deaf people themselves, through a demographic survey and life story narrative interviews, speaking for themselves in their own language, American Sign Language. A rich collection of stories of lived experiences emerged.

Qualitative research sometimes incites a circular evaluation process. As the researcher develops research questions, gathers data, and evaluates data, information gleaned from participants' influences the researcher to refine the original questions. Refined questions often influence the understanding of data and the cycle may begin again. (Creswell, 2003).

Problem Statement

Little is known about the lived experiences of Deaf people, their perspectives about Deaf identity and inclusion in American Deaf Culture, and the historical and societal challenges to American Deaf Culture.

Purpose of the Study

The purpose of this study was to identify historical and societal challenges to American Deaf Culture and describe perspectives on identity and inclusion in an evolving American Deaf Culture, through the voices of deaf people in ASL. The study explored, through generationally varied life stories, common life experiences and personal perspectives on Deaf Cultural values, beliefs, norms and history through ASL.

This knowledge can be applied to better understand the Deaf community as a cultural and linguistic minority, to recognize the remarkable ability of ASL story to transmit culture, and to acknowledge the historical resilience of the American Deaf Culture in spite of efforts to control, fix, and even annihilate its members (Branson & Miller, 2002; Lane, Hoffmeister & Bahan, 1996).

Additionally, this study sought to support the claim that Deaf people have a world-view different from hearing people, theirs is a visually based interaction and they view the world from a “different center” (Lane, 1999).

Deaf culture is rich with traditions. Even though ASL is manually produced, Deaf Culture is still considered a culture with an oral tradition. History, folktales, storytelling and the simple ease of face-to-face daily communication are all evidence of the value of the oral tradition (Padden, 2002; Padden & Humphries, 1988, 2005; Breivik 2005). As such, this study lends itself to a phenomenological approach.

This study used phenomenological methodology, primarily interviews and life story narrative inquiry, as research tools. The study sought to find meaning from Deaf people’s lived experiences related to their membership in Deaf culture, the changes over time in their cultural group, and how this information is generated, stored and passed along through ASL. This study is designed to give voice to Deaf people's perspectives through narrative inquiry.

Research Questions

1. How have the lived experiences of Deaf people changed over the last 60 years?

2. What are the common cultural themes found in stories of lived experiences of Deaf people?
3. What are the Deaf participants' personal perspectives on their life experiences and Deaf Cultural values, beliefs, norms, and history?

Participants

Six Deaf people from Minnesota were recruited through local Deaf community organizations such as the Minnesota Association of Deaf Citizens (MADC), and the State of Minnesota Deaf and Hard of Hearing Services, and from direct recommendations of Deaf community members. They represented equally three age categories: 18-34, 35-54, 55 and up. Each age group included one man and one woman.

Age groupings were deliberately created to represent milestones in deaf history. For example, people older than 55 would not likely have had the opportunity to attend mainstreamed schools for any part of their K-12 education, while those between 36 and 55 represent the first generation of students educated partially or completely after Public Law 94-142 mandated the opportunity to attend public schools with appropriate support. Each age group also coincides with specific eras of innovation in technology used primarily by deaf people, such as TTYs, closed-captioning devices, home-alert signaling devices, and various Internet capable applications.

All participants were white, and socioeconomically middle class. All were given alias names to protect their identity and privacy. All participants used ASL as their preferred or native language, and self-identified as Culturally Deaf. All were Deaf children of hearing parents, as this represents the majority experience. Half of the

participants also had Deaf siblings. A variety of school placement experiences were represented, as was diversity in teaching methods (oral-only, manual, ASL, and Signed English). Family background was also varied, both in family of origin and current family status.

Brief Biographies of Participants

Introductory biographical information was taken from written demographic surveys given to the participants prior to the first interview. The survey tool and results can be found in appendices A and B.

John, who was 19, and Lauren, 34, were the youngest participants. John was born Deaf and the family began to learn sign language shortly after his deafness was discovered. His parents were both hearing, and he had one hearing sibling and one Deaf sibling. His Deaf sibling also signs fluently, his parents and hearing sibling sign pretty well, his grandmother fingerspells and the rest of his extended family did not sign. John received a cochlear implant as a toddler, but does not currently use it. He was placed in a Deaf pre-school program and was mainstreamed in elementary, middle and part of high school. John went to a residential Deaf school for high school, where he was also partially mainstreamed into the local public high school for some subjects. At the time of the interviews, he planned to attend Gallaudet University.

Lauren was born hard of hearing and progressively lost more hearing during childhood. She was born in a small, rural Wisconsin town, and was the only Deaf person in her family, her school and her town. Her mother signs a little, her siblings fingerspell, and the rest of her family, including her father, does not sign. Lauren is married to a Deaf man, and has four hearing children. Her spouse signs fluently, and their children all

sign well. She did not attend pre-school, and was mainstreamed for her elementary years. Lauren was in a mixed program in high school – some instruction with a Deaf/Hard of Hearing teacher and some instruction in the regular classroom. She attended a public four-year university, with the accommodation of sign language interpreters and note takers. Lauren was one of the first children in the United States to receive a cochlear implant, when the procedure was still experimental.

Representing the 35-54 age group are Kristine, 37 and Paul, 53. Kristine came from an all-hearing family, and was mainstreamed pre-school through college. She was born hard of hearing and progressively lost more hearing. She learned sign language, mostly signed English, early. Her mother signs a little. Her father, three siblings, grandparents, aunts, and uncles do not sign. She is married to a hearing man, who signs pretty well, and their school-aged daughter signs a little. She was relatively successful with speech therapy, and communicated with her family primarily using voice, residual hearing and speech reading. Kristine is currently a teacher for Deaf and Hard of Hearing students (D/HH).

Paul was born Deaf in rural Michigan to hearing parents, and has one Deaf sibling and two hearing siblings. His parents moved to the town where the residential Deaf school was located, so their Deaf children could live at home and still go to the state Deaf school. His father signs only a little, and his grandparents, aunts, and uncles do not sign at all. One hearing sibling signs pretty well, and his mother, Deaf sibling, and one hearing sibling all sign very well. He is married to a Deaf woman and has two hearing children, both sign very well. Paul attended the state Deaf school and lived across the

street, so he did not live in the school dormitory. He attended a Deaf college, National Technical Institute for the Deaf (NTID), located within a larger public institution, Rochester Institute of Technology (RIT), and had both Deaf and mainstreamed class experiences.

Will, 58, and Anne, 77, represent the 55 and over group. Will, age 58, was born Deaf to hearing parents. He has one older sister and one younger sister who are also Deaf, and two other hearing siblings. He was raised in New York and attended a mainstream pre-school program for a short time. His elementary school was a Deaf oral-only program, and in high school he transferred to a Deaf residential high school that allowed sign language. He attended a Deaf college for his undergraduate degree and a mainstream university for his graduate degree. Will is married to a hearing woman and their three children are all hearing. Will's Deaf siblings, his spouse and their children all sign very well; his mother and one hearing sibling sign pretty well, his father and the other hearing sibling sign only a little. Will's extended family of grandparents, aunts and uncles do not sign at all.

Anne was born hearing to an all-hearing family in rural Minnesota. She lost her hearing to illness at the age of 12. She attended her neighborhood elementary school, but after she became Deaf, she was required to go to the Minnesota School for the Deaf, a residential school hundreds of miles from her home. She came home only for holidays and summer vacation. Anne did not attend post-secondary education. No one in her birth family signs at all. Anne is married to a man who is hard of hearing. They have

two daughters and one son, all hearing. Her husband signs very well, as does one daughter. Anne's other daughter signs pretty well, and her son fingerspells only.

Data Collection Procedures

Six Deaf people from Minnesota were recruited through local Deaf community organizations. Participants received information outlining the scope of the research, explaining risks and benefits, confidentiality procedures, and a consent form, as prescribed by the University of Minnesota Institutional Review Board. Copies of these forms can be found in appendices F, G, and H. Participants were made aware of their rights, and recourse procedures, and were informed that they could refuse to answer any question for any reason. After each participant signed the consent form, the first interview was scheduled. Using a narrative inquiry model, participants completed a short demographic survey and participated in a series of three interviews, organized chronologically. Interview questions can be found in appendices C, D, and E. These interviews followed a life story narrative schema. The first interview (Appendix C) focused on the Deaf person's early history, schooling from primary through secondary, family of origin, and early uses of technology. The second interview (Appendix D) focused on the Deaf person's current situation: family, post-secondary education, work experiences, and uses of technology. The third interview (Appendix E) explored participants' beliefs about the Deaf community, knowledge and awareness of cultural issues and history, and perspectives on the future. All interviews contained an emphasis on interaction within the Deaf community. Each consecutive interview occurred approximately one month from the previous one.

All interviews were conducted in American Sign Language and were videotaped. As expected, each interview lasted from 1.5 to 2 hours in length, such is the nature of ASL communication to elaborate, expand and provide great detail through narrative. Notes were taken from the videotapes, and themes emerged. Interview segments were translated into English for the purposes of the written reports, otherwise, evaluation of visual information was done through American Sign Language.

Most topics were introduced as open-ended prompts: “Tell me a story about an early school experience;” “Tell me about the communication you had with your family.” The goal was twofold: first, to let the participant decide what was important to tell, and second, to allow for storytelling, a common cultural tool in ASL and Deaf Culture. All participants were asked the same series of open-ended questions and were given freedom to share more or less about any particular idea. They were also informed that they did not have to answer any questions that they did not feel comfortable with, and were not required to share information that they did not want to share.

Data Analysis

Phenomenological research dictates identifying essential statements, ethnographic research requires rich description of the settings and/or individuals, and narrative inquiry involves the retelling of personal stories within the context of the research (Creswell, 2003.) Using elements of narrative inquiry, interview responses were coded by theme. Some elements of phenomenological research, and ethnographic research influence the analysis. After reviewing video of each interview and taking notes on participant stories and responses, a theme/story matrix for each interview was developed. Within each

interview matrix, stories of similar experiences unfolded and created common themes.

The following themes emerged:

1. Family Theme: communication/inclusion in birth family and adult family
2. Educational Theme: early experiences, developmental awareness, social environment, and educational progress
3. Social Theme: cultural identity, support system, involvement in Deaf and hearing cultures
4. Perspectives on the Deaf community: historical, culture Identity and practices, and the future of Deaf Culture
5. Technology: first experiences, common use, and perspectives on technology and Deaf Culture

Stories that appear in multiple narratives, suggesting phenomena that may be consistent with common life experiences in the Deaf community, were identified and highlighted. These stories were compared to accounts in recent literature identifying common experience among deaf individuals.

Conclusion

This study seeks to identify how Deaf Cultural themes are conveyed through ASL narratives, and which cultural themes demonstrate the continuity of Deaf cultural values, despite generational differences in lived experiences of Deaf individuals and the historical and societal threats to Deaf culture. Similar stories emerged as illustrative of common lived experience in the Deaf community.

These results produce more questions to guide future research. The rich experiences and stories of the six Deaf participants yielded ideas and suggestions on how to better understand Deaf people and the Deaf community.

CHAPTER FOUR

Results

Most Deaf and hard of hearing children are born to hearing parents, and most hearing parents, before they have Deaf children, have little or no knowledge of the Deaf community. Most have never met a Deaf person. Such families have to navigate a plethora of decisions, often guided by the first professional they trust. This process is complicated by the parallel emotional journey of grief experienced by hearing parents who learn their child is Deaf.

All participants in this study were born to hearing parents, and their journeys are in some ways remarkably similar. All spoke of their families' search for the best education, although results were different. Three participants were the only Deaf child in their family; three also had at least one Deaf sibling. All have at least a little experience in mainstream settings, four also attended Deaf schools. All talked about their journeys towards a Deaf identity. All participant names are aliases.

John, who is 18, and Lauren, 34, are the youngest participants. Representing the 35-54 age group are Kristine, 37 and Paul, 53. Will, 58, and Anne, 77, represent the 55 and over group.

Research Questions

The following research questions guided this study:

1. How have the lived experiences of Deaf people changed over the last 60 years?

2. What are the common cultural themes found in stories of lived experiences of Deaf people?
3. What are the Deaf participants' personal perspectives on their life experiences and Deaf Cultural values, beliefs, norms and history?

RESEARCH QUESTION 1

How have the lived experiences of Deaf people changed over the last 60 years?

The age groups represented in this study correspond to significant events or factors affecting the Deaf community. Trends in education, social consciousness, and legislative action, and advances in technology, are major influences affecting Deaf participants' lives over recent history.

Anne's elementary educational experiences in the 1940's, and Will's in the 1950's, are similar in many ways. There was little question that they would attend a Deaf school. Will's first day school was a strict oral program. Anne's residential school used an oral-only approach to teaching in the classroom, but she learned to sign in the dorms. Students were punished if they signed. In both schools, a great deal of time was spent engaged in speech therapy; in fact, speech therapy was part of every class. Will says that in his elementary math class, an answer would not be considered correct unless the student got the right numerical answer and could also *say* it correctly.

In the 1940s and '50s, American Sign Language was not considered a legitimate language, and the oral method was the predominant approach to teaching Deaf children. Deaf schools typically had mostly hearing teachers and Deaf dorm staff.

At the residential school, Anne was far from her family. They wrote letters during the school year, and she went home for the summer. Her school community became her second family.

Will's mother was president of the Oral Education Organization, and followed the guidance given to her by hearing medical professionals. The family rarely saw Deaf adults. Will remembers one of the first times he met a Deaf person, a peddler who came to the door:

I was a child and he came to our door selling charms with the fingerspelled alphabet on the back. My mother was embarrassed, but I was fascinated – another Deaf person, like me! It was not a negative experience for me, it was wonderful to know there were others like me.

Telephones, common communication technology at the time, effectively isolated Deaf people from hearing people. Deaf people who needed to make calls had to ask for help from hearing people, which was often demeaning and embarrassing.

Will's and Anne's early education experiences were characterized by the oral-only philosophy, prohibiting signing, allowing little contact with other Deaf adults until they went to Deaf schools, and limiting natural communication with family members.

Paul and Kristine have some similar experiences, and some that indicate changes from what Will and Anne lived, in social and educational environments and opportunities for Deaf people. Significant legislation during this period affected the choices available to them and their families.

Section 504 of the Rehabilitation Act of 1973 provided civil rights protections and allowed for reasonable accommodation for students with disabilities. This law affected programs that received federal funds and focused on higher education and the workforce. Section 504 mandated that Deaf students could attend mainstream colleges and educational programs, and, if a program received federal funds, appropriate accommodation must be made for them.

Public Law 94-142, then known as the Equal Education for all Handicapped Children Act of 1975 requires that handicapped children and adults ages 3-21 be educated in the least restrictive environment (LRE) to the maximum extent possible, that students with disabilities were to be educated with children who do not have disabilities, and that special classes, separate schools, or other removal of children from their regular educational environment occurs only when the severity of the disability is such that education in regular classes cannot be achieved. Before Section 504 and PL 94-142, virtually all Deaf children were sent to the state schools for the Deaf. This law allows parents the freedom to choose their own local school for their Deaf child.

During the '60s and '70s Stokoe proved that Deaf people's sign language is a true language. This new language was named American Sign Language. The discovery led linguists, educators and Deaf people to take a new look at sign language, its linguistic structure, and its viability as a language of instruction in education. Public schools were not prepared to fully adopt ASL, but some manual communication began to find its way back into the schools in the form of Signed English systems.

Paul's experience in the 1960s illustrates the continuing influence of oral-only methods. Paul's parents were told by professionals not to sign. Although he attended a Deaf school in the 1960s, the classrooms remained oral-only environments. The school day including significant time spent in speech therapy. Paul was made to sit on his hands or put them on a specific place on his desk, to keep him from signing in the classroom. Signing was widespread out of class, though, and some teachers chose to sign with their classes when the principal was not watching.

Kristine's parents had the opportunity, in the 1970s, to keep Kristine in her home school. She was taught some sign language, mostly Signed English early on. She was in a self-contained program or mainstreamed for her entire K-12 education. She had speech therapy and used hearing aids and interpreters.

The 1970s also brought new technology to the Deaf community. Teletypewriters, like those used in Western Union offices, were being discarded, and Deaf people reclaimed them and used them to communicate by typing over telephone lines. This was the first time Deaf people had independent access to telecommunication that hearing people had enjoyed for over 60 years.

Paul's school experiences were more like Anne's and Will's, while Kristine's experiences demonstrated the new approach to Deaf education--mainstreaming, more similar to the experience of John and Lauren, including interpreters and sign language. This was a time of rapid change.

By the time Lauren and John had entered school, mainstreaming was the new norm. Fewer Deaf children went to state schools for the Deaf, and various forms of

signing and other communication systems were gaining popularity in schools. Signed English systems were predominant in public schools with Deaf programs, and cued speech was introduced. Oralism, while still present in speech therapy, was less exclusively applied.

Cochlear implants had been introduced, and both Lauren, at age 15, and John, at 4, had been implanted. Lauren was involved in the implant decision; John's parents made the decision for him.

Lauren and John had sign language interpreters with them in public schools. Their mainstream experiences were lonely. Their social lives were limited as a result of communication barriers, and they had few opportunities to develop one-on-one relationships with teachers or students.

Deaf students in mainstream settings often did not have access to Deaf peers or role models. Summer camps became places where deaf children could meet and learn from other Deaf peers and adults. These opportunities were very important for John and Lauren to begin developing their Deaf identities.

From Anne's time, when letter writing was common, and the telephone was inaccessible, to John's time, where access to captions, videophones, text messaging and the Internet is commonplace, technology has influenced life for Deaf people in many significant ways.

Teletype machines (TTYs) were a breakthrough in telecommunications access for Deaf people. TTYs were used to type over the phone lines to others with the same equipment. Will remembers how exciting it was to be able to contact people directly and

talk (type) for hours, just because they could. Typing over a TTY line took comparatively longer for the same amount of information. Will amassed hundreds of dollars in monthly phone bills, due to the long distance charges, angering his parents, who began to limit his time on the TTY. Later, as TTYs became commonplace and the novelty wore off, they were used more to send and receive brief messages and less for extended conversation.

Today, TTYs are virtually obsolete. John has had very little experience with TTYs, since his generation routinely uses text messaging, email, and videophones. Staying in touch with family and friends, Deaf or hearing, is easy and efficient with these technologies. Text messaging and email provide equal experiences to hearing and Deaf people. Videophones now provide a visual avenue for phone calls, and the Deaf community has enthusiastically embraced this technology. For the first time, people can see each other on a video screen and communicate naturally, directly and clearly in sign language with friends and family.

The Internet has opened up avenues of access to Deaf people unimaginable even 25 years ago. Because of communication barriers, access to information was limited and efforts to find information cumbersome and time-consuming. Because of limited access, Deaf people often didn't know what they didn't know. They often had to rely on hearing people to gain access to information or to shepherd them through complex processes. Now, Deaf people can learn about nearly anything with a simple mouse click, and can send requests for information over the Internet without having to speech read hearing people. This access to current events, trends, merchandise, and news has helped Deaf

people catch up in areas of American cultural common knowledge. Even better, Deaf people can have immediate access to other Deaf people, Deaf news, and Deaf websites, and can keep up with Deaf community events easily.

Technology in the entertainment industry has also helped Deaf people become more engaged and culturally current. Anne remembers going to the movies when she was at the Deaf school:

“We went to movies in town, even though there were no captions, we still enjoyed watching. Plus, movies only cost 12 cents.”

In the 1970s and 1980s, the U.S. Department of Education sponsored a captioned film project, and 16 mm films were captioned and made available to Deaf and hard of hearing subscribers. Will experienced this service:

Before VHS and captions on movies, we would get films on loan from the government that had open captions. These were reel-to-reel films! We would gather at someone’s home and watch movies that were a year or two old, but had just come out with captions.

Later, VHS and DVD versions of feature films were produced with captions, but often long after the commercial theater run had ended. Early on, only a few movies were captioned, but the demand and the awareness increased, and now it is rare to find a current movie on DVD that does not have language and subtitle choices.

RESEARCH QUESTION 2

What are the common cultural themes found in stories of lived experiences of Deaf people?

“I’m Different Somehow...”

Deaf people frequently report having one or more formative experiences where they realize they are different. They may not yet understand *deaf* and *hearing*, but they sense something is different. They may have a realization that they misunderstood instructions, or that other people somehow have additional information that they do not have. Lauren described an experience she clearly remembers from kindergarten in her local public school:

One time the teacher explained a project and I did it. But I looked at everyone’s finished product and mine was really different than everyone else’s. I knew it wasn’t right, but I didn’t understand how that happened. I remember hiding my project under my shirt. I didn’t want to show it to everybody because I had done it wrong and I thought I would be in trouble for missing the instructions.

She had a similar experience in Girl Scouts:

When I was six I went to Girl Scout day camp and I remember that it rained torrentially for a whole week. They would say “Tomorrow don’t come in the morning,” and I’d show up in the morning with my bag lunch. We made bags that we sewed around the edges. One day they told us not to bring those the next day -- but the next day there I was, and I brought my bag because I had misunderstood. I was the only one that had my bag. Everybody else didn’t, so

that was embarrassing. I noticed I was always doing the wrong thing or being at the wrong place, and I was just six. But I remember clearly being wrong so many times.

Will explained an experience in his kindergarten program, that he would not fully understand until decades later:

It was a kindergarten program in the public school. I attended for only a short time. I saw a boy come over and snip the braids off a girl sitting in front of me. The next day, I got ready for school and my mother said I was not going to school that day, or the day after and so on. I did not go back to that school. Many years later, I asked my mother why I never returned to that school. She said it was because I cut the braids off the girl sitting in front of me. I learned I was blamed for cutting her pigtails and had been expelled from the school.

John described a situation where he realized he and his whole class were different:

In elementary school I was in a self-contained classroom within the public school. There were about 10 kids in the program. This public school had two floors—one floor housed the hearing students, the other floor housed the deaf and disabled students. Upstairs was like a different world where we did not belong. I was afraid of it.

Realizing that hearing loss is a contributing factor to missing information brought some children more anxiety. In elementary school, Lauren was afraid she might miss the fire alarm:

In first grade I often wet my pants, and the reason why is the bathroom was up on the second floor, and my classroom was on the first floor, and I was always afraid that if I left my classroom to go to the bathroom I would not be able to hear a fire alarm go off so I wouldn't go. And I would hold it and hold it and hold it till finally I would have an accident. One time, the teacher asked me, "Would you mind passing out these cards?" and I took the cards and then wet my pants right there. That happened several times. I thought I would die if I didn't hear the fire alarm so I wet my pants.

Deaf students frequently recognize the potential for communication misunderstandings and embarrassment, and find ways to avoid these situations. Kristine explained why she found herself withdrawing from classroom interactions:

I used my voice to talk to the teachers, but I was very self-conscious about my voice, and was very soft spoken. They would continually tell me to "Speak up, I can't hear you!" This became very embarrassing, so I eventually stopped asking questions, and if I didn't understand something, I would ask my mom after school—and she would call the teacher to get the information. Later, I had interpreters in the classroom, but eventually I stopped raising my hand to answer any questions. Too many things could go wrong: 1. The interpreter might not understand me; 2. The teacher might not understand me; 3. I might not understand the interpreter or the teacher; 4. I might not even be on the right topic.

Many Deaf children clearly lived with the fear that miscommunication would impact their behavior, causing stress or embarrassment. In mainstream settings, this fear only escalates during middle and high school, when peer admiration or disdain is a guiding force in a child's life, and social inclusion is vital.

Lauren remembered her experiences:

Communication and inclusion was limited--remember it was a small school--only 25. We all grew up together, so they knew me, and yet there was limited communication. They included me in elementary school, but I wouldn't say that it was equal. It was like dragging me along, you know, just letting me be there but not be fully included. Some of them, most of them could finger spell, but that was still very limited communication. I was behind with my emotional development--even when I was 12 I felt like I was only six because I had had such limited social experience. The hearing children could gather together and socialize easily, and they criticize each other and they kept each other up to date and I was completely out of the loop. I missed out on all of that. So I was emotionally isolated from that socializing experience. I really never got any of that incidental learning, and as a result I fell further and further behind. And I developed some behavioral problems and some problems with the teachers. I wish someone had taught me or explained more to me about the rules of socializing--you know, for example if someone said "You know when you repeat self over and over again it's not really that funny." I wish I had some instruction on the rules of social behavior. In high school the social experience was also important. All the other subjects at

school--I could do them--I could learn--that was no problem. But in my home school, my social life was extremely limited--it was as if there was a wall. In high school, I wanted to date, but the problem was that I had no patience with the communication. There was one guy, he was really cute and he asked me out. I went and we were in the car with a bunch of friends, and everybody was talking, and I didn't know what was going on. Now I have avoided this kind of activity in the past because it was just so hard to put up with the communication issues. It was awkward and quite a struggle. In high school, social life is very important. I was a mainstreamed Deaf person and I really wanted to be involved. But honestly, dating for a mainstreamed Deaf student was very difficult. Also I was paranoid, too, and that's not uncommon for Deaf people--because you see people talking, but you can't hear what they're talking about. It's natural to think they might be talking about you, or to have that curiosity and your imagination kind of running away with you. It was such a struggle to learn the rules of socialization, I really didn't catch on to that till I was in my 20s. In college was the first time really that I had more true communication, and that's where I began to learn my socialization skills. In a lot of ways I was still growing up when I was in college. I still had a lot of growing up to do.

Kristine shared these memories of her social experiences in the mainstream setting:

Recess was my release. I was very active and sports minded--I loved playing games, and when I was young, as long as we were all playing we all got along fine. By junior high, when there was no recess, I became lost socially. The junior high girls' "talking thing" never worked for me, and I was excluded. All of my

friends from my church sports teams went to parochial school, as did my siblings. But I had to go to the public school because of the Deaf program. I felt really different and resentful about this.

Kristine and Lauren's experiences occurred during the 1970s and through the 1980s. One might assume that the social experience has improved for Deaf students in the public schools since then. John, who was in middle and high school in the first decade of the new millennium, gives us these illustrative accounts of his experiences:

In my school, out of 1,400 students, only a handful of students had any signing skill. There were sign language classes in junior high only--none in high school. I had one friend in junior high who learned some ASL, but in high school we drifted apart. Mostly, the kids ignored me, or if they HAD to talk to me, they used the interpreter--it was bad. When I was fully mainstreamed, in grades 7-10, I pretty much went to class and went home. No socialization, no activities.

The importance of social inclusion for teens cannot be underrated. Lack of genuine inclusion reduces self-esteem, self-confidence, learning and classroom participation.

Can public schools not serve Deaf students well? Are all their experiences negative? When asked about positive experiences and favorite teachers, the interviews revealed several highlights for Deaf students. John shared these two stories:

My favorite teacher in my public school was my 8th grade science teacher. When I would answer a question, he would actually look at me--instead of at the interpreter. It was unsettling at first, and I felt more pressure to have the right

answer. But I got used to it, and appreciated that he made that effort to have a relationship with me. Then in high school, the teachers that would look at ME instead of the interpreter got a lot more out of me. It demonstrated that they were not brushing me off or marginalizing me. This changed my approach, too. I began to look at the teacher more too, as if to challenge them to look at me. There was one time I felt higher than the hearing kids--it was a joke my teacher used in my world history class. The subject was evolution and he commented on the fact that human senses have decreased--sight, hearing, etc. The joke was that I was more evolved than everyone else in the class. It was funny--nice of this teacher to use humor to help me feel included.

Kristine shared these two experiences:

My school district had a self-contained program in the public school. It was actually pretty good. There were about 4-5 kids of all ages in the program when I started. I bonded with my teacher because she was hard of hearing. I felt she was kind of like me.

I don't remember having any teacher that was a problem for the Deaf or hard of hearing kids. In fact, in 4th grade, my reading teacher knew how to sign, so I was placed with her. I was AMAZED! And I just watched her sign--no need for an interpreter--IMAGINE! I really felt involved in that reading class!

Lauren's positive experiences occurred in extracurricular activities. She played basketball:

It took me a really long time--years and years, really, to understand the rules of the game. But once I did, I excelled and I was all-conference, all-region. The school provided an interpreter--that was nice. During play it would be the coach, and the coach was nice to include me. He'd have different signals for plays, and he would use those, and that was very nice. Once I understood the game and how the rules worked and everything, then communication also improved because I knew what I was doing. My coach was concerned about the wire from the cochlear implant to the processor. He suggested (get this) that I wind the wire around my neck (laughs). So I didn't wear the cochlear implant! But it was fun, and I felt included.

Finding Others Like Me

Deaf children in mainstreamed settings are often the only Deaf people in their grade, school, or community. As an enrichment opportunity, summer programs for Deaf children have been offered by state agencies, service organizations, or special camps. Among these are the Minnesota Conservation Corp, Courage North, and Lion's Camp. The three participants who attended mainstream schools, Kristine, Lauren and John, all participated in these programs. For all three of them, their experiences in these programs proved pivotal in their understanding of themselves as Deaf individuals within a Deaf community. All three came away from their camp experiences with a heightened sense of self-identity and a deep desire to attend school with other Deaf children. Some were

angry that they had not been exposed to this world before. When asked about when they realized there was a Deaf World and a hearing world, Kristine, Lauren and John all identified their summer camp experience as the point that this idea became real to them. All identified their camp experience as an epiphany. What Oliva (2004) calls the “Met Deaf, Wow!” moment is essentially what these three mainstreamed Deaf children experienced at their summer programs.

Kristine’s described her experience at Courage North:

I remember very clearly when I realized there was a Deaf world and a hearing world. Before my 9th grade year, I went to Courage North, a Deaf camp. There were many Deaf kids from Faribault, and I learned A LOT from them. They all signed ASL and talked about my rights as a Deaf person. I went home and was pretty angry and aggressive with my parents. I told them I wanted to go to the school for the Deaf in Faribault, where they signed and could understand me. I was really angry! They said no. Courage North was very important for Deaf identity. The counselors were Deaf--good role models. We had peers like ourselves and great interaction.

Lauren told about Lion’s Camp:

It was really fun! I didn’t want to go, but my mother forced me. I think I was 10 or so, and it was really fun! Many young kids the same as me-- we had so much fun. Our communication styles matched, and we just had a ball! It was two weeks, and I thought I would die being away from home for that long. But once I got there, it was really the first time in my life that I’d really had fun socializing with kids my

own age. But it was only once, and it was only two weeks, and that was that. I never went back, and I don't know why. There was quite a variety at the Lions camp--hard of hearing and Deaf--and that was really nice. They were very accepting--it was really cool. I had my first boyfriend there. He was hard of hearing. We were 10 (laughs)! And we wrote letters back and forth for a while after camp. And I met another girl who was really the same as me--it was really fun. After that I really wanted to go to the Deaf school. I really wanted to go there. I found out just recently when I asked my mom, "Why didn't you ever send me to the school for the Deaf?" and she said the teacher for the Deaf and hard of hearing said I would never fit in there. Personally, I think she (the teacher) was trying to preserve her job. So camp was in the summer of my fifth-grade year, and it was during my sixth grade year that I really wanted to go to the Deaf school. I had just had this marvelous experience of being immersed with other kids like me, and it was amazing! It was so different! Wow just WOW! My mom told me a couple years ago they were looking for a way to send me to the Deaf school in Delavan. They were looking for an opportunity for both mom and dad to find work in Delavan so we could move as a family. They really didn't want me to go alone. But remember what I said about the teacher for the Deaf and hard of hearing? She convinced my parents that I wouldn't fit in there, and in the process saved her job. That one experience at Camp was absolutely huge for me! It had quite an impact. I remember my teacher told me that I wouldn't fit in there, that I was different. Maybe she was right, but I knew that I could go there and be

happy, I knew it. Nothing was a perfect match for me, and I didn't have to be exactly like the other kids there. But my experience at the camp convinced me that I would fit in at the Deaf school.

John had a life-altering experience with the Minnesota Conservation Corp:

I realized kind of late that there was a Deaf world and a hearing world, and they are different. One summer, I worked for the Minnesota Conservation Corp--there were 50 hearing kids and 8 Deaf kids. The hearing kids were required to learn the fingerspelled alphabet and some basic signs--for safety. But most of the hearing kids wanted to learn more, and they were not afraid to approach the Deaf crew. We all became friends, and by the end of the 8-week program, they had functional signing skill--it was cool. I realized at my public school, I was "no one," I was invisible. I wanted to be someone, so I decided to transfer to the Deaf school in the second semester of my junior year. That's when I understood the Deaf world for the first time.

All three students wanted to transfer to the Deaf school after having a rich social experience with other Deaf children and adults for the first time. John, however, is the only one who was allowed this opportunity.

The Deaf School: A New Home and Family

Once a student makes his or her way to a Deaf school, it is frequently referred to as a second home or a second family. Some even consider the Deaf school to be their first home and family. Four participants in this study attended Deaf schools for all or part of their primary and secondary education. Their attendance at Deaf schools spans 70

years, beginning in the 1940s and culminating with John's graduation in 2008. Many changes have occurred over the 70 years, but the essence of school as Deaf family continues.

Deaf schools provide the opportunities for students to participate in a variety of activities that might, in mainstream settings, be considered highly unlikely or even impossible. Academically, students may experience greater meaningful inclusion than they experienced in the public school. John addressed some surprises he discovered after transferring to the Deaf school in his junior year:

When I got to the Deaf school, I realized I had innate skills in debate. I won almost every debate, including debates with teachers. I can argue with the best of them! I would never have realized this skill in the public school.

In the Deaf school, one teacher particularly inspired me. It was in creative writing. The exercise was to look at a picture for 5 minutes and then write about it for 15 minutes. She told me that a boy in the 1980s had the best story, and no one had beaten him. Well, guess what? I took that challenge and I beat him, so now my story is the best one.

Anne, who attended Deaf school in the 1940s, shared her memories of extra-curricular activities:

Oh there was SO much to do at the Deaf school! Everything was planned by the school and always chaperoned. Girls and boys ate separately, and had alternating 'town days.' There were picnics and dances, and we went to town on Saturdays. I was in the Luther League and in the marching band/choir. You

might not believe it looking at me now, but I was a cheerleader, and pretty good too! As a junior I was selected to go to Gallaudet as a student ambassador.

The Deaf School: A Panacea?

With the difficulties faced by children in mainstream settings, Deaf schools might seem to provide appropriate communication and social environments. Very often they do, but not always for study participants. Two participants, Paul and Will, attended Deaf schools from an early age, but they provided mixed reports about their experiences.

Paul remembered:

K-6 was a strict oral program. There were only hearing teachers. If we signed, our hands were slapped with a ruler, or were tied together. To prevent signing, we often had to put our hands behind our backs or under the tables. I did not learn my name until the age of 6. Grades 7 and up had some Deaf teachers, but it was still an oral program. Some of these teachers would “rebel,” and when the principal was not present, would sign to us. I feel I was mostly self-taught in school. I sat through oral classes where I could not follow anything, then did reading on my own and checked in with other students to compare what we understood--this was preferable to asking the teacher.

Will had a similar experience:

Lexington School for the Deaf was an oral-only program. Teachers were hearing, and dorm parents were Deaf. Signing was prohibited. But the dorm environment was a rich language environment with ASL the language of choice. We had to remember not to sign in classes. It was hard. If you were not caught

signing for one month, you got to go on a field trip as a reward. I think I only got that reward once or twice in three years! Part of each student's math evaluation was correct pronunciation of math vocabulary, rather than math concepts. I was labeled hyperactive (what today is ADHD) and given daily medication. I sometimes did not take the medication and threw it away. It made me nearly catatonic. They could not control me. I was frequently in trouble. Eventually, I was kicked out of Lexington school and labeled an 'oral failure'.

Will and Paul, as boys, had similar experiences when staying with schoolmates who had Deaf parents. Here is what Paul related about that experience:

"One of my friends had a father who was Deaf and signed. I always wanted a Deaf father. These Deaf parents of my peers also influenced my parents."

Similarly, Will's experience is described here:

I met other Deaf children with Deaf parents. I stayed overnight with a friend who had Deaf parents. I could not believe the home environment! His parents were signing! It was unbelievable to me, as if I went to someone's house and the parents were signing! It was normal for them and I could not get over it. I went home and told my mother "I want different parents – I wish I had Deaf parents!"

Speech Therapy

Speech therapy was part of nearly every Deaf child's curriculum, whether they were in a mainstreamed setting or a residential Deaf school. In oral-only programs, speech was often the focus of nearly the entire curriculum. Students spent hours in speech therapy at the expense of content learning. As Will described, his math evaluation

included the skill of pronouncing all the math vocabulary correctly. Answers might not be considered correct if they could not be uttered correctly. During the interviews, all participants mimed many of the same exercises they were required to perform day after day, in order to try to articulate correctly a sound that they could not hear. These mimes included blowing on paper, puffing out a candle, or placing their hands on their nose or throat to replicate a vibration demonstrated by the speech therapist. When these explanations were signed in the interviews, an important ASL grammatical element was consistently present--the non-manual marker showing tedium, boredom, and careless action. Most participants shared similar experiences and opinions on the value and need for speech therapy.

Anne, who became Deaf at the age of 13, was released from the requirement of speech therapy at the Deaf school because she had retained an understandable amount of speech quality. In fact, she became the one student always chosen to speak at school functions, such as graduation. She was named co-valedictorian with another girl. The other student was allowed to sign her speech, but Anne was required to speak aloud to deliver her speech. Here is what Anne remembered about speech therapy at the Deaf school in the 40s:

“I did not have much speech therapy because I had good speech skills from my hearing years, but the other kids hated it.”

Will, who attended Deaf schools from the ‘50s to the late ‘60s, tells about speech therapy being a fundamental focus of the school. He recalled:

At Lexington, we had speech class, but speech was also infused in every class all day long. In math class we had to SAY 'two plus two is four.' It didn't really matter if we knew the math, what was important was that we could say it. I did not learn my multiplication tables until I was 15! I was confused by division for a very long time! In speech class, we worked on one sentence for weeks at a time. I remember being drilled on these sentences: 'Christopher Columbus sailed the across the ocean. He discovered America in 1492.' Weeks and weeks learning the sounds--that 'CH' in Christopher is really a 'K' sound, that the 'A' in different words is produced differently. Weeks and weeks. There was great competition surrounding our speech. Student speech evaluations were posted on the bulletin board and we could clearly see who was the best and who was the worst. Another sentence we spent weeks on was, 'I would like to order a strawberry ice cream soda.' After weeks of practice, we went as a class to the Woolworth drug store soda fountain. With the whole class and teacher watching, we would recite the sentence to the waiter. If the waiter said 'What?' we had failed and had to repeat. All the students would count the number of times we each had to repeat the sentence. The fewer repeats, the more recognition we got from the teacher and the other students. Another exercise was trying to decipher a sentence spoken by the teacher with a piece of paper covering her mouth. I am so Deaf, I could only guess. These exercises were tremendously stressful--so much pressure to perform correctly and most often I had no way to understand it.

Paul attended deaf schools from the '60s through the mid '70s and this is part of his speech therapy experience:

"In elementary school, we had one hour of speech therapy every day and auditory (listening) training too. Even though I won a lipreading award, I felt it was a worthless waste of time."

Kristine attended a mixed program--some mainstream classes, some self-contained Deaf classes, from the '70s to the late '80s. Kristine shared this about her experiences:

I didn't mind speech therapy in elementary school, but by high school, I was sick of it. I told my mom that I wanted to quit. She said I could quit, but if my speech quality declined, I would have to go back. And we agreed to cancel my speech therapy. It was so repetitious and really boring. They should change it up a bit--especially in high school--should incorporate other high school subjects and activities in speech therapy--to make it more relevant. I have problems with "S" and "Z." I still can't hear em, still can't say em. I'm still self-conscious about these sounds, but brave enough now to ask.

Lauren, who attended a mainstreamed program in the '80s and '90s, had this to say:

I have pretty good speech. Whether that's lucky or not lucky, I don't know, because I don't really value speech. I know it's a nice benefit, but sometimes I wish I didn't have it because I get labeled as hard of hearing, or even worse, as hearing. And that's not me, that's not who I am. As I lost my hearing, my speech quality became more nasal and I had to learn to control that and also control the volume, but that worked pretty well. It wasn't bad. After I had my cochlear

implant I really had no rehab or no therapy to speak of. We tried that one summer, but the teacher never showed up for anything and so we just dropped it.

Finally, John, who was mainstreamed from pre-school through ninth grade, reflected on his speech therapy experiences that occurred in the '90s and '00s:

I had speech therapy from the ages of 1-10. I hated it. Hated it. I hated having people touch my face, throat, nose, etc. Looking back, the speech therapist knew nothing about Deaf culture. They were after-school therapy sessions, and I learned nothing! The in-class speech teacher was better. Her approach was more language oriented--parts of speech, verbs, nouns, etc. This proved to be much more beneficial to me.

Sign Language Interpreters

When Public Law 94-142 was passed in 1975, it mandated that all children be educated in the least restrictive environment (LRE), but the assumption was that a child's neighborhood school was a natural LRE, and accommodations could be provided to accomplish full inclusion. As many Deaf students headed back from Deaf schools to their home schools, sign language interpreters were needed at all levels. The sign language interpreter was the accommodation or link that would provide equal education. This marked the infancy of educational interpreting as a profession. Interpreter training programs were few, and there were no required standards for interpreter skill, methods, and professional behavior. The participants who attended residential schools for the Deaf had very little experience with educational interpreters until college. Those attending

mainstream programs experienced sign language interpreters in classrooms, meetings, and extracurricular activities. For some, working with an interpreter was unpleasant.

Lauren shared this experience:

Well, the first ones were interns, but they had no mentor, no one observing or supervising them, so how did that benefit the interpreters? It was strange. Now times have changed. That was a long time ago. They were from Wausau, and they sent someone every six weeks at that time. I had these interpreter interns from sixth grade to when I graduated--six years.

John explains his relationship with interpreters in his home school:

It was difficult. Virtually all communication went through the interpreter. Teachers and students communicated with me only through the interpreter. At one point the experienced interpreter I had had for 10 years left and a new interpreter was hired. This interpreter was inexperienced, awkward, and very tentative. She avoided letting the teacher call on Deaf students.

Kristine looked back on her elementary school understanding of her interpreter's role, and on the high school interpreter who had difficulty signing certain vocabulary:

I had interpreters and at first, I thought they were all my 'school buddies' and I thought that was cool when I was little. They functioned more as 'helpers'-- maybe even creating some co-dependency issues....In high school I had an interpreter who was a strong fundamental Christian. She refused to sign the word 'HELL.' Instead, she signed the phrase 'FIERY PLACE.' I really could not

understand what she meant. It was so absurd in context. The sentence was something like 'We worked like hell.' Imagine!

Lauren spoke to the complexities involved in a student-interpreter relationship:

You asked about my relationship with my interpreters. Some were good some were not. Sometimes I notice that hearing parents who have Deaf children may not be really adept at reprimanding them or explaining things to them. And for me that was somewhat true. I didn't have the proper behavior all the time. And sometimes the interpreter was just not a good match. The best one was a guy. He was gay and he was really cool. I thought it was cool--he was fine. He didn't tell me how to ... how do I explain it.... some relationships are good and the reason is they don't allow me to, you know, behave crazy--but they also don't treat me like a child or preach to me. Now the bad ones, for example, some of them were personality mismatches. Some were interns, some just were not very good.

Deaf Schools as the Vault of Cultural Knowledge

Elements of both mainstreaming and all-Deaf schools were distasteful to Deaf students. Oral-only education, hearing teachers who could not sign, and undue emphasis placed on speech therapy are some of the unpleasant memories from participants' public and Deaf school experiences. How, then, did Deaf schools become such revered places in Deaf Culture? Deaf schools in the United States have historically been the heart of the Deaf community, the trustee of cultural knowledge, the vault in which information and cherished stories are held and passed on to succeeding generations in the language of Deaf people--American Sign Language.

When Anne found her way to the Deaf school, the first year was difficult for her, but she settled in during her second year. It became a second home, a second family to her.

I went to Faribault when I should have been 9th grade, but I was moved back to 8th grade, because I was learning sign and because the 9th grade class was almost all boys. I went home the first summer and I did not want to go back, but my mother was adamant about me getting an education, so at the end of the summer, she packed my things and I went back. By my second year, I really felt part of this world--these people became my second family--and we were very much like a family. We care about each other, but we also fight and make up.

After Will was dismissed from the Lexington School, he enrolled in the American School for the Deaf. About this time, his mother, who had formerly been president of the Oral Education Organization, had a revelation. She met a Deaf boy who had Deaf parents. This boy could describe in detail all that he knew about the game of baseball--in sign language. Her own son, now an oral failure, could not even come close to this much functional literacy, and they were the same age. Will describes his first impression of the American School for Deaf:

I was moved to the American School for the Deaf in Hartford. It was night-and-day difference. Freedom, freedom! Language was ASL. At first the students there criticized my signs—even that was amazing--to be discussing sign language so freely! It was no longer taboo. There were Deaf teachers who were allowed to

use sign language. It was more academically rigorous than the oral program. It was such a rich language environment, I needed no medication to keep me in line.

Although Paul's school was predominantly oral, and he was a commuter student living a block from the school, he remembers the dorm life as having the greatest impact on him:

"Even though I was a commuter student, the dorm environment saved my life. It was there I experienced Deaf role models and language models, and benefitted from significant informal learning."

John's reflections on being able to attend the deaf school:

I decided to transfer to the Deaf school in the second semester of my junior year. That's when I understood the Deaf world for the first time. It was at the Deaf school during my senior year that I became truly myself as an individual and a deaf person.

Cochlear Implants

John and Lauren have cochlear implants. John was implanted at the age of 4, Lauren at 15. John no longer uses his implant, Lauren uses hers only when she is interacting in the hearing world.

Lauren was involved in making the decision to get a cochlear implant:

I got my cochlear implant a long time ago, when I was 15, one of the oldest children to get one. I think it was 1988 or '89. I had had a profound hearing loss since the age of 11. How it happened is an interesting story. I always read a lot ever since I was small, and I read about it in a magazine at a hearing aid store. It showed a big unit that you wore at your waist with cords going up to the

hearing aids. I was not interested at the time. I remember even though I was young I still felt proud at my Deaf identity. I wasn't involved in the Deaf community or fluent with ASL communication but I still had a feeling of pride in my deafness. Isn't that interesting? I remember clearly my mom was driving and I was in the car. I was thinking about this and I was changing my mind. I was thinking that I'm ready for a change, I'm ready to be able to communicate. It was like I wanted to switch modes and be able to communicate better. I was 13 or 14 and in junior high school at that time. I was very lonely and really wanted to be able to communicate and interact and socialize with my peers. I had met some Deaf people, but I didn't feel that I really fit with the Deaf community then. They seemed uncool and kind of backwards to me. My mom did a lot of research. She never encouraged me one way or the other, she just gave me information that she thought I would be interested in. She was always a really good support for me. You know, she paid for it back in 1988! My mom paid for the surgery in '88, can you imagine? I went to Iowa because Minnesota wasn't doing the surgery yet. They didn't have a program yet, so there were only a few cochlear implant programs in the country--New York, Iowa, so I went to Iowa. I was number six out of the Iowa children. I was the sixth child to get a cochlear implant. In the whole United States there were still less than 100 kids who'd gotten cochlear implants, and I was number six. Did the cochlear implant help me in school? Oh, socially, yes, absolutely. It really helped a lot. Remember I was in the world of the hearing, and remember that I had a memory of sounds in my brain, so my

brain still could work in an auditory way. My brain still had that pathway you see, so it did help me. I remember with the cochlear implant, while it was still new to me I would get really offended by people saying now you can hear, but I think I still have a right to sign. So right away I was still stubborn about demanding that people sign to me. In school, it was their responsibility after all. Now, at home I don't use it at all. Out in the world, when I'm socializing or at the children's school, it really helps

Here is John's perspective on his cochlear implant:

I have a cochlear implant that I received when I was too young to remember. I do not use it any more. I don't like it. The sound is artificial. I still can't understand differences between "a" and "e." It makes even quiet noises very loud, like my clothing layers rubbing together, or the sound of my breathing inside my head. I prefer quiet, and the cochlear implant is not quiet. The only time it was really successful was when I was watching The Terminator movies--with Arnold Schwarzenegger--the tinny, robot accent sound worked with these movies!

Post-Secondary Experiences

For Deaf students, the choice to attend post-secondary education is often not only an educational, but also a cultural decision. High school Deaf students who have a strong Deaf identity are more likely to attend a Deaf post-secondary institution. Mainstream Deaf students with less exposure to the Deaf community may choose a public institution closer to home. Students whose identities are forming may find themselves unsure about

either choice. Three participants attended well-known Deaf post-secondary schools, two selected public four-year institutions, and one did not attend college. Their levels of preparation, maturity, and success varied. Even with some rocky starts, four went on to complete graduate programs at mainstream colleges or universities.

Anne had an opportunity to attend Gallaudet. She had visited the campus and was offered a scholarship. She chose not to go, but her reasons were, in part, based on misinformation. Anne explained:

I received a scholarship to Gallaudet, but one reason I turned it down was because I didn't want to be a burden on my parents. What I did not understand was that the scholarship went for four years, and the state could help if the family could not afford college expenses. I didn't know that. So I didn't go. If I had gone to college, I would have been a history teacher. It wasn't until years later that I learned I could have applied for state aid.

For Will and Paul, comparing two high profile Deaf programs was key. Both were looking at Gallaudet and The National Technical Institute for the Deaf (NTID), a college of the Rochester Institute of Technology. Congress signed the charter for Gallaudet College in 1864. NTID was established 101 years later, in 1965. In the 1960s and '70s, Deaf students were beginning to recognize the patriarchal traditions at Gallaudet, and looked to the new and modern NTID to provide more freedom. Will and Paul visited both schools, and both decided on NTID at the beginning. Paul explained:

I planned to go to Gallaudet to become a teacher. During my senior year in high school, I went on a tour of the new program at RIT. I loved the environment at

NTID and changed my plans. In 1974, I entered the prep program there. First, I was interested in forestry, then later changed to social work.

Will's decision was based in large part on being able to participate competitively in a sport:

"I went to NTID, mostly at first for the opportunity to swim with the RIT team. Also, the rules at NTID were quite a bit more lax than at Gallaudet."

However, Will did not stay at NTID.

"I could not find the right major at NTID, so I transferred to Gallaudet. The rules were much tighter--very patriarchal. The students fought against this, and finally the rules changed when Gallaudet realized students were choosing NTID."

John is attending Gallaudet.

My mom is fine with me going to Gallaudet. My Dad wanted me to consider the University of Minnesota, but he respected my decision--he just wants to make sure I get a good education. I have some fears about going off to college, but they are not about distance from home or academics. I am more afraid of peer pressure to party, and money management. I am going to college to get an education, and I don't want to be sidetracked by parties. I don't want to end up dropping out.

After years of being alone in the public school K-12 system, a Deaf student may find a public college to be more of the same, or a completely different experience.

Lauren and Kristine attended public four-year universities with interpreters and note-takers. Both found the experience to be positive, but in very different ways.

Lauren was amazed by the quality of education and her ability to succeed:

WOW! I loved college. Loved it! I loved learning and I realized I was capable of learning and succeeding. The interpreters were great and I also had note-takers. I remember when I first came to the university as a freshman, socially I was overwhelmed and frightened; academically I was incredibly happy. My mind was finally satisfied with my ability to learn, and I just soaked everything up and I was so excited about biology! It was a very hard class, but I aced it and I realized I was capable. And I could show people that I could succeed. I remember one of my friends from high school, we're actually still friends now, but in high school she was kind of an asshole, she tutored me in chemistry. She was so impatient, with heavy sighs, rolling her eyes if I didn't get something--it was awful. It was really not her personality to be a tutor--she knows that now--and we're still friends. When I took chemistry, although I still struggled, I understood and I aced that too! The reason was a good teacher and a good interpreter!

Kristine felt underprepared for college, but initially succeeded in a different way:

I was accepted at Gallaudet, California State University at Northridge, and NTID, but I was afraid to go away from home. I went to St. Cloud State University and graduated with a BFA in graphic arts. As I look back on my high school years, the teacher of the D/HH "helped" me a lot, but did not truly prepare me for college. Likewise, the interpreter in high school "helped" me, but in college, it was hands off with regard to the interpreter role. It was a difficult transition for me and I learned through many mistakes and mishaps. Now I feel adamant about the D/HH teachers' role in high school--to back off a bit in high

school, not do so much FOR the D/HH student. It is easy to become dependent and passive as a high school student when everything is done for you. My first two years in general education requirements were very difficult academically. I got a lot of Ds and Fs. But socially it was amazing. I lived away from home for the first time, and I lived in a house of 20 girls. My roommate was also Deaf, and another good friend was a Child of Deaf Adults (CODA). We hung out together, partied, talked, and had so much fun! I had been so isolated in high school. I was very delayed in my social development. Here is where I was catching up--to the detriment of academics. I entered the Miss Deaf Minnesota pageant and was asked about my future goals for my life. I realized I had none. This realization gave me focus, and I became more serious about school.

Lauren also identified some social development gaps, and recognized that interpreter relationships require boundaries.

Looking back on my first year in college, I think it's inappropriate for interpreters to become friends with young students. One of my interpreters did that. As a college freshman I was very lonely and thirsty for contact, and thus accepted anything. And I think in that position interpreters should know they have a big impact on young Deaf students who are mainstreamed and may be very innocent with regard to college life. The dissatisfaction I felt in my social life meant that I should have been more brave getting out with my peers at college. And this attachment to one of the interpreters may have prevented this. Was it hurtful? No, I don't think so. But in hindsight, it may not have been the best choice. One

of my interpreters was struggling one day in Chemistry class, misspelling some of the technical terms (I still got what she meant), and at the end of the class she scooped up her stuff and said "I hate this job!." I felt terrible, guilty and responsible. But she needed to take responsibility for her skill level and lapses, too. But I still have very warm feelings for her in retrospect.

Even students who intentionally chose a Deaf post-secondary institution will likely find themselves, at some point, in a mixed setting with both hearing and deaf students, or in a predominantly hearing setting with sign language interpreters provided as an accommodation. This can be a startling experience for students who are accustomed to getting information directly from a Deaf or signing instructor and Deaf peers. Will and Paul faced this adjustment with different results. For Paul, his choice of major moved him to the mainstream program in social work at RIT. He described his experience:

The social work department was in the mainstream part of the college. When I entered that program, I experienced total culture shock. It was traumatic. I dropped out for a year and worked as a tool and die maker. I went back a year later and completed my BSW. I went on to get my MSW. In both these programs, the predominant signing system was Signing Exact English (SEE). Lots of SEE signs. I met and was influenced by a professor who could speak 27 languages. He singled me out in class and said, "Don't let your language and culture get away from you. Preserve and cherish it. Don't be seduced by the hearing world. " Profound. After that, I embraced ASL and left the SEE signing behind.

Will's experience:

After sophomore year, I had to decide on a major. I chose sociology/social work and graduated from Gallaudet. I attended NYU for my masters in D/HH teaching. There were only two deaf people in the program. All the rest were hearing. It was the first time I had used interpreters.

Communication With Family

All participants in this study were born to hearing parents. This is typical, since over 90% of deaf children are born to hearing parents. Communication in such families is a life-long challenge. Even if sign language is allowed in the educational setting, it is not necessarily common at home. As with any language, ASL requires time, practice, and patience to learn. It is more difficult for adults to learn a new language than for children, especially during their formative years, when their brains are flexible towards language learning. Children's progress in sign language acquisition may rapidly exceed that of their parents. If children attend a residential school, the opportunity for parents to use and improve their signing with their children is limited. There are numerous challenges to family communication when a deaf child enters a hearing household.

Anne became Deaf at a time when sign language not accepted by hearing people and Deaf children were sent away to the state Deaf schools. No one in her family signed when she was growing up. Will's family enthusiastically embraced an oral-only approach, at least initially. Paul's parents were told not to sign. Later his mother grew frustrated that Paul and his Deaf sister had conversations that she could not understand, and she eventually learned sign language. By the time Kristine was born, signing was

again a communication option for Deaf students, although usually not ASL, but SEE signs. Kristine's whole family took sign classes, but Kristine describes their skill as survival level signing. Lauren and her mother took ASL classes, but the school used SEE signing. John's mother also enrolled in sign classes and began teaching John sign language as soon as she learned he was deaf.

John described his communication with his parents and his extended family:

I can talk about anything with my parents; but communication is slow, laborious, and somewhat limited. My parents have no Deaf friends. Family communication? Nothing (Blow on palm). It's "Dinner Table Hell". I eat my food and go watch TV. I prefer not to have my parents interpret for me--they don't understand, can't read my fingerspelling, and they keep asking "what?, what?" Plus, my independence is gone. So if I HAVE to be in these situations, I prefer to keep it simple with 'Yes/No' questions. If my mom interprets, the communication is still limited.

John's *Dinner Table Hell* is a common experience for Deaf people. If everyone at the table is hearing, conversations happen quickly and speakers change rapidly, making it difficult to keep up if one is speech reading. Deaf people often tell the same story of feeling excluded, and when they ask "what did s/he say?" commonly they are told "Nothing," "Never mind," or "I'll tell you later"--and 'later' never happens.

In participants' married families, communication expectations are different. Five of the six participants are married, three to deaf spouses, two to hearing spouses. All married participants have at least one child, and all of these children are hearing. All of

the children sign or fingerspell. John, at age 18, is the youngest participant and not married. He talked about how he envisions his future family:

I can't predict what will happen, but I can tell you what I want to happen. Yes. I want to get married some day and I want children. I hope my child will be deaf and I want a girl. Boys are more difficult to live with in my opinion. I have had some experience here, but I never had a sister. If my children are hearing, they will sign, but I won't force them into the deaf world, as I felt forced into the hearing world.

Lauren, who is married to a Deaf man, described their children:

We have four hearing children. The eldest daughter signs very well, typical of a CODA. Also, the youngest son seems to have an innate ability to sign. We use home signs and ASL signs. They all sign to some degree. I would not say they are fluent in their expressive skills, but in their receptive skills, they are fluent.

Will, who has a hearing spouse, explained their children's signing skill:

"All three of my children sign; two had innate skill, one had to work hard to learn."

The participants all gave examples of situations in their families where communication posed a challenge or played a part in an important event. Paul told about meeting and marrying his wife, who is also Deaf, and the dynamics of his relationship with her parents:

I met my wife at school, attending an Assembly of God church. Her parents were quite wealthy and she was raised orally. Her father was very strict and controlling. He told me exactly what to do and what not to do. Later, after he

passed away, my mother-in-law came to my church and saw me preach. My son interpreted my sermon. She exclaimed that her husband would have loved that sermon and the great ideas and deep thoughts. He never took the time or effort to get to know me, to communicate with me.

When Kristine met the hearing man who would later become her husband, she did not make it easy for him, because she did not trust hearing men. When he asked her for a date, she told him he needed to contact her by TTY. He would have to figure out what that meant and how to do it. It was a test to see if he was sincere or not. He not only contacted her by TTY, but he purchased his own TTY, so he could call her whenever he wanted to. Kristine talked about how they negotiate living in both worlds:

My husband is hearing. Now we sometimes have to find the happy medium with regard to communication issues. He really helped me find myself. Sometimes there are issues with the Deaf community. It can be an issue if my husband is not there, but if we go together, I sometime want to use Deaf club as “me” time. Now we often take two cars when we attend an either all-hearing or all-deaf event so we can each leave whenever we want. I needed to teach him some Deaf behavior norms about interacting at deaf events.

A mixed marriage between a hearing and a Deaf person can be a source of contention. However, in Will and his spouse’s family, Deaf/hearing was secondary to a larger issue. Will’s spouse is also hearing, but was fluent in ASL when he met and worked with her.

My wife is hearing. In fact, she was the interpreter I worked with in California when I was presenting on 504/94-142. It was actually she who taught me about ASL as a true language. When we decided to get married, our families accepted the Deaf/ hearing thing pretty well. It was the Jewish/Catholic issue that was much bigger.

Anne said that when she and her husband had their first child, they could not hear if their baby was crying in the middle of the night, and there were no electronic devices that could alert them to these sounds. They did what many Deaf parents did at the time; they moved in with their hearing parents. Anne explained:

With our first child, we stayed with my parents for one month. My mother was so worried I would not wake up if the baby cried during the night. She rigged up a string that was tied to the crib and to my wrist, but somehow, I slipped it off during the night. So that didn't work. After one month, my husband wanted us to go home – not keep staying with my parents. My mother was so worried. I set an alarm (visual or vibrating) to go off at 2:00 AM every night. I woke up and checked on the baby. Sometimes she was crying, sometimes not. One night it got really cold in the house because the furnace shut off. I woke up because of the cold. The baby was freezing! She was all wet and so cold. I changed her and brought her in bed with us to warm her up. She was so cold; it was scary. When our second child was born, our first child would come in and wake us up when the baby was crying. In some ways she was more of a mother than I was.

Anne and her husband had three children, all hearing. This is how Anne described their household:

We both used sign and voice with our children. We did not formally teach our children sign. Oldest daughter learned to sign on her own; son will talk slower to make sure I understand. Our youngest daughter signs some, but not at home. Younger two often relied on the oldest to “Tell Mom” this, or “Ask Mom”... If anything came up, the school nurse would come to our house to tell us about it. Oh here’s a funny story: when she was in elementary school, our oldest daughter told her teacher that she couldn’t hear. They gave her three different tests and the tests “showed” that she was deaf. The school nurse came to our house and told us that our daughter was deaf. I said “No she’s not!” She was trying to be like her mom and dad. She wanted to be like us. Every summer when we had all the Deaf visitors, she was fascinated with the Deaf people, their signing, their communication. After that visit from the school nurse, they tricked her with some different tests and found out she was, indeed, hearing.

Kristine told a story about something she thought she knew when she was growing up, but later understood differently:

My family always said a prayer at the beginning of meals. Later, when I was pregnant, I realized I never really knew the words to our dinner table grace. I mimicked this prayer and thought I was actually saying it with the family at every meal. I never realized that I didn’t actually know the words until I thought about teaching it to my child.

Family communication is complicated, even when family members share a common culture and language. When hearing families, with no exposure to Deaf people and no experience in the Deaf community, have a Deaf child, the communication issues can be exponentially complex. Many parents cannot communicate naturally with their deaf children, so hearing parents and Deaf children often go through life knowing little about each other.

Finding Our Way in the World of Work

Finding suitable employment has always been a challenge for Deaf people. Historically, Deaf men were trained at the schools for the Deaf for specific trades: shoemaking, printing, farming, baking, woodworking and tailoring. Those who continued to college might become teachers. Deaf women were typically trained in domestic skills: sewing, cooking, and dressmaking. The influence of technology on certain vocations, combined with greater opportunity as a result of legislation mandating equal opportunity, ushered in new professions to consider. More positions were available to Deaf people in human service settings such as vocational rehabilitation and social work. More teaching positions opened up as a result of legislation and recognition of ASL as a language. With the popularity of American Sign Language courses in colleges and high schools, many Deaf people were hired to teach ASL. However, these new professional positions were in some ways limiting. Deaf professionals were often limited to working with a Deaf case load only, or teaching only ASL and nothing else. Many Deaf people found themselves unemployed or underemployed.

The six participants were asked about their employment history, how they got their jobs, and how their work history led them to their current positions. It is interesting to note that outside of the Deaf world, they frequently sought jobs that had limited communication risk. In describing these jobs, participants frequently commented not only on the jobs and duties, but also on the communication environment.

Anne, who did not attend college, praised a teacher at the Deaf school in the 1940s and '50s for working very hard with groups of female students to make sure they understood and possessed the skills and behaviors needed for the workplace. In Anne's words:

My first job was keypunch operator. Our teacher, Miss Petra Howard, encouraged us to apply to work for the state highway department. She trained us in keypunch operation. There were four of us from the Deaf school. Some worked for the summer only. I worked for over a year. We were responsible to input information such as offender, offense and punishment onto cards. It was very interesting. I liked it a lot.

Later, Anne and her husband moved back north. Anne's mother was instrumental in getting a job for her husband. Here is Anne's account:

We moved back to my hometown in Northern Minnesota. My husband got a job with the city. This was difficult to do. Typically you had to live there for a long time to be considered for a city job. But I had grown up there and my mother talked to the people at the city and he was hired.

After 16 years there, the family moved to southern Minnesota, Anne's husband's hometown. As her children were growing up, Anne was a homemaker, but picked up some part-time work as their children got older:

I was mostly a stay-at-home Mom, but in the summers, my niece would watch the children while I worked at a hotel cleaning, or at an ice cream parlor. My work was all part-time summers only. Later, when the kids were in high school, I worked at a local nursing home as a cook for the afternoon/evening shift. I resigned from there because my shoulders were so bad. When the kids were grown and gone, I didn't really have anything to do, so I went back to work at the nursing home, only this time as the evening dishwasher. I did not want to cook anymore. I communicated with co-workers by lipreading and using my voice. No one ever wrote anything down for me. I just had to lipread everything.

Anne ended up going on disability, but not in the way she expected to. Here she reflected on what she considered an absurd experience:

When my husband retired, I wanted to retire too, but I was not of retirement age yet. My shoulders were so bad, I had to use a heating pad on them every night after work. At Social Services the worker suggested I apply for disability. So I did. When I went there, they thoroughly tested my hearing. They found out I was totally deaf and had no vibrations in the bones. I was approved for disability because of my hearing loss, not because of my shoulders! How silly! Later on, talking with others, I found that to be a common practice. It didn't sit well with

me, but that's what happened. I didn't like the idea at all--that if you are Deaf, you can't work.

Will was a swimmer, and competed in high school and college. This helped him get his first job as a lifeguard. However, after graduating from college with a teaching degree, it was not easy to find a professional position. Will said:

I worked as a lifeguard and did yard work as I was growing up. After graduating with an MA in D/HH education, it was still very difficult to find a job. It was before 504 and ADA, and there was still significant discrimination in D/HH education. I went to California and got a job as a Social Worker. Soon after, 504 and PL 94-142 passed, and I became a presenter on 504 and PL 94-142. I did presentations with an interpreter. Subsequently, I got a job teaching in a one-class program. Twenty-three Deaf students, pre-school through high school, all children of color. Later, I got a teaching job in Minnesota, and it was a shock because the students were all white! I worked several year teaching D/HH, then I transferred to teaching ASL full-time in a high school. I am also in private practice as a consultant. Odd to look back--in the '50s, '60s and '70s, there was oppression and Deaf people were invisible and overlooked. Now many of us are in high demand.

Kristine found her first job with the aid of a youth programming agency. Her experience after graduating with a degree in graphic art was mixed, but it led her to a new profession:

My first job was through Job Core for Youth. I worked at the local college library, shelving books for a couple of summers. Later, when I enrolled at this same college, I applied for a student job in the library and I got the job because they knew me from before. I also worked at a grocery store in produce with a bunch of guys I knew. We became good friends--they were all SO cute. One lived in my apartment building. If I needed to make a phone call, I'd knock on his door and he would make a phone call for me. Everyone at the grocery store was very nice and supportive. They knew they needed to face me to talk to me. We had a great time and did a lot of teasing--it was fun. If one of my friends from work needed to talk to me, they would drive over to my house. This was before any relay services were available. After I graduated, I worked in graphic design. I liked the work, but I didn't like the phone work. I wanted to have control of my projects. I would fax my questions to my clients, but they would always call and talk to someone else. The project didn't seem to be mine anymore. After eight years, I got tired of this and wanted to do more. I had more to give. I taught ASL in community education. I was offered a full-time job teaching ASL in high school, but I needed to be enrolled in a teacher preparation program. My current job is as an itinerant teacher. I hope they know what they are in for! If I need an interpreter, I will request one and be firm. I'm afraid they may be sorry for hiring

me because they tend to like to do things on the cheap. In general the district does not respect interpreters or the work they do. If an interpreter is absent, they will claim inability to find a sub, but they are unwilling to pay the going freelance wages.

When Paul left school for a year, he went home to Michigan and got a job as a tool and die maker. The money was good, and he had encouragement to stay, join the union, and have life-long job security. The bottom line for Paul was that it was boring work with no opportunity to think or be creative. This realization motivated him to return to school and pursue his degree in social work.

Living in a small town can be helpful when looking for work. Lauren was hired by the local nursing home when she was in high school. She described her employment history:

My first job in high school was in a nursing home. I liked it! I liked working with the older people – they had some of the same communication problems I had, so it was no big deal. The staff took time to communicate with me. In college, I worked in the chemistry lab stock room. It worked out well. I provided students with materials from the stock room based on a list or form they handed to me. Not a lot of potential for confusing communication. After college, I worked for an independent living center in a small town. I moved up quickly to manager. Realizing I liked management, I enrolled in a masters' in management program. I was frequently asked to sit on Deaf panels for workshops and classes, and at one of these I was recruited by the state D/HH agency to work with them.

Lauren worked for the State Department of Deaf and Hard of Hearing for a number of years, and now she is a self-employed consultant and editor.

John's first job was as a maintenance worker at a local golf course, which led to the summer Minnesota Conservation Corp position, a program that specifically hired a team of Deaf young people to work on trail building crews with leaders who were Deaf. This proved to be a pivotal personal experience for him. When he is home from school on vacations, he now works at a local coffee shop:

My first job was the summer after ninth grade. I worked on maintenance for a golf course. I got this job through the D/HH teacher at my school. The golf course supervisor knew some Deaf people. It was a good experience and helped me get a job with the Minnesota Conservation Corp (MCC) the following summer. MCC was a great experience. I got a glimpse of what "could be" between hearing and deaf people. There were several crews of deaf, hard of hearing, and hearing kids. We learned a lot! The hearing kids learned to sign so we could communicate well. It gave me hope, but also helped to decide to go to the Deaf school. Now I work for a local coffee shop. My duties are varied: make coffee, sandwiches, stock work, cleaning. Nice place, the people are willing to write notes, the owners and boss know some fingerspelling. It's not a job that requires a lot of communication, so it's fine. I do not expect to work during college, as I will be a full time student on supplemental security income (SSI).

Technology

Technology is a very broad term, and participants answered questions about their use of it in many different ways. Some talked about current, state-of-the-art technology, some gave a historical perspective. Clearly, technology plays an important role in the lives of all participants, whether for good or ill.

Will talks about his first experiences with TTYs.

“When TTYs first came out, they were very popular. We would spend hours on the TTY talking about anything. They are now passé. If they are used at all, it is only for very short business.”

Anne waited for a TTY, and has a particularly amusing story about the day she and her husband finally got their first TTY:

Our first TTY, now that is a funny story. The day we went to pick up our TTY was a snowy day in January. We were instructed how to use it, and we stopped for a nice leisurely dinner on the ride home. The next day we were scheduled to babysit our granddaughter, because our son and his wife were scheduled for a C-section that day. Well, we arrived home and our son was at our house and fit to be tied. “Where have you been?” We said, “We thought it was tomorrow”. Well, her water broke, so they had to go to the hospital and they couldn’t get a hold of us. We sure could have used the TTY that day! Later the kids all bought their own TTYs, so we could talk easily. Now we use a videophone and relay. The TTY is collecting dust!

On a trip to Europe, Paul had a mishap with his TTY and was left with no way to be contacted.

“I traveled to Europe and brought the wrong electrical plug. Early on I fried my TTY, so I was completely out of touch for seven weeks. Now, TTY technology is now so slow and out of date.”

TTYs were common technology when Kristine was growing up. As an adult, she has experienced many options in communications technology. Kristine told about using multiple devices:

Technology can be so complex. For a several years, I had three separate devices--a cell phone with a T-coil to use only with my husband, my mom and my sister, a Sidekick device to use with my Deaf friends, and a pager for work. Now, at last, I have one device for everything and it's great! I use technology, and I think it's great. I love the Internet, but it cannot replace face-to-face communication.

Paul explained how his family uses technology and his desire to be current on new developments in technology.

We rely on text messaging, email, and Sidekick cell phones for family communication. Video relay service, WOW! This is amazing. I hate being the last person to know something. I like being on the cutting edge of technology. Deaf people really just want functionally equivalent access. Soon it will mean video on mobile phones.

Several of the participants had clear memories of getting captions on network television. When captions were first available, Deaf people had to purchase a closed

caption decoder, which was the size of a VCR unit and cost several hundred dollars.

Later, the ADA made it mandatory for televisions to come equipped with the caption chip installed, so an auxiliary device was no longer needed. At first, very few shows were captioned, and choices for Deaf people were limited. Anne reported:

“I had no interest in TV until we purchased our first closed caption decoder. I can’t remember what we watched, but there was not much captioned yet. It was still a fight to get the news captioned. I remember one show we liked to watch was ‘Golden Girls’.

Will’s recollection:

“When TV began to be captioned, I remember the first TV show I watched was ‘Three’s Company’.

For Paul’s children, captions were part of the house rules.

When we got a TV with the caption chip, we had a house rule when our hearing children were small. If the TV was on, the captions had to be on also. My hearing son still uses captions today, because he grew up with them.

All participants agreed that videophones and video relay services are a huge breakthrough in telecommunications for Deaf people. Rear window captioning in commercial movie theaters for first run movies allows Deaf people the opportunity to see a current new release on the big screen, a luxury most Deaf adults have not enjoyed until recently. Will commented on the challenges still to face in technology:

“Now the issue is Internet accessibility. News videos should be captioned, and many are not. Some chat rooms are audio-only and inaccessible to Deaf people. This will only serve to reestablish the dividing line between Deaf and hearing.”

RESEARCH QUESTION 3

What are the Deaf participants' personal perspectives on their life experiences and Deaf Cultural values, beliefs, norms and history?

The Origin of the American Deaf Community

Deaf participants were asked several questions about their own perspectives on the Deaf community. First, they were asked about how the Deaf community was established in the United States. Each participant could recite the basic story of the establishment of the first school for the Deaf and the important people in this story.

The more extensive story can be found in chapter two. It is the story of the Reverend Thomas Hopkins Gallaudet, who went to Europe to learn about education of the Deaf at the bequest of Mason Cogswell, a wealthy businessman with a Deaf daughter, Alice. Gallaudet went to France and met Laurent Clerc, a Deaf student and later teacher at a school for the Deaf in France. Gallaudet recruited Clerc to come to America and help him set up a school for the Deaf. Once the school was established, a community of Deaf people developed from the teachers and students who use sign language. The students became teachers and established Deaf schools in other states. The American Deaf community was born. This has come to be known as a creation story for the American Deaf Community. It is important to Deaf people because it gives a sense of history and belonging. In American white cultural tradition, it might resemble the story of George Washington, credited with being the father of America.

Each participant knew the story of Gallaudet and Clerc and could retell it, either in a simple form or with great detail. Will, in particular, had an additional interpretation of the story:

It is the language that brought people together. We are like immigrant groups, but we can't assimilate in the same way. Thomas Hopkins Gallaudet and Laurent Clerc are key figures. Gallaudet provided the liaison to the hearing world, getting support and promoting Deaf education. Clerc was the on-site master teacher, running the school (American School for the Deaf). They would travel together and Gallaudet would highlight Clerc's skills and accomplishments, but Clerc did most of the day-to-day on-site work. In my opinion, Gallaudet University should have been named "Clerc University" for Laurent Clerc, the Deaf teacher.

Deaf Heroes

Participants were also asked if they had any Deaf heroes. Heroes named were historical and current, famous in the Deaf World, or ordinary people who supported or inspired them. Anne's heroes:

I look up to those people who have invented devices to help Deaf people – like doorbell flashers, etc. I don't know their names. Petra Howard is a hero of mine. She did so much to help Deaf people get jobs. She would make sure we understood what we needed to know to be employable. I'm ambivalent about Marlee Matlin, but I do admire Linda Bove, who was a sign language teacher and consultant on the movie "Sweet Nothing in My Ear". Dummy Hoy is another

hero. He helped develop signs that are now used in professional baseball. I. King Jordan was wonderful.

Will's heroes:

Deaf parents of my friends were my first heroes and Deaf role models. I went to a friend's house in Brooklyn--his parents were Deaf. We sat around the dinner table and they all signed! IT BLEW MY MIND! I wanted Deaf parents. My parents loved me, cared for me--but that communication part was missing. I had many important Deaf role models and this was crucial for me. The actors in the National Theatre of the Deaf were heroes and role models for me.

Paul's names his heroes, and comments on the Gallaudet protests:

Thomas Hopkins Gallaudet and Laurent Clerc are two of my heroes because they gave their whole professional lives to deaf education for the benefit of deaf children. Many people consider I. King Jordan a Deaf hero, but please consider that I. King Jordan was NOT the first Deaf president of Gallaudet. He was the first Deafened president. He was hearing until the age of 20, when he lost his hearing in a motorcycle accident. But it was better than nothing. The second Gallaudet protest was about the unfinished business of the first.

Kristine's heroes:

My first Deaf heroes were the Deaf adults in the local bowling league. My mom would drop me off for deaf bowling when I was about 12 or so. All the Deaf people talked about St. Paul TVI. I was sure I would go to either St. Paul TVI or Gallaudet. My mom is also a hero to me for taking me there, and the deaf adults

for being my role models. My first D/HH teacher was also a role model for me. She died recently. She was hard of hearing and she was a great teacher. This teacher set up opportunities to get together with other deaf from Faribault and the Twin Cities. I remember many of her lessons still. In fact I use many of her ideas and lessons now. She instilled in me the idea that I could be whatever I wanted to be.

Lauren and John were both in school when the famous Gallaudet “Deaf President Now” (DPN) protest occurred. It proved to be influential to their identity. Both named individuals involved in the protest as Deaf heroes.

Lauren’s heroes:

My first true connection with the national Deaf world was in 11th grade when the “Deaf President Now!” protest at Gallaudet was happening. Even though I was in a mainstreamed program where we functioned more as hard of hearing, I recognized that this was my world. Every night the DPN protest was on the news--the HEARING news! I’d call my parents in and say “Come here! Look at this!” Now, I actually know some of those people--what a small world! I would say that I. King Jordan was my first Deaf hero. Most of my Deaf heroes are current, not historical figures. Later, Heather Whitestone, the first Miss America who was Deaf became a hero for me. Many Deaf people were opposed to her because she grew up oral, but I didn’t care. She was like me. I have always liked Deaf people with Deaf parents (Deaf of Deaf). I feel like I have more in common with them.

They tend to have better English, more confidence, and feel less threatened by others.

John's heroes:

My heroes are the student leaders in the DPN--one who roused the masses, and one who worked behind the scenes with the administration. I had no exposure to Deaf heroes growing up. There was no reading about famous deaf people. I remember learning about Dummy Hoy, but not really as a hero. I also knew about Marlee Matlin, but I am not particularly impressed with her. I am more interested in real heroes, like the DPN leaders. Sean Virnig is also a Deaf hero to me. He used to work at the Deaf School, but opened his own successful bicycle business.

Deaf Community Involvement

How people in the Deaf community interact with each other has become more varied, perhaps due to the influence of technology. Changes in educational choices that affect deaf people's proximity to each other, and even typical schisms between generations also affect interaction in the Deaf community. When asked about their own personal participation in the Deaf community, most participants' answers reflected a long-held assumption about how and where Deaf people meet each other. Many commented that they are involved in the community in various ways, but for reasons including work, family, and time; they do not attend Deaf Club regularly. The notion of the historical Deaf Club as a *place* was dominant in answers, as the traditional avenue for involvement in the Deaf community.

John's experience is particularly divergent from traditional thinking:

I am involved, but I don't attend the Deaf club much. It's not really up to my standards. I think a Deaf college campus will be a better fit. Right now, I am just hanging out with Deaf friends my own age--just doing nothing really, talking about everything and anything until late in the night--driving to the gas station, sitting on the curb with a bottle of pop shooting the breeze, hanging out at the lake, just enjoying the company. That's my Deaf community right now. I am still young and don't really know yet what my role in the Deaf community might be yet--but I know what I don't want it to be. I don't want to be stuck complaining about everything--about unfair treatment of Deaf people, about disability. I don't want to be limited to Deaf-only careers or ways of thinking.

Likewise, Lauren did not see herself as involved in the traditional way, but she has participated in the past in the "Deaf Club" experience and noted both positive and negative aspects:

My friends and I are all raising our children now, so we don't go to Deaf club often, but we keep in touch by email daily. If I had a videophone at home, we would use that every day, too! I am involved in the Minnesota Association for Deaf Citizens and the Deaf Business Owners Group. I also edit and write for Deaf publications.

I first became involved with the Deaf community before most of the technological advances. While working at the Independent Living Center, one of the Deaf Board members encouraged me to go to the local Deaf Club. I resisted, but he would

not take no for an answer. In fact, he would show up at my house on Deaf Club night to pick me up! He had to force me to go the first couple of times, but after that, I was hooked. I've experienced the tight-knit group that physically gathers in a common place to interact and socialize. Now, this is no longer as common--with so many other ways to keep in touch. In that sense we have become more like hearing people. Some Deaf people may lament this change, but when I was growing up, that tight-knit community was all but closed to me and others like me. That social order could be almost tribal--with a clear power and leadership hierarchy, as well as in-fighting. The positive part, though, was the ability to pass on and share Deaf Culture. And, when a member is in need, all are there to help. I realized I was finally "IN" when I was asked to drive a Deaf woman to get her hair done on the morning of her husband's funeral.

Kristine is a leader in her local Deaf community. Her involvement reflects her interest in Deaf children and her teaching profession, and her interest in promoting activities and awareness for Deaf people.

I have been extensively involved in the Deaf community since college. I'm secretary of the local Deaf club. I help set up workshops and we meet once a month locally. We have entered a float in the city summer festival and parade, and have won many times! I was involved in the group trying to set up a Deaf charter school, but I had to resign--too much in-fighting. I was neutral, but I could see both sides. The two sides were fighting like crazy and I just had to get out. I'm also involved in the American Sign Language Teachers Association

(ASLTA), and Minnesota Athletic Association for the Deaf (MAAD)--especially softball tournaments. We are working on ideas to get kids involved, maybe sponsoring kids to go to sports camps, or to set up our own camps--like a summer drivers' education camp with Deaf instructors.

For Paul, his involvement in the Deaf community has an international element to it. He has traveled extensively, for work and pleasure, and always makes a point of developing relationships with Deaf people all over the world.

I am involved in the Deaf Community mostly through organizations, not purely social. Also, much of my interaction with Deaf people occurs on my travels--in the US and around the world. When I travel, I don't want to only see all the sites in a country as if I would never be back. I want to see places and meet people that will help me develop relationships. I prefer to invest my time in meeting and experiencing the people and the culture. I have many long-term friends in Europe and Japan. I will send them an email and they will translate it into the languages they know and send it off to other friends and contacts. It's a great way to maintain relationships with Deaf people all over the world. I am very well travelled, and I now know many sign languages. I have many "deaf families" in Europe."

Will is involved professionally in the Deaf community, but also has found his social, face-to-face participation on the decline.

I have been involved in the Deaf community for many years, but less now. In 1979, in California, I was a key protester against the movie "Voices", in which

Amy Irving played the role of a deaf teacher. In the past we gathered at bars or for captioned film showings in homes. Now, my wife is hearing, my children are hearing, my work colleagues are hearing. With rear-window captioning, I can go to the movies just like anyone else. It's different now.

Anne's involvement in the Deaf community is in some ways more traditional:

We have a once a month Deaf Club, where we can all get together – it's mostly social. And now we have Deaf church services once a month, so that's another opportunity. I also keep in touch with lots of Deaf friends on the videophone. That is a great invention.

Threats and Challenges to the Deaf Community

Participants were asked what they perceived to be threats to, or challenges for Deaf people and their community. Cochlear implants, oralism, parents' or teachers' attitudes, and Deaf people themselves all were identified as posing a threat or challenge.

Anne feared the demise of Deaf schools:

"The worst thing I could think of is if the states decide to close their schools for the Deaf. That would be terrible."

Will lamented lost potential for leadership in the community:

"Cochlear implants are a threat to Deaf community. Many Deaf people with cochlear implants are functionally hearing and may choose to live only in the hearing world. As a result, the Deaf Community may lose many potential leaders."

For Paul, attitude and one-size-fits-all thinking is of great concern for the future of the Deaf community:

The problem is the attitude of educators about one method, period. Their flawed logic is that cued speech or SEE signs may help students learn English, therefore it should be used everywhere--all subjects and for social interaction. The problem with all these new solutions is that we have to keep re-educating people about Deaf identity.

Kristine called on Deaf people to be open to change for the health of the community:

Some challenges are from Deaf people themselves. Often they can be very rigid and unaccepting of difference. Different signs, different approaches to Deaf club. We must learn how to respect the difference. Sometimes, people get categorized and may not be accepted. This is very short sighted.

Lauren named several factors that threaten or challenge the Deaf community:

In my opinion the biggest threat is hearing parents' denial of sign language--especially those who get cochlear implants for their Deaf children. Cochlear implants alone are not a threat to the Deaf community, but combined with the exclusion of ASL they are a big threat. Another threat is mainstream education, which typically sets very low expectations for Deaf students. Also, Deaf kids in mainstream will not feel connected to the Deaf community and not really connected to the hearing community either. Without ASL, they may not be able to function in the Deaf community, and will grow up isolated.

John's concern was that Deaf people may be forced back into oral-dominant philosophies:

I have heard there is a resurgence of the AG Bell influence of oralism--coupled with cochlear implants on a massive scale. This is a fear. My primary fear is that we may again face a stigma of "deaf and dumb". I also fear that Gallaudet or other colleges and programs for Deaf students will disappear.

Historical and Current Issues

Historical and current issues were discussed in the interviews. Participants were asked their opinions about oral vs. manual approaches to education, signed English systems, cued speech and American Sign Language, cochlear implants and hearing aids, and educational choices for Deaf children.

Oral Training or Sign Language?

When asked about the oral or manual approach to communication and education, participants addressed the questions from both practical and personal perspectives. John saw this question as a challenge to a Deaf child's self worth.

I don't know why anyone would want oral. It is so limiting. People I know who are oral seem to require very careful planning of every aspect of their life. Their life seems to be based on this premise: "You were born deaf. That's bad. If you want to fit in at all you must do things this way." I will never ever be a supporter of oralism. I recognize there may be some benefits--but it is more how this philosophy is applied that I find offensive.

Lauren spoke from personal experience on the difficulty of an oral-only environment:

Deaf people should have some oral training, but not at the expense of content learning. Signing is absolutely vital, but some oral training could be beneficial. Oralism is very difficult. When I had my first job, I realized how difficult it truly was--speech reading all day long--it was exhausting. In school, I was used to interpreters--much easier. Signing is natural and free.

Kristine's response highlights the need to consider each child's individual needs carefully when making this important decision, but she also shared personal frustrations with oralism:

Really, I am in favor of whatever works. I grew up with oralism and SEE signs--it worked for me, but I do remember being afraid to raise my hand and offer anything to the class because I may have speech-read incorrectly. Children need a base language from which to learn other languages. For me it was English, but for many Deaf kids it is ASL. When we are oral Deaf, we struggle so much to pronounce words correctly. It can be very difficult when you have never heard the word. And people will look at you like, "What's your problem? You can't even say that word." Some examples are quesadilla, and champagne.

Will, an "oral failure," stated simply:

"The oral versus manual controversy still exists today. I am seeing more Deaf children who are oral again. Like the "old days."

Anne had strong opinions on this topic:

Sign is much better. Oral is so hard for Deaf people who have never heard sound or speech. Now there is an organization to promote ASL for children from the

very beginning. It's called the Deaf Bilingual Coalition. They are addressing the issue of teaching sign language to hearing babies, but ignoring it for Deaf babies. The Deaf Bilingual Coalition is opposed to the A.G. Bell Association that is still promoting oralism. I don't understand how they could want oral-only still! How can a Deaf person talk if they cannot hear the sounds of speech? Parents who have Deaf children and don't want their child to be Deaf force them to be like hearing people, force them to be oral. I think it's debasing to force a Deaf person to talk. God made them that way and they should be allowed to sign. Deaf people can't really be themselves until they meet other Deaf people.

Signed English (MCE), Cued Speech and ASL

Signed English and cued speech are the methods of choice for many parents and teachers. Each has its own particular structure and application to Deaf education. Participants were asked their views of the use of these education and communication tools in comparison with American Sign Language. Here are some of their responses: For Kristine, who is a teacher, these tools were all equally valid in the right circumstance, but the larger issue is more important:

"I have no bias against any of these tools. They are all great. But still remember we are Deaf and need that identity."

Lauren also accepted cued speech and SEE signs as potentially helpful, but stresses the proper application:

"SEE signs or cued speech – simply more tools, OK for a specific purpose, but not as a language, not for communication and socialization."

Paul, concerned with the long-term health of Deaf children, provided more explanation in his opinion:

Cued speech--I have no problem with that. Cued speech is a specific tool to assist in speech reading and understanding specific voiced English words. But it is not to be applied to every aspect of life. It is not really for communication. It does nothing to help develop knowledge or emotional development. I know some Deaf people who used cued speech. They now use ASL. Their parents made that decision and they could only acquiesce to it. When they graduated, they discarded cueing. All of these issues--cochlear implants, SEE signs, cued speech have no concern whatsoever for the long term emotional health of Deaf people.

Recognizing the efficacy of cued speech in certain specific situations, Will provided this perspective:

Signed English is a joke. Cued speech has a place and can be helpful. As an example, I participated in a legal workshop that included a test at the end. In ASL I understood every concept but I did not get the exact English terms for those concepts. Cued speech would have been helpful in that kind of situation.

Anne indicated a willingness to accept these tools as long as it is in addition to sign language:

“On the whole, I prefer sign language. Cued speech, SEE, speech therapy... it’s up to the individual to add whatever they want to add, but never in place of ASL.”

Cochlear Implants and Hearing Aids

Two of the six participants, John and Lauren, had cochlear implants. Their opinions reflected their own personal experiences as well as more general reflection on the issue.

John shared his perspective:

I got my cochlear implant at the age of four. I think children should be allowed to wait to get cochlear implants--until they can have a say in it. I think four is too young to make that decision. It's hard to see the influence on young children. You can't really ask them their preference. Often the impact is not seen until they are older. I will never use my cochlear implant again. When I decided to stop using my cochlear implant, my dad said I was wasting his money. I said I didn't choose the CI, he chose it. So he wasted his money. It's like asking a black person to become white. Is that racist? No, but would you change your identity just because it might make your life easier?

For Lauren, a chance encounter with a child who had a cochlear implant and his father was particularly disturbing to her:

Our family went to Disney World. I saw a young child with a cochlear implant in the same line with us. I saw him watching my daughter signing to me, so I signed a little to him. He didn't sign to me, but he understood what I signed to him. I just assumed he would sign. Later, his father came over and I said to him (while signing too), "I have a cochlear implant too and I just met your son--he is really cute." The father looked startled and said, "Oh he never HAD to learn any sign language." The thought is you only NEED sign language if you fail with the

cochlear implant. That encounter really bothered me for a long time. I have thought about it often since then. It really helped me better understand the Deaf community on this issue. I realized, "Ohhh, THAT'S why the Deaf community is opposed to the cochlear implant." I have a cochlear implant. I was Deaf before I got it and I am still Deaf with it. REMEMBER a cochlear implant is only a tool--one of many--and it does not make sense to limit Deaf children to only one option. The issue for these children is that they may grow up not fitting into either world. We need to understand that a cochlear implant is OK if you give children sign language too. More options.

Cochlear implants--it's tough. I see young kids, age five or so, who were implanted at 12 months. They are functionally hard of hearing. They are lucky. They can function fairly well. But know this: they will never, ever function 100% smoothly in the hearing world, and, when they are adults, they will not be able to socialize easily in the Deaf community, either. Some kids who have cochlear implants are thriving, because they also know ASL and have Deaf friends. EVERYTHING is open to them. If parents want their kids to get cochlear implants, fine, but let them know and interact with Deaf people. I know a young man, now 18, who got a cochlear implant at the age of two. Now he is fluent in ASL and can interact easily with Deaf people. When he puts on the cochlear implant, he can talk on the phone and interact with hearing people successfully, too. I don't want to limit Deaf children to oral-only, sign-only or cochlear-implant-only.

Paul was skeptical about the motives and reasons behind implanting so many deaf children:

Regarding cochlear implants...there is one doctor who is very frustrated with us, calls deaf people militant--ha ha ha. Actually, it is they who are militant, forcing cochlear implants on deaf children. The medical profession historically experiments on adults, not children. But they are experimenting on children when they are only weeks old. What is with their profession? They don't practice what they preach. Why do parents want it? Because doctors say "I can fix your child for \$25,500.00." I know several people who have had cochlear implants. I don't hold it against them. It's not their fault. It's the system's fault. Ideas and trends come and go. There is always a pattern. Do these trends really help anyone? I don't know. Many deaf people are deciding to have their cochlear implants removed. I have also heard that 40-50 deaf people have died from the procedure. We don't hear about the problems, complications, or deaths.

For Will, who loved his high-tech digital hearing aids, one issue is the importance of Deaf identity:

Many Deaf people have cochlear implants now, and I can see why. It can open up the world to them. BUT I know that Deaf people can have a cochlear implant and a Deaf identity. I have seen it. Deaf people who can function well in the hearing world, but who also use ASL and can interact well in both worlds. Many Deaf students at Gallaudet have issues with their parents who decided to have them implanted. They think, "What's wrong with me? Don't you accept me?"

Now they are implanting at 5 months--before it was 18 months. Also, more and more people are now getting two cochlear implants. Money to support this comes from rich corporations and special interests. The Deaf community, in contrast, is poor and powerless.

When I went in to get my new digital hearing aids, they told me it would be like the difference between black and white TV and color TV. When I got my digital hearing aids, I was hooked! I can't hear words, but I do get a lot of environmental sounds and cues--in color instead of black and white!

Anne was adamant in her opinion about cochlear implants in babies and young children:

Cochlear implants in a baby? No way! Leave the babies alone. Later, when they are old enough, if they chose it, fine. I've heard some very scary stories. One boy died from an infection. Some have complications like twitches or seizures from the surgeon hitting a nerve. I think it is just wrong for babies. But I know one deafened adult who got one and she swears by it. I have another friend from school who was hard of hearing (although at school she functioned as Deaf). She got a cochlear implant. She was very happy with it at first, but it's not as good now as in the beginning. She wants to be able to be 50-50 in the deaf and hearing worlds. She has a sister who is Deaf and she still retains a Deaf identity.

Educational Choices for Deaf Children

All participants had experience in both mainstream schools and Deaf K-12 or post-secondary schools. Reading was a key skill or passion identified as promoting and supporting success in school. All participants described themselves as being avid readers

and grateful that they had developed excellent reading skills. Many of their opinions on educational choice are influenced by personal experience or the experience of someone they know. Anne, who was sent to the state school for the Deaf at the age of 13, supports Deaf schools:

Mainstreaming will limit Deaf children. It's not equal. At the schools for the Deaf, everyone is the same and can be involved in whatever they want. For example, I was in the marching band at the Deaf school! It was like a drum line. We all wore short red satin skirts and white blouses with saddle shoes and spats. It was really fun! So I am against mainstreaming. The idea that they can get ahead in the hearing world better if they are mainstreamed, I just don't think that's true. When Deaf kids meet other deaf--they often blossom! We have a Deaf nephew. He was mainstreamed and he didn't communicate or understand very much at all. He didn't know much vocabulary. We suggested to the family that he go to the school for the Deaf and they got very angry. They accused us of trying to break the family up. So we backed off, we didn't want to cause a rift in the family. Later, they visited the school for the Deaf during the summer and decided to send him there that fall. He was about 11 then. Between September and when the family got together for Christmas, his progress was amazing! He was communicating with everyone! He knew who everybody was and could sign their names--he was a real chatterbox! My parents sent me to the Deaf school, and I am so glad they did. I learned I was not the only person in the world who could not hear. If I had stayed at the hearing school, I would never have gotten

the education I got--I just could not lip read fast enough! At the Deaf school, even though I could not understand them at first, I knew I would eventually learn. They were my people, and I was not ashamed or embarrassed about being Deaf.

Will recognized the complexities of the choices, and supported an approach to Deaf education more than a place:

"I favor the bi-lingual, bi-cultural model of education, but I recognize that public schools often have more course options for students."

Kristine focused on the personal well-being and self-esteem of Deaf students:

Many mainstreamed Deaf kids are so isolated they have no idea what is or could be out there for them. It's the teachers' job to expose them to more and help them understand. It is important for Deaf kids to find others like themselves. They know they are different. They figure it out more and more as they get older. It's a very difficult time. Now Deaf children of Deaf parents is a whole different story. On the whole, they will be age appropriate in knowledge and affect, more confident and more fluent. I met a new "Deaf of Deaf" student recently and it was amazing. Deaf identity is so important.

Paul expressed concern about the quality of education provided to Deaf students, and the qualifications of teachers for Deaf and Hard of Hearing students. He also questioned the motives of those who are instrumental in making educational decisions:

Teachers make language decisions based on their own benefit at the expense of students. Teachers don't want to learn another language and they fight against it. They are not creating an equal or language rich environment for students. It is a

false world. D/HH teachers are generally less qualified for their jobs than their peers. In D/HH education, a teacher does not need to have content-area degrees, so they are less qualified than content-area classroom teachers, and this harms Deaf students. It's all part of lower expectations for "special needs" students. They dumb it down for us.

The professionals and education force their way on Deaf people for a set period of time, and then they are done, leaving incomplete Deaf people to fend for themselves. "Good luck, you are on your own"--often with no identity and little language. The result can be long-term emotional damage and psychological adjustment problems, for which the education system takes no responsibility. They have done their work. Then Deaf people are left on their own, looking for appropriate counselors that their insurance, if they have any, will cover. I speak from experience, as I have a background in social work. People ask, "Why do Deaf people have so many mental health issues, why do they seem to have difficulty coping?"

My own parents couldn't communicate with me until I was ten years old. My survival was my Deaf sister--she kept me from losing it.

However, I support partial mainstreaming because, in general, the mainstream teachers are more competent in their disciplines than D/HH teachers, who are often predominantly focused on mode, not content. For example, in the mid-1980s, my wife graduated with a M.A. in deaf education and the program included only two weeks of sign language training and one credit of Deaf

Culture--and this was in New York. My wife was stunned. This was only 20 years ago, and these are likely the teachers still in the field. That's one of the reasons I support some mainstreaming. Those teachers have degrees in their content areas, and are more well-rounded in their teacher preparation. They may also be more adept at life-skills application. If D/HH teachers were skilled in the same way, then I would favor comprehensive Deaf Education.

Lauren's concerns about equal expectations for Deaf and hearing students, and about Deaf students' social development, also came from experience. She also expressed concern about the roles and ethics of hearing people who become teachers for Deaf and hard of hearing students.

I like the idea of Deaf day schools. Children can attend a Deaf school during the day with educational and communication freedom and still be home with the family at night.

Mainstreaming is hard. Very lonely. It's difficult to learn social skills. Even with interpreters and teachers, it is not a natural learning environment. Mainstream is bad for Deaf kids. And yet, Deaf schools are weak--some because of the popularity of mainstreaming, but also because of the quality and low expectations. I think a Deaf 18-year-old should be equal to a hearing 18-year-old at graduation, but that is not the expectation.

Deaf Education should be owned and led by Deaf people.

Deaf children should receive instruction in BOTH ASL and English.

Mainstreamed kids are so confused. Teachers speak and sign at the same time,

doing both poorly. Children do not receive adequate language modeling in either language. They often have poor skills in both ASL and English as a result of inconsistent language models and instruction. English and ASL are both very important.

As these teachers retire, will their replacements be an improvement? More Deaf professionals are joining the teaching professions and that's really good. Also, interpreters are more qualified. Older teachers of Deaf and hard of hearing students who won't or can't sign need to get out of the profession. Interpreters as well; improve or leave.

It's also important to recognize the role of hearing people in the deaf community. Parents MUST sign, whether or not children have a cochlear implant. Deaf kids will always need some time with the cochlear implant off.

After my own experience with a hearing teacher of Deaf and hard of hearing students, I grew to distrust hearing people in the teaching profession. My teacher for the Deaf and hard of hearing was awful! Her ethics were very shaky. She was just not a good person. And I still to this day have a tainted impression of the profession, of teachers of Deaf and hard of hearing students. I just don't trust them. I'm sorry but I don't. Hearing people should not be in that profession. I feel strongly about that. Because they think like a hearing person, and I would say few make really good teachers of Deaf and hard of hearing students. I have always been a little suspicious of them.

John shared his experiences in both Deaf residential and mainstream environments, and his opinions about the pros and cons of each:

Seems like all the formidable mainstream Deaf programs are closing. I'm not sure what the experience of a solitary Deaf person in a rural setting is. But residential school is great! It may seem like the academics at a deaf school are more limited than at a hearing school--not as many course offerings, fewer levels of math classes, foreign language classes limited, etc. At first I had my doubts about the Deaf school, too, but once I got there, I understood. What I learned was of great benefit. The Deaf school allowed me to think and ask questions, and take time in class to explain my ideas--time I would never take, or be allowed, in a mainstreamed school. I learned how to participate in class and how to feel comfortable raising my hand and "putting myself out there," and asking questions of the teacher. In my mainstream school, I was reluctant to ever raise my hand. I had to go through an interpreter, and I mostly wanted to avoid all that complexity. Interpreters sometimes understood me just fine; other times it would be a gamble. Sometimes I might use a specific sign or word, and I could see they were using a different word, and I wondered if they really understood me, and if they were really saying the right thing. There was less connection with the teacher when communication went through an interpreter. Socially, for example, in my mainstream school, kids would wait for their friends and would always cluster in groups in the hallways between classes to talk and hang out till the next class started. I never could do that. I always just went directly to the next class.

I never had anyone to wait for. At the deaf school, I would wait in front of my locker, and the kids would just gather there and chat until the next class started.

Technology

Participants were also asked what effects technology has had and will have on the Deaf community. Most of the responses indicated a belief that technology has improved life for Deaf people. John, the youngest participant, and perhaps the one who grew up with the most technological advances, is not a big fan.

Technology promotes human stupidity. People put out less effort to get together face to face. This can be lazy. For example, while texting, it is rare to even say “Hi” or “How are you?” anymore, which is customary and polite when starting a conversation with someone face to face.

Lauren and Kristine both said that technology is positive for Deaf people. The Internet allows them to be engaged in the world, and to keep current on world news and events. Email is a tool to keep in touch with friends and family, and to develop new friendships with Deaf people in other cities, states, or countries. Will provided an extensive historical account of his personal technological evolution:

In the past, we wrote letters with a three-day delivery time. We planned weeks ahead of time. Now, with technology, pagers, texting, we can be in contact all the time and change plans immediately. TTYs were big, now no one uses them anymore. The first captioning on TV involved only five hours per week. My Deaf sister lives in Washington, D. C. Long ago, we would write letters back and forth, saying, “I can’t wait to see you.” Then TTYs came, but we could only talk for a

limited time because the cost of long distance was so expensive. Now, with videophones, we talk every day. We text each other simply "VP," and then we get on the videophone and talk. It's free, and no time limit! Some Deaf couples just leave the VP connected to each other all day, and just check in from time to time. But the funny thing is that the excitement of meeting in person is diminished due to the fact that we can see each other every day! When it was my birthday, my sister and her partner and me, my wife, and our children all gathered around the videophone to open presents and celebrate my birthday together. The only limitation was that we couldn't share the cake with them! WOW. Wonderful. Texting is awesome, too. With this technology, Deaf people are less dependent on hearing people to make calls for them. I always hated that--it was very paternalistic, like hearing people had to take care of you. I lost my wallet once, and I needed to ask a hearing person to make a call for me. This person was all pathetic: "Oh, you poor thing, you lost your wallet" I just thought "Fuck you, just make the call." Now, we don't have to be beholden to hearing people like that. Captioning for first-run movies is also a great advancement. In the past, I would have to wait as long as two years to see a movie. It would take that long for it to come out with captions--first in reel-to-reel movies loaned by a government agency, later commercial VHS, and now DVD with a language menu. Now we have rear window captions on first-run movies in theaters. Now I can go to opening night, I can be in on the hype, the interviews, the clamor around a new release. Before, I'd have to wait for it to come out with captions--I'd read the

book, read all the interviews, all the hype and thenWAIT. Technology is amazing!

The Future for Deaf People

Finally, looking into the future, participants were asked about three topics: 1. What they thought the Deaf community might look like in the future; 2. What hopes they have for Deaf children in the future; and 3. What their perfect world for Deaf people might look like. Participants identified many common themes in their responses to these questions, including equal opportunity, Deaf pride, skill in American Sign Language and written English, and the health and well-being of Deaf children.

Future of the Deaf Community

John wanted Deaf people to be accepted as capable and to be perceived as more than their deafness:

I want to break down the stigma of “Deaf people can’t...” or “Deaf people can’t do as well as..” Deaf people are more capable than they are given credit for. When Deaf people can have their deafness as part of their persona, but not the only thing, then they will have a more open world. I believe the stigma and barriers for Deaf people will be broken down as Deaf people show they are capable of doing just as well as hearing people. For example, I want to be a screenwriter, and being Deaf is no reason why I can’t achieve that. I think Deaf culture may eventually be threatened with extinction. With more medical advancements, the prevalence of deafness will decrease, and many of the causes of deafness will be eradicated. However, even if the numbers of Deaf people

shrink, there will still be a Deaf culture and Deaf identity. I am part of the first ADA generation. The theory is that things will just keep improving for Deaf people. I hope that's true. When I am 50, I hope I'll be able to look back and see how the history developed and know that I was there at the beginning.

Lauren described the future of the Deaf community with both positive and negative elements:

I believe the core community may be smaller, but the outer "rings" of the community may actually grow. The community will be more varied and more diverse. Deaf people have typically been behind hearing people socially, educationally, and politically. I think Deaf people will catch up some. There will be more technology, more cochlear implants, but Deaf people will have greater educational achievement and more confidence. For Deaf purists, the future may be negative, but for most, it will be positive. The world's attitudes towards Deaf people are changing--becoming more open, more accepting. This will lead to more opportunities.

So I see some positive and some negative. Some of the negative is the fault of Deaf people themselves, who can't accept change. Some feel that cochlear implants will lead to the demise of the Deaf community, but technology is also a great tool for the voices of Deaf people to be heard.

Kristine believed that Deaf people themselves will ultimately be responsible for the success or failure of the Deaf community of the future:

Many Deaf clubs are closing around the country. Some blame it on technology, but I don't know. Seems like older Deaf still go to face-to-face gatherings, but younger deaf don't. I say give them time. Healthy? Some are and some aren't. Sometimes a deaf club can fall prey to mob theory. Some feel threatened by Deaf people who go beyond the stereotype and succeed. They should be congratulating them, but instead they are jealous. We need successful, competent Deaf role models.

The future for the Deaf community will be the same, but smaller and with more technology. As long as Deaf clubs can evolve, they will.

Paul also saw the future of the Deaf community in the hands of Deaf people and dependent, in part, on its ability and willingness to adapt:

The future of the Deaf Community depends on Deaf people themselves. It is their responsibility. It is not the job of hearing people to preserve or protect it.

Health of a culture is often measured by the third generation. For Deaf people, because they tend to have hearing children, if their grandchildren sign, it indicates positive perspective on Deaf pride, that they are not ashamed of the Deaf people in their family. They pass on sign language from their parents to their children. That is a sign of health, pride and respect. The point is, we have only scratched the surface of what deaf identity means, and the future of Deaf culture may be endangered if we can't figure that out. Deaf culture will always be around. Deaf people need to adjust and catch up.

The Deaf community is set up on the premise of common experience, common ground. It is not just for fun, it is, at its heart, a support group. It is positive. The purists may struggle, but we need to recognize that the Deaf community is not about the past. We can use history to help us learn from our mistakes and create a better future. But it is really about the current and the future, working together for the good of all. If we ever found ourselves fully satisfied, would that be the end of the Deaf community? Never! Remember we will always have the welfare of deaf children in mind.

Paul also reflects on the sign 'CULTURE' and its place in the ASL lexicon, particularly when describing the community of Deaf people:

Words have power. Among Deaf people, the sign for CULTURE is not necessary. The sign for DEAF embodies all the aspects of Deaf life and identity. For hearing people, the word deaf means something very different. For most hearing people it represents a medical condition. A loss. The word culture attached to the word Deaf is for and from hearing people, and provides additional meaning for hearing people. Other minorities do not routinely need to use the word culture--they can simply say "I am Black, or Hispanic, and no more is needed to understand an implied cultural element. There is not yet a single sign that means "DEAF CULTURE" that is different than the sign for DEAF. One Deaf friend thinks culture is an outdated word, but it will continue to be with us because it carries meaning for hearing people.

Will considered what he would like his own future to be like in a deaf community:

Deaf Culture will stay strong. It has to. It has to. But things are changing.

Veditz said “As long as we have deaf people on earth, we will have sign language.” Doctors say deafness will be eradicated, but I don’t know.

Minnesota is lucky to still have a strong Deaf club. When I am older and need assisted living, I would like to live in a Deaf senior independent living facility, with staff that can sign. It would be like Deaf school days again!

Deaf people are less isolated now, and not so dependent on hearing people.

Anne saw how the Deaf community is already changing in ways that provide opportunities to be with other Deaf people outside the historical “Deaf Club” model:

I think there will always be a Deaf community, but they may interact in different ways. For example, now there is a lot of opportunity to go on Deaf tours or Deaf cruises. We have done this and it is really enjoyable.

I think the future for Deaf people is bright. With all the new technology coming out, we are more equal than ever before. The Deaf Culture will survive because Deaf people need each other.

Hopes and Dreams for Deaf Children

Children who are Deaf are highly cherished in the Deaf community, and Deaf adults care deeply about their well-being and their identity. Of course, most Deaf adults were at one time Deaf children, and share many of the same experiences and ways of interacting with the larger hearing world. With this in mind, participants were asked about their hopes and dreams for Deaf children. John was practical in his description of his vision of the future for Deaf children:

“Deaf kids now will have more advantages. They will not know life before captions, videophones, and other technology. Kids can grow up having equal access to films, movies and TV. Also, having interpreters is the norm now.”

Anne also commented on their advantages and her hopes for them:

“I think the future is bright for Deaf children. Deaf kids today are so much more advanced than we ever were. I hope they will be proud of their Deaf world.”

Kristine also works with parents of Deaf children, to help them, through sharing her own experiences, understand more about their children’s experience as a Deaf person:

When I share my experiences with parents, they often gain more awareness. As a result, they respect me for my experiences, and trust that I only want the best for their children. I know kids need a lot of exposure to the larger world, and to Deaf people. Critical thinking skills are very important--we do a lot of what if problem solving activities to help them learn how to use their minds!

It’s important for kids to understand their feelings and what’s normal to be feeling. I really did not get that support till college. I was also very angry in high school. I wanted to go to the Deaf school, but my parents said no. Angry, whew. I knew something was missing. I would like to see Deaf kids interacting with more Deaf people, more mentoring. It’s important to give Deaf children a sense of value that they can do or be anything they want. We just have to figure out how to get there.

Lauren expressed her own concern about Deaf children's mental health:

They will grow up to see more successful Deaf people. There are many more books and materials with positive Deaf characters.

But for children whose parents choose cochlear implants and no signing, the future will be sad. I just don't want them to suffer the way I suffered. Because you never feel 100% connected, and are always asking, "Where do I fit?"

I have studied and read a lot about families who have experienced suicide. I learned that one of the most common reasons for suicide is "I don't fit in anywhere. What is my role, my purpose?" As I thought about that, I realized that is exactly what deaf people experience: "Where are my roots?" I felt this often when I was growing up. It was painful. As Deaf children grow up, are not engaged with the Deaf community, and become independent from their family and all the supports of education, they may wonder where they really belong.

For Deaf children's future to be brighter, education must change. Teachers must have more ASL skill. I have seen some of these teachers – they should not be teaching.

Paul highlighted the importance of instruction in ASL laying a foundation for reading and writing English:

I would like to see schools for Deaf children with Deaf teachers and an all-Deaf curriculum. English in the written form would be taught, which is important. A parallel curriculum in ASL and written English.

Where does ASL fit into this future? In all of my 50 some years, I have never had any instruction on the rules or grammar of ASL. Where is the formal instruction in ASL? We have formal instruction in reading, English, and speech therapy, but no ASL. If Deaf children had this instruction, they could pick up so much more, so much faster. The history of ASL research is only 30 years, but growing stronger. We've had a history of oralism since 1880 in Milan, when formal instruction in the rules and grammar of ASL was lost. But the language was not lost. It survived.

In a Perfect World...

Finally, participants were asked to describe their dreams for Deaf people, or what might be a perfect world for Deaf people in the future. Many of the responses indicated that opportunity and acceptance were key elements of a perfect world.

John's perfect world:

"I don't know if there will ever be a perfect world for Deaf children, but a bi-lingual, bi-cultural approach, where everyone signs, could come close. I hope that hearing and Deaf people can understand each other better."

Lauren's vision:

"I would like to see a Bi-lingual, Bi-cultural model of education. I'd like to see more Deaf professionals in fields beyond 'Deaf fields.' I'd like to see more Deaf people in politics."

Kristine's hope for the future:

I hope that what we have now will continue for Deaf people, including more exposure to other Deaf people, ASL and technology. Because I am Deaf and have experienced almost everything that could be experienced by a Deaf person, I can give that advantage to the children I work with. I want to help and teach Deaf children to accept themselves. Because we share that, I can connect with Deaf children.

Paul's vision:

I would like for Deaf people to have equal access to all aspects of society. There will always be Deaf people, maybe fewer, but enough to keep Deaf schools and programs in business. No matter what procedures or medical advancements are introduced, there will always be deaf people. I would hope for the future that Deaf people would not only teach in Deaf schools, but in hearing schools also. I would like to see a world where Deaf people could interact in both worlds, not giving up the Deaf world, but having both. I see that some of the shame and stigma of deafness in the family has diminished. I would like to see that continue and develop into pride in Deaf people. For example, I was recently in Seattle, and I went to a restaurant. The server could sign very well--it was a shock! What a great experience! It was natural and it represented an attitude change.

It would be great if ASL were more common in the hearing community. Why? Because English is so limited visually, if more people displayed some of the visual grammar and expression found in ASL, it might be easier to understand each other. With more appreciation of ASL, Deaf people have an easier time out in the hearing world. ASL is so rich compared with English.

Will's dreams for Deaf people:

I don't want Deaf people to be isolated any more. A perfect world would mean full accessibility, everywhere. I went out to eat with my hearing colleagues at a Mexican restaurant. I looked at the menu--I didn't really want to make anyone interpret for me, but I wasn't sure I would be understood. When the waitress arrived to take the orders, it turned out she could sign. We had a wonderful conversation--I got all my questions answered and placed my order directly! It was great! If I know a store has a Deaf employee, I will make a special effort to frequent that store and talk to or order from the Deaf employee. It makes me feel great to have those interactions with other Deaf people.

Anne's idea is very simple, yet profound:

"I hope that Deaf people have opportunity to do anything they want – equal to hearing people."

Summary

This chapter reviewed the results of narrative interviews with six Deaf participants and grouped the responses by the research question posed. Within each

research question, common themes emerged and participant responses were noted for similarities and differences of experience or perspective.

CHAPTER FIVE

Conclusions and Recommendations

In this study, I sought to listen to Deaf people as they shared and reflected on their life experiences. In the listening, I hoped to learn more about the experience of Deaf people. In the learning, I hoped to gain valuable insights for parents, educators and others who interact with Deaf people.

Six Deaf adults provided narrative accounts of their life experiences, and perspectives on many topics related to the Deaf community. Their stories were funny, profound, heartbreaking, illuminating and joyful. I am deeply grateful for their willingness to share their stories so candidly and honestly with me.

In this chapter, responses to each research question will be summarized, main ideas will be explored, and recommendations will be identified.

Research Questions

The following research questions guided this study:

1. How have the lived experiences of Deaf people changed over the last 60 years?
2. What are the common cultural themes found in stories of lived experiences of Deaf people?
3. What are the Deaf participants' personal perspectives on their life experiences and Deaf Cultural values, beliefs, norms and history?

RESEARCH QUESTION 1

How have the lived experiences of Deaf people changed over the last 60 years?

There has been remarkable progress in the last 60 years for Deaf people, not only in the many technological advances that allow easier accessibility to information, but also in social attitude and educational opportunity. This progress presents a paradox for the Deaf community.

The Deaf and hearing worlds of 60 years ago were nearly impermeable to each other. Isolation and marginalization of Deaf people in the early part of the 20th century contributed to the development of a strong cultural community. Deaf children had essentially one educational choice--the state sponsored school for the Deaf--and it provided a place for Deaf children to learn American Sign Language and Deaf Culture. Adult Deaf people gathered in Deaf clubs and formed tight-knit communities. Attainment of speech was the measure of educational and social success, without it, integration into the larger hearing society was very difficult. With little, or difficult, access to the hearing world, Deaf people were dependent on hearing people to gain information about and access to the hearing world.

Today, technological advances, such as the Internet, captions, and text and video communication, provide Deaf people with direct access to information of all kinds, without having to be dependent on others. There are many avenues for Deaf people to interact with the hearing world more equally, and many of these avenues do not require speech. American Sign Language has been recognized as a true and natural language and has become increasingly popular as a second language for students in high school and

college. More hearing people can sign, and sign language has reappeared, in some form, in many Deaf education settings. In fact, one of the most perplexing contemporary dichotomies is the tremendous popularity of curriculums teaching ‘Baby Signs.’ Hearing people have come to understand that babies can sign before they can speak and look to the introduction of sign language as a way that babies and their parents can communicate successfully at an earlier age. Millions of hearing babies are being taught ‘Baby Signs,’ while Deaf babies are receiving cochlear implants and speech therapy, and sign language is being discouraged or withheld.

Civil rights legislation, such as the Americans with Disabilities Act (ADA), provides protections to Deaf people in employment and education. More Deaf people are working with hearing people in all aspects of the work world. Now, the hearing world and the Deaf world are both increasingly permeable to each other, and Deaf people maintain connections to each other in many new and different ways.

RESEARCH QUESTION 2

What are the common cultural themes found in stories of lived experiences of Deaf people?

Each of the participants had a unique and individual story, yet, when combined with the other participants’ stories, elements of a grand cultural narrative emerged. With the exception of Anne, who lost her hearing at 12, all participants reported one or more critical formative experiences in which, even if they did not yet grasp the meaning of ‘Deaf’ and ‘hearing’, they understood that they were different and their difference was negative. They felt they existed outside of their family or school community, and, in

many instances, were deprived of communication and language. They all experienced joy at finding others who were also Deaf, and for some this experience was an epiphany of identity.

All reported communication challenges with their birth families, mostly because the family members either refused to sign or had limited signing skill. However, more family members of the younger participants could sign at least some, while the older participants reported little or no signing in their families when they were young. For most participants, these communication challenges extended into the classrooms, whether they attended a mainstream or Deaf school. Sign language was forbidden in some classrooms; in others, artificial Manually Coded English was allowed, but few students received competent language modeling. Participants who attended mainstream schools all reported experiencing loneliness and isolation, and shared negative experiences of interacting with teachers and interpreters. Participants who attended Deaf schools in the 1970s and earlier felt less lonely and more socially involved, but were often punished for signing and felt that the amount of time spent in speech training negatively impacted their content learning. All participants felt English and ASL were both very important for Deaf people. Most participants credited their desire and ability to read well as a major reason for their educational and vocational success—not their teachers or any particular educational method.

As adults, some of the participants' life decisions were influenced by communication access: which college to attend, what major to choose, which job to apply for, and even where to live. Unemployment or underemployment is an ongoing reality.

Participants' adult families were on a bilingual continuum-all adult families had at least one child who could sign fluently; in two families, all members were fluent in ASL and English.

Technology was an influence across all ages. Most participants were enthusiastic about the advantages of technology and use text messaging, videophones, captions and the Internet on a daily basis. The two youngest participants had cochlear implants, which they use infrequently, if at all. Some used hearing aids selectively, and all used ASL.

Interestingly, all participants felt that while they were currently involved in the Deaf community, they all perceived themselves as being involved in an unconventional way-different than what they had come to know as the traditional Deaf social world-the Deaf club. 'Deaf club as place' seemed to be fading in favor of 'Deaf club as process'. Now, Deaf people keep in touch with other Deaf people in many different ways, so the notion of a weekly social night at the Deaf club is becoming obsolete. Instead, Deaf people use videophones and computer applications such as Skype and Facebook to keep in touch visually with hearing and Deaf family members and friends.

RESEARCH QUESTION 3

What are the Deaf participants' personal perspectives on their life experiences and Deaf Cultural values, beliefs, norms and history?

Pride was a consistent theme through the interviews. Participants were proud of their Deaf identity and did not feel disabled by it. If given the opportunity, they would not want to become hearing, because it is not who they are. However, technical advances that allow them access to the hearing world are welcomed. Videophones, Internet, text

messaging, email, and captioning are all tools that facilitate interaction and access to general American cultural knowledge. Interacting with the hearing world in an appropriate, useful, and authentic way, without sacrificing identity, is preferred over feeling forced to *be* hearing or *act* hearing through exclusive use of speech training or cochlear implants. They enjoyed the ability to be *in* the hearing world, but not *of* the hearing world. Being able to function well in both worlds was of value to them and important for Deaf children.

Important also, was the concern about who makes decisions for Deaf people. Leaving Deaf people out of the dialogue about communication options and education for Deaf children was seen by participants as short-sighted and oppressive, and has resulted in devastatingly poor educational outcomes for Deaf children. Participants generally felt that Deaf people had higher expectations of Deaf students at all levels than did hearing professionals.

While the participants had a range of opinion on cochlear implants—who should get them and when, and who makes the decision, all agreed on one thing. A cochlear implant cannot make a Deaf person into a hearing person, even if the implanted person can function relatively well in the hearing world. Deaf children with cochlear implants should routinely and simultaneously be allowed to learn and use American Sign Language along with moderate levels of speech therapy. The approach should be *both/and*, not *either/or*. Participants felt American Sign Language enhances communication and literacy.

Likewise was their thinking on other communication tools. Manually Coded English systems, cued speech, speech therapy, and amplification were all supported-based on individual need and circumstance-as long as American Sign Language was not taken away. The view is that Deaf people, and especially Deaf children, for whom decisions are largely made by hearing people, will have access to more options for communication. It was clear to the participants that even though ASL is the heart and soul of the Deaf community, both ASL and English are important. If Deaf children have a true, natural and complete language (ASL) from the beginning, their ability to acquire a second language will be enhanced. Both languages will aid in their educational success. Even if ASL was to be again banned in schools, it will still survive, so great is its value to Deaf people.

Finally, the Deaf participants' perspectives on the future demonstrated a positive outlook for Deaf people and their community. They generally felt that the Deaf community could survive and thrive, but in new and different ways. However, they felt Deaf people must be open to change and willing to take advantage of all the new opportunities available to them. Deaf children, in particular, have a bright future, with all its opportunity, as long as they are not denied their birthright—American Sign Language and their Deaf identity.

Conclusions and Contributions

This study contributes to the body of knowledge about the life experience of Deaf people by providing stories of actual lived experiences of Deaf people in education, work, families and social interactions. These rich stories of lived experiences provide

insight into how Deaf people live in and experience the hearing world, and how they develop, embrace and live out their Deaf identity. Their poignant, humorous, and sometimes devastating experiences, along with their personal perspectives on these experiences can inform decisions made in education and human service professions.

Although the number of participants is small, that there were many similar experiences is significant. Vast generalizations cannot be made from this study, but as the stories and perspectives from the six Deaf participants are added to the body of knowledge in the field Deaf Studies, they will contribute to the grand narrative of Deaf people. As Deaf people themselves have more access to the experiences of other Deaf people, their own lived experiences may take on new significance, value and legitimacy.

Two Big Ideas

This study explored the lived experiences of six Minnesota Deaf people and their perspectives on their experiences and issues facing the American Deaf community. After watching and analyzing over 30 hours of videotaped interviews with these six participants, two surprisingly simple, but profound ideas repeatedly found their way into my analysis:

1. Listen to Deaf people.
2. Adopt a both/and instead of an either/or approach.

These two ideas are uncomplicated, yet have been difficult to achieve. Hearing people, who are typically gatekeepers in education settings, have difficulty listening to Deaf people, in part because they do not see Deaf people often, and they do not know their language. Hearing people have long held the power to make decisions for Deaf people in education, in the workplace, and in the family. What do Deaf people think

Deaf children and adults need and want? Listening to the experiences and perceptions of Deaf people can inform hearing educators, policy makers, and parents about the values and needs of Deaf children from those who were once Deaf children.

The goal of oral-only education methods of the past, and, for many today, cochlear implant surgery, is to eliminate the need to depend on sign language, because it is thought sign language will impede English development. As described in chapter two, Deaf children of Deaf parents who have ASL as a first language perform significantly better in all subject areas—including English. This research supports the notion that ASL can enhance English literacy, not hinder it. Allow every tool, especially those that have been proven to be successful.

Recommendations

Incorporating the two big ideas above, I propose the following recommendations for administrators and policy makers in Deaf and regular education:

1. Listen to Deaf people about issues surrounding Deaf education.
2. Actively recruit and hire Deaf professionals, and include Deaf professionals and lay people on Deaf education committees, task forces and work groups.
3. Promote the presence of Deaf adults in mainstream classrooms, to serve as role models and language masters.
4. Set high standards for Deaf education, expect more from Deaf students, and provide leadership to create a challenging curriculum.

5. Strive to better understand the complex issues in Deaf education, including first and second language acquisition, literacy in both ASL and English, communication, socialization, and inclusion.
6. Support research on American Sign Language, bilingual education, and Deaf student success, and take steps to incorporate research results into action plans for improving Deaf education.
7. Develop policies and expectations that improve the learning climate for Deaf students including academic instruction in ASL, highly qualified teachers, and appropriate social and cultural environments.
8. Support approaches to education and methods of instruction that reflect a both/and, not an either/or approach to Deaf education and include ASL along with any other tools that may support student success.

Summary

From the voices of the Deaf people in this study, a larger narrative emerges. This narrative highlights the need for dialogue between Deaf people and hearing people who have decision-making power over Deaf childrens' lives. Honoring the experiences that the participants have shared, the following quote is offered from Padden and Humphries:

What do Deaf people want from the future? What they have always wanted and what every culture and linguistic community wants: a preservation of their sign language and their ways of being. This does not mean that they expect things to remain the same. It does mean that they want to be free of inhumane threats... The problem for Deaf people is, as always, how to articulate their views of

*science and knowledge in a world that finds it easier **not** to understand them*

(Padden & Humphries, 2005).

It is hoped that this study will aid in the understanding of Deaf people and their lives.

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Appendix A: Demographic Survey

Cultural Themes Across Generations: Exploring Changes in Lived Experiences of Six

Deaf Individuals

Demographic Survey for Participants

Please answer the following questions. All information will be held in strict confidence and surveys will be destroyed at the end of the research period.

Name: _____

Address: _____

City, State, Zip: _____

Phone #: Voice: _____ TTY: _____ VP: _____

Email: _____

DOB: _____

ALIAS NAME: _____

Please circle the most correct answer:

Gender: Male Female

Age: 18-35 36-55 56+

Ethnic background: Caucasian (white) Hispanic/Latino African-American

American Indian Other: _____

I became deaf: At Birth age 0-2 age 2-10 age 10-18 age 18-30 age 30+

I learned sign language: After Birth age 0-2 age 2-10 age 10-18 age 18-30 age 30+

My parents are: Both Deaf Mom hearing, Dad Deaf Dad hearing, Mom Deaf

Both hearing Both Hard of Hearing Mom or Dad hard of hearing

My siblings are: All hearing All deaf Mixed ___#deaf, ___#hearing

I am an only child

My spouse/partner is: Deaf Hearing Hard of Hearing

My children are: All hearing All deaf Mixed ___#Deaf, ___#hearing

I don't have children

Who signs in your family? Please check the best answer:

| | No signs | Fingerspell only | Signs a little (so-so) | Signs Pretty good (OK) | Signs very well (SKILL!) |
|----------------|----------|---------------------|---------------------------|---------------------------|--------------------------------|
| Mother | | | | | |
| Father | | | | | |
| Sibling | | | | | |
| Sibling | | | | | |
| Sibling | | | | | |
| Grandmothers | | | | | |
| Grandfathers | | | | | |
| Aunts | | | | | |
| Uncles | | | | | |
| Spouse/Partner | | | | | |
| Daughters | | | | | |
| Sons | | | | | |
| | | | | | |
| | | | | | |

My schools:

Pre-school: Mainstream Deaf program Deaf Residential School No pre-school

Elementary: Mainstream Deaf program Deaf Residential School Mixed

High School: Mainstream Deaf program Deaf Residential School Mixed

College: Mainstream Deaf program Deaf only University

No college

THANK YOU!

Appendix B: Demographic Survey Results

| | Y-M | Y-F | M-M | M-F | E-M | E-F |
|--------------------|---------------------------------|-------------------------------------|---|---|------------------------------------|--|
| Alias | John | Lauren | Paul | Kristine | Will | Anne |
| Age | 19 | 34 | 53 | 37 | 58 | 77 |
| Ethnic | C | C | C | C | C | C |
| DEAF when? | birth | Age 2-10 | birth | birth | birth | Age 10-18 |
| Learned sign ? | After birth | Age 2-10 | Age 2-10 | Age 0-2 | Age 2-10 | Age 10-18 |
| Parents? | Both hearing | Both hearing | Both hearing | Both hearing | Both hearing | Both hearing |
| Siblings? | 1 D, 1 H | All hearing | 1D, 2H | All hearing | 2 D, 2H | All hearing |
| Spouse/partner | NA | Deaf | Deaf | Hearing | Hearing | HoH |
| Children? | NA | All hearing | All hearing | All hearing | All hearing | All hearing |
| Signs very well? | Deaf sibling | Spouse | Mother, 1 deaf sibling, 1 hearing sibling, spouse, children | | 2 deaf siblings, spouse, children | Spouse, 1 daughter |
| Signs pretty well? | Mother, Father, hearing sibling | Daughter, Sons | 1 sibling | Spouse | Mother, hearing sibling | 1 daughter |
| Signs a little? | | Mother | Father | Mother, Daughter | Father, hearing sibling | |
| Fingerspells only? | Grandmother | Siblings | | | | Sons |
| No sign? | Grandfather, Aunts, Uncles | Father, Grandparents, Aunts, Uncles | Grandparents, Aunts, Uncles | Father, 3 siblings, Grandparents, Aunts, Uncles | Grandparents, Aunts, Uncles | Parents, Grandparents, siblings, aunts, uncles |
| Pre-school | Deaf program | No pre school | Deaf Residential | Mainstream | Mainstream | No pre-school |
| Elementary | Mainstream | Mainstream | Deaf Residential | Mainstream | Mainstream/or al | Hearing school |
| High School | Mixed | Mixed | Deaf Residential | Mainstream | Deaf Residential | Deaf Residential |
| College | Deaf program | Mainstream | Mixed | Mainstream | Deaf Program (BA); Mainstream (MA) | NA |

Appendix C: Interview 1

Birth or Adoptive family:

1. Are any other family members deaf? Tell me about that.
2. How did family members communicate?
3. Who are you closest to in your family and why?
4. When did you first learn sign language?
5. When did you realize there was a deaf world and a hearing world? Tell me more about this.

School Experiences:

6. When did you begin school?
7. What type of school did you attend?
8. Tell me about your first day of school.
9. Was sign language allowed at school?
10. How did students communicate with teachers?
11. How did students communicate amongst themselves?
12. Please share some stories about your school days.
13. Did you receive speech therapy? Tell me more about this.

Technology

14. Tell me about the first time you used a TTY
15. Tell me about the first time you watched TV or a movie with captions.
16. Tell me about the first time you used a computer and email.
17. Tell me about any experiences you have had with hearing aids or other amplification systems.

Appendix D: Interview 2

Work Experience

1. Please tell me about your first job.
2. Tell me about how you got from your first job to your current job.
3. What do you like about your current job?
4. Tell me about your co-workers.
5. How do you communicate on the job?

Post-secondary education

6. Did you attend postsecondary school? What was your field of study?
7. Tell me about your post-secondary experience.
8. Who were your good friends in college? Tell me about the social aspect of college life.

Current family

9. Do you have a life partner? Tell me about meeting your partner.
10. What type of communication occurs in your home?
11. Do you have children? Are they deaf or hearing?
12. Is your family involved in the deaf community?

Technology

1. Tell me about how and how often you use technology in your daily life (computers, Sidekicks, VRS, captioning, flashing signals, etc.)

Appendix E: Interview 3

Deaf Community Past

1. Tell me about how the American deaf community formed.
2. Tell me about the history of deaf education
3. Tell me how you became involved in the deaf community?
4. Who are your heroes in the Deaf-World?

Deaf Community Present

5. Are you involved in the deaf community now? In what ways?
6. How do you perceive the health and vitality of the Deaf Culture?
7. Tell me about some of the challenges to Deaf Culture?
8. How do you feel about the oral vs. manual controversy?
9. How do you feel about Signed English systems?
10. How do you feel about mainstreaming?
11. How do you feel about cued speech?
12. How do you feel about cochlear implants?

Deaf Community Future

13. What do you think will be in the future for deaf people?
14. Are you optimistic or pessimistic about the future for Deaf Culture?
15. Tell me about your hopes and dreams for deaf people?
16. Tell about your feelings about the future of education for deaf children?

Appendix F: Consent Form Information

Consent Form

Cultural Themes Across Generations: Exploring Changes in Lived Experiences of Six Deaf Individuals

You are invited to be in a research study comparing the life experiences of Deaf people in different generations. You were selected as a possible participant because you are a member of the Deaf community and use American Sign Language as your preferred language, and you are in one of the age ranges we are interested in studying.

We ask that you read this document and ask any questions you may have before agreeing to be in the study.

Nancy McFarlin Diener is conducting this study as part of the requirements for an Educational Doctorate Degree from the University of Minnesota. Nancy has worked as a sign language interpreter for 25 years and as an academic counselor for Deaf college students for 18 years. She holds National Certification (CI & CT) from the Registry of Interpreters for the Deaf.

Background Information

The purpose of this study is to identify historical and societal challenges to the American Deaf Culture and to describe dynamics of identity and inclusion in this evolving culture, through the voices of Deaf people themselves.

Through individual life story interviews, Deaf participants will provide rich information about their life experiences across generations. From these interviews, we hope to find

common cultural themes in the Deaf world that demonstrate the continuity of Deaf cultural values, despite generational differences in the lived experiences of Deaf people.

Procedure

If you agree to be in this study, we will ask you to do the following things: Participate in three (3) separate interviews, scheduled approximately 2-4 weeks apart. These interviews will be videotaped and are expected to last 2-4 hours each, for a total of 6-12 hours of participation time. There will be one interviewer present with you during the interview. It is anticipated that the first interview will be in mid-late March, the second in early April and the third in late April 2006. Interviews will be scheduled at your convenience within the scheduling time frame, and at a location that is comfortable for you.

Risks and Benefits of Being in the Study

The study has the following risks:

First, you may find some of the questions too personal, embarrassing or sensitive to answer. While the likelihood of this occurring is minimal, you can decide not to answer any question at any time for any reason.

Second, you may feel that some of the questions invade your personal or family privacy. While the likelihood of this occurring is minimal, you can decide not to answer any question at any time for any reason.

There is no direct benefit to you as a result of participating in the study and there are no monetary benefits.

A possible indirect benefit to you is knowing that you will be contributing to the body of knowledge concerning Deaf Culture.

Confidentiality

You will be asked to provide an alias or pseudonym for the purposes of collecting the stories and writing the dissertation report. Your specific interviews will be anonymous and any information taken from them for the report will be referred to by your chosen alias name. The interviews will be recorded onto DVDs and transcribed into written English. The DVDs will be stored in a locked cabinet and only the researcher will have access to them. At the end of the research and writing process, you will be given the DVDs of your interviews and the English transcripts, if you so desire. It is expected that the researcher will use the interview data for a period of 6 months.

Voluntary Nature of the Study

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota or the researcher.

Contact and Questions

The researcher conducting this study is Nancy McFarlin Diener, M. Ed., CI & CT.

You may ask any questions you have now.

If you have questions later, please contact Nancy at 218-340-4529 txt or relay, or ndiener@d.umn.edu; or contact Nancy's advisor, Dr. Frank Guldbrandsen at 218-726-8172 or fguldbra@d.umn.edu

Appendix G: Consent Form Signature page

Consent Form

Cultural Themes Across Generations: Exploring Changes in Lived Experiences of Six Deaf Individuals

I agree to be in a research study comparing life experiences of Deaf people in different generations.

Responsibilities:

I understand that I will participate in the following events:

1. I will sign a consent form to be involved in the study.
2. I will complete a short demographic survey
3. I will be interviewed three (3) times and each interview will be 2-4 hours long. Interviews will be videotaped.
4. I will create an alias name for the study

Risks and Benefits:

I understand that the following risks are possible:

1. I may find some of the questions too personal, embarrassing or sensitive to answer.
2. I may feel that some of the questions invade my personal or family privacy.

I understand the following indirect benefit is possible:

1. Knowing that I will be contributing to the body of knowledge concerning Deaf Culture.

Rights:

1. I understand that my participation is entirely voluntary and I may withdraw from the study at any time.
2. I understand that I may decide not to answer any question at any time for any reason.
3. I understand that I can contact the researcher, Nancy McFarlin Diener, or her advisor, Dr. Frank Guldbrandsen if I have any concerns or questions.

I agree to participate in the research study “Cultural Themes Across Generations: Exploring Changes in Lived Experiences of Six Deaf Individuals”.

Print Name

Signature

Researcher Signature

Date

Date

Appendix H: IRB Review

University of Minnesota

Continuing Review of IRB - Approved Social & Behavior Science Research

Review Period:
09/13/2009 - 12/06/2010

Rev: 03/01/2005

Study Number: **0601P79792**

Principal Investigator: **Nancy M Diener**

Title(s): Cultural Themes across Generations: Exploring Changes in Lived Experiences of Six Deaf Individuals

Study Status

Data Analysis Only

Funding Source(s)

There are no funding sources for this study.

Personnel

Diener, Nancy (Student P. I.)

Guldbrandsen, Frank (Advisor)

Study Enrollment

Number of Subjects Approved for study:

6

Number of subjects enrolled this review period:

| Male | Female | Unknown | Total |
|------|--------|---------|-------|
| 3 | 3 | 0 | 6 |

Number of subjects enrolled to date:

| Male | Female | Unknown | Total |
|------|--------|---------|-------|
| 3 | 3 | 0 | 6 |

Is this a multi-center study?

No

Unanticipated Problem Reporting

Have there been any unanticipated problems, subject withdrawals, or complaints about this research?

No

Has the risk/benefit relationship for subjects changed from the initial expectation?

No

Study Summary

Summarize preliminary information about any results and/or trends:

Currently analyzing data and writing final version of dissertation.

Have there been any changes in protocol approved by the IRB since last continuing review?

No

Since the most recent IRB continuing review approval, have there been any progress reports on the research?

No

Since the most recent IRB continuing review approval, have there been any multi-center trial reports?

No

Since the most recent IRB continuing review approval, have there been any other information relevant to this research discovered, especially information about the risks and benefits associated with the research?

No

Since the most recent IRB continuing review approval, have subjects experienced any benefits?

No

External Findings

Is there anything in the relevant recent literature that the IRB should know about concerning this research?

No

Other Comments