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When the hearing world will not listen: Deaf Community care in hearing-dominated healthcare

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Thesis

**WHEN THE HEARING WORLD WILL NOT LISTEN:
DEAF COMMUNITY CARE IN HEARING-DOMINATED HEALTHCARE**

by

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DEDICATION

I would like to dedicate this thesis to my participants and members of the Deaf
Community, from whom I learned so much.

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**WHEN THE HEARING WORLD WILL NOT LISTEN:
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ABSTRACT

The Deaf Community has faced a great deal of historical oppression from hearing people that still resonates throughout the Community today. Recent literature has acknowledged the disconnect between the Deaf and hearing worlds, particularly in healthcare and education settings. Likewise, there have been many advocacy and service projects and programs to try to improve these situations. However, much of the existing literature and projects have failed to include input from Deaf Community members. As such, hearing perspectives dominate the lives of Deaf individuals. This study examines how the dominant biomedical perspective of deafness affects Deaf individuals' ability to receive adequate healthcare. Using standard ethnographic methods, including in-depth, open-ended interviews, and immersion in the research population through ongoing participant observation at a Deaf agency and Deaf Community events, this study highlights the perspectives of Deaf Community members themselves. The findings confirm previous studies' assertions that the dominant biomedical perspective toward deafness negatively affects Deaf people overall, particularly because of communication obstacles and a lack of understanding about Deaf Culture, specifically in the realm of access to biomedical care. This has never been more worrisome for Deaf people in America than in the current unstable political climate that now threatens access to subsidized healthcare, disability services, and legally protected accommodations.

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LIST OF ABBREVIATIONS

ACA	Affordable Care Act
ADA	Americans with Disabilities Act
ASL	American Sign Language
CMA	Critical Medical Anthropology
CODAs	Children of Deaf Adults
DGM	Deaf Grassroots Movement
ER	Emergency Room
FSL	French Sign Language
HeLPS	Hearing Loss and Prostheses Simulator
IRB	Institutional Review Board
MBTA (T)	Massachusetts Bay Transportation Authority
MCB	Massachusetts Commission for the Blind
MCDHH	Massachusetts Commission for the Deaf and Hard-of-Hearing
PCP	Primary Care Physician
PTSD	Post-Traumatic Stress Disorder
RID	Registry of Interpreters for the Deaf
RP	Retinitis Pigmentosa
VRI	Video Remote Interpreting

INTRODUCTION

It was a blustery May morning as we exited the Park Street T¹ station and walked across Boston Common toward the Massachusetts State House. Over the sound of the wind and common city noises, I heard many people stomping their feet and clapping their hands, cheering and yelling, as someone somewhere was banging on what sounded like a five-gallon bucket. Many people might assume that a Deaf rally would be silent. It was anything but.

A sea of people wearing lime green shirts absorbed me once I received and donned my own shirt. These shirts read, “Deaf Rights NOW!” which encapsulated the purpose of this entire rally. Along the fence between the road and us, numerous posters in various bright colors caught my eye. Children from the Marie Philips School for the Deaf made these posters in order to make their voices heard at the rally. These posters read things like, “Don’t limit Deaf people’s abilities,” “Deaf NOT Dumb,” and “Deaf can do everything!” (fieldnotes, 5/4/16).

¹ Local name for the Massachusetts Bay Transportation Authority (MBTA).

² This is the ASL sign for the Deaf Grassroots Movement. The two hands come together to represent the strong roots of the movement as well as their growing goals.

³ In the context of education, mainstreaming is the process of educating students with special



Signs made by children from the Marie Philips School for the Deaf (Source: Photo courtesy of Charlotte Kelleher)



Getting attendees pumped up (Source: Photo courtesy of Charlotte Kelleher)

This powerful rally occurred simultaneously throughout the country in major city centers. Members of the Deaf Community attended, as well as interpreters and hearing advocates for the Community. All gathered together to stand in solidarity, to rally for Deaf people's rights to equal opportunities in every aspect of their lives. As a relatively new intern/volunteer at Advocates, Inc., a Deaf organization, I felt honored to be a part of it. The National Deaf Rally's mission was to invite Deaf civil rights activists to engage in nonviolent, direct action. They aimed to demonstrate the needs of the Community, specifically focusing on education, employment, and communication access. The leaders of the Rally said,

Our goal is to promote equality for all, with the quality of life improved for us. We want this day to make the most powerful impact possible on our nation that would last long, and influence our legislators to pass laws and amendments that would benefit us on the whole as a society. The impact we are seeking to make would not only be on legislators but would alter the perceptions of other entities such as law enforcement at all levels, services, and private sectors in our society toward Deaf people in a positive way, to effect changes that are necessary in order for us to lead productive lives, that will provide opportunities for which we seek, that will put us on the same level as hearing citizens. We will not fight as individuals; we will fight as a team to make change
(www.facebook.com/DeafGrassrootsMovement).



Many people at the rally either held or wore signs all related to the focal points of the rally and their individual frustrations. Several people got up to tell stories of specific frustrating experiences, or general areas where they would like to see improvements. They argued for Deaf children to be educated, in their native American Sign Language (ASL), with their fellow Deaf Community members. They argued against mainstreaming³ Deaf children into English-speaking schools because they feel as though children will miss out on both Sign and English language acquisition (Higgins, 2016, Staten, 2011, Sutherland, 2014).

² This is the ASL sign for the Deaf Grassroots Movement. The two hands come together to represent the strong roots of the movement as well as their growing goals.

³ In the context of education, mainstreaming is the process of educating students with special needs in regular classes during specific times based on their skills. www.lifeprint.com.

Some people told stories of feeling as though they were stuck in dead-end jobs or could not get a job at all, because employers think their deafness means they are stupid. A story that particularly stood out for me came from an elderly Deaf man. He explained that he has worked at the same post office his entire adult life and has never been promoted in any way, regardless of his good work ethic. He wanted a better job but was afraid to quit the post office for fear of not being able to get another job, so he stayed with the post office. It was clear how much this frustrated him as he signed furiously fast with emotion.

While this rally garnered many stories of frustration from attendees, it was a day filled with activism. These stories of frustration and the need for activism stem from a history of oppression against Deaf people. Explained in further detail throughout the entirety of this thesis, I will provide a brief background about this historical oppression and how it is still negatively affecting members of the Deaf Community today.

I first became interested and invested in advocacy for the Deaf Community during my undergraduate education. Sign Language always fascinated me but I never had the opportunity to learn it. That opportunity finally came about during college. I excelled in the language and was ecstatic to learn sign after sign. My department required two semesters of a foreign language, but I continued beyond this requirement. In my American Sign Language-3 (ASL-3) class, an advanced level course, I worked closely with my professor and spent time with her at the high school where she worked teaching ASL classes and two Deaf students. This experience not only helped strengthen my ASL skills, but also opened my eyes to the fact that there was so much more for me to learn beyond the language alone. I had a better understanding of both the language and Deaf

Culture than when I started, but I wanted to learn more.

While enjoying my major of anthropology, I still did not know what I wanted to do after I graduated. My applied anthropology professor came to my rescue, introduced me to the concept of medical anthropology, and suggested I look into it. Since medical anthropology draws on anthropological views and values while looking at factors that influence health, I would still be able to apply my anthropological knowledge and training, and combine it with my interest in Deaf Culture. As such, a research project took root and my research question eventually bloomed into: How does the dominant biomedical perspective of deafness affect Deaf individuals' ability to seek healthcare, and their overall health?

Varying Perspectives of Deafness

There are three prevalent, but vastly different, perspectives of deafness: the biomedical view, the social view, and the cultural-linguistic view. I will discuss these varying perspectives throughout the entirety of this thesis. The biomedical model of deafness is based on seeing deafness as a deficit and that it is the pathological absence of hearing. As such, Deaf people are commonly regarded as impaired or disabled. It is called the biomedical model because medical interventions, such as cochlear implantation, are often recommended by medical professionals (DeVault, 2014, Fjord, 1996, Lentz, 2014, Senghas, 2002).

The social view focuses on individuals with disabilities gaining access into general society. The social view combines aspects of the biomedical perspective and the

cultural-linguistic view. While this perspective provides advantages for Deaf people on certain levels, it does not address the central issues related to Deaf Culture and Sign Language. The ultimate goal of mainstreaming individuals with disabilities into society unwittingly isolates the Deaf person from their own people and language (DeVault, 2014, Fjord, 1996, Lentz, 2014, Senghas, 2002).

The cultural-linguistic model of deafness has gained momentum in recent years. This perspective focuses on recognizing Deaf people as a minority cultural group with their own language. In this view, deafness is regarded as just another human variation that becomes part of an individual's identity. Similar to other minority cultures, the Deaf Community has its own histories, traditions, values, and social norms that are passed down through generations (DeVault, 2014, Fjord, 1996, Lentz, 2014, Senghas, 2002).

The biomedical model argues that deafness is a disability and an impairment of the body itself, so it is a medical problem; the cultural-linguistic view argues that existing social structures and ideologies of society disable the individual because they do not accommodate or accept disabilities or differences (Mauldin, 2012). In more recent years, the Deaf Community has explored strategies to reduce the lack of awareness by increasing ASL's prestige, the Community's legitimate power in the eyes of the dominate community, and creating a strong presence in the educational system (Lentz, 2014).

There is a simple, yet meaningful, distinction that must be made between two terms: '*Deaf*' and '*deaf*.' Many people think that these terms are the same, but that is not the case. With a lowercase *d*, *deaf* refers to the sensory inability to hear to the extent that one cannot understand speech for everyday communication purposes. With a capital *D*,

Deaf refers to the particular cultural group who shares a language and embraces the cultural norms, beliefs, and values of the Deaf Community (Cleall, 2015, DeVault, 2014, Munoz-Baell, 2000, Padden, 2000, Senghas, 2002). For example, an individual who loses their hearing later in life (late-deafened) might consider themselves *deaf* but not *Deaf*, and will not consider themselves as being part of the Deaf Community. For the entirety of this thesis, when *Deaf* is used, I am referring to someone who is culturally Deaf and embraces the Deaf Community; when *deaf* is used, I am referring to the condition in which one's sensory ability to hear is gone.

These varying perspectives highlight the need for more education about the Deaf Community and their Culture. I argue that overall, the dominant biomedical perspective toward deafness negatively affects the Deaf Community. While the views of Deaf people cannot be generalized across the whole Community, Deaf people could have a more positive healthcare experience overall if medical professionals had a better understanding of and more respect for the Deaf Community. The dominant biomedical perspective creates a lack of access, trust, and respect that Deaf people often feel toward the healthcare system.

As such, this thesis aims to better illuminate how Deaf people perceive the hearing-dominated healthcare system and how this affects their overall health and well-being. The perceptions of Deaf people in Boston in their own words, as documented through in-depth interviews and participant observation, may enhance respectful collaboration between healthcare providers and Deaf individuals, as well as enhance anthropological approaches to health. In a time such as now when various marginalized

groups of people, including the Deaf, are worried about what the future might hold for them, due to the political climate and Donald Trump's rhetoric against anyone with any sort of difference, anthropological approaches to improving health have never been more relevant.

BACKGROUND:

HISTORICAL OPPRESSION AND ITS IMPACT TODAY

This chapter provides the necessary background information to understand this thesis as a whole. I discuss membership within the Deaf Community. The formation of the Deaf Community and American Sign Language stems from two differently influential historical figures: Thomas Gallaudet and Alexander Graham Bell. The history of the Deaf Community has had a big impact on how Deaf people have come to self-identify. A person's self-identity will greatly influence whether they agree with the biomedical and disability perspectives toward deafness. Previous research regarding Deaf people often has not been inclusive. There are obstacles in healthcare settings that hearing people have made difficult for Deaf people to overcome.

Membership in the Deaf Community

As described in the introduction, members of the Deaf Community will identify themselves as *Deaf*, with a capital *D*, because they see themselves as belonging to a distinct cultural group. With the definition of Deaf in mind, what constitutes the Deaf Community? Depending on who is describing it, the Deaf Community could be explained in various ways. To many people, the Community is not compiled solely of people who lack the sensory ability to hear. Rather, they see the Community as being comprised of those who are Deaf, Deaf-Blind, Hard-of-Hearing, Late-Deafened, Oral-Deaf, Children of Deaf Adults (CODAs), and even hearing people who are advocates for the

Community.⁴

How much a Deaf person can hear is highly variable, so membership in the Deaf Community is not based on the degree of hearing loss (Fjord, 1996). Membership in the Community must be earned, and being deaf or having a certain degree of hearing loss is not the only criterion for potential inclusion. A common language, shared experiences, social participation, and a sense of cultural identity are other recognized criteria (Munoz-Baell, 2000). A value that appears to underlie all traits of Deaf Culture is allegiance to the Deaf Community (Lane, 2010).

An individual not only needs to identify themselves as Deaf, but other members of the Deaf Community must accept them as part of the Community as well. Carol Padden, a Deaf individual herself, and a professor in the Department of Communication at the University of California, San Diego, explains the Deaf Community as including,

Individuals who have usually acquired deafness at birth or shortly after, and have for the most part, spent most of their lives with the condition. For this group, deafness is not only a sensory condition, but also a way of life characterized by membership in a signing community, participation in educational programs for the Deaf (such as residential boarding schools), and a network of social organizations, clubs, and affiliations are used (2000: 57).

Ultimately, someone who is a member of the Deaf community accepts and supports the values and goals of the Community as a whole. This factor seems to be more important than whether or not a person is actually Deaf (Cokely, 1980, Fjord, 1996, Lane, 2010, Munoz-Baell, 2000, Padden, 2000). This means that not everyone who is deaf is a member of the Deaf Community. Some individuals with a hearing loss prefer to identify with the hearing world and try to function as a member of that group. This is especially

⁴ All of these terms are used throughout this thesis. They are explained in detail in Appendix A.

common among hard-of-hearing people or people who lose their hearing later in life, because they are losing a sense that have known and relied on their whole life (Cokely, 1980, Lane, 1992, 2010). Similarly, there are hearing people who can be considered members of the Deaf Community due to their activism in supporting the values and goals of the Community. For example, a qualified Sign Language interpreter who has worked in the field for a long time might be considered part of the Community if Deaf people respect them for adhering to the values and norms of the Community (Cokely, 1980, Lane, 1992, 2010, Padden, 2000).

Influential Figures in Deaf History

The Deaf Community has had a long and turbulent history to get to where it is today. Deaf people did not always feel as though they had a community to belong to and it took a lot of hard work to create a Deaf Community presence in America. It is impossible to discuss the history of the Deaf Community without discussing two prominent hearing figures: Thomas Gallaudet and Alexander Graham Bell.

In the early 1800s, Thomas Gallaudet was studying to become a minister at Yale University. Gallaudet's neighbor, Mason Cogswell, a well-known doctor in Hartford, Connecticut, had a deaf daughter named Alice. When Gallaudet and Alice met, he tried to teach her to read and write a few words, with some success. Dr. Cogswell was impressed with Gallaudet's work and encouraged him to consider starting a school for deaf children. Dr. Cogswell and a group of concerned citizens raised enough money to send Gallaudet to Europe to learn about their methods for instructing deaf people (Cokely, 1980, Lane,

2010, Nomeland, 2011).

Starting in London, Gallaudet was unsuccessful in convincing the Braidwood Schools to teach him their methods, which focused on lip-reading and speech training. While in London, he witnessed the French method of instructing deaf students. This method used signs from French Sign Language (FSL); with an added set of signs called, *les signes méthodiques* or *methodical signs*. Abbé Charles de l'Epeé, the founder and director of the first school for deaf students in Paris, invented this set of methodical signs. Gallaudet, impressed with the demonstration he saw in London, decided to continue on to Paris (Cokely, 1980, Lane, 2010, Nomeland, 2011).

While in Paris, Gallaudet learned French signs and studied the teaching methods used at the Paris school. When he was ready to return to Hartford, Connecticut, he convinced Laurent Clerc, a deaf man and instructor at the Paris School, to go with him and establish a school for deaf students in America. On April 15, 1817, Gallaudet and Clerc established the *Institution for Deaf Mutes* with funds from the State of Connecticut, the United States Congress, and other sympathetic groups. Clerc originally planned to stay in America for a short time but he remained an instructor at this school for over forty years. The school was later renamed, *The American Asylum at Hartford for the Education and Instruction of the Deaf and Dumb* and is presently called, *The American School for the Deaf* (Cokely, 1980, Lane, 2010, Nomeland, 2011, Padden, 2006, VanCleve, 1982, 1999, 2007.).⁵

⁵ For the sake of this thesis, this is a brief, condensed history of Thomas Gallaudet. For more information, see the sources listed within the text or go to <http://www.gallaudet.edu/dpn-home/thomas-hopkins-gallaudet.html>.

Thomas Gallaudet passed away in 1857. By the time of Laurent Clerc's death in 1869, there were thirty residential schools for deaf children in the United States with over three thousand total students and almost two hundred teachers. Nearly half of the teachers were deaf themselves (Cokely, 1980, Lane, 2010, VanCleve, 1982, 1999, 2007). The success of the residential schools led to the creation of high school and then college preparatory classes. This resulted in the foundation of the *National Deaf-Mute College*, currently known as, *Gallaudet University* (Lane, 2010). Gallaudet University has played a large role in the development and strengthening of the Deaf Community. The university paved the way to higher education and college degrees for Deaf students, who became teachers and other professionals in the Deaf Community (Greenwald, 2008, Lane, 2010, Nomeland, 2011, VanCleve, 1982, 1999, 2007). It is still in operation today and continues to be a beacon of inspiration throughout the country (Lentz, 2014).

Before inventing the telephone, Alexander Graham Bell was dedicated to teaching deaf people speech and lip-reading in the 1870s and 1880s. Even though Bell was able to sign because his mother and sister were deaf, he believed that deaf people should accommodate the hearing majority who did not sign by learning how to speak and lip-read (Baynton, 1996, Burch, 2004, Lane, 1992, Lentz, 2014). Bell believed that the very future of the nation depended on eradicating minority languages. He said, "It is important for the preservation of our national existence that the people of this country should speak one tongue" (Lane, 2010: 8). Bell was a respected individual, and became even more so after his invention of the telephone. His point of view toward deafness and Sign Language influenced society's view. Sign Language and the emergence of Deaf Culture

became either invisible to or regarded negatively by the public (Burch, 2004, Edwards, 2012, Lane, 1992).

Alexander Graham Bell advocated the technique of *oralism* to educate deaf people. This term refers to the system of teaching deaf people to communicate with speech and lip-reading, and forbidding the use of Sign Language (McKee, 2013). Bell was also one to believe in and stress the notion of *audism*. This is the notion that one is superior based on one's ability to hear and the belief that life without hearing is futile and miserable, which results in a negative stigma toward anyone who does not hear and their use of Sign Language (MacDougall, 2015). As such, Bell followed and taught the now popular biomedical perspective toward deafness, which sees deafness as a deficit. Due to his negative perceptions, Bell forbid the use of Sign Language in his schools because he believed it would lead to interaction solely between deaf people, which would lead to deaf intermarriage and to the continuation of a "deaf variety of the human race" (Fjord, 1996: 62).

In 1884, Bell gave a speech regarding this "deaf variety of the human race" that was contentious even then. It has since been widely criticized by disability activists as *eugenic*. Eugenics is the concept of intentionally breeding desired characteristics to *improve* the human population (Kevles, 1995). Deafness was seen as an undesirable human trait and a "social burden" on the rest of society. Deaf people were among those that could be legally sterilized in order to ensure what was called, "better breeding" (Cleall, 2015: 1, McKee, 2013: 2174).

In his speech, Bell was quoted as saying, "We should try ourselves to forget that

they are deaf. We should try to teach *them* to forget that they are deaf (Bell, 1884, as cited in Cleall, 2015: 1). Bell was not arguing for equal opportunities; he actively sought the “forgetting of deafness.” Bell also advocated for the intermarriage of hearing and deaf people in an attempt to “breed out deafness” (Bell, 1884, as cited in Cleall, 2015: 1).

Due to the influence of prominent societal figures like Alexander Graham Bell, new legislation was formed regarding the education of deaf people. In 1880, the *International Conference on the Deaf and Dumb* met in Milan, Italy. Currently named the *International Congress on the Education of the Deaf*, this conference still meets annually. In 1880, this conference consisted of self-selected hearing *professionals* in the field of deaf education (Lentz, 2014), with 164 delegates in total – only five deaf (Cleall, 2015). No deaf teachers were invited to attend (Lane, 2010). This group voted nearly unanimously to ban Sign Language from deaf children’s education and declared speech as the preferred method of education – institutionalizing oralism. As a result, many deaf teachers and administrators were laid off (Cleall, 2015). These methods remained strictly in place until the 1960s when research emerged that proved oralism as ineffective and the Deaf Community made progress establishing itself as a reorganized cultural and linguistic group during this era of Civil Rights work (Lentz, 2014).

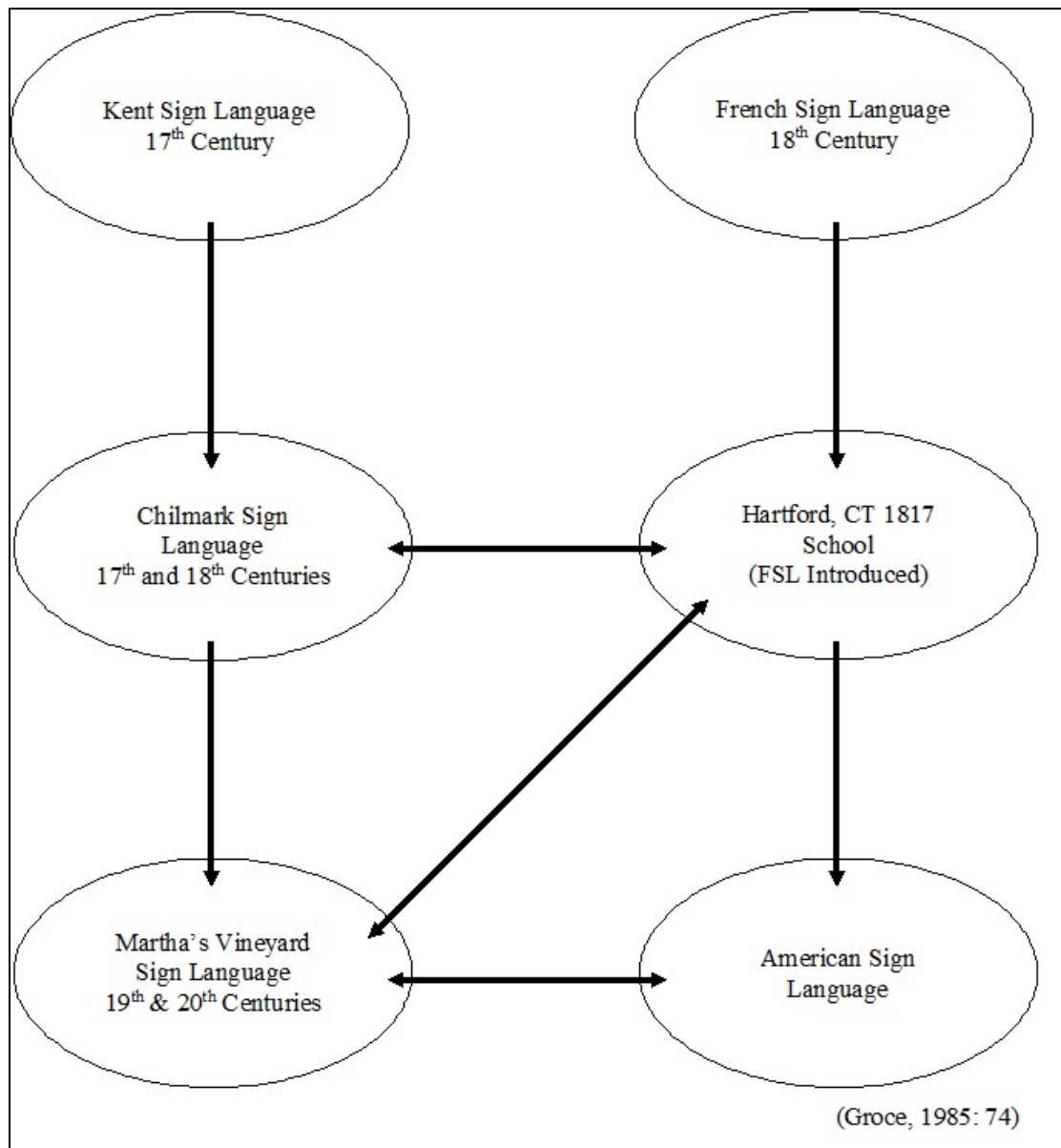
The History of American Sign Language

American Sign Language (ASL) is not a written language: scholars often have to use English to write about ASL. This often leads people to mistakenly believe that ASL is “bad English” or “broken English” because the grammar is different from English, yet the

signs are based on English words (Burch, 2004, Cokely, 1980, Padden, 1990, 1999). ASL is directly related to French Sign Language (FSL) due to what Gallaudet learned at the Paris school. About sixty percent of ASL signs are related to their equivalent in FSL. However, ASL is not solely based on FSL. It is incorrect to say that ASL was “brought to America” by Gallaudet and Clerc. Rather, the French signs they brought were combined with signs that deaf people in America were already using (Cokely, 1980, Edwards, 2012, Groce, 1985, Padden, 1999).

In the past, it was believed that deaf people in America suddenly started learning and using French signs when Gallaudet and Clerc established the school in Hartford and did not know or use any signed languages before then. In her exhaustive ethnohistorical account about Martha’s Vineyard from the late 1600s to the early 1900s, Nora Ellen Groce tracked the use of Sign Language and the frequency of hereditary deafness on the Island. The people on Martha’s Vineyard lived in a bilingual community. Island residents used both English and Sign Language interchangeably. People used Sign Language at town meetings, church, informal gatherings, the post office, general stores, etc. Hearing people would often sign to each other even if no deaf people were present (Groce, 1985).

In *Everyone Here Spoke Sign Language* (1985), Groce documents the full integration of deaf people on Martha’s Vineyard into community life. The example of Martha’s Vineyard confirms the existence of indigenous signed languages before the advent of the school in Hartford. In Groce’s work, she was able to document the emergence of modern ASL, as it is known today.



One concrete way in which a person demonstrates support for the values and goals of the Deaf Community is by showing respect for and acceptance of ASL. Deaf people have often been cautious about using their language around hearing people and allowing them to learn it. Barbara Kannapell, a Deaf person at the *1977 National Symposium on Sign Language Research and Teaching*, clearly explained this, stating,

It is important to understand that ASL is the only thing that has grown out of the Deaf group. Maybe we are afraid to share our language with hearing people. Maybe our group identity will disappear once hearing people know ASL. Also, will hearing people dominate Deaf people more than before if they learn ASL? (Cokely, 1980: 5).

The teachings of Alexander Graham Bell and the oralist establishment negatively affected the lives of Deaf people for many years and are still negatively affecting them in different aspects of their lives. Since ASL is such a crucial component of Deaf identity, Deaf people are protective of it and if someone disrespects its use, they feel as if that person is disrespecting everyone who uses it.

The Clash of Different Perspectives

Deaf people still struggle to gain recognition as a cultural group, especially in the political and educational arenas. The Deaf Community's own perspectives are frequently overlooked and hearing legislators often make decisions regarding the lives of Deaf people without any real input from Deaf people themselves. This can affect them in every aspect of their lives, including healthcare. Michel Foucault (1994) said that classificatory medicine "detaches individuals from experiences of physical suffering, conceiving of subjective experiences as secondary to the manifestation of diseases or ailments (Foucault, 1994, as cited in MacDougall, 2015: 156). Biomedical approaches to deafness parallel these perspectives by classifying it as an ailment requiring medical treatment while overlooking the important role that deafness and signed languages play in collective experiences of identity within the Deaf Community (MacDougall, 2015).

The Deaf Community fights to be recognized and respected as a minority cultural

group, with their own language, which encapsulates the cultural-linguistic view. However, this view is often disregarded and ignored by the dominant hearing society that is more inclined to see deafness as a negative. These perspectives often affect an individual from a young age. Roughly 90% of Deaf children are born to hearing families (Fjord, 1996, Senghas, 2002). Given that parents likely first learn of their child's deafness in a medical setting, deafness is often presented from a biomedical perspective. This is rooted in a disability and impairment perspective in which the intent is to *fix* or *cure* the child's deafness, with the overarching goal of functioning in the dominant hearing environment using spoken language and lip-reading (Higgins, 2016). The biomedical and social view are closely related in that they both focus on integrating/mainstreaming Deaf people into hearing society through interventions like medical technologies and assistive listening devices.⁶

As members of a minority culture, Deaf people in the United States are surrounded by the majority culture and language: hearing American culture and English. Deaf people have both positive and negative daily experiences with hearing people and their actions affect Deaf people in various ways (Lentz, 2014). Overall, there is an extensive lack of knowledge about and disregard toward the Deaf Community and their Culture and language (Munoz-Baell, 2000). This lack of knowledge creates communication obstacles that make it difficult for Deaf people to access necessities in their daily lives. This has unfavorably influenced medical, legal, and educational policies regarding Deaf people. I will discuss these in detail throughout this thesis.

⁶ These assistive listening devices are discussed in detail in Appendix A.

Self-Identity

Ultimately, without prior knowledge of and exposure to the Deaf Community, hearing people are more inclined to agree with the biomedical and/or social perspectives of deafness. However, the inability to hear does not automatically mean that a person will agree with the cultural-linguistic view of deafness. How a person was raised and when they lost their hearing can affect which perspective they agree with. In turn, this can affect what kind of treatment they might want to receive in a healthcare setting. Medical professionals need to be made more aware of these cultural differences and preferences so they can adapt their treatment plan accordingly.

If an individual loses his or her hearing later in adulthood, they are more likely to see this negatively because they have lost a sense they have been accustomed to using and relying on until that point in their lives. Communication breaks down when spoken language has already been learned and is already in use. People grow reluctant to change or adapt their usual means of communication and find it difficult to adjust to the new situation they are in (Munoz-Baell, 2000, Senghas, 2002, Sutton-Spence, 2010). As such, these individuals are more likely to seek interventions such as hearing aids or anything that will allow them to remain a functioning member of hearing society. Similarly, if a deaf child is born to hearing parents, the parents will more likely feel as though their child is missing something. As a result, they will be more inclined to seek medical interventions and to mainstream their child to try to give them the same experiences as their hearing counterparts (Munoz-Baell, 2000, Senghas, 2002, Sutton-Spence, 2010). The deaf child born to hearing parents might be taught to regard their deafness negatively

and grow-up thinking they are faulty if they are never exposed to a social support system like the Deaf Community. In comparison, the Deaf child born to Deaf parents is more likely to have their deafness seen positively, they will be taught ASL, and experience Deaf Culture firsthand (Munoz-Baell, 2000, Senghas, 2002, Sutton-Spence, 2010). As universal newborn hearing screenings⁷ become more readily available, the future of children who are identified as deaf or hard-of-hearing is critically impacted by parents' "reactions to, acceptance of, and advocacy for, such children" (DesGeorges, 2003: 89).

A social support system through the Deaf Community is crucial for the development of Deaf identity. Nearly forty years ago, Gaylene Becker (1981) studied two hundred Deaf people over the age of sixty in the San Francisco Bay Area to determine their coping mechanisms for dealing with stigma as they grew up. Becker determined that the majority of these people had hearing parents with whom they were unable to have satisfactory communication. Controversies over the education of deaf children exacerbated hearing parents' emotional crises over their inability to teach their children language and to socialize with them. However, about eight percent of the population Becker studied had Deaf parents from whom they learned ASL and developed adequate communicate skills. They did not experience the same conflicts with their parents as their hearing counterparts did and they felt more accepted (Becker, 1981).

Deaf people from Deaf families see themselves as carrying on a cultural tradition to which little or no stigma is attached. Becker's (1981) findings indicate that Deaf

⁷ Defined as a strategy for early detection of permanent hearing loss. Three electrodes are placed on the baby's head to measure the nerve response. For more information see, "Universal Newborn Hearing Screening" by H. Patel and M. Feldman, 2011.

identity and the development of a social support system are two factors that positively influence coping with stigma. Likewise, competence in ASL is at the core of Deaf identity in the United States (Lane, 2010). Identity is defined as that cognitive structure which gives a sense of coherence, community, and social relatedness to one's image of oneself. As such, Deaf identity is crystalized early in life and is maintained throughout the life course (Becker, 1981), when supported in the home and at school. The Deaf world becomes a surrogate family and offers many Deaf people, especially those with hearing parents, what they could not find at home: a positive identity, a language model to emulate, easy communication, and lives they can imagine leading (Lane, 2010).

The Disability Model of Deafness

A person's self-identity influences whether or not they agree with the disability model of deafness. This model parallels the biomedical perspective in that it is premised upon a disability image of deafness as measured against an image of the standard "healthy" body (Fjord, 1996). There is a stark contrast between the medical and social models of disability. In the medical model, disability is an impairment located on the body so it is classified as a medical problem; the social model argues that one is disabled by social ideologies that do not accept or accommodate disability (Mauldin, 2012). The medical model considers degrees of hearing loss and possibilities of amelioration; the social model demands we learn more about human difference and how it is expressed socially (DeVault, 2014).

Deafness is classified as a “low incidence disability” (Higgins, 2016: 9). Deafness is also called an “invisible disability” because it is only noticeable when a person attempts to communicate. Hearing people often freeze and withdraw from the situation or may behave inappropriately by teasing and mocking the Deaf individual (Becker, 1981: 21). Disability is often naturalized as a state of being that is different from and inferior to an imagined norm (Tucker, 1997). The social construction of disability means that to be Deaf largely depends on the attitudes of a given society toward any impairments, as well as resources and education available to Deaf people (Cleall, 2015).

One implication of labeling deafness as a disability is the lack of acknowledgment of the social process through which a Deaf child could become ostracized and excluded from society. It is commonly argued that if a child becomes isolated, it was the fault of the disability itself, not the society at large. Ato Quayson, a disability theorist, has described what he terms the “crisis of representation” that surrounds the literary portrayal of people with disabilities (Quayson, 2007, as cited in Cleall, 2015: 11). Quayson discussed the apparent invisibility of people with disabilities and argues, “The problem is not one of being seen, but of being framed within a discourse of stereotypes and expectations that serve to efface a person’s identity.” He goes on to say, “People with disabilities are seen only as their disability; their gender, ethnic or class identities, for example, are forgotten because they are only seen as disabled (Quayson, 2007, as cited in Cleall, 2015: 11).

Historically, the dominant hearing culture has relegated Deaf people to social categories such as *handicapped*, *disabled*, and *outsider* (Munoz-Baell, 2000, Tucker,

1997). An ever-increasing number of Deaf people do not consider themselves to be handicapped or disabled, but demand to be recognized and respected as a distinct cultural group with its own beliefs, needs, opinions, customs, and language (Bernstein, 2016, Higgins, 2016, Keating, 2016, Nović, 2016). The Deaf Community disputes deafness as a disability and they are currently experiencing a period of activism, striving for their basic human rights to language, communication access, education, and employment. Discussed in more detail in chapter five, most Deaf people do not see their deafness as a disability, yet it is classified as one under the Americans with Disabilities Act (ADA). According to Irma Munoz-Baell (2006), Deaf people are disabled more by their “transactions with the hearing world than the pathology of their hearing impairment” (40).

Laura Fjord (1996) asked several Deaf people, “What if there was a cure for your deafness?” Fjord said, “I have yet to see a Deaf person wish to be ‘cured.’ Instead, they have responded that their deafness is an integral part of their wholeness, a sentiment common among people who fall into other ‘disabled’ categories” (66). This exemplifies the cultural-linguistic perspective toward deafness, not the biomedical or social perspectives. As such, hearing people need to be made more aware of Deaf peoples’ own perspectives and include Deaf people in decision making so that laws and regulations are not made that negatively impact their lives. Seeing deafness as a relational mismatch between the abilities of an individual and the design of the social and material surroundings, as opposed to a medical condition, allows for the recognition that the problem is not always within the individual, but rather, due to the lack of existing knowledge about it as a cultural condition, not just a sensory one (Haualand, 2014).

Historical Research: Implications for the Deaf Community

The existing literature illustrates a disconnect between what hearing people think the Deaf Community wants/needs and what they actually want/need. Hearing parents, clinical providers, and medical researchers often lack familiarity with the Deaf Community, which further places Deaf people at risk for medical and cultural misunderstandings. The Deaf Community rarely has an opportunity to express its views. Hearing people decide what is best for Deaf people and codify their beliefs in policy statements. This process takes place with minimal input from the Deaf Community because they are not asked for it (Higgins, 2016).

Historically, deafness-related research tended to focus on the elimination of deafness using medical technologies and genetic engineering (McKee, 2013). As such, Deaf people are akin to any marginalized group, having experienced linguistic and cultural colonization through “hearing colonialist regimes associated with the practice of normalization and audism” (MacDougall, 2015: 157). Considering the historical oppression Deaf people have faced from people like Alexander Graham Bell, they have well founded fears that prenatal screening could permit the opportunity for hearing parents to terminate pregnancies, or to select genetic engineering to avoid the birth of a deaf infant (McKee, 2015). Deaf people rarely participate in clinical research and surveillance activities in part because of exclusion criteria, inaccessible informed consent processes, inadequate recruitment and engagement strategies, and culturally misguided genetic testing and engineering (Barnett, 1999, Jones, 2005, McKee, 2015).

Beyond a research setting, Deaf people also face barriers to receiving even the

most basic healthcare. These are barriers that their hearing counterparts likely do not have to worry about. The medical classification of deafness does not fit with the needs of health promotion strategies in so far as members of the Deaf Community define deafness as a cultural phenomenon, rather than an audiological problem (Munoz-Baell, 2000). Deaf people face barriers to healthcare before they even reach the consultation room (Fellinger, 2012). Deaf peoples' access to health-related information is limited by barriers to spoken or written language: they cannot overhear information, they have limited access to television, radio, and other channels of public information, and the average reading level of Deaf adults is at a third or fourth grade level because English is not their first language (Barnett, 1999, 2011, Fellinger, 2012, Hanks, 2014, Jones, 2005, Mackenzie, 2009, Mathos, 2015, Neuhauser, 2013, Pollard, 2009).

Multiple groups of people are considered vulnerable populations who are at higher risk for negative healthcare experiences. Deaf people are one of these groups. Deafness occurs across all ethnic groups, so many Deaf Community members are also members of ethnic minority groups. Obstacles to adequate education such as being mainstreamed and being forbidden from using ASL has made the average education level of Deaf adults lower than that of their hearing counterparts. Deaf people can also have secondary disabilities that can be further impacted by deafness, such as vision related diseases like Usher's Syndrome⁸ (Jones, 2005). The combination of communication barriers, low income, limited education, secondary disabilities, and membership in ethnic

⁸ A chronic hereditary eye disease characterized by black pigmentation and gradual degeneration of the retina. This inherited disease causes a slow loss of vision, beginning with decreased night vision and loss of peripheral vision, eventually resulting in blindness (Hartong, 2006).

minority groups puts Deaf Community members at increased risk for compounded biases that can result in adverse health outcomes (Jones, 2005, Mathos, 2015, Pollard, 2009).

One of the most common issues that Deaf people face in trying to receive adequate healthcare is the fact that many clinicians lack understanding about the Deaf Community and their Culture. This further exacerbates the medicalization of deafness. Medicalization refers to the process in which nonmedical problems are defined and treated as medical problems, usually in terms of illnesses or disorders (Conrad, 1992). As such, deafness fits into this definition in that those who are culturally Deaf do not see their deafness as a medical issue. Deafness is often viewed through a medical framework because it goes against the image of the idealized normal and healthy body.

To medicalize something or to apply an infirmity model to members of a certain group is to regard and interact with them with respect to our cultural conception of bodily defects. The institutions that are primarily associated with this conceptual framework are the biological sciences, and the health and social welfare professions (Conrad, 1992, Conrad & Schneider, 2010, Lane, 1990). To apply a cultural model to a certain group of people garners a different conceptual framework. This model focuses on the interdependent values, traditions, and language that characterize this culture. It also questions how the physical and social environment in which it is embedded influences it (Lane, 1990). An infirmity model can be appropriate for someone who lost their hearing later in life due to things like age or illness. It is more common for them to view deafness as a loss and that they are now less than whole, so they seek medical interventions to help them. An infirmity model is inappropriate for culturally Deaf people who do not see their

deafness as a loss and embrace it as a cultural identity. To medicalize all Deaf people, disregarding whether they identify as culturally Deaf, is to impose this infirmity model on anyone who has any degree of hearing loss.

The medicalization of deafness influences people seeing Deaf people as handicapped or disabled, which leads to them being stigmatized. Erving Goffman argued that those who are in some way deviant from the idealized norm could be considered to have a social stigma, something that is felt to be “deeply discrediting... a failing, a shortcoming, a handicap” (1963: 3). According to Mary Douglas, people who deviate from the idealized norm come to be seen as polluted or impure (1966: 3). Ultimately, it is the dominate society that establishes this idealized norm and determines who falls into the category of *deviant* because they do not fit into the *normal* category. Goffman said, “Society established the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories” (1963: 2).

There has been previous research that has recognized the need for knowing, understanding, and taking into account the cultural, linguistic, sociological, psychological, educational, and prosthetic aspects of hearing loss as the first step in the delivery of quality healthcare for Deaf people (Munoz-Baell, 2000). Much of this work has taken place within the field of public health. Beyond that, previous research has not been inclusive for Deaf people.

The Deaf and hearing worlds have virulently clashed throughout history. This has resulted in Deaf people mistrusting the medical community since it is predominantly comprised of hearing people. Medical professionals lack awareness about Deaf Culture

and the Community. This leads many to believe that Deaf people want/need medical technological solutions to their deafness, when culturally Deaf people do not want them (Barnett, 1999 & 2011, Fellingner, 2012). The vast majority of physicians are not necessarily trying to discriminate against Deaf people. The fault lies in the lack of training associated with cultural competency about the Deaf Community that medical students receive in medical school. This can produce physicians who jump to conclusions that they know better than their Deaf patient does. Over recent years, more medical professionals have become more aware of the community and have tried to be culturally sensitive (Jones, 2005, Pollard, 2009, Sheppard, 2013). Inequities in health and healthcare among Deaf patients have become an area for concern in the public health arena.

A research study done by Steven Barnett and colleagues (2011) is one such study in which they describe issues that underlie health inequities for Deaf people and how public health entities can address them. They describe four issues that underlie health inequities the Deaf Community has experienced: data on the health of Deaf people are lacking, many adults Deaf since birth or early childhood have low health literacy, barriers limit healthcare with the Deaf Community, and Deaf people may have biological basis for some health differences.

As has been stated, English is often a second language for most Deaf people; ASL is their first. Unfortunately, most surveys and questionnaires distributed to Deaf people are in written English. Deaf people can have a hard time understanding and subsequently filling them out. Telephone surveys also often exclude Deaf people. There is a lack of

even the most rudimentary health data from Deaf people because these methods exclude them. This thwarts efforts to engage the Deaf Community in setting priorities for health improvement and chronic disease prevention campaigns (Barnett, 2011).

Information commonly considered common knowledge among hearing people often does not reach Deaf people. This results in low health literacy (Barnett, 2011). Health literacy is the ability to obtain, understand, and use the information needed to make wise health decisions. Low health literacy affects health status in several ways and creates barriers to access to care as well as comprehension of diagnosis and treatment options (Kimbrough, 2007). For example, many adults Deaf since birth or early childhood do not know their family's medical history. As children, they were unable to overhear their hearing relatives discussing this. Family history can be a risk factor for some chronic diseases, such as heart disease and diabetes. If Deaf people do not know their family medical history, they cannot inform their doctor, so they cannot take the necessary precautions to combat those problems (Barnett, 2011).

Deaf Community members' knowledge of English medical terminology parallels that of non-English speaking immigrants to the United States (Barnett, 2011). Many barriers prohibit the development of basic health literacy, including poverty, limited education, low reading levels, and inadequate English language skills. Additional barriers arise because clinicians often inadvertently make it difficult for the average person to understand what to do. Throughout medical school and early career training, physicians are taught to use precise technical language to discuss body parts, disorders, and treatments (Kimbrough, 2007). Low health literacy among these minority populations,

Deaf people included, affects healthcare seeking behaviors, interactions with clinicians, adherence with medical advice, and health outcomes for chronic diseases (Barnett, 2011).

The aforementioned barriers contribute to the fact that many adults Deaf since birth or early childhood are less likely to have seen a physician than their hearing counterparts. Deaf Community members are often dissatisfied with physician-patient communication. Physicians have reported that Deaf patients require more time and effort than hearing patients do and that interpreter services are not always available or reimbursed. Studies have shown that Deaf people who attended a primary care practice that utilized full-time interpreter services were more likely to report receiving preventive services than a comparison group of Deaf people who attended a practice that did not utilize interpreter services (Mackinney, 1995). Studies like this show that addressing language barriers can improve adherence with some preventive services and may help to prevent chronic diseases or improve patient's long-term outcomes through earlier detection (Barnett, 2011).

Illnesses that occur during fetal development or early childhood that cause deafness may have consequences unrelated to the ear. Several genetic conditions that affect hearing involve other organ systems. For example, Usher's Syndrome is a combination of congenital hearing loss and later-onset vision loss.⁹ Consequences unrelated to the ear of other deafness-related genes have not been extensively studied. Biology can explain some differences Deaf people experience. However, their condition-

⁹ A chronic hereditary eye disease characterized by black pigmentation and gradual degeneration of the retina. This inherited disease causes a slow loss of vision, beginning with decreased night vision and loss of peripheral vision, eventually resulting in blindness (Hartong, 2006).

related health outcomes will likely be worse than those of hearing people with the same condition due to inequities in access to healthcare, health information, education, and economic resources (Barnett, 2011).

Research such as that done by Barnett and colleagues (2011) shows how public health entities are trying to improve healthcare experiences for Deaf patients. However, hearing professionals carried out this research. They did not discuss their methodology, nor did they make it clear where this data for these four issues came from. Sources like this are good for comparative purposes to show what hearing people have highlighted as the biggest issues facing Deaf people in receiving adequate healthcare, versus what Deaf people themselves say are the biggest issues they face. This thesis will expand on these findings and use information obtained from Deaf Community members in the Greater Boston Area for comparison.

METHODS

Initial Design and Fieldwork Site

As a study in medical anthropology using qualitative methods, I did not set out to test a hypothesis, but rather, to explore an open-ended research question. In the beginning, I did not have a specific research question in mind. I was interested in learning more about Deaf individuals' personal views toward their deafness. I wanted to let my research and experiences at my internship guide me to a more concrete research question. In order to do this, I planned to gather participant observation data through my volunteer internship at Advocates, Inc.¹⁰ from October 2015 through August 2016. The main reason I chose Advocates, Inc. as my internship site was that it is one of the only organizations in Massachusetts run for and by Deaf people. Around 85% of the staff are members of the Deaf Community, including the Executive Director. They offer several programs related to healthcare, and supporting consumers in advocating for themselves while seeking healthcare.

Conducting my fieldwork at Advocates, Inc. allowed me to gain a more emic perspective¹¹ of the Deaf Community. I gained insight into their social norms, values, and beliefs. The *voice* of the Deaf Community is often not heard in the larger hearing community so the needs of Deaf people are not recognized. The emic perspective I

¹⁰ All names of organizations and people are pseudonyms to protect the anonymity of the participants.

¹¹ David Fetterman (2006) explains, "An emic perspective is the insider's or native's perspective of reality."

gained at Advocates, Inc. allowed me to speak with more authority about the Deaf Community's perspectives on the hearing-dominated healthcare system and how they prefer to be treated in healthcare settings.

Advocates, Inc. serves approximately 1000 individuals annually across their four locations throughout Massachusetts. They reach out to youth, adults, and seniors regardless of sex, gender, race, ethnicity, disabilities, immigration status, country of origin, religion, sexual orientation, or employment status. Advocates, Inc. provides many services to Deaf people with three core programs focused on helping Deaf people live autonomously, Deaf-Blind advocacy, and health education programs.

My initial participant observation occurred during my internship at Advocates, Inc. from October, 2015 to May, 2016. Even though I worked directly under a hearing woman, I was still able to spend time daily with Deaf individuals. Many of the staff would eat lunch together at a large table and they always invited me to observe what people were talking about even if I was not necessarily part of the conversation. Normally, this would be considered rude and akin to eavesdropping in the hearing world. However, everyone knew that I was still in the process of learning the language so they allowed me to observe and further strengthen my skills of understanding ASL.

There was a fellow intern who was from Japan and we spent time working together. We were both learning ASL and we had to find various ways to communicate when we could not understand one another. Not only was I learning more about American Deaf Culture and ASL, I was able to learn about Japanese Deaf Culture as

well. I acquired a name-sign¹² from the Executive Director about three weeks into my internship. I regarded this as a symbol of acceptance and trust toward me because one can only acquire a name-sign from someone in the Deaf Community. As I became more comfortable at Advocates, Inc., people mentioned my improvement in the language and my confidence in myself.

While this was great participant observation initially, the most rewarding came from the Deaf events that I attended. During my internship, I was taking ASL classes through Boston University and I learned about numerous Deaf events through both my classes and my internship. I was required to attend many different events for my classes; others I attended by choice. Several events were geared more toward hearing students to practice ASL so there were not many Deaf people in attendance. I went to several events where many members of the Deaf Community were present. After my internship and ASL classes ended, I had to keep my eyes open for Deaf events throughout Boston. I followed several Deaf Community pages on Facebook and kept up to date on what was happening at Advocates, Inc.

In addition to participant observation at Advocates, Inc., I hoped to conduct semi-structured interviews with consumers who utilized the health education programs. I figured I would receive the richest data by interviewing these consumers since this is the program most associated with healthcare. My initial interview guide consisted of background and open-ended questions, as opposed to structured questions. I did not want

¹² A name-sign is a formalized gesture that refers to an individual's proper name. For more information see: "Name Signs as Identity Symbols in the Deaf Community" by Kathy Meadow (1977).

to have questions that set me up to receive similar, structured answers from every participant. As Kathy Charmaz said, “By creating open-ended, non-judgmental questions, you encourage unanticipated states and stories to emerge” (2006: 26). This is the type of data I was hoping to receive.

I planned for interviews to take place during a time when the participant was already at Advocates, Inc. if that was the most convenient for them. I foresaw interviews lasting anywhere from thirty minutes to two hours, and I would interview each participant once unless they asked me to meet again. Since Advocates, Inc. has quite a few consumers, my goal was to conduct ten interviews with a combination of consumers and staff, though I aimed to conduct more. While this number may seem small compared to a quantitative sample size, it was adequate for this research design due to the specific nature of the research question, the potentially sensitive nature of the topic, and that I would use qualitative medical anthropological methods. Many researchers aim to reach *data saturation*, which means the point during data analysis when no new themes or information appears. However, saturation is not appropriate for all types of qualitative research, including phenomenological studies. Phenomenological research such as this project study a limited number of individuals in-depth, with an interest in the range of meanings they might assign to particular phenomena (Barnes, 2009). As such, I argued in my Institutional Review Board (IRB) protocol proposal that a small sample would be more than adequate to address this topic and to constitute a substantial contribution to extant data about the topic. The original inclusion criteria incorporated people over the age of eighteen who were Deaf, Deaf-Blind, Hard-of-Hearing, Late-Deafened, or Oral-

Deaf, as well as people who provided services at Advocates, Inc. The Institutional Review Board (IRB) at Boston University School of Medicine approved this study, and I conducted formal data collection between June and August of 2016.

To aid in my later analysis, I planned to video-record all interviews so that I could focus on the participant during the interview and not have to frantically take notes to remember it all. I could be looking at the participant and see their signs, rather than have to look away to take notes and potentially miss seeing what they signed. During the later analysis stage, I was able to take my time with the videos, just as a researcher would with a recording of an audio-recorded voice interview, and pull out the emergent themes.

I had taken three semesters of American Sign Language (ASL) during my undergraduate career but I knew I still had quite a bit to learn. I signed up for ASL classes through Boston University but I had often heard that the best way to become proficient in a language is to immerse yourself in the language and communicate directly with native speakers. I believed that being at Advocates, Inc. would drastically improve my ASL skills and make me more confident for future research purposes, while I gave back to the Deaf Community and learned about their experiences seeking healthcare, and navigating through the hearing world, in general. I knew I could not consider doing interviews with Deaf people until I became more proficient in the language. Establishing further proficiency in the language not only reinforced my dedication to the research, but also aided in my efforts in building rapport with Deaf Community members prior to formal recruitment.

Data Collection and Themes that Emerged

Unfortunately, research rarely goes exactly as planned so I had to adjust my original research design. Despite initially signing off on my research design, the Executive Director of Advocates, Inc. later paused my interview recruitment process, indicating her concern that participants might have difficulty understanding my ASL, or vice versa. While I had proved my conversational ASL skills, she was worried about the more structured format of an interview and the possibility of consumers mistrusting my skills as a researcher and the data I collected. I reasoned that video recording would allow me to take my time with the data during the analysis process. However, while she agreed with that, she believed it would not help during the actual interview process. As such, she did not feel comfortable signing the language attestation form required by my IRB until we came up with a different solution. The Executive Director explained she would feel more comfortable if I focused on interviewing staff and board members of Advocates, Inc. since most of them already knew me and my ASL skill level. She also wanted me to have someone at the agency to check-in with my progress. While I will not deny that I was frustrated about having to change my research design, I was respectful and understanding of her concerns. I was willing to change what I had planned to do if it meant that it helped her feel more comfortable about everything. I did not want to present myself as an entitled, hearing researcher who ignored the wishes of the Deaf Community.

As stated previously, I initially planned to focus on recruiting consumers who utilized the health education programs. However, this program has the smallest staff of the programs at Advocates, Inc. The Executive Director was concerned that the staff

would not be able to adequately work with me to check-in with my progress. She met with the coordinator of the program focused on autonomous living, which also supports consumers attending medical appointments, to see if my research project was something the coordinator would be interested in helping with. This program is much larger and better staffed than those focused on health education so the Executive Director hoped I would have someone working with me to keep up with my progress. This way, I could check-in with this woman every step of the way, practice my interview guide, and meet with her about any concerns that arose. She agreed. Practicing with her allowed me to become more confident in my ASL skills and the interview process in general.

The Executive Director was also concerned that I would have trouble recruiting consumers to participate in my study. She was right about this. Ideally, having an Advocates, Inc. staff member as a research contact would allow me easier access to recruit consumers. This way, a trusted staff member could explain my research to the consumers and determine whether they were interested in participating. These people would have spent a decent amount of time with her so they would have ideally been comfortable with her and trusting of her opinions of me and my research. However, even though consumers often informally told me about their experiences and frustrations in numerous settings, including medical ones, this is not how my recruitment process turned out.

Since ASL is a visual language, one of the best ways to reach members of the Deaf Community is through videos. My research contact at Advocates, Inc. and I decided that this would be my best option for recruitment purposes, along with a recruitment

flyer. We worked together to plan out a script for my video and I finished making it in early June. However, Advocates, Inc. frequently makes vlogs so they are particular about what the videos look like in terms of background and lighting, as well as the signing fluency and content of the video. While I was proficient and confident in my conversational ASL skills, I did not want to risk participants thinking I was fluent in the language. I wanted to portray I was a student who was still learning ASL. I kept making changes to the video and several Advocates, Inc. staff members reviewed it. I did not receive the necessary feedback from them until the beginning of August. Thus, despite my original research design, I never used the recruitment video or flyer and only one of my participants was an Advocates, Inc. consumer.

I determined that it did not make sense to continue with the video due to IRB and time constraints so I did the best I could without it. My original goal was to interview primarily consumers, but this no longer seemed plausible, so I supplemented with Advocates, Inc. staff and board members. While it may not seem like staff and board members would provide the same kind of data that consumers would, when it all comes down to it, they are all members of the Deaf Community. Every one of the staff and board members I recruited had some experience with healthcare so I knew I would still receive rich and relevant data from these interviews, albeit just not as much as I had originally hoped. I met one participant back in October, 2015, and she was a consumer who was immediately interested in my research. I emailed her during the summer of 2016 and she quickly agreed to be interviewed. I emailed board members whose emails I had and only received two responses, one of which was a yes and the other a maybe, but I

never received a confirmation after my follow-up, so I only had one interview with a board member. I emailed all of the staff whose emails I had and tried to see as many people as I could in person, but schedules were often different and people were busy so it was difficult to get in touch.

In total, I interviewed four individuals. One identified as male and three identified as female, with their ages ranging from 27-65. The interviews spanned from thirty minutes to two hours and I conducted all of the interviews in person. The consumer participant was hard-of-hearing so we conversed in spoken English because she was just starting to learn ASL. The board member was Deaf so we communicated in ASL and I video recorded it. I did two interviews with Deaf-Blind staff members and we communicated in ASL. However, one of these interviews was with a close-vision, Deaf-Blind woman, which means that she could still see close to her face so I signed close to her in order to communicate with her. The other Deaf-Blind participant was fully blind so we used tactile communication, which means that she put her hands over mine to feel what I was signing.



Close-Vision Signing (Source: Google Images)



Tactile Signing (Source: Google Images)

To supplement my participant observation data and data from the existing literature, I geared these interviews toward things that I had come across previously, using semi-structured questions. While I kept these interviews open-ended and allowed the participants to speak freely about whatever came to mind, I also had an interview guide with topics that I wanted to be sure we covered. I figured if they often came up in articles or at events, then they had to be important.

Since I was only able to interview one consumer and three staff and board members, my particular sample is limited because it leaves out Deaf Community members who might not be so actively involved in this service agency. Advocates, Inc. staff and board members are all activists for the Community but their perspectives and experiences cannot be generalized across the Community. Their perspectives and experiences also cannot be ignored. The ability to include a wider range of participants with varying levels of interaction within the Deaf Community would have strengthened the sample. However, my year of participant observation and informal conversations with various other members of the Deaf Community gave me alternate sources of information. Considering I interviewed one Deaf person, one hard-of-hearing person, and two Deaf-Blind people, I am confident that even with few participants, I received diverse information, which illuminated differences among various Deaf identities and perspectives.

Data Analysis

I engaged in a phenomenological theory analysis of my data. I selected

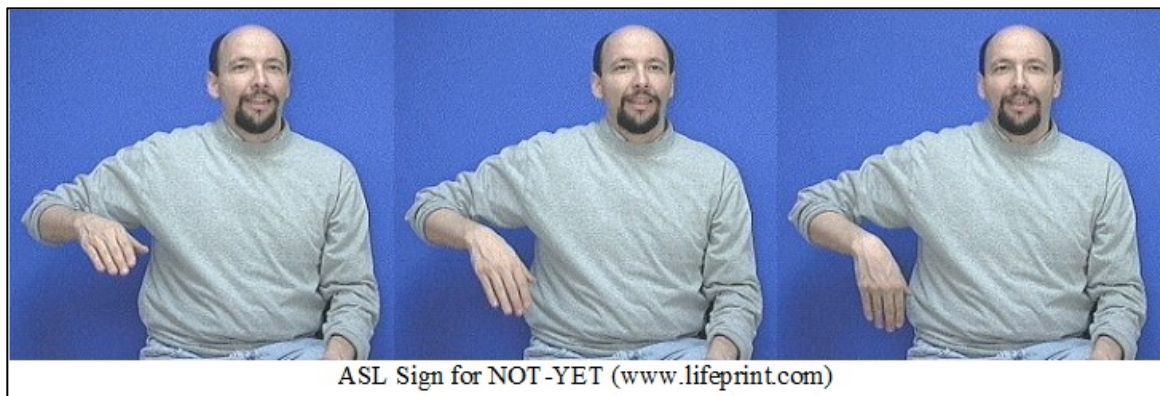
phenomenology because the simplest explanation of my research is that it focuses on the shared experiences of Deaf individuals, with an emphasis on perspectives about healthcare. Phenomenological analysis aims to understand how an individual experiences various phenomena and how that experience shapes culture, meaning, and worldviews. It also offers an opportunity for an analysis of bodily experiences and the senses in relation to health and illness (Hycner, 1985). Since my research is concerned with how the dominant biomedical perspective toward deafness affects Deaf peoples' ability to receive care, a phenomenological approach made the most sense.

After recording each interview, I transcribed the interviews manually, meaning I would pause the recording as I went and wrote down what transpired in the interview. There are many softwares meant to aid in the transcription process but I felt more comfortable with a pen and paper. Most transcription software programs are only for audio recordings. I could not find one to work with videos, and it became more work to find a software and learn how to use it than it was to transcribe the interviews myself. As has been said, ASL is not English and it has no real written representation, so I struggled with how best to transcribe the interviews without feeling as if I was losing the *voice* of the individual who was using ASL. Ultimately, I decided that I would transcribe the interviews in written English for the sake of writing an English thesis, and make it clear where someone used ASL and that I interpreted it into what it would be in English.¹³ I felt as if this stayed true to the language as a whole while not getting confusing in trying to consistently portray ASL in a written or visual form on paper.

¹³ See Appendix C for an example of an interview segment transcribed in ASL-Gloss to see how it cannot adequately be represented in written English.

Doing interviews in ASL for research is not common so I had to learn as I went in terms of transcription and coding. There are transcription systems that make note of pauses, different inflections, and facial expressions but this would not work with ASL interviews because the language works completely differently. Facial expressions when used in correspondence with English might have a completely different meaning than facial expressions used in ASL and facial expressions in ASL might make the same sign mean something completely different. For example, there are subtle aspects of ASL which can make two signs that have the same movement, mean completely different things because of the facial expression associated with it. A transcription software likely will not pick up such subtle differences.





As can be seen above, the hand movement for both the signs *late* and *not yet* are the same, but they are different solely because of a facial expression. For the sign *late*, the mouth is closed; for the sign *not yet*, the mouth is opened. The subtle difference between these two signs shows the complexity of ASL and how a transcription software likely would not recognize such subtle differences. Transcribing by hand allowed me to take my time with the recordings and make sure I knew what someone was signing, rather than relying on a software to figure it out for me. I worried about the accuracy of a software, as well as the consistency across interviews.

Following transcription, I decided to hand code for the same reasons I decided to transcribe by hand. There are benefits to using coding software in that they often allow the user to code large amounts of text more quickly than if completed by hand. However, as was the case with the transcription software, I felt it would be more effort to figure out how to use the coding software as opposed to hand coding. I kept a list of my codes and went through all of my transcripts, literature review notes, and field notes, and highlights wherever the codes came up. I present and analyze the themes that emerged from the data in detail in the ensuing chapters.

CHAPTER 4

COMMUNICATION AS AN OBSTACLE TO ADEQUATE HEALTHCARE

This chapter analyzes how and why communication is an obstacle to adequate healthcare. I highlight healthcare as an issue among Deaf people in Boston through events like the Deaf Community Health Forum. Much of this stems from the lack of awareness many physicians have about Deaf Culture because they do not receive the proper education and training. This further exacerbates the medicalization of deafness.

Video remote interpreting (VRI) is a communication obstacle that many people do not like to use because of its unreliability. Regardless, many medical professionals utilize VRI because it is less expensive than a real interpreter is, yet the interpreters on VRI are not always qualified. Communication obstacles also present themselves when Deaf people try to acquire quality insurance. When people struggle to communicate with their insurance company, they can feel discriminated against because they often will not receive the coverage they need. Participants highlight where the specific problems lie and how these issues have affected them.

Healthcare as a Concern

Through a yearlong internship and subsequent fieldwork, it became obvious that receiving adequate healthcare was a prominent issue Deaf people face. This was first noticeable in that one of the three major programs at Advocates, Inc. is associated with healthcare services. This program supports health services to Deaf Community members

such as prevention education, case management, and peer support. They also educate medical care providers about Deaf Culture and working with interpreters to increase healthcare accessibility for the Deaf Community. Finally, they provide education opportunities in health-related topics for interpreters to keep them up to date on information so they are better prepared to interpret within these fields.

The concern over healthcare services was evident through the sheer number of flyers and brochures at Advocates, Inc. As I met with Kelly to interview for the internship position, she led me down a long, narrow hallway to get to the door that led upstairs where several offices and the conference room were located. On one side of this hallway, there was a long, skinny table with various brochures and flyers. As I was leaving the building later, I looked at them in more detail. They varied from things regarding insurance, acquiring caption-call services to aid in communication, and advertisements about upcoming events in the area (fieldnotes, 9/29/15).

As stated previously, the average reading level of Deaf adults is around a third or fourth grade level because English is not their first language. An issue that arises with using flyers and brochures is that they are in written English. They can be difficult for some people to understand. This is why Advocates, Inc. often spreads information through vlogs since they can use ASL. However, they know that not everyone has internet access so they still use brochures and flyers to get the word out about things. I could notice a difference between those that Advocates, Inc. and other Deaf agencies made and those that came from elsewhere. The ones made by Advocates, Inc. and other Deaf agencies had little written on the page and large text so that things were as clear as

possible; those from elsewhere were denser and not as clear.

During my internship, I assisted my supervisor with grant-writing and various things for Advocates, Inc., and one of these was working on the Annual Report. In many of my first drafts of sections that I sent to my supervisor, she told me that my writing was often “too academic” and “not clear” enough. I had to learn how to make things as clear as possible and only include what was absolutely necessary so that things would be easy for everyone to understand. One of Advocates, Inc.’s core missions is to ensure full inclusion for all, so making sure everybody can understand their flyers and brochures is a big part of this.

Deaf Community events further proved to me that access to adequate healthcare is a priority among Deaf people in Boston. One powerful event I attended was the Deaf Community Health Forum on June 26, 2016. This Community Health Forum was a three hour event run in collaboration with the Massachusetts Commission for the Deaf and Hard-of-Hearing (MCDHH). I sat toward the back of the room and left the front seats available for Deaf people in attendance to give them a better view of whomever was signing, and better access to the front if they wanted to get up and share something. I was there to observe and listen with my eyes. I sat surrounded by members of the Deaf Community, all ready to share their experiences. The first hour was spent going through a survey that everyone was asked to fill out. The remaining time was spent in a public forum. Organizers asked attendees to the front to discuss thematic points and share their experiences. Almost everyone shared something and some people got up more than once. It was clear that it could have easily lasted longer than three hours. People had so much to

discuss about every topic mentioned. In the end, the public health officials in charge of this forum recognized the gap in the data on the health of Deaf people. One woman said,

This is the best information we have ever been able to receive. We understand that these are your real experiences and frustrations. I understand the skepticism that we will not be able to make a difference because there is not a good track record for attempts like this. I know it will not be an easy solution but I want you to know that we will do our very best to make improvements. I actually cried learning about some of your experiences. I want you to understand how committed I am to changing things for the better in the future (Health Forum, fieldnotes, 6/26/16).

The women in charge of this forum were respectful and understanding of the frustrations of attendees. I got the sense that they had some knowledge about historical grievances and did not want to repeat any program that failed or made things worse. They were patient and took note of everything everyone shared and encouraged people to email them with further information. They proved their commitment to improving services for Deaf people.

The Health Forum illustrated that due to cultural misunderstandings, it can be difficult for Deaf patients to find a doctor who understands how to work with them (Health Forum, fieldnotes, 6/26/16). Many Deaf people recognize that things have improved compared to how they were in the past but their experiences show that there is still quite a ways to go. Most Deaf people I met with felt as though there are simple measures that clinicians can take to make the experience better for both the Deaf patient and the hearing clinician. Many of these measures have to do with educating clinicians more about the Deaf Community as well as better communication methods.

Harrison, the Deaf man I interviewed, told me,

Many older people's views have not changed. But I think it depends on where one is, which hospital they are at, and who the doctor is, and how well educated they are about Deaf people and our culture. And their knowledge of communicating with Deaf and hard-of-hearing people. But it varies depending on who you meet and talk to about it. Now, I see more and more people in my generation [age thirty to forty] with more knowledge about the need for better communication with Deaf people. It is better than past generations.

Harrison and other people at the Health Forum recognized that receiving adequate healthcare could depend on the clinician. Just as all patients are different, every clinician is different as well. Some clinicians could have knowledge about the Deaf Community and be understanding and respectful from the start; others might know nothing about the Deaf Community. Deaf people also recognize that it can be intimidating to work with Deaf patients and clinicians might be anxious about it because they do not understand ASL and Deaf Culture, and do not want to do something wrong. Deaf people just ask clinicians to be patient with them and allow enough time in appointments with Deaf patients to allow for more adequate communication (Health Forum, fieldnotes, 6/26/16).

As adults, many Deaf people must become their own advocates. As children, many have to rely on their parents to communicate with their doctors for them. Many Deaf adults have had enough experiences by this stage in their lives to know what works best for them. Deaf people face several obstacles in trying to adequately communicate with their providers. The lack of understanding clinicians often have about the Deaf Community exacerbates these negative communication experiences.

Harrison and I discussed various communication issues he has faced,

Whenever I have an appointment of any kind, I tell the nurse not to write anything down. I tell them that they must allow me to bring in my laptop because my thought process is much faster when I am typing. Some doctors have used voice-to-text communication technology and then show it to me. I can then reply by

typing back on my laptop and we can communicate back and forth this way. For the most part, I have never really had a problem getting doctors to agree to communicate in this way. If I do have a problem, I do not continue with the appointment and I go elsewhere. Doctors must be aware of and willing to try different communication methods with their Deaf patients (7/27/16 interview with Harrison).

This excerpt demonstrates Harrison's personal self-advocacy. While he mentioned that he has not had much trouble communicating in the way he prefers, he also made it clear that he would not continue with an appointment, and instead go elsewhere, if the nurses/doctors did not accommodate his communication preferences.

Similarly, the close-vision, Deaf-Blind woman I interviewed, Daisy, and I discussed barriers to communication early in our interview and throughout. She told me,

Receiving good healthcare depends on the doctor. My primary care physician (PCP) is kind of so-so. My PCP does not follow-up with me. I remember one time they mailed me a letter tell me to call and set-up an appointment – it was something about my Vitamin D. I called and asked, can the doctor please email me about Vitamin D and that is it? They told me no, I have to come in for an appointment so they can talk with me in person. So we argued back and forth about that. I told them to save us both time why not just email me. But they told me no, so I finally went in. They were good about providing an interpreter for me at least. But sometimes I go to the doctors and there are no interpreters available. I do not read Braille but I have something on my computer that allows me to read things so I really prefer email. So if I go to the doctor and there are no interpreters, I ask the doctor to figure out how to continue the appointment with me. It usually works out okay (7/28/16 interview with Daisy).

Also a self-advocate, Daisy was adamant about having doctors email her because it is the communication method that works the best for her. She is not one to give up if the office does not provide her with an interpreter. She makes it the doctor's responsibility to figure out some way to continue with the appointment.

Deaf people often have particular preferences and perspectives that doctors need to be more aware of so appointments can go more smoothly. The Deaf Community often

has particular views toward medical interventions and technologies that medical professionals frequently do not share. A lack of understanding about Deaf Culture exacerbates these different perspectives, which can result in negative experiences at appointments.

Communication Obstacles: VRI and Qualified Live Interpreters

When I asked about obstacles to and frustrations with receiving adequate healthcare, many Deaf people mentioned video remote interpreting (VRI). VRI is a telecommunication service that uses devices such as web cameras or videophones to provide signed or spoken language interpreting services. These services allow the provider to call up a remote interpreter, who appears by video on a portable monitor in the exam room or by the bedside (DeVault, 2014). Video interpreting services have existed in the United States since 2000. They are defined mostly as a telecommunication tool, not as an assistive technology. A telecommunication tool allows communication over a distance by cable, telegraph, telephone, or broadcasting. Assistive technology is defined as a device that is used to increase, maintain, or improve the functional capabilities of someone with a disability. When the technology first came out, the services were expensive and few, if any, were designed for Deaf people as a target group (Hauland, 2014). More recently, many facilities have been using VRI to replace real people. Many Deaf people report that these services are often unsatisfactory (DeVault, 2014).



An example of what VRI may look like in a hospital setting. (Source: Google Images).

Interview data and existing literature proves that many Deaf people would prefer to work with a live interpreter as opposed to VRI. However, it is not enough for the interpreter to be there in person, they must also be qualified. Many Deaf people have had experiences with an unqualified interpreter and they felt like they did not receive the information that they needed. Healthcare settings are not the only arenas where there is a shortage of qualified interpreters, nor is it only a problem for ASL interpreters. Some unqualified interpreters can slip through the cracks and end up interpreting at an extremely important event. For example, at Nelson Mandela's funeral, a man was "interpreting" in what was assumed to be South African Sign Language but it was quickly determined by Deaf people in attendance that he was unqualified and they were

not receiving the necessary information.¹⁴ The example of Nelson Mandela's funeral is both frustrating and a disgrace to both the Deaf Community and the interpreting world. This is exacerbated in a healthcare setting where an individual's life could potentially depend on the information received.

Deaf people recognize the severe shortage of qualified interpreters everywhere, but especially in medical settings. There can be scheduling conflicts between doctors and interpreters or just not enough interpreters in a particular setting in general (Health Forum, fieldnotes, 6/26/16). Proof of the shortage of the interpreters comes from the fact that Advocates, Inc. and the Massachusetts Commission for the Deaf and Hard-of-Hearing (MCDHH) had to cancel the Community Health Forum and reschedule due to the lack of interpreters available. Advocates, Inc. worked closely with the MCDHH and others to get all the interpreters necessary but unfortunately, they still did not have enough for the original date. Since these are Deaf agencies, they are committed to full inclusion and accessibility for all members of the Deaf Community, so the event could not continue without full inclusion available.

The *Registry of the Interpreters for the Deaf, Inc. (RID)* is the national certified agency for qualifying interpreters. The RID has played a leading role in establishing a national standard of quality for interpreters. They encourage the growth of the profession, educate the public about the vital role of interpreters, and work to ensure equal opportunities and access for all individuals. The RID promotes excellence in the delivery of interpreting services among diverse users of signed and spoken languages through

¹⁴ For more information see: <http://www.nbcnews.com/news/other/fake-sign-language-interpreter-nelson-mandela-memorial-provokes-anger-f2D11723934>.

professional development, networking, and standards (www.rid.org, 2015).

As I sat surrounded by various members of the Deaf Community at the Health Forum, it was easy to see how frustrations with VRI echoed throughout the Community. Many people mentioned how incredibly frustrating it can be to secure a live interpreter for an appointment. One woman explained simply, “VRI is terrible. It does not work like they think it does” (Health Forum, fieldnotes, 6/26/16). Many Deaf people are tired of trying to make VRI work and completely refuse to use it. At the Health Forum, one man explained that if a nurse wheels VRI into his room, he does not even proceed. He writes to the nurse or doctor that they absolutely *must* provide a certified live interpreter. If they do not, he refuses to continue with the appointment (Health Forum, fieldnotes, 6/26/16).

At the forum, one Deaf woman got up and told the story of when her father had a stroke. He did not want the ambulance to come because communication is such a struggle. Even after they asked for a certified live interpreter, the hospital staff still wheeled in a VRI machine. Eventually, they brought in a paper and pen after many futile attempts to use VRI. This woman simply explained, “VRI does not work!” They waited for five hours and they still did not have a live interpreter present. The emergency room staff once again brought in another VRI machine. She felt as though she was the only one willing to provide care to her father. She went to the restroom while her father was in the hallway waiting for the doctor to see him. While she was gone, her father had actually fallen and when she returned, he was lying on the floor struggling to get up and nobody seemed to be around to help. This woman angrily questioned a nurse about how they allowed this to happen. The nurse said, “We had other patients to attend to and we were

busy,” in a dismissive tone. As his daughter, this woman was furious. She was finally able to discharge her father and bring him to another hospital the next day. They spent two days in that first hospital and never received a live interpreter as they asked, nor an answer as to why they did not receive one. They certainly did not receive the quality of care that she wanted and her father deserved (Health Forum, fieldnotes, 6/26/16).

Unfortunately, many nurses and other staff often do not know how to work the VRI machines. People have had doctors turn off the machine, so the Deaf individual did not have a chance to communicate. There have also been cases when only an unqualified interpreter was available on the VRI system. Some people at the forum told stories of instances where they outright refused to use VRI and had nurses, doctors, and other hospital staff becomes angry with them. One man signed, “The doctors control communication, I do not” (Health Forum, fieldnotes, 6/26/16).

Doctor controlled communication is common in all medical encounters, not just in the case of Deaf patients. Patients are more likely to be satisfied with their medical care overall if the quality of communication is high (Stewart, 1999). For all patients, the most common communication problems identified are inadequate explanations of diagnosis or treatment and patients feeling ignored. Other communication problems include physicians misleading patients, not understanding patient and family perspectives, devaluing patient and family views, desertion, and patients feeling rushed (Stewart, 1999). These already present communication problems are exacerbated when there is a distinct language barrier present, as is the case with Deaf people.

In my interview with Harrison, he recounted an experience in the emergency

room at about three or four in the morning in which the nurse came in with the VRI machine and was trying to figure out how to set it up. He explained,

I told the nurse, ‘Why do you think I need VRI?’ I have already told you about my symptoms, why do we need VRI?’ The nurse still tried to set it up and when it finally connected, the interpreter on the screen said, ‘Oh, you need a Sign Language interpreter? We do not have one available. I will have to call you back.’ So we waited and waited and when an interpreter finally came on, I told them, ‘The nurse does not know what to ask me. I asked the nurse and the doctor what questions they had for me, and they said, ‘Oh, well, we need to find an interpreter for you.’ I was like, ‘Well you are supposed to have something to say for me to tell the interpreter. What is the information you need?!’ [sighs] No, VRI is bad. I do not like it. I mean, sometimes if it is absolutely necessary, like it is the *only* means of communication, then it can be okay. But it needs to be used appropriately and well and doctors cannot ignore requests from patients not to use it. There is a reason we do not like it (7/27/16 interview with Harrison).

It was clear that this experience frustrated Harrison since he sighed and distinctly signed that VRI is bad and he does not like it. He recognizes that it can be a solution if it is the *only* possible means of communication. However, he knows that it is no substitute for a real qualified interpreter. He seemed especially annoyed with the fact that the nurse ignored his request not to use VRI and thinks that it is wrong for medical professionals to ignore Deaf patients’ requests not to use it.

The lack of understanding that clinicians often have about the Deaf Community is especially present when working with Deaf-Blind patients. Not only can these patients not hear, but they are also unable to see. This means they require more specific means of communication, as well as more patience from the clinician. Just as there are various degrees of hearing loss, there are also various degrees of vision loss. *Total blindness* refers to the inability to see anything with either eye. *Low vision* is frequently used interchangeably with *visual impairment* and refers to a loss of vision that may be severe

enough to hinder an individual's ability to complete daily activities such as reading, cooking, or walking outside safely, while retaining some degree of usable vision. *Legal blindness* is a level of vision loss that has been legally defined to determine eligibility for benefits. The clinical diagnosis refers to a central visual acuity of 20/200 or less in the better eye with the best possible correction, and/or a visual field of twenty degrees or less. People diagnosed with legal blindness often still have some useable vision (Thylefors, 1995).

I interviewed two Deaf-Blind women: one totally blind, one low vision (close-vision). However, regardless of their different vision levels, both of them identified as Deaf-Blind. Both use ASL but require different methods of communication. Since they have some useable vision, most low-vision, Deaf-Blind people can communicate in ASL through close-up signing. This usually means others need to sign within two feet or less of their face, to allow them to see. It can also mean signing a little more slowly to make sure they catch everything, especially in terms of fingerspelling (Emmorey, 2009). Totally blind Deaf-Blind people usually require what is known as *tactile communication*.¹⁵ This means that they need to receive linguistic information by feeling the other person's hands while they sign. This requires sitting close together and allowing the Deaf-Blind person to put their hands over the signer's hands in order to feel what they are signing. This also requires signing a little more slowly because some signs can feel similar to others so the signer needs to be clear about what they are trying to get across (Collins, 1998). For example, in my interview with Gwendoline, a totally blind Deaf-

¹⁵ Refer back to Chapter 2: Methods to see images of close-vision and tactile signing.

Blind woman, I signed '*MEDICINE*' but for a moment, she mistook what I signed for '*INTERNET*' because they use similar handshapes and movements.



The ASL Sign for MEDICINE. (Source: Lifeprint.com)



Unfortunately, this is yet another element of the Deaf Community that many medical professionals are unaware of, so Deaf-Blind people often have a difficult time communicating with their providers.

One of the biggest issues that arises from this lack of understanding about Deaf-Blind people is the fact that clinicians try to use VRI with them. These video interpreters are on a small screen than be hard to see anyway, but a low vision Deaf-Blind person would have an extraordinarily hard time with this. Daisy, the close-vision, Deaf-Blind woman I interviewed was born with both her hearing and sight but an illness when she was six years old led to the full loss of her hearing and gradual loss of her sight. When we met, I signed about a foot away from her face for her to be able to see what I was signing. The other Deaf-Blind woman I interviewed, Gwendoline, was totally blind. She was born

Deaf and lost her sight due to Usher's Syndrome,¹⁶ a condition characterized by partial or total loss of hearing and vision that worsen over time.

I had communicated with both of these women a few times at my internship/fieldsite prior to our interviews, but not for an extended amount of time. Initially, the prospect of interviewing them was intimidating for me. I would still be using ASL but was worried about this different way of communicating. However, Gwendoline suppressed my reservations when she told me,

I remember when we first met. You were so nervous and you told me, 'I have never talked to a Deaf-Blind person before, I am nervous. Sorry if I mess up,' I tried to tell you to relax and we would learn together but I do not think you really listened to me that day. I could feel your hands shaking as we continued [laughs]. But look at you now! You have improved so much since we met last October. I can feel the confidence. I am so proud of you! (7/28/16 interview with Gwendoline).

Despite my initial reservations, I was able to conduct enlightening interviews with both Daisy and Gwendoline. When I met with Daisy, she recounted a frustrating experience with VRI,

One time in the ER, the nurse wanted me to use VRI. I told her no, I could not. I cannot see so it does not work for me. But this nurse was stubborn. [sighs] She brought in the VRI machine anyway. The interpreter showed up on the screen and I was like, 'I cannot see you so this is not going to work.' When the doctor came into the room, I asked him to please write things down in large letters for me. That would be nice and work better for me than this stupid machine. The doctor agreed and was nice and helpful but that nurse was not very good. It was not a very good ER experience. I have had other doctors and nurses ask me to use VRI but I tell them no because I cannot see. I need a live interpreter. And they listen to me. Just that one nurse did not listen to me (7/28/16 interview with Daisy).

Daisy was thankfully able to convince the doctor to accommodate her communication

¹⁶ Defined in detail in Appendix A.

needs. I could tell she was frustrated in remembering this experience of the nurse bringing in the VRI machine anyway even though Daisy clearly told her she could not see it.

Due to her blindness, Gwendoline has not experienced VRI. Because she cannot see it, she cannot use it. She has never had a doctor try and force her to use it. When I asked her about VRI, she simply told me, “I need a live interpreter. I cannot use VRI of course because I cannot see it” (7/28/16 interview with Gwendoline). However, Gwendoline also informed me that her wife has had to use VRI. She told me,

My wife is Deaf and she has used VRI. She has never really had a problem with it though. She prefers a live interpreter of course because it is more personal but she can cope with VRI. She learned English well when she was growing up so she can usually communicate well with doctors and nurses. We both like to talk to different people – anybody! [laughs] So we find different ways to communicate (7/28/16 interview with Gwendoline).

This is an example of how doctors need to be aware that VRI will not work for everyone. Gwendoline’s wife is able to make it work for her but she would still rather have a live interpreter. VRI will not work for people like Gwendoline and Daisy because they cannot see it. Doctors need to be aware of these differences and respectful if an individual does not want to or cannot use VRI.

In my interview with Gwendoline, she explained to me what it was like for her to lose her sight,

I knew Sign Language and I was fine with being Deaf since it was all I ever knew. I prefer it. I started to become blind at twenty-four. I prayed and hoped that I would not go blind. I was hoping it would wait until I became old – like in my nineties. But I was wrong and became blind at twenty-seven. I have been part of the Deaf-Blind world for thirty-three years now. I do think positively now. Initially I did not really know where I fit – was I in the Deaf world or the blind

world? But then I realized I am part of both of them. It was not easy at first but I did grow to accept it (7/28/16 interview with Gwendoline).

Gwendoline has had more positive experiences than many others have in the Deaf Community with whom I met, largely due to her primary care physician. As has been said, all doctors are different and a good doctor can make all the difference in the world for the patient. However, her doctor is not the only reason for Gwendoline's positive experiences. She is a strong advocate for herself and the Community and her spirits are always high. She signed to me while smiling and laughing, "I am very knowledgeable about how to communicate with others. I am a good communicator. I am good at talking with different people! I am sure you are aware of this by now!" (7/28/16 interview with Gwendoline).

Insurance Obstacles

Insurance is another major issue that Deaf people face in terms of communication and healthcare access. The Health Forum survey included questions related to insurance, while differentiating between private and public coverage. For example: "Do you find it hard to find a doctor who accepts your insurance?" and "Do you feel like your health insurance covers all of your needs?" Such questions prompted attendees to discuss related frustrations.

When this research began, I did not anticipate insurance as a relevant problematic theme Deaf people face. However, the Health Forum proved that insurance is a barrier for many Deaf people so I adapted my interview guide to incorporate insurance-related

questions. At the forum, some people told stories of struggling to get their insurance company to understand their needs. Many insurance personnel do not understand the cultural views of the Deaf Community, which in turn, can lead to communication problems.

Similar to spending time finding a good doctor, it can also take time to find a quality insurance company that meets a person's needs. Many attendees at the forum mentioned needing to switch between different insurance companies until they found one that worked better for them. It was also common for people to have insurance through work, as well as combined private and public insurance. People at the forum and interview participants discussed insurance problems that they had in the past and how things have improved some now.

Just as everyone's experience with a clinician is different, so is everyone's experience with insurance companies. While there are positive experiences, the fact that there are negative experiences shows it is a problem worthy of exploration. If insurance companies had a better understanding about Deaf Culture and various communication preferences, things could improve on both sides. Deaf people would not feel like they are being blindsided if they do not understand a policy; insurance companies would not receive as many complaints related to communication.

At the Health Forum, one of the most common criticisms of insurance companies¹⁷ was that they often do not provide for hearing aids. People did not

¹⁷ Various insurance companies were mentioned by name during the Health Forum and my interviews. Specific names will not be used as excerpts are meant to reflect perspectives and experiences with insurance overall, not specific companies.

understand how they could still have out of pocket expenses for things like prescriptions even when they supposedly had good insurance. Furthermore, people felt as though they could not comprehend the policies because people from the insurance companies did not take the time to make sure that they did understand (Health Forum, fieldnotes, 6/26/16).

One Oral-Deaf woman had a daughter with Usher's Syndrome. Doctors and geneticists wanted to test for other issues that may be present. This woman spent two years fighting with her insurance company for these tests to be covered. She said, "There's no easy communication and things are not accessible to Deaf people. You have to use the phone and it just does not work!" Her insurance told her that she was not eligible to receive hearing aids and get them paid for because her "speech was too good" (Health Forum, fieldnotes, 6/26/16).

During the forum discussion about insurance, one man got up and signed, "Co-pays can be killer and there is no warning about them. It is not fair." Another man needed to get oral surgery and he was unable to get a second opinion. Coverage for dental work can be even more difficult to come by than coverage for basic healthcare. This man needed a procedure that cost about ten thousand dollars, but his insurance would not cover any of it. He signed, "My dentist felt like it was wrong for my insurance not to cover it and felt like it was discriminatory but he also felt as though there was nothing he could do to help me" (Health Forum, fieldnotes, 6/26/16).

During my interviews, every person had some experience associated with insurance that they shared with me. When conversing with Gwendoline, she told me,

I can read Braille. My insurance company has often mailed me papers with no Braille. I tell them no do not give me those because I cannot read them. I have to

tell my wife to read them for me to be able to do what they said. That is a problem because sometimes they will send me letters and I cannot read them so it is pointless. I should not need to ask my wife for help with that. I have asked them to please send me Braille letters and forms but they never listen. I am thankful that my wife is able to help me and read them for me but she should not have to do that. Another thing – businesses, hospitals, whatever, they never make Braille available. Well almost never, I guess (7/28/16 interview with Gwendoline).

Gwendoline was clearly frustrated with not receiving Braille letters even after she asked and having to rely on her wife to read things for her. However, often cheerful, these negative experiences did not stop Gwendoline from sharing her positive experiences as well. She told me,

Things have been pretty good for me here in Massachusetts. It has been relatively easy for me to find quality healthcare. When I was in Connecticut and in college it was a little more difficult for me since my insurance was not that good. Once I got my job here and moved to Massachusetts and had better insurance, I never really had problems with receiving care. I receive good insurance from [my job]. I know insurance policies can depend on the procedure. I know I have to ask my doctor before a procedure about checking with insurance to see if it is covered. Nobody wants to pay out of pocket for anything but especially not an expensive surgery. Doctors need to let the insurance company know that a procedure is absolutely necessary and that it should be covered. Nobody should have to pay for a procedure that they truly need. It is important for me to have patience and trust that things will work out. And they have – hopefully they continue to! [laughs] (7/28/16 interview with Gwendoline).

When people struggle to communicate with their insurance company, they can feel discriminated against. They often do not receive the coverage that they need. In my interview with Daisy, I asked her if she ever felt discriminated against in a healthcare setting. She thought for a moment and replied,

I never really felt discriminated against at an appointment. Hospitals have been a little tough at times but I do not know if that counts as discrimination. I have felt discriminated against with insurance but my experiences with doctor's offices have been mostly good in things like finding a qualified interpreter. Mostly good (7/28/16 interview with Daisy).

After conversing further, we both realized that she did have some experiences that were not part of this “mostly good” description she was remembering. Before we got to that, however, I was interested in what Daisy meant when she said she felt discriminated against by insurance, so I prompted her to go into more detail. She told me,

I have had a hard time with insurance before. I have [private insurance] and insurance through work. [Private insurance] told me that they cannot cover me as my primary insurance and that I have to apply for [another insurance company] as my primary insurance. [Private insurance] is not really good about working with me. I pay into [private insurance], they should be better. But at the same time, I did like to have them because I was able to get more services. It was tough. I had to switch to [another insurance company] as my primary. I recently had surgery and I was afraid that I would be responsible for paying so I had to change. [Private insurance] told me it was for legal reasons. I asked why some have different laws. I do not know, I think it is the same with Social Security. Social Security tells people with disabilities that they cannot work because if you work then you are not a person with a disability. So because I am a person with a disability, [private insurance] told me that [another insurance company] must become my primary insurance (7/28/16 interview with Daisy).

What stood out to me with what Daisy told me was that she was frustrated with her private insurance company and they should have been better but she also liked having them because she felt like she was able to receive more services. It seemed like Daisy felt as though she had no other options because her private insurance company would not accommodate her the way she needed and she was forced to find another insurance company to be her primary insurance.

Harrison described a mixture of both positive and negative insurance experiences. Similar to other Deaf people I interviewed, the more negative experiences happened in the past; the more positive experiences happened more recently. He told me,

I have had trouble with insurance in the past. I have had trouble having to pay for my prescriptions when I am not supposed to have to do that. But my pharmacist knows how to take care of this for me. So I do not really have to do anything to

fix the problem. Now I have [public insurance] as well as private insurance. My primary insurance is through the private company. My primary insurance charges a fifteen dollar copay but [pubic insurance] covers most everything so I pay next to nothing. So I guess I cannot really complain about that (7/27/16 interview with *Harrison*).

Some people have actually taken steps to acquire a legal advocate to help with insurance. When I interviewed Carrie, a hard-of-hearing woman, our discussion about her experiences of losing her hearing led to a discussion about needing a legal advocate to help her with her job and insurance. She told me,

Carrie: Sometimes there are people who have hearing loss that do speak well and there are some people that do have a hearing loss and don't speak well. It is in both, it doesn't matter if one speaks well or doesn't speak well, they have hearing loss anyway. You know, even if they have hearing loss in both ears, they can speak well.

Interviewer: Yeah, I've heard of people struggling with insurance companies or something with trying to get a hearing aid or something and they're saying like, well you speak fine, you're not – are you even deaf? Like that kind of stuff.

Carrie: And that's so frustrating! And that's why I have a, an advocate, a legal advocate who helped me out with that last year. With the insurance company. I told them we gave them the proof. I gave them what I have. Even the doctor actually wrote a note telling them that I need a hearing aid, that I should require one. It was right in black and white. With the [insurance] health plan that I have, they did have it for free, there was no cost on it, no authorization. Although, I did have to prove to them and say that I do have hearing loss that I do really need a hearing aid you know. And I think I need another hearing aid because it's now that I'm completely deaf on my left side and I need another one for my right hand side now. [Sighs] It's kind of frustrating that there's some other people that couldn't be able to have anything and they deserve the right to be heard by other people. And having a legal advocate really works because it helped me a lot. I could not, I – just so you know, psychologically, I deal with anxiety, PTSD, and I have cognitive disability. I can't deal with people you know – conversing with them like they don't believe what I have so that's why I had a legal advocate to help me with that issue. And [h/she] actually helped me with that (7/1/16 interview).

Carrie's use of a legal advocate is an example of what Merrill Singer called “*systems-*

challenging praxis.” This is the “conscious implementation of minor material improvements that avoid any alteration of the basic structure in the existing social system” (Baer, Singer, & Susser, 2003: 361). In this application of critical medical anthropological theory to understand healthcare recipients’ responses to power inequalities, people may work within the healthcare system in order to get what they need – until the system fails them. Then, people who are willing to resist and defy power inequalities may challenge those inequalities, and push back against unfair treatment (Cheyney, 2008, Ostrach & Cheyney, 2014, Ostrach, 2017, Singer, 1995a). Carrie did not try to change the entire system; she worked within the system by acquiring a legal advocate to get her needs met. Clearly, Carrie is grateful for the fact that she had a legal advocate to help her deal with her insurance company. This interview excerpt shows that insurance personnel, along with many other people, are not aware of the varying degrees of hearing loss and how this can affect a person’s ability to speak. As Carrie said, some people with any degree of hearing loss can speak well; others do not. It can depend greatly on how one was educated. If they received oral education, they might presently have better speech than someone who received ASL education. However, another person might have received that same oral education but refuse to use speech in spite of that education because they feel as though it takes away from their Deaf identity. It depends on the individual.

Conclusion

Video remote interpreting is a communication service that does not work as well

as many hearing people might think it does. It is unreliable in that calls may drop, the screen is too small, and/or the interpreter may not be qualified. As such, most Deaf people are vehemently opposed to using VRI and would prefer to use a live interpreter. However, they are adamant that the interpreter must be qualified, specifically with a qualification from the Registry of Interpreters for the Deaf. Participants have had numerous experiences with unqualified interpreters so they deserve to communicate in the way that works best for them to give them a better appointment experience. Deaf people also struggle to communicate with their insurance companies and receive the necessary coverage. I argue that these communication obstacles stem from a lack of awareness about Deaf Culture due to a lack of education and training received in medical school. This exacerbates the medicalization of deafness and the continued disregard for Deaf perspectives.

CHAPTER 5

THE “DEPENDENCY DUET” OF DEAF AND HEARING PEOPLE

Much of the world is structured as though everyone were physically strong, as though all bodies were shaped the same, as though everyone could work, hear, and see well...
(Wendall, 1995: 59)

This chapter briefly examines how the Americans with Disabilities Act (ADA) came to be. I examine each component of the ADA in terms of how it has excluded Deaf people when they needed it the most, with examples from fieldwork and interviews. The ADA can be controversial for Deaf people in that many do not consider themselves disabled, but they rely on the ADA in various ways. As such, disability is a social construction.

There is a distinct rift between the Deaf and hearing worlds and there is often a certain degree of stigma associated with being Deaf. Deaf people are often seen as less than whole because they have deviated from the so-called norm of general society. Deaf people do not want to be seen as disabled but they cannot receive the necessary accommodations in order to survive in the larger hearing society without labeling themselves as disabled. As such, Deaf and hearing people interact in what is called a “dependency duet.”

Brief History of the Americans with Disabilities Act

Historically, people with disabilities were treated as ‘out of sight, out of mind.’ Many people with disabilities were institutionalized because it was socially perceived easier to deal with them by not dealing with them. Beginning in the 1960s, disability

advocates saw the opportunity to join forces alongside other minority groups fighting in the Civil Rights Movement to demand equal treatment, access, and opportunity¹⁸ (www.archive.adl.org, 2005, Clapton, 1997, Scotch, 1989, Welch, 1995). Upon the passing of *Section 504 of the 1973 Rehabilitation Act*, public policy shifted profoundly. Modeled after previous laws which banned discrimination based on race, ethnic origin, and sex, this act banned “discrimination on the basis of disability by recipients of federal funds” (www.dredf.org, 2012, Scotch, 1989, Welch, 1995). Previously, people assumed that the unemployment and lack of education people with disabilities faced were inevitable consequences of the physical or mental limitations imposed by the disability itself. The implementation of *Section 504* led to the further recognition that the inferior social and economic statuses of people with disabilities was not a consequence of the disability itself, but the result of societal barriers and prejudices (Clapton, 1997, www.dredf.org, 2012, Welch, 1995).

First introduced in 1988, the Americans with Disabilities Act (ADA) went through numerous drafts, revisions, negotiations, and amendments before officially passing in 1990 (www.dredf.org, 2012, Scotch, 1989, Welch, 1995). It is a complex civil rights law that prohibits discrimination against people with disabilities in all areas of public life. These include employment, education, transportation, and all public and private places that are open to the public. The purpose of this law is to guarantee that

¹⁸ The history of disabilities and disability advocacy is dense and goes well beyond the scope of this thesis. For more information see: “Politics and Policy in the History of the Disability Rights Movement” (1989) by Richard Scotch, “The History of Disability: A History of Otherness” (1997) by Jayne Clapton and Jennifer Fitzgerald, and “A Brief History of Disability Rights Legislation in the United States” (1995) by Polly Welch and Chris Palames.

people with disabilities have the same rights and opportunities as everyone else. It provides similar protections against discrimination as the Civil Rights Act of 1964, which made it illegal to discriminate based on race, religion, sex, national origin, and other characteristics. The ADA is divided into five sections (titles) that relate to accessing different areas of public life: employment, state and local government, public accommodations, telecommunications, and miscellaneous provisions (www.adata.org, 2011, Scotch, 1989, Welch, 1995).

The ADA defines an *individual with a disability* as a person who has a physical or mental impairment that substantially limits one or more of the major life activities of such individuals. A *disability* is a physical or mental impairment that substantially limits one or more major life activities. A *physical impairment* is a physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the body systems. A *mental impairment* is any mental or psychological disorder (www.adata.org, 2011).

Ways in which ADA Titles are Lacking for Deaf People

Title I of the ADA is designed to help people with disabilities access the same employment opportunities and benefits that are available to their non-disabled counterparts. This title requires that employers must provide *reasonable accommodations* to qualified individuals with a disability. A *reasonable accommodation* is a modification to a job, the work environment, or the way things are normally done that enables an individual with a disability to have an equal employment opportunity (www.adata.org,

2011, Welch, 1995). *Title I* is regulated and enforced by the United States Equal Employment Opportunity Commission. In order to be covered by the ADA, an employer must have a minimum number of employees (www.eeoc.gov, 2011, Scotch, 1989, Welch, 1995). This statute excludes many small businesses, leaving many people left uncovered.

As stated previously, one of the three focal points of the Deaf Grassroots Movement Rally was the lack of employment opportunities. The total United States unemployment rate is about 5%. In comparison, the rate of unemployment among the United States Deaf population is about 72.5%. As such, Deaf adults earn an average income that is roughly 40-60% of that of their hearing counterparts. The small percentage of Deaf adults who are employed often earn less and are overlooked for promotion, raises, and recognition. Approximately three-fourths of all Deaf adults rely on some form of government assistance (fieldnotes, DGM Rally, 5/4/16).¹⁹

At the Rally, Deaf people were fighting for the development of Deaf job training and career advancement opportunities. They also advocated for a hiring preference for Deaf people in jobs that require ASL and cultural competency. Ultimately, Deaf people argued for the same employment opportunities as their hearing counterparts because they deserve the same opportunities to buy houses, support their families, give to charity, and pursue their dreams just as hearing people do (fieldnotes, DGM Rally, 5/4/16).

In late October 2015, Boston University's Deaf Studies Department hosted a presentation about the Deaf Grassroots Movement in anticipation of the upcoming rally to be held the following May. Attendees got up to share their frustrations and many had

¹⁹ For more information on statistics see: www.libguides.gallaudet.edu.

to do with employment. Many Deaf people felt as though they were stuck in dead-end jobs or that they could not even get a job. Several attendees got up on stage and told their stories of struggling to get a job or move-up in their careers because their superiors think they are not qualified due to their inability to hear. One woman said simply, “Employers think we are stupid because we cannot hear” (fieldnotes, DGM presentation, 10/30/15).

Title II of the ADA prohibits discrimination against people with disabilities in all programs, activities, and services of public entities, which applies to all state or local governments, their departments and agencies, and any other programs. This title established detailed standards for the operation of public transportation systems, including commuter and inner-city rails. *Title II* is regulated and enforced by the United States Department of Justice. It outlines the administrative processes to be followed, including requirements for self-evaluation and planning, requirements for making reasonable accommodations to policies, practices, and procedures to avoid discrimination, identify architectural barriers, and the need for effective communication with people with hearing, vision, and speech disabilities (www.adata.org, 2011, Scotch, 1989, Welch, 1995).

Hearing people take many things for granted when it comes to public transportation. Often, people listen for their stop because that is the most convenient for them. Otherwise, they can look for landmarks to know where they are, or hope the transit system visually states which stop is next. Using the MBTA (T) System of Massachusetts as an example, there can be several issues that a Deaf person may face in trying to utilize it. For instance, the visual system that says which stop is next and the final destination of

the train is not always working. Instead, the T conductor will use the intercom to say which stop is next. This will not work for a Deaf person. There are added difficulties for a Deaf-Blind person because they cannot see the visual system.

I attended a meeting about how to make the T more accessible for Deaf-Blind people. The T can be hard enough to access and understand for 'normal' people but especially so for someone with any sort of disability. The woman leading the meeting was from a company called "Ways 2 Go." There was a map about the size of a shower curtain that had the entire T map on it. Each train line had a different tactile marker to show it was a different track. The T stops were written in Braille and marked by a bead. This was the third of a four-part meeting and each session was updated with feedback from the previous session. There were four Deaf-Blind people in attendance; two were fully blind and used tactile communication, one had partial vision but still mostly used tactile, and one woman was blind and hard-of-hearing so someone spoke into a microphone connected to earpieces. There were eleven interpreters working which was fascinating to observe. They were in various places throughout the room. Most were working directly with one of the attendees, often two for each attendee. They would switch on and off to make sure they were refreshed enough to interpret to the best of their ability. Each attendee had a chance to practice with the map and any other things the woman had, like tactile foot pads to mark where the end of the platform was. Everyone had opinions about the map and for the most part, they were negative reviews. They said there was too much on the map and that it was confusing. I give the woman who ran it a lot of credit because this project was her first time ever working with Deaf-Blind people and the Community. She handled responses and working with interpreters very well. This was basically an experiment to try to come up with solutions and get feedback from the Community. This was not just some hearing people thinking that they knew what was best for the Community. There was a woman from the company furiously taking notes so that they could make changes for the next session. It will not be an easy process but I am so happy they are taking some steps in the right direction (fieldnotes, 5/20/16).

As can be seen from this fieldnotes entry, the T system is inaccessible for Deaf-Blind people unless they have someone accompanying them. The regulations of the ADA are meant to help people labeled with disabilities lead lives that are more independent. The T falls short of following these regulations and making it more accessible for Deaf-Blind people. It likely will not be an easy solution but such inaccessibility shows that

something needs to be done.

Title III of the ADA prohibits places of public accommodation from discriminating against people with disabilities. Examples of public accommodations include privately owned, leased, or operated facilities: hotels, restaurants, doctor's offices, day care centers, health clubs, and movie theaters. This title is also regulated and enforced by the United States Department of Justice. *Title III* directs businesses to make *reasonable modifications* to their usual way of doing things when serving people with disabilities. The ADA states, "A public entity must modify its policies, practices, or procedures to avoid discrimination unless the modification would fundamentally alter the nature of its service, program, or activity (www.adata.org, 2011).

Unsurprisingly, any reasonable modifications regulated by the ADA are ultimately defined by money. These public accommodations are required to remove existing barriers in buildings where it is easy to do so without much difficulty or expense (www.adata.org, 2011). Who has the power to decide what counts as one of these reasonable modifications? Businesses could easily say it is too difficult and expensive to change something already in place when that is not the case.

In terms of healthcare access, Deaf people's experiences can thus be understood through the lens of theories of the political economy of health and critical medical anthropology (CMA) (Singer, 1995b). Political economy is a central component of CMA and focuses on the influence of government policy and capitalism on all aspects of life. Health services can be differentially allocated based on race, class, and gender, and these interact to affect health and health services (Minkler, 1994). As such, CMA highlights the

structural causes of poor health or constrained access to health services as they relate to capitalism and neoliberal economics, and to health systems. In the case of Deaf people, they are discriminated against and face obstacles in receiving adequate healthcare because general social customs do not accommodate their bodies (Lane, 2005). Through this theoretical framework, researchers can emphasize the structure of social relationships, rather than purely biomedical factors in analyzing health and accounting for its determinants (Baer, 1986, Singer, 1994, 1995b).

Title IV of the ADA requires telephone and internet companies to provide a nationwide system of interstate telecommunication relay services that allow people with hearing and speech disabilities to communicate effectively over the telephone. This title also requires captioning of federally funded public service announcements. It is regulated and enforced by the Federal Communication Commission. Video Remote Interpreting (VRI) is one such telecommunication technology that is meant to ensure effective communication. However, as seen from previous discussions regarding VRI, it does not work for most Deaf people in the way many hearing people think it does or should. In a way, the use of VRI is another form of systems-challenging praxis (Cheyney, 2008, Ostrach & Cheyney, 2014, Ostrach, 2014, Singer, 1995), which ultimately fails. Healthcare providers try to use VRI to address the failure of the healthcare system to be more accessible to Deaf patients, but it does not adequately address their communication needs or account for the power inequalities.

While few of my participants explicitly mentioned the ADA as an obstacle to healthcare or other day-to-day needs, many of the frustrations they did mention resonate

with how the ADA does not extend its services to Deaf people where it is the most necessary. The ADA dictates that healthcare settings will provide reasonable modifications, but attendees of the health forum and interview participants have reported not receiving them. The fact that one of the focal points of the Deaf Rally was communication access, particularly in healthcare settings, demonstrated this was a major concern for the Deaf Community. The three biggest priorities of the communication access platform were to “enforce equal access to government and public services, increase qualified ASL interpreters, and enforce effective communication for equal access to healthcare” (DGM Rally, fieldnotes, 5/4/16). As one Deaf man explained,

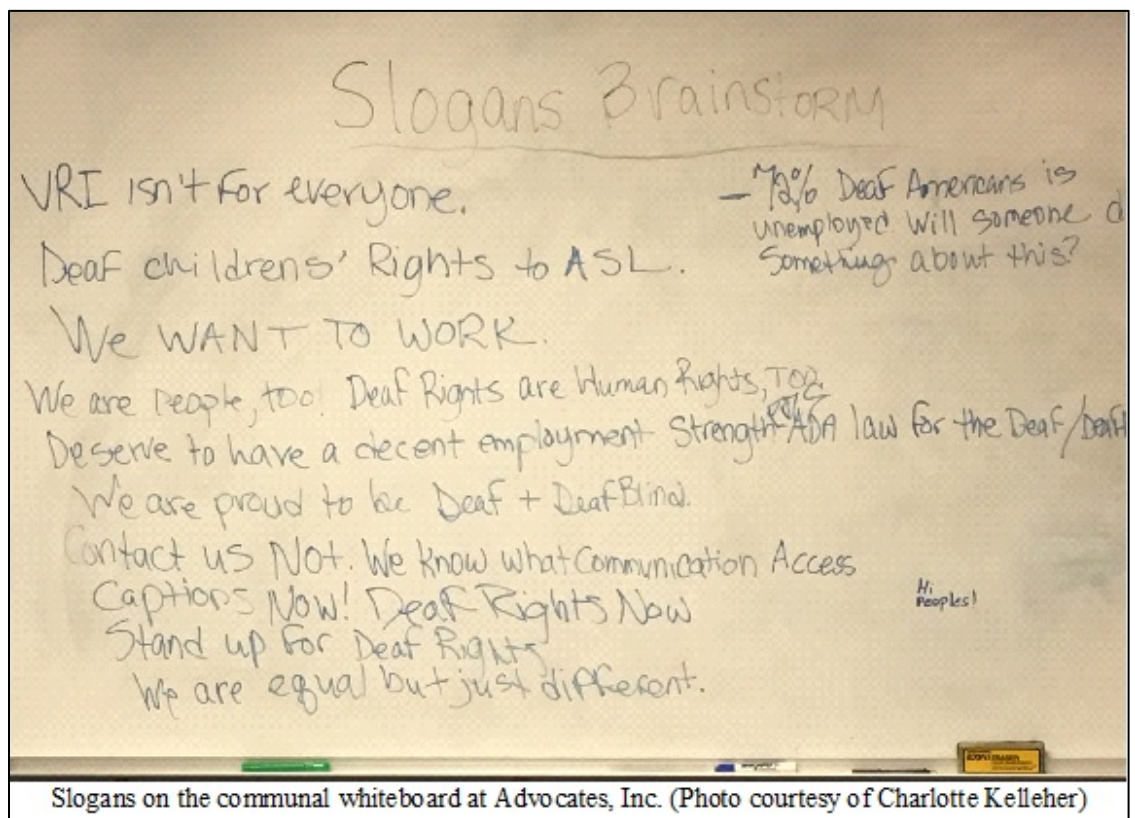
Government and public services still are not accessible – there are no interpreters, unqualified interpreters, unwillingness from offices to pay for communication access, technology [VRI] is unreliable, and people are unaware of the ADA law (DGM Rally, fieldnotes, 5/4/16).

The ADA is supposed to provide accommodations to ensure equal communication that allows for equal opportunities. From what Deaf participants in Boston told me, and expressed at community events, this is not happening.

At the Rally, one woman wore a homemade sign taped to her back that read, “MCB [Massachusetts Commission for the Blind] stinks 4 DB [Deaf-Blind] services. Families don’t care. The world likes \$\$\$ over us” (fieldnotes, DGM Rally, 5/4/16). MCB is a state agency, established in 1906 and meant to provide a wide-range of social and rehabilitation services to Massachusetts residents of all ages who are legally blind (www.mass.gov/mcb, 2016). This woman at the Rally evidently disagrees that MCB provides her with the proper services she needs as a Deaf-Blind person. While not explicitly said, this is an area where the regulations of the ADA should be enforced to

ensure that this woman and others like her receive the quality of care they are entitled to. This Deaf-Blind woman's sign is another example of systems-challenging praxis (Cheyney, 2008, Ostrach & Cheyney, 2014, Ostrach, 2017, Singer, 1995a). This woman's sign is a physical embodiment of systems-challenging praxis by speaking out against systems that are not meeting her needs.

At *Advocates, Inc.*, there was a white-board in the public space near the kitchen that anybody could use. On any given day, I would see doodles, signatures, and various things associated with *Advocates, Inc.* including upcoming events. One day when I walked in, there were various short sentences on the board under a title of "Slogan Brainstorm." While I do not know what these slogans may have been for, or if they were even used, they were powerful to read all the same.



These slogans, while brief, show that these are legitimate barriers the Deaf Community is facing. Interestingly, among these powerful slogans, you can see a small, “Hi people!” in the lower right corner. This shows that this is a communal board that people are comfortable using at all times. The slogans that stand out here are the slogans related to employment and the ADA. The one that is especially relevant is, “We are people, too. Deaf Rights are Human Rights, too.” This applies to every title of the ADA. It shows that there are external structural forces that have control over the lives of Deaf people. It shows the struggle that the Deaf Community has had in their fight for recognition as a distinct cultural group who deserves the same rights as their hearing counterparts.

Where healthcare settings have implemented the regulations of the ADA, this can make a significant difference for Deaf patients. While conversing with Daisy, she discussed two experiences in two different healthcare settings. One of these experiences was a mixture of both positive and negative; the other more negative:

Recently, I went to a doctor’s office for orthopedics and the doctor was good about asking for and working with an interpreter. I wanted to work with an interpreter I had worked with before but the doctor was kind of so-so about figuring that out for me. So he referred me to a different doctor. So I went to my referred orthopedic surgeon and that doctor was good about emailing me like I wanted and working with an interpreter I knew (7/27/16 interview with Daisy).

While this experience ultimately turned out positively for Daisy, she still had to take an extra step to reach the desired goal because her first doctor did not accommodate her – despite the ADA. She had another experience in which she could not continue her appointment because the office did not provide the necessary accommodations. I asked her if she had ever benefitted from any of the services available at Advocate’s, Inc. Daisy

responded:

One time I used [Deaf-Blind provider services] because I needed help to get to my appointment. That is what they were there for [transportation to medical appointments] but the doctor wanted me to use [the Deaf-Blind service provider] as my interpreter. I told him no. I said you knew I had an appointment today and you know you have to set up an interpreter for me. It is not this provider's job to interpret for me. I need a qualified live interpreter and you are supposed to find one for me. So I left.

Deaf-Blind provider services is an Advocates, Inc. program that works to empower Deaf-Blind people to increase their independence. Daisy's discussion about utilizing Deaf-Blind provider services to get to an appointment but not for interpreting services can be seen as another example of systems-challenging praxis (Cheyney, 2008, Ostrach & Cheyney, 2014, Ostrach, 2017, Singer, 1995a). In Daisy's example, the doctor did not do what they were required to do – provide an interpreter for Daisy's appointment. Daisy stood up to her doctor and challenged this power relationship by not continuing with her appointment. In a sense, every individual who goes to Advocates, Inc. to receive community-based services is going outside the traditional healthcare system, as well as outside the ADA, to get their needs met. This constitutes a systems-challenging praxis – they are using a community-based agency to challenge inequalities in the healthcare system and even challenge the idea that Deaf people are disabled.

Title V of the ADA contains a variety of provisions related to the ADA as a whole. These include its relationship to other laws, state immunity, its impact on insurance providers and benefits, prevention against retaliation and coercion, illegal use of drugs, and attorney's fees (www.adata.org, 2011). People cannot claim “reverse discrimination” under the ADA, meaning they cannot seek help from the ADA if they

feel they were discriminated against because they do not have a disability (www.adata.org, 2011, Welch, 1995).

The ADA provides a list of non-qualifying conditions that are not covered. Included among these conditions are, “transvestitism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, and other sexual behavior disorders” (www.adata.org, 2011, Scotch, 1989, Welch, 1995). Homosexuality and bisexuality are also excluded, even though they were argued to be mental health impairments in the past. Other mental health conditions including compulsive gambling, kleptomania, pyromania, and psychoactive disorders resulting from current illegal drug use are excluded as well (www.adainfo.org, 2016), though other mental health conditions, if ‘disabling,’ are. It is interesting that there has been a need to explicitly state what does and does not qualify as a disability under the ADA. Where this can become controversial is the fact that most Deaf people do not see their deafness as a disability, and yet they are specifically covered under the ADA. They rely on the ADA and they want it improved upon to ensure more equal opportunities, but it is a conundrum since they fight to not be seen as disabled.

As explained at length in the Background Chapter, many members of the Deaf Community do not regard their deafness as a disability. Instead, it is an element of their identity of which many are proud of due to the common language, cultural experiences, and shared history with fellow Deaf people (Cokely, 1980, Fjord, 1996, Lane, 2010, Padden, 2006, VanCleve, 2007). As such, Deaf people do not want people to focus on a *cure* for deafness, but instead want to be accepted as a minority cultural group and

respected for who they are (Tucker, 1997). In other words, “Let the Deaf be Deaf” (Munoz-Baell, 2000: 40). When a reporter asked I. King Jordan, the first Deaf President of Gallaudet University in 1988, if he would rather be hearing, he replied,

That is almost like asking a Black person if he would rather be white... I do not think of myself as missing something or as incomplete... It is a common fallacy if you do not know Deaf people or Deaf issues. You think it is a limitation (Lane, 2005: 298)

It can be difficult for hearing people to understand how the inability to hear is not necessarily a disabling condition. To hearing people, it is a fundamental sense we take for granted and struggle to imagine what life would be like without it. However, Deaf people, especially those born Deaf, are equally used to being Deaf. They want to be seen as more than their deafness and prove that they are capable of doing most everything that hearing people can. This is related to the anthropological concepts of cultural relativism and ethnocentrism. Ethnocentrism is the evaluation of another culture based on the preconceptions originating from the standards of one’s own culture (Jost, 2000). The opposite of this is cultural relativism – regarding another culture’s values and practices based on the perspective of that culture itself (Herskovits, 1972, Donnelly, 1984). Being culturally relative would mean understanding and respecting the perspectives of the Deaf Community and recognizing them as a cultural group; not seeing deafness as a medical anomaly in need of a cure.

While Deaf people fight to be seen as a non-disabled group, there are certain accommodations that Deaf people do require in the dominant hearing world, such as flashing smoke alarms and medical interpreters. Deaf people and advocates insist that the larger and more dominant hearing society should compensate by providing assistance to

people who cannot hear, specifically through the ADA. As mentioned in the Background Chapter, deafness is seen as a disabling condition because hearing people and institutions in a hearing-dominated world have made it one, and as such, disability is a social construction (Becker, 1981, Cleall, 2015, Higgins, 2016, Munoz-Baell, 2000, Tucker, 1997).

Stigma

Almost everything can be stigmatized in some way; if one deviates from the so-called *norm*, they are at risk of being stigmatized (Goffman, 1963). Something as simple as being a geek can be stigmatizing on a different level than how living with certain diseases can be so stigmatizing. As described in detail in the Background Chapter, Deaf people face stigma in various ways. Gaylene Becker (1981) determined that Deaf identity and a social support system are two key elements of coping with stigma. The Deaf Community might not face the same level of stigma that some other groups of people do, but there is still an element of stigma associated with being Deaf. It can be especially difficult for people to deal with in the larger hearing society.

Throughout my fieldwork and data collection, participants' signing was noticeably bolder and more pronounced while they were with each other, but Deaf people became more reserved around hearing people or when trying to communicate directly with hearing people who did not know ASL. At the annual Advocates, Inc. Thanksgiving dinner party, an event full of Deaf Community members and trusted hearing advocates such as myself, nobody was shy about their signing. However, when I left dinner with a

fellow intern and went to the closest T station, I became aware of a noticeable difference:

We saw a few other people who were at the party and it was cool for me to just be able to jump into conversation with them because they recognized me as being associated with 'Advocates, Inc.' It was interesting to be on the T with 5 of us signing and the rest were carrying on spoken conversations or sitting in silence listening to music. I half expected to hear someone make some comment but I did not hear anything. I definitely felt and noticed eyes on us as we were signing and I doubt I was the only one to notice. I would not be surprised if many of these looks were mostly due to curiosity and maybe even a little envy toward knowing ASL. I was worried someone would say something though because many Deaf people make noises as they're signing that can best be described as almost 'guttural,' but they're not really aware of doing it as far as I know. As a hearing person who has spent a lot of time communicating with Deaf people and understands Deaf Culture, this does not faze me. But I worried about what others around me might be thinking or even say. I feel like these kinds of sounds might enhance the old "Deaf and Dumb" stereotype that is unfortunately still present in some cases even though it is not true at all (fieldnotes, 11/20/15).

I never witnessed a hearing person necessarily back away from communicating with a Deaf person but I did witness someone get incredibly frustrated and judgmental with a Deaf person for not understanding what they wanted right away, demonstrating how normalized hearing-dominance is and how Deafness can be stigmatized without intent, reinforcing the hearing world's assumptions that Deafness is a disability:

'Margaret' [director of autonomous living] introduced me again to 'Nadine' [autonomous living staff] to try to recruit her to take part in my research. Afterward, they were talking about something else so I waited in the lobby to go back to Margaret's office when she was done to continue our meeting. While I was waiting, there was a family sitting there waiting as well. The mother and father were speaking in a language other than English that I could not recognize and the daughter was silent. 'Cherie' [autonomous living staff] came into the lobby and the father jumped out of his seat and asked when they were finally going to meet with whom they were there to see. I could tell 'Cherie' knew how flustered he was and she tried to explain to him [signing and speaking] that she could not really communicate with him so she was going to go get someone who could. He said something like, "Oh, great, you can't even understand me. I should have expected that from a place like this." I could tell 'Cherie' was trying to follow along with what he was saying. While knowing I was not remotely qualified to interpret or anything, I intervened anyway and asked again whom they were

there to see. I told 'Cherie' they were there to see 'Mary' [autonomous living staff] and she went and got her. He said to me, "I didn't expect anyone here to speak English." I replied, "Well, we're not all Deaf here, but we are all advocates. 'Mary' is great and she'll help your daughter get everything figured out" (fieldnotes, 6/27/16).

Regardless of the fact that I am a timid person who tries to avoid confrontation, I felt like I had to step in in this situation. The father's tone while saying "from a place like this," was judgmental, and as an advocate for the Deaf Community, I could not sit idly by. While I do not know the whole story, I got the sense that this man was worried about his daughter's well-being and her future as a result of her hearing loss. I wanted this man to become aware that Advocates, Inc. is a great agency that would help his daughter live her life to the fullest extent possible.

Both of these situations I witnessed, exemplary of participants' much more common experiences, illuminate a widespread lack of understanding about the Deaf Community and possible real and feared repercussions for them, including within the realm of healthcare. A distinct rift exists between the Deaf and hearing worlds; a rift exacerbated in healthcare settings that do not fully comply with the ADA. Most hearing doctors think that a person's deafness is a medical issue, and, moreover, one it is their own responsibility to overcome in order to access care, while culturally Deaf people see it as a part of their identity that those around them should accept. This emic perspective among Deaf participants was evident at the Deaf Community Health Forum:

At the end of the forum, there was one woman who questioned the effectiveness of forums such as this one. She said, "Who's qualified to talk about what we [the Deaf Community] need? We are! They just need to listen and understand. Open your eyes and listen. But nobody does so I don't see this forum making much of a difference." This event was quite overwhelming actually, because many people made powerful statements such as this one. Most importantly, it made me feel like

my work is truly worthwhile because some of the stories people were telling were absolutely heartbreaking and proved that something needs to be done (fieldnotes, 6/28/16).

This moment illustrates the struggle that Deaf people have faced in order to be *heard*. The statement, “open your eyes and listen” not only relates to the fact that most Deaf people use ASL to communicate but also that Deaf people are right in front of hearing people’s faces. They are not going anywhere. My participants are adamant that they deserve to be seen and their needs deserve to be met. As written on the whiteboard open to all and highly visible at my fieldsite, “Deaf are people too. Deaf rights are human rights too” (fieldnotes, 4/19/16). This simple slogan encapsulated everything the people I interviewed and among whom I carried out fieldwork told me Deaf people have been fighting for, and how they have been so easily and frequently cast aside by the dominant hearing society.

As described in detail in the Background Chapter, such drastically different perspectives toward deafness show that disability is socially constructed. As Susan Wendall, a critical disability theorist, argues,

Disability is socially constructed in ways ranging from social conditions that straightforwardly create illnesses, injuries, and poor physical functioning, to the more subtle cultural factors that determine standards of normality and exclude those who do not meet them from full participation in their societies (1996: 58).

As such, disability cannot be defined solely in biomedical terms because the biological and the social interact in creating disabilities.

One of the clearest examples that shows disability as a social construction comes from Nora Ellen Groce’s *Everyone Here Spoke Sign Language* (1985), as discussed in the Background Chapter. Frequently, in many modern Western societies, people who are

labeled as disabled have been expected to adapt to the ways of the dominant, non-disabled society. Groce's ethnohistorical account of Martha's Vineyard is an example of where this did not happen. She wrote,

The fact that a society could adjust to disabled individuals, rather than requiring them to do all the adjusting, as is the case in American society as a whole, raises important questions about the rights of the disabled and the responsibilities of those who are not. The Martha's Vineyard experience suggests strongly that the concept of a handicap is an arbitrary social category. The most important lesson to be learned from Martha's Vineyard is that "disabled" people can be full and useful members of a community if the community makes an effort to include them. The society must be willing to change slightly to adapt to all (1985: 108).

Not all who cannot hear consider themselves culturally Deaf. As explained in the Background Chapter, people who are deaf but not culturally so may have vastly different perspectives toward deafness than Deaf people. This can apply to people who are hard-of-hearing or became deaf later in life due to age or an illness. Their perspectives will often more closely resemble those of the larger hearing society (Cokely, 1980, Lane, 1992, 20120a). This makes sense because they were once hearing and losing this sense makes them feel as though they lost an important element of who they are. They are more inclined to see and experience their deafness as a loss and a disability, and rely on the ADA. One hard-of-hearing participant, Carrie, told me, "I know the Americans with Disabilities Act from the top of my head. I know all the chapters. I know all the subtitles. I need it" (7/1/16 interview with Carrie).

Carrie has unfortunately had several negative experiences throughout this process of losing her hearing,

Interviewer: So with this experience would you say that you almost felt like a change with whom you identify with or spending time with or anything like that?

Carrie: I kind of feel like I was alone. Like I had no one who had my experience at all of what I was going through. I mean it was the first time ever going through it. I am very, very upset with it but I'm trying to remain strong. I was working during the time so what really made me so upset was that people aren't... people are being frustrated with me for asking them twice of what they're saying and I said well just so you know that I just had hard-of-hearing recently. I've been diagnosed, I thought I'd let you know that I'm deaf in my left ear now. It's hard to actually tell them that. There are some people out there that don't know anything about the American's with Disabilities Act policy. I even asked the managers that, you know, about accommodation to tell them hey you know I can't – I can't hear you guys whenever you guys are telling me everything of what needs to be done. Even in a conference, you know, like in a conference, I can't, you know, communicate and hearing a lot of people at once is – it's hard for me because I have a hearing problem. I told them I have a hearing disability and you're not really helping me. I was like hey you're actually breaking the law. You're not accommodating me (7/1/16 interview with Carrie).

Carrie had an impressive amount of knowledge regarding the ADA. At the end of our interview, she actually brought me up to the second floor of her local library where we met for the interview and showed me exactly where to find a copy of the ADA to use. She also told me to email her with any questions I might have about it. She really opened my eyes about the ADA and made me want to look into it in more detail (fieldnotes, 7/2/16). All Deaf people may rely on the ADA in some form, but it is interesting to see how much more adamant about it a person who does not identify as culturally Deaf is compared to other Deaf people.

The “Ideal” Body

There is often some aspect of someone's body that is labeled and often judged as something that is not ideal. Numerous people worldwide wear glasses, utilize inhalers, and/or wear braces. Braces can sometimes be a more aesthetic fix to conform to an idealized perspective of beauty being equated with having straight teeth, but there can

also be medical reasons behind them as well. These are all examples of *solutions* to problems that people have no control over. People also have no control over whether they can hear, yet deafness is far more stigmatized than the aforementioned *issues* with the human body. There is an element of *control* over bodies; if someone deviates, whether by their actions or not, they are viewed as being less than whole.

Nancy Scheper-Hughes and Margaret Lock (1987) discuss three different constructions of how the body can be viewed: as an individual body-self, as a social body, and as a body politic. Simply put, the individual body is the phenomenological sense of lived experience someone has in their own body. The social body refers to how the body is represented as a natural symbol that is utilized to think about nature, society, and culture. The body politic refers to the regulation, surveillance, and control of bodies in terms of reproduction and sexuality, work and leisure, sickness, and other forms of deviance and human difference²⁰ (Scheper-Hughes & Lock, 1987: 8). All of these relate to how deafness is viewed in terms of the ideal body but most relevant to deafness as a disability and the ADA is the body politic.

Scheper-Hughes and Lock said, “The body politic under threat of attack is cast as vulnerable, leading to purges of traitors and social deviants...” (1987: 24). The “traitors” in this instance are those who are Deaf because they deviated from the idealized norm. Trying to “cure” deafness is a way of controlling people. As mentioned in the Background Chapter, during the 1870s and 1880s, prominent figures such as Alexander Graham Bell stressed the “breeding out” and “forgetting” of deafness (Cleall, 2015: 14).

²⁰ For more information regarding these descriptions, see: “The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology” by Nancy Scheper-Hughes and Margaret Lock, 1987.

In 1927, the United States Supreme Court upheld the Sterilization Act, written in 1923 by Harry H. Laughlin, which was the model for Hitler's eugenics laws. In this Act, Deaf people were in the eighth category of "social inadequate" person, "regardless of etiology or prognosis," and they could be legally sterilized (Fjord, 1996: 63). While things have improved some over the years, many would still prefer to "cure" deafness without any regard for the cultural Community. In recent years, Deaf people have been labeled and pitied as less than whole and technologies such as cochlear implants are meant to remedy that. Cochlear implants are an example of a cultural misunderstanding of a medical technological "solution" to deafness that many Deaf people do not want. I will discuss perceptions toward cochlear implants in more detail in Chapter Six.²¹

As my participants perceive and describe, Deaf people and others labeled as disabled are expected to conform to the ways of non-disabled society. As such, the ADA is an aspect of regulation over the lives of Deaf people. They are expected to contribute to society but they cannot do so if they do not receive certain accommodations. Deaf people do not want to be seen as disabled but they cannot receive the necessary accommodations they need in order to survive in the larger hearing society without labeling themselves as disabled and requesting services under the ADA. As such, Deaf and hearing people interact in what is called, the "*dependency duet*."

First associated with educational settings, this *dependency duet* can be expanded to all social institutions and most aspects of life. For example, Harlan Lane explains,

²¹ While I will discuss cochlear implants in more detail later in this thesis, for further information see the work of medical anthropologist Erin Mellett (2016): "Cochlear Implants and CODAs: The Impact of Technology on a Community."

In some cases, hearing professionals and Deaf people enter a dependency relationship mandated by law, as when a Deaf child is sent to school or a Deaf adult to an institution. In other cases, the dependency duet is mandated by circumstances: for example, a Deaf college student engages an interpreter (1992: 75).

Lane goes on to say,

The Deaf person is unlikely to be a healthcare provider because dependency relations are at work throughout Deaf education and he will find it difficult to rise to such professional heights – the more so as there are frequently barriers erected specifically to help keep him out (1992: 76).

The system as a whole is structured to establish and perpetrate the dependency of Deaf people on the audist²² establishment (1992: 90).

Because audists seek to sustain the dependency duet, they frequently treat Deaf children and adults in ways that preempt their opportunities to learn self-reliance (1992: 90).

The Deaf child or the adult client learns what the school or other audist agency expects of him; in order to please those in power, and frequently as a condition of receiving benefits, the Deaf person is compliant and may even make a positive and sincere effort to be who he is expected to be (but knows he is not) (1992: 90).

While Lane mostly focused on the dependency duet of the audist educational system, it can also apply to other aspects of life as well. Lane mentions how a Deaf person is unlikely to be a healthcare provider because the system makes it difficult for them to rise to such heights. This is unfortunate because who better to work with a Deaf patient than a Deaf doctor? The fact that Lane said Deaf people are compliant “frequently as a condition of receiving benefits” shows that there is a particular role that Deaf people fill in order to receive the necessary accommodations to live their lives. Lane refers to a desire among Deaf people to live side-by-side with hearing people and not have to rely

²² Audism is the notion that one is superior based on one’s ability to hear and the belief that life without hearing is futile and miserable, which results in a negative stigma toward anyone who does not hear and their use of Sign Language (MacDougall, 2015).

on them. This was also evident at Advocates, Inc. during my internship when I was explaining my research to somebody,

There were several people at lunch today so I got a lot of ASL practice. I conversed with 'Adam' from [Deaf-Blind provider services] a lot, which was cool because I had never officially met him before. I have gotten better at coherently explaining my research. He said it sounds interesting and he told me I am doing good work. He asked me if I knew about Deaf history and the oppression that has occurred and I said yes. He said that is a good thing because that history is so important to the work I am trying to do now. He said, "We need more people like you to talk to and educate people on our behalf. I wish we did not have to rely on others but nobody listens to us otherwise. We are ignored." It felt good to 'hear' him tell me I am doing important work (fieldnotes, 11/6/15).

At the time, it had not struck me how interesting this was. It is not as if Deaf people hate all hearing people, but they would prefer to be their own advocates. As Deaf people and Deaf Community members, they know what the Community needs, so who better to advocate for them overall? This is why Advocates, Inc. is a unique agency since it is run both for and by Deaf people who are committed to improving things for the Deaf Community with input from members of the Community itself since the majority of the staff are members of the Community. As seen above, the problem is that Deaf people are often ignored and not taken seriously by many hearing people, so Deaf people realize that they do need to rely on hearing people to a certain extent in order to make sure their *voices* are heard and their needs are met.

Deaf people are *dependent* on hearing people on certain levels because hearing people are the majority. They are often the ones creating regulations regarding the lives of Deaf people. However, the *duet* reflects the dependency of both Deaf and hearing people. As said previously, many hearing people, medical professionals included, are not aware of Deaf Culture. They might be under the impression that Deaf people are not

accepting of their deafness, so the provider will work within the framework they are aware of and they are dependent on preconceived perceptions and solutions to deafness. For example, the existing literature and interview data show that many Deaf people do not like to use VRI but many medical providers use it because they think it is fine. Since the provider does not know ASL, they might worry about how best to communicate with their patient so they are *dependent* on the VRI machine to be able to communicate with their patient.

Conclusion

In this chapter, I have argued that Deaf and hearing people interact in a dependency duet. Since hearing people have labeled Deaf people as disabled, Deaf people are forced to embody this label in order to receive the necessary accommodations. The stigma associated with being Deaf can often make it difficult for Deaf people to interact with the larger hearing society. There are structural obstacles that prevent Deaf people from easily receiving adequate healthcare. Deaf people push back against these inequalities through systems-challenging praxis. Deaf people prefer to be their own advocates but recognize that they need to rely on hearing people to a certain extent to be their voices, since their signs have been ignored.

CHAPTER SIX

“OPEN YOUR EYES AND LISTEN”²³

A September, 2015 article in *The Baltimore Sun* (Maryland) highlighted difficulties Deaf people faced in hospitals (McDaniels, 2015). In July, 2016, Deaf patients sued a hospital in Seattle, Washington for discriminating against Deaf and hard-of-hearing patients (www.drlegal.org, 2016). Also in July, 2016, the State of Connecticut Department of Rehabilitation Services laid off all Sign Language interpreters due to budget cuts (Keating, 2016). Massachusetts lawmakers allocated less money to the Massachusetts Commission for the Deaf and Hard-of-Hearing (MCDHH) in the proposed 2017 fiscal budget for Massachusetts (Young, 2016). What follows is a detailed analysis of each of these current events and their relationship to activism, broadly among the Deaf Community, and as I observed during the course of my fieldwork.

The current volatile political climate, hostile to many vulnerable communities including people with disabilities, also has many Deaf people worried about certain protections of the ADA being revoked under the Donald Trump presidency (Nović, 2016). There is also concern about the possibility of mandatory cochlear implantation, the closing of Deaf schools, and forbidding the use of Sign Language. Since there are more hearing people than Deaf people, hearing perspectives dominate society. Throughout history, Sign Language has often been equated with a lack of intelligence; spoken language has been stressed as the ideal and the only way to really be a full functioning

²³ A quote from a woman at the Deaf Community Health Forum (6/26/16).

part of society. Interview excerpts from participants highlight why mainstream education and cochlear implants are not a solution and usually are not positive experiences for Deaf people.

Current Events

In September, 2015, the Maryland Governor's Office of the Deaf and Hard-of-Hearing worked with hospitals to improve Sign Language interpreting services and establish regulations that ensured the use of only qualified interpreters.²⁴ This was a result of many complaints from Deaf people that the interpreter services provided earlier were often inadequate. There were specific complaints about VRI, discussed previously in Chapter Four, because it lacks reliability in that calls can drop, the screen can freeze, or unqualified interpreters may be used. For example, a Deaf mother of three told the story of when she gave birth to one of her sons. The hospital staff used VRI during the cesarean delivery, and she said it was extremely difficult to see the screen as she lay on her back during the C-section, affecting informed consent and her understanding of what the doctors were doing to her. Her son also needed to have several reconstructive surgeries for a cleft palate after birth. The Deaf woman said,

On one occasion, the interpreter left halfway through [her son's] surgery because she was only paid for two hours. When the doctor arrived after the surgery, he just gave me a thumbs up to let me know everything was OK. That was unacceptable. If your child just went through something so complicated, you want to know what happened (McDaniels, 2015).

²⁴ For a more detailed look at this instance see: *Deaf Patients say it can be Difficult to Communicate at Hospitals*, in The Baltimore Sun, by Andrea McDaniels (2015).

Harrison, the Deaf man I interviewed, also recounted an experience in which he had difficulty communicating with hospital staff,

One time I was waiting in the ER and many different doctors were coming back and forth to talk to me. Many were friendly and were just checking in with me. But I remember one came up with his charts and things and was looking down at them while talking to me. I was like [sighs] hello! I am Deaf. Look at me, speak and write. And this doctor was like, “Oh... [demonstrating a panicked look on his face] I will be right back...” And that doctor never came back (7/27/16 interview with Harrison).

Ultimately, Harrison did end up seeing another doctor and receiving care but it was evident that this experience frustrated him. While there are likely extenuating circumstances, this could have been a potentially dangerous situation for him, or for future patients like him, if something similar happened again. All cases should be taken seriously but especially in an emergency room setting.

Daisy, the Deaf-Blind, close-vision woman I interviewed, also had a similar experience in which she struggled to adequately communicate with hospital staff. She told me,

I had another experience in the E.R. where I was throwing up a lot and waited in the waiting room for two hours but they said they had to wait for an interpreter for me. They did not tell me anything. They just expected me to wait. Finally, I got up, went to the desk, and asked, “What’s up?” Then the E.R. doctor finally saw me and called in some medicine for me. I had to go back to the doctor two times for this and it was difficult to get what I needed (7/28/16 interview with Daisy).



Daisy never found out if the hospital staff had qualified Sign Language interpreters available or if they normally relied on VRI. Of course, she would not have been able to use VRI if it were available, since she is Deaf-Blind. The hospital never told her exactly what took so long even when she asked.

In July, 2016, Deaf patients sued a hospital in Seattle, Washington for discriminating against people who are Deaf or hard-of-hearing.²⁵ They accused the hospital of failing to provide effective communication to these patients – a violation of the ADA (Scotch, 1989, Welch, 1995). One plaintiff said she requested an interpreter when she scheduled an appointment, but when she arrived, the receptionist told her that no interpreter had been booked and thus the doctor would not see her. The lawsuit sought

²⁵ For a more detailed account of this see: <http://dralegal.org/press/northwest-hospital-sued-discriminating-deaf-hard-hearing-patients/>.

a court order to develop and implement policies to ensure that qualified Sign Language interpreters and other necessary accommodations are provided for all medical services (www.dralegal.org, 2016).

Such instances have led some Deaf people to seek legal advocates in order to help them in similar situations, or in the aftermath. Carrie, the hard-of-hearing woman I interviewed, told me,

Just so you know, psychologically I deal with anxiety, PTSD [post-traumatic stress disorder] – I have a cognitive disability. I can't deal with conversing with people that don't really believe what I have. It is really frustrating that there are people out there who can't get what they deserve and they deserve the right to be heard by others. This is why I have a legal advocate to help me with that.

Carrie's previous diagnoses of anxiety and PTSD must have made her diagnosis of hearing loss more difficult to deal with at times. As mentioned previously, she struggled at work to get people to accommodate her new needs and they did not believe her because she was still able to speak well. This situation was frustrating enough for her but things only got worse as time went on. Carrie was able to acquire a legal advocate who helped her get through these difficult situations. As such, she was adamant about recommending that other people acquire a legal advocate as well.

Carrie went on to say,

[The legal advocate] really helped me with that. I think anybody with a situation like mine should have a legal advocate with them during any important conversations. I know there are some people out there that are going to have a hard time talking with and trusting the representative but they should really have another person along with them. I think someone like me who has a lot of anxiety, stress, and pressure because of losing their hearing, should definitely have a legal advocate. It is so important (7/1/16 interview with Carrie).

This is an example of many of my participants', and many members of the Deaf Community's strong desire for self-advocacy/activism. Unfortunately, regardless of how helpful a legal advocate can be, this kind of situation is like a catch-22.²⁶ People should not need to acquire a legal advocate in the first place just to ensure adequate communication in a medical setting or to be treated fairly overall. Legal advocates might not always be able to improve situations. If someone acquires a legal advocate who does help them, like Carrie, their situation might be improved but this does not necessarily improve things for others in similar situations. While a step in the right direction, this kind of advocacy is still on a small scale and does not get at the heart of the issue.

Related to my discussion in Chapter Five about systems-challenging praxis, this is an example of systems-*correcting* praxis, in that it is a way of working *within* the system to get needs met, despite power inequalities (Ostrach, 2017, Ostrach & Cheney, 2014). Yet, seeking social and institutional support to challenge inequality reproduced in bureaucratic and medical settings, by having a legal advocate, is simultaneously a form of systems-challenging praxis, in that by having the advocate, a Deaf person is calling attention to the power relationships that require it (Ostrach, 2017, Ostrach & Cheney, 2014). Many marginalized people seeking healthcare engage in both (Ostrach, 2017, Ostrach & Cheney, 2014).

In July, 2016, the Connecticut government severely cut funding for the Deaf and Hard-of-Hearing Interpreting Unit within the Department of Rehabilitation Services,

²⁶ Defined as “a dilemma or difficult circumstance from which there is no escape because of mutually conflicting or dependent conditions (www.merriam-webster.com).

ostensibly to try and combat debt.²⁷ Every member of the 35-person unit laid off with only two weeks' notice. Because of these cuts, protests broke out in Hartford, Connecticut and throughout the country (Keating, 2016). The founder and president of an organization called *We the Deaf People* said,

This is a disturbing development for Deaf people, not only in Connecticut, but throughout the nation. The Americans with Disabilities Act supposedly guarantees that our communication rights be respected. So imagine our feelings of outrage and betrayal when essential services to the Deaf Community are cut by the very government that is supposed to support our rights! We are beyond tired and beyond infuriated when decisions directly affecting Deaf people's quality of life are made without their input. Is [Connecticut] Governor Malloy perhaps unfamiliar with the meaning of the slogan "Nothing about us without us?"²⁸ (www.fox61.com, 2016).

I wrote about this incident in my fieldnotes journal,

Since I am from Connecticut, several people who know about my research and interest in ASL and Deaf Culture shared the article about the budget cuts to my Facebook page. I shared it as well. I am glad to see people I know are recognizing this issue and are even angered by this. But unfortunately, I do not think this will do that much good. There needs to be more direct activism. I wish I was home and could be part of the upcoming protests in Hartford. I told my mom to keep her eyes peeled since she works there. When I met with Margaret at Advocates, Inc. today, I asked her if she had heard about the budget cuts for interpreting services in Hartford. She told me she had and was extremely angered and concerned by it. She told me she knew people who live in Connecticut and wished she could be there to help make a stand. She also said that if anything similar happened in Massachusetts she would be one of the first people to stand up. I said I would like to be right there with her. After my meeting with Margaret, I said a quick hello to Gwendoline. She actually asked me if I had heard about what happened in Connecticut. She remembered we discussed once how we were both from Connecticut so she wanted to know what my thoughts were about the cuts. I told her I was frustrated by them and rather disgusted in our [home state]

²⁷ For more information on this issue see: <http://fox61.com/2016/07/19/protest-held-after-sign-language-interpreters-laid-off-during-budget-cuts/>.

²⁸ This is a slogan used to convey the idea that no policy should be decided without the full and direct participation of members of the group(s) affected by that policy. For more information see: *Nothing about us without us: Disability Oppression and Empowerment* (1998) by James Charlton.

government. She agreed and told me that she was never overly impressed when living in Connecticut, which is part of what brought her to Massachusetts. She said there is a stronger Deaf Community in Massachusetts and that because of this, Massachusetts needs to stand with Connecticut. I could not agree more (fieldnotes 6/30/16).

As the founder of *We the Deaf People* stated, these budget cuts were not only a disturbing development in Connecticut, but throughout the rest of the country as well. Massachusetts also had a similar situation in which the state cut Deaf services funding for the 2017 fiscal year,²⁹ something I became aware of late in my fieldwork and data analysis. The state government allocated \$230,000 less to the Massachusetts Commission for the Deaf and Hard-of-Hearing [MCDHH] than they had the previous fiscal year (Young, 2016). As Gwendoline mentioned to me, there is a bigger and stronger Deaf Community in Massachusetts than in Connecticut (fieldnotes, 6/30/16). Yet funding for MCDHH was still cut. This is troublesome for many Deaf people because they are already struggling to access adequate communication in many healthcare settings. For example, the president of the Massachusetts State Association of the Deaf explained to a reporter,

Several years ago, I had to wait six weeks to get an interpreter at the hospital. I do not know if it was the fault of the Commission [MCDHH, who provide funding for medical interpreters] or the fault of the hospital, I am not sure, but I was left in the middle without an interpreter (Young, 2016).

Also of note in this instance is that Senator Pat Jehlen of Massachusetts commended the Deaf Community for advocating for their rights. She said,

I had no idea these cuts have been so dramatic because they have happened over several years so that this year's cut is on top of many others. I think this is a group

²⁹ For more information see: <http://www.telegram.com/article/20160304/NEWS/160309593>.

of people whose voices have not been heard and I commend you [the Deaf Community] for being organized and articulate this year (Young, 2016).

Recent attacks on medical interpretation services and other accommodations strongly affected Deaf Community members with whom I met. Carrie actually met with Senator Jehlen, quoted above from a news article, and recounted talking with her about difficulties receiving the necessary accommodations. Carrie told me,

Yeah I actually met with Senator Jehlen and I think I impressed her [laughs]. I told her about my situation with work and how I was a claims receiver and how they didn't accommodate me and that they actually let me go. I spouted off how they were actually breaking the law, which was 'Title 2, Section 504' and she was totally impressed that I knew the exact title. She said I was right that the person with a disability has the right to receive accommodations. Senator Jehlen is pretty awesome. I have to get there more often though because I want to keep tabs on what's happening and advocate more. I think they only have like half of the necessary funds, which is really unfortunate. Along with Senator Jehlen, I also met three other senators personally. In this meeting, some senators were sympathizing and some were empathizing, but some of them weren't you know? And that needs to change. Every legislator needs to know that things need to be improved and that we deserve these rights (7/1/16 interview with Carrie).

Once again, Carrie demonstrates her strong resolve and desire to advocate for herself and people in similar situations, as so many members of the Deaf Community did throughout my research. This is yet another example of systems-challenging praxis (Cheney, 2008, Ostrach, 2017, Ostrach & Cheney, 2014, Singer, 1995) – Carrie directly challenged the power structure, demanding that the Deaf Community's needs be acknowledged. Carrie was happy that Senator Jehlen and some of the other senators she met were sympathetic and empathetic to the Deaf Community's situation – because of her own and others' advocacy on their own behalf. However, I could also tell that Carrie was deeply affected by the fact that some senators did not seem overly invested in what she had to say, proving that more advocacy is still needed. These current events reminded the Deaf

Community in the Boston area their healthcare access, medical interpretation, and other accommodation needs are a legitimate concern – and have never been a more serious concern than in the current volatile political climate.

Many Deaf Community members have serious concerns about the current Trump administration. Trump did not always provide Sign Language interpreters at his rallies so Deaf people could not always be included or even aware of what he said on the campaign trail (Melaka, 2016). Trump came under fire early in his campaign, in the fall of 2015 when he mocked a reporter with arthrogryposis – a chronic condition that impairs the movement and control of his limbs (CNN, 2015). Many people with disabilities and disability rights advocates were/are appalled that this alone was not enough to end his campaign run. As he got closer to actually achieving the presidency, he outwardly called Oscar-winning Deaf actress and outspoken Deaf activist, Marlee Matlin, “retarded” (Almendrala, 2016). Matlin actually appeared on Trump’s well-known television show, *The Celebrity Apprentice*, back in 2011. In October, 2016, *The Daily Beast* reported that Trump repeatedly called her “retarded,” a derogatory term in itself, and made demeaning sexual comments toward her on the show. Trump mocked the sound of her voice and treated her as if she were intellectually disabled (Almendrala, 2016). Matlin responded to this and commented on the election as a whole on October 14, 2016,

Recent media reports have circulated that Donald Trump allegedly referred to me as “retarded.” This term is abhorrent and should never be used. The fact that we are talking about this during a very important moment in American history has upset me deeply. I am Deaf. There are millions of Deaf and hard-of-hearing people like me, in the United States and around the world who face discrimination and misunderstanding like this on a daily basis. It is unacceptable. So, what’s my response? It’s not about insults or talking each other down. As a person who is

Deaf, as a woman, as a mom, as a wife, as an actor; I have a voice. And I'm using that voice to make myself heard, and vote (www.twitter.com/marleematlin, 2016).

Nyle DiMarco, a famous Deaf model, actor, and activist, responded on Twitter to what Trump said about Matlin. He wrote, "Trump called Deaf Marlee Matlin "Retarded"... That means I'm also retarded, along with 70 million Deaf people worldwide?" (Almendrala, 2016).

After Trump was officially named the winner of the presidency under the Electoral College vote, Deaf and disabled people, as well as advocates, voiced concerns about a potentially weaker ADA under the Trump presidency (Nović, 2016). In the Frontline documentary, *The Choice*, Trump biographer Michael D'Antonio said that Trump believes his family's success is genetic. He said,

The family subscribes to a racehorse theory of human development. They believe that there are superior people and that if you put together the genes of a superior woman and a superior man, you get superior offspring (Fang, 2016).

The perspective that particular genes make better people is an echo of eugenics, the pseudoscientific philosophy that aims to "improve the human race by breeding out supposedly bad characteristics" (Nović, 2016). Infamously preached by the Nazis and supported by famous Americans from Theodore and Eleanor Roosevelt to Margaret Sanger, founder of Planned Parenthood (Akhter, 1992), eugenics was a driving force behind many atrocities against several minority groups of people, including Deaf people. As mentioned in the Background Chapter, in 1884, Alexander Graham Bell, renowned inventor, proposed a ban on Sign Language and Deaf intermarriage as a way to "breed-out deafness" and eradicate a *variety* of humanity that he saw as "defective" (Cleall, 2015).

Considering Trump's mocking of a disabled reporter and thinking some people are inherently superior to others, Deaf people are one of many groups concerned with their future survival and rights. As Sara Nović, a Deaf woman and the author of an article titled, *Why the Deaf Community Fears President Trump* (2016) said, "We can't know for sure what Trump will do, but if he does what he says he wants to do, it will hurt us. His words already have." Trump's efforts to repeal the Affordable Care Act [ACA], or parts of it, will result in many Deaf people losing healthcare coverage because their "condition" [deafness] could be classified as "preexisting" (Nović, 2016). Those who depend on Medicaid for insurance or to cover medical devices not covered by other insurance are also concerned. Some Deaf people have voiced concerns about the possibility for mandatory cochlear implantation, the closing of Deaf schools, and forbidding the use of ASL (Nović, 2016), as modern forms of eugenics and threats to Deaf Community civil rights and visibility.

"The Ability to Speak does not make you Intelligent"³⁰

Many hearing perspectives regard Deaf people as intellectually inadequate compared to their hearing counterparts. Some people still follow the teachings of people like Alexander Graham Bell in that they think that Deaf schools should not exist and students should be mainstreamed³¹ and not use ASL in order to become more adapted to the dominant hearing society. Similarly, hearing people are often shocked to learn that

³⁰ *Star Wars: Episode 1 - The Phantom Menace*. 20th Century Fox; Lucasfilm: George Lucas, 1999. DVD. Said by Qui-Gon Jinn to Jar Binks.

³¹ In the context of education, mainstreaming is the process of educating students with special needs in regular classes during specific times based on their skills. www.lifeprint.com.

many Deaf people actually do not want to utilize cochlear implants and that they do not work as well as many hearing people believe. Spoken language is equated with intelligence and competence; Sign Language is equated with stupidity and incompetence. There are around 130 different Sign Languages worldwide, all fully developed languages with their own lexicon and structure (Buckley, 2016). Why is there such a negative stigma associated with signed languages? Other spoken languages are regarded as *real* languages, but signed languages are often not recognized as *official* languages. Why?

Most Deaf people I interviewed and met during my fieldwork believe that a goal of the dominant hearing society is to mainstream Deaf people into hearing society, which means, most importantly, learning spoken language – especially for children. Gwendoline mentioned to me that many Deaf children no longer attend Deaf schools, do not have Deaf friends, and are not learning ASL “like they should” (7/28/16 interview with Gwendoline). Lower attendance rates at Deaf schools means there is now a legitimate concern that Deaf schools that use and teach ASL will close and become nothing more than a memory. However, as seen by my participants, the mainstreaming style of education did not work well when it was introduced and it still does not work well. Harrison told me,

My brother and I first learned cued speech.³² We did go to a Deaf school but we were taught using oralist³³ techniques. Everything was auditory. This was until after eighth grade. We were mainstreamed through high school. We had Sign Language interpreters and we began to learn ASL through them while we were in hearing classrooms (7/27/16 interview with Harrison).

³² A type of sign language that uses hand movements combined with mouth shapes to communicate. <http://www.cuedspeech.org/cued-speech-definition.php>

³³ The system of teaching Deaf people to communicate by the use speech and lip-reading rather than sign language. www.dictionary.com

Harrison and his brother had each other in school, which meant that they had at least one person to talk to, unlike so many Deaf children who are mainstreamed (Buckley, 2016, Doyle & Dye, 2002, Niparko, 2003, Staten, 2011). They were denied the use of ASL until high school, something that should be a fundamental right for all Deaf children the moment they are born (Buckley, 2016, Staten, 2011). Oral education systems often do not allow the use of Sign Language or access to the Deaf Community (Doyle & Dye, 2002, Staten, 2011).

Daisy told me,

I was mainstreamed through high school. I did not have much support. This was during the 1960s so it was a different time. So I sat in the front but I was still unclear. Sometimes the teacher would ask another student to help me but that only did so much. I bluffed my way through school [laughs] (7/28/16 interview with Daisy).

Even though she laughed while telling me this, Daisy clearly felt it was wrong that she had to bluff her way through school. As she said, she did not have much support once she was mainstreamed, which left her feeling isolated. Education is often the stepping-stone to the rest of someone's life. If they feel isolated in school, they might continue to feel isolated once they finish school because they do not know how to connect with people like them.

Moreover, medical education often does not acknowledge Deaf Culture and stresses medical interventions primarily as a way to "cure" deafness. As such, deaf people who are not exposed to Deaf Culture can internalize a sense of inadequacy (Buckley, 2016, Higgins, 2016, Lane, 2011, Mellet, 2016). Gwendoline told me,

I first learned ASL when I was five. Before that, it was speech and lip-reading. I learned gestures first. I went to a Deaf school but they did not teach sign, they

taught with oral education. I went to this school for fifteen years. I first learned ASL from the students there. I would watch my classmates sign and think ‘Yes! I want to learn that!’ Some of the first signs I learned were mother, father, sister, and brother. A friend taught me the ABCs³⁴. My friends and I would sign under the tables. We had to be secretive about it. Oral education is bad. ASL is good. I was always in trouble in school [laughs]. I am stubborn and did not like what they taught so I rebelled (7/28/16 interview with Gwendoline).

Similar to Harrison, Gwendoline was taught through oral education methods for much of her childhood until high school. She made it obvious that she does not agree with oral education – she clearly said it is bad, while ASL is good, echoing what many at my fieldsite expressed and what is in much of the literature about the attitudes of Deaf Community members (Buckley, 2016, Higgins, 2016, Horejes, 2012, Mellet, 2016, Staten, 2011). While it is not usually a good thing to get in trouble a lot in school, I could tell Gwendoline was proud of having done so, as part of her advocacy for Deaf education and visibility. Gwendoline’s strong resolve to advocate for herself and her Community started when she was a child. She knew what she was taught was wrong so she fought back in her own way, something she still does today – another form of a systems-challenging praxis by a marginalized member of society (Cheyney, 2008, Ostrach, 2017, Ostrach & Cheyney, 2014, Singer, 1995a).

A commonality among these conversations is the dislike and suspicion of oral education and not being allowed to sign, resulting in the isolation of Deaf students. Harrison had his brother with him while they were mainstreamed, but Daisy was alone and felt isolated because she could not relate to her peers. Gwendoline related to her peers in that they were forbidden from signing but they did it anyway. Daisy said, “Yeah,

³⁴ Picture representations of these signs are included in the Appendix B.

kids can learn speech and lip-reading but it is really difficult and kids are denied a fundamental right of being Deaf: ASL” (7/28/16 interview with Daisy).

Educators have debated the pros and cons of Deaf schools. Fredrick Staten (2011) wrote his dissertation about what brought Deaf students to Deaf schools and whether or not it influenced their sense of Deaf identity. One of his participants said,

I am really comfortable obviously when everyone is signing. I feel very confident with that. I am very proud with Sign Language and the visual language that it is. It is hard when people are talking and I am unable to be part of the conversation (Staten, 2011: 61-62).

There were several similar stories of people feeling completely comfortable at Deaf schools because they are surrounded by people like them. As previously stated, many mainstreamed students often feel isolated.

Many Deaf and hard-of-hearing children perceive themselves as different because they wear hearing aids, cochlear implants, and/or FM systems and may have difficulty communicating with others (Doyle and Dye, 2002: 15).

This quote comes from “Mainstreaming the student who is Deaf or Hard-of-Hearing: A Guide for Professionals, Teachers, and Parents,” (2002), a manual about how best to mainstream deaf children, and was in the section about how to deal with bullying. The authors recognize that bullying will likely occur due to the child’s “difference,” yet it is still seen as a better alternative than sending children to Deaf schools with their peers.

One of the best examples and arguments of why Deaf schools have a more positive influence on Deaf people comes from Gallaudet University, the only American university devoted solely to Deaf and hard-of-hearing people, where all staff and students are required to know and use ASL. The university opened in 1864 and yet it did not have a Deaf president until 1988 during the Gallaudet Revolution for a “Deaf president

now!”³⁵ The school continues to be revolutionary in that just last year they appointed the first female president in its 152-year history, Roberta Cordano. In an article about President Cordano, Parth Shah wrote,

ASL flourishes at Gallaudet. Students chat with their peers in the lunchroom and as they walk through the hallways to class, carrying out their conversations with their hands and facial expressions instead of spoken words. Gallaudet feels like any other college campus, just quieter (2017).

Along with interviewing President Cordano, Shah also met with several students and discussed their experiences at Gallaudet. A third-year student told Shah she chose Gallaudet because she did not have to rely on someone else to translate for her. She did not enjoy having an interpreter in elementary school. She told Shah,

The interpreter did not go with me to lunch. I was completely left out of any kind of conversation. Here, not only can I have my own conversations at lunch, but I can just look over to a table and see what other people are talking about because everyone is using the same language (2017).

Ultimately, the biggest positives of Deaf children attending Deaf schools are: there is no communication barrier, it is easier to relate to their peers, there is a more individualized approach to deafness, and they have Deaf adult role models. In opposition, the argued cons of sending Deaf children to Deaf schools are: limited exposure to the hearing world, they will not receive the same education as their hearing counterparts, their personal growth may be stalled, and their communication could be stunted (www.healthresearchfunding.org, 2015). These cons are all based around the idea that it is better to be hearing and one can only be an integral part of society, dominated by hearing people, if they can utilize spoken language. One “solution” some people see to

³⁵ For more information see: <http://www.gallaudet.edu/dpn-home.html>.

make everybody understand and use spoken language is through cochlear implantation.

Many hearing people believe that Deaf people should be eager to acquire cochlear implants³⁶ because they are seen as magical “cure-alls.” As stated previously, the focus is on hearing spoken language and learning how to communicate in that way. Although it has been proven that cochlear implants do not restore *normal* hearing (Mauldin, 2012, Mellet, 2016, Niparko, 2003, Tucker, 1998), it is as if hearing anything resembling sound is deemed better than being Deaf.

Since there are more hearing people than Deaf people, hearing perspectives dominate society. Deaf people are seen to have diverged from societal norms and come to be seen as deviant. Social deviance is any behavior that disrupts social norms and often garners disapproval from the majority of society. Social norms vary considerably across cultural groups and often develop over time (Akers, 2009). Deaf people regard their deafness as normal and ideal for themselves; hearing people regard the sensory ability to hear as normal and ideal for all.

In terms of cochlear implants, the risks of surgical implantation³⁷ and impending social isolation from the Deaf Community are ignored in order to get children to achieve some sort of spoken language. Gerard O'Donoghue, a member of The Hunterian Society, a group of physicians and dentists based in London, wrote,

³⁶ My discussion on cochlear implants focuses on what members of the Deaf Community have said about cochlear implants in comparison to what the existing literature says. For further information on CODAs' perceptions of cochlear implants, see the work of medical anthropologist Erin Mellet (2016): “Cochlear Implants and CODAs: The Impact of Technology on a Community.”

³⁷ See the FDA's list of the risks and benefits of cochlear implantation:
<http://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/ImplantsandProsthetics/CochlearImplants/ucm062843.htm>.

Profound deafness in early childhood has major consequences for the child, its family and society. Inadequate sensory input during these periods leads to lifelong linguistic and communicative deficits. Until the advent of cochlear implantation, the outlook for children who were too deaf to hear speech through a hearing aid was less promising and they often failed to develop intelligible spoken language (1999).

This discussion focuses on the supposed consequences and negatives of being Deaf without any mention of the Community and the possible struggles of living with cochlear implants. O'Donoghue regards cochlear implants as the solution to children being a burden on society due to their inability to hear. He does not see any positives to being Deaf and thinks cochlear implants are the answer.

Deaf people do not see cochlear implants as a magical cure-all because they do not make things easier for Deaf people. In fact, many Deaf people and hearing people associated with the Deaf Community see cochlear implants as a way of “mutilating” Deaf people (Cleall, 2015: 14, Mellett, 2016). Anybody who spends time on the internet has likely seen one of those videos where somebody “miraculously” hears for the first time. Rife with emotion, these videos reinforce and reify the essentialist view that cochlear implants magically restore *normal* hearing, and not just some sound. They also do not acknowledge what sort of background an individual might have in terms of whether they were born deaf or not, born to hearing or Deaf parents, and other criteria that might influence perspectives toward deafness. Laura Mauldin, an assistant professor of human development and family studies at the University of Connecticut wrote, “You see those videos on YouTube of people having their implant turned on and hearing for the first time and it is supposedly this beautiful thing. But the implant is not the treatment” (Buckley, 2016).

Mauldin's statement that the implant is not the treatment argues that cochlear implants are not magical devices that restore normal hearing. The implants may be able to give a person some sense of sound, but that is not the treatment. Many people do not realize that the individual, often a child, is then required to undergo regimented audist³⁸ education where they are required to learn to speak and lip-read, while Sign Language is often forbidden.

While it is common for emotional videos of people "hearing for the first time" through cochlear implants to circulate around the internet, these videos do not mention the fact that they do not work perfectly. The videos that do touch on this sort of information are much harder to find. For example, there is a video that represents a Hearing Loss and Prostheses Simulator (HeLPS), which is a software tool designed for audiologists to help their clients and clients' family to make informed hearing-health choices. It provides examples of various degrees of hearing loss and how things like background noise can have a big impact on someone with hearing loss. Of particular importance for this discussion is from around 1:08-1:38 when it provides examples of what *sound* is like through a cochlear implant compared to *normal* hearing. In these examples of *The Gettysburg Address* and *Eine kleine Nachtmusik*, by Wolfgang Amadeus Mozart, the simulation of what they would sound like with a cochlear implant is robotic, rather unpleasant, and it is difficult to understand what is playing. It is clear that cochlear

³⁸ Stressed by Alexander Graham Bell, the idea that life without hearing is futile and miserable so the Deaf should be taught to speak, lip-read, and be forbidden from signing.
<http://www.lifeprint.com/asl101/topics/audism.htm>

implants do not restore *normal* hearing as many believe they do.³⁹

As a common controversial topic for Deaf people, I knew cochlear implants would come up during my interviews. In all of my interviews (n=4), I asked my participants if they were aware of the biomedical perspective toward deafness that perceives it as a loss, and if so, how it made them feel. In my interview with Daisy, the close-vision, Deaf-Blind woman, she explicitly told me that she does not like how the medical community views deafness, especially in terms of stressing the use of cochlear implants. She told me,

Medical people try to force young children into surgery and I do not like that at all. They should be allowed to choose for themselves when they are old enough. Cochlear implants can be good for some people, especially those with retinitis pigmentosa (RP).⁴⁰ If people have RP and are Deaf or hard-of-hearing, cochlear implants can help them with that, but I do not like them, and definitely not when young children – even *babies* are forced to use them (7/28/16 interview with Daisy).

Significantly, *I* did not mention cochlear implants; I only asked if she was aware of the biomedical perspective of deafness. Daisy clearly equates cochlear implants with the biomedical perspective. Later in our interview when I more specifically did ask her about cochlear implants, she told me,

When I grew up, there were hearing aids but the technology was not as good as it is today and cochlear implants did not become available for a while. I did not use any of that stuff. I do not like them. They did not help me anyway. My parents and doctor always wanted me to have them but they did not help me hear, it was just a lot of useless noise. So I said I was not going to use them. They do not work for everyone and some people just really do not like them. Nobody should be forced into using them (7/28/16 interview with Daisy).

³⁹ The link to this video is: <https://www.youtube.com/watch?v=-OfER1t2g-Y>.

⁴⁰ A chronic hereditary eye disease characterized by black pigmentation and gradual degeneration of the retina. This inherited disease causes a slow loss of vision, beginning with decreased night vision and loss of peripheral vision, eventually resulting in blindness (Hartong, 2006).

Daisy lost her hearing at six years old. Her parents and doctors always wanted her to use hearing aids regardless of her arguing against them. It was obvious that she was frustrated in her own experience and does not think that cochlear implants should be forced on anybody.

Carrie, the hard-of-hearing woman I interviewed said,

There are some people who do want to change that [their deafness] and there are some people who don't. There are some people that are against it. They don't want to change. It kind of depends on their psyche and it kind of depends on how they feel. The parents – they're the ones that are providing it for them. They're the ones who are saying 'OK, let's do this. I want my kid to hear and be normal.' If it was my child, I'd rather wait until they're grown up and can understand and see – like when they're 18 – and see if they want to do it. Because there are some kids that don't and some kids that do. You know, some of the grown-ups don't want to change at all. They accept for who they are and accept for what they want to do as a human being. Look at me, I'm accepting of who I am as a person who has hearing loss. I'm OK with that now (7/1/16 interview with Carrie).

Unlike my three other interview participants who were born deaf or lost their hearing in early childhood, Carrie is hard-of-hearing, which means she is in the process of losing her hearing, a sense she has known and relied on her whole life. As mentioned in the Background Chapter, many hard-of-hearing or late-deafened people might struggle with coming to terms with their hearing loss. Regardless, Carrie argues that it should be a personal choice for someone to receive a cochlear implant or not, and that people should be accepted no matter what they choose.

An individual's background can drastically influence their perceptions of cochlear implants and the Deaf Community. The work of medical anthropologist Erin Mellett (2016) focused on the perspectives of children of Deaf adults (CODAs) of cochlear implants. As children of Deaf parents, CODAs grow up simultaneously inhabiting both

the Deaf and hearing worlds. Their unique position and loyalties between the Deaf and hearing worlds makes them important to the cochlear implant debate. Mellett discovered that cochlear implants influence CODAs' identity and sense of belonging, and CODAs identity and positionality influences their attitudes toward conceptualizations of cochlear implants. CODAs can also be powerful activists for the cultural-linguistic view toward deafness and advocates for the fact that there is nothing wrong with their parents, or any Deaf people (2016). However, while offering a unique perspective, CODAs still cannot know what it is truly like to be Deaf. Deaf people's perceptions of cochlear implants are crucial to discussions about healthcare because cochlear implants are such a biomedical *solution* or *cure* to deafness. Deaf people are more personally affected by the biomedical push for cochlear implants. Participants stressed a dislike toward cochlear implants, especially how they are often used among young children. Medical professionals likely are not aware of Deaf Culture so it is not usually taken into consideration when deciding whether to implant.

About ninety-percent of deaf children are born to hearing parents (Fjord, 1996, Mitchell, 2004, Senghas, 2002) so hearing ideals are often thrust upon them. It makes sense that a parent would want their child to be like them (Anstey, 2002), but in these cases the parents also often feel as though their child is missing something, so they try to find a solution. Influenced by the dominant biomedical perspective, which sees deafness as a deficit and seeks medical interventions, the parents ask a physician what the next step should be. Few physicians are taught about the Deaf Community and lack cultural competency about Deaf Culture, so many will recommend things like cochlear implants

with the hopes of acclimating the child to the dominant *ideal* hearing society (Fjord, 1996, Mitchell, 2004, Senghas, 2002). The issue with this is that the child does not have a choice. Regardless of whether the parents believe they are truly doing what is best for their child, many Deaf people believe that it is wrong to implant children who cannot make the choice for themselves.

Gwendoline, the fully blind, Deaf-Blind woman I interviewed told me,

I always complain about cochlear implants. Especially when they are used on babies and young children. No. If someone grows up and makes the decision themselves then fine. But pressure from parents and doctors deciding something so big for their kids is wrong. I do not think it is a good idea for babies. I mean it is a surgery – it is crazy! It makes me sad. It makes me sad because I worry about the future of the Deaf Community. I wonder where it will be in the future. I think Deaf Culture will diminish. I am old. I am 60. So I do not think I will see it. So many kids are not sent to Deaf schools and do not have Deaf friends and do not learn ASL like they should. They might not even be aware of Deaf Culture and our Community. It is sad and it makes me worry about the future. The Community can be such a positive influence and have such a big impact on a Deaf person (7/28/16 interview with Gwendoline).

Gwendoline was born Deaf so it was all she ever knew. In her sixty years, she has witnessed many developments throughout the Deaf Community and she is proud of the Community and her Deaf Culture. She is worried that cochlear implants will force Deaf Culture to diminish if so many young children continue to be implanted in the future. The fear that her culture will be destroyed clearly shows her animosity toward the way cochlear implants are presented and utilized in young children who are unaware of Deaf Culture and the Community.

As Mellet (2016) also discovered in her earlier research with CODAs (adults), a common theme throughout these three conversations is that cochlear implants should not be used on young children who cannot make the decision for themselves, and the

importance of not forcing them on someone. The advocacy for Deaf peoples' right to choose whether they want cochlear implants, as well as their overall rights to ASL and Deaf Culture, is a concise application of the cultural-linguistic perspective toward deafness. The key feature to understand, according to my participants and in keeping with the cultural-linguistic view rather than the biomedical view, is that they do not work as well as many people think, and not everybody wants them. Countless people are perfectly happy being Deaf and using ASL and do not want to be forced into something else. To quote Irma Munoz-Baell again, "Let the Deaf be Deaf" (2000).

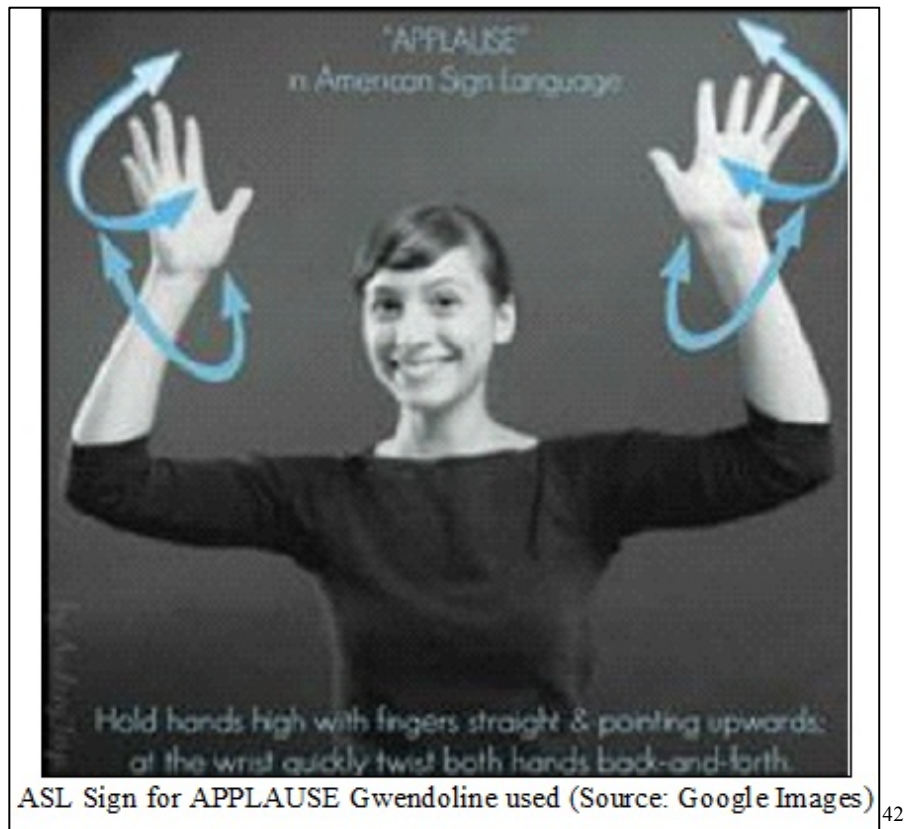
Conclusion

Hearing people set limitations, either purposefully or not, which hinders Deaf people from reaching their full potential. Historical oppression still resonates throughout the Deaf Community today and is more worrisome now under the Trump administration because of his rhetoric against people with differences. Participants recognize that there has never been a more dire need for activism and advocacy, both from within the Deaf Community and from outside. They are continuously trying to prove that being Deaf and utilizing ASL does not make a Deaf person intellectually inferior to a hearing person. After all, as Janet DesGeorges said, "A communication difference is not the same as a communication disability" (2003: 90).

CONCLUSION

“NOTHING ABOUT US WITHOUT US”⁴¹

People just need to realize that we are just different. That is it. Who says that is a bad thing? Embrace the differences! I think that is a starting point to making the world a happier and better place all around. Everyone is different and I love that! I would not want to live in a world where everybody is exactly the same. Boring! [laughs]. It is well beyond the time for acceptance for everyone. And we need more activism. Which I think you have seen by now that I am quite passionate about [laughs]. And I can tell you are too so yay! [laughs and cheers] One step forward at a time (7/27/16 interview with Gwendoline)



⁴¹ This is a slogan used to convey the idea that no policy should be decided without the full and direct participation of members of the group(s) affected by that policy. For more information see: *Nothing about us without us: Disability Oppression and Empowerment* (1998) by James Charlton.

⁴² While Deaf people do clap in the same way as hearing people, they also have their own sign for applause where they raise their hands over their head and twist them back and forth.

As I have demonstrated through this thesis, the dominant biomedical perspective of deafness has negatively affected the Deaf Community. This perspective stems from a history of historical oppression, which, in turn, has led to misunderstandings about Deaf Culture, especially on the part of medical professionals, and a lack of adequate services and protections. Ultimately, the overall goal of this study was to explore a research question and find out what participants experienced and thought about it. A subsequent goal of this research has been to stress the need for activism on the part of both Deaf and hearing people. As seen by what Gwendoline said above, activism is necessary in order to improve the lives of Deaf people.

People can feel as though communication differences means that Deaf people are disabled and intellectually inferior to hearing people. Different views of deafness, unequal power relationships, and the lack of understanding about the Deaf Community, have led the dominant hearing society to believe that they know what is best for Deaf people. As such, many Deaf people have become strong advocates for themselves and others in order to provide people with a better understanding of their Community.

As mentioned in the Background Chapter, Deaf people have faced oppression throughout history. The different influences of two prominent figures largely affected the Deaf Community today. Thomas Gallaudet had a more positive influence on the foundation of the Deaf Community with Deaf education, and was instrumental in creating the first Deaf school in America. Alexander Graham Bell was also influential in his teachings of Deaf people, but his education curriculum focused on oral education – to make Deaf students use spoken language and lip-reading. Current advocates of the Deaf

Community more closely follow the example of Gallaudet; many hearing people and medical professionals more closely follow the example of Bell.

The influence of people like Bell has exacerbated communication barriers between Deaf and hearing people, which has carried over into healthcare settings. As argued in Chapter Four, video remote interpreting (VRI) is a troublesome technological symbol of hearing people's assumptions that they know what is best for Deaf people, and a practical obstacle to appropriate healthcare. Another obstacle to adequate healthcare for Deaf people is health insurance coverage and communication with insurers. If Deaf people struggle to communicate with their insurance provider, and/or the provider has no knowledge about Deaf Culture, the Deaf patient might struggle to obtain the necessary coverage they need for a procedure. The access to adequate communication in healthcare and insurance settings should be regulated and enforced by the Americans with Disabilities Act (ADA) but as discussed in Chapter Five, the ADA fails Deaf people when they need it most.

Due to the oppression Deaf people have faced throughout history, they fight back against the disability label, and for better accommodations. However, they recognize that there are some things they do need access to, such as interpreters, in order to have equal opportunities as their hearing counterparts, so they need to rely on the ADA to a certain extent. The varying perspectives of deafness show that disability is socially constructed, which garners an element of control over the 'disabled' body. Deaf people do not want to be seen as disabled but they cannot receive the necessary accommodations in order to survive in the larger hearing society without outwardly labeling themselves as disabled.

Therefore, applying theoretical concepts from critical medical anthropology, I have argued that many Deaf people engage in self-advocacy, picking and choosing which services they accept or reject, and what they fight for within and outside of existing systems.

The dependency duet⁴³ within which Deaf and hearing people, and societies are locked, and the limitations of the ADA, have an impact on legislation. Hearing perspectives dominate society so hearing people make laws regarding the lives of Deaf people that have broad implications for services and coverage. Current events such as budget cuts throughout the country have negatively affected the lives of Deaf people. Even more troublesome for many Deaf Community members is the fear of what the future might hold for them under the Donald Trump presidency.

According to my participants and their wider networks, there has never been a more dire need for activism, both from within and outside the Deaf Community. The biggest element of activism must come from Deaf people's inclusion in any sort of discussion that might have an impact on their lives – 'nothing about them, without them.' No regulations should be made regarding the lives of Deaf people without consulting with Deaf people themselves. As such, the recommendations of Deaf people themselves need to be followed. I knew this would be an important element of future activism and improvement in the lives of Deaf people, so I made sure to specifically ask my participants what their recommendations were.

⁴³ As mentioned in chapter 5 and used by Harlan Lane (1992), hearing professionals and Deaf people can enter a dependency duet mandated by law, as when a Deaf child is sent to school. In other cases, the dependency duet is mandated by circumstances, for example, when a Deaf college student utilizes an interpreter (75).

Harrison, the Deaf man I interviewed, focused on communication. He told me,

Doctors must allow for enough time for an appointment with a Deaf patient. Most doctor visits are much too brief to begin with but they are especially brief for Deaf patients because communication often takes a lot longer. So there is not enough time to get to the actual issue. This can leave the patient feeling as though they do not know what is wrong with them because the doctor just quickly moves on to their next patient. I know I have certainly felt like that numerous times and I know many people who have felt the same. Most importantly, doctors need to allow for more time in appointments with Deaf patients in order to adequately communicate with them (7/27/16 interview with Harrison).

Harrison recognizes that not all healthcare is perfect – there can be improvements made for all patients, even those who are not Deaf. However, he also recognizes that there are added obstacles for Deaf patients because of communication issues. Communication issues can be especially problematic in a healthcare setting because of potentially life-threatening situations. As such, medical professionals need to allocate enough time in appointments with Deaf patients to make sure they understand exactly what is going on.

Harrison went on to say,

Every patient is different. That means doctors should have an open mind. They need to find a way to communicate depending on the patient's preference. Whether it be through an interpreter, typing or writing, spoken language and lip-reading... Whatever. They should listen to the preference of their patient and do their very best to accommodate them. And if they do use an interpreter, they have to be sure to find the right place to find a qualified interpreter. That is key to adequate communication. What is the point of using an interpreter if they are not qualified? (7/27/16 interview with Harrison).

Harrison has faced these obstacles before, along with other participants, so he has put thought into possible solutions that could help remedy these obstacles. He has had doctors and nurses not listen to his request to communicate in the way he prefers – through typing on his laptop. This is frustrating for him and he thinks a patient's communication preference should never be ignored. As discussed in Chapter Four, many

Deaf people have experienced working with an unqualified interpreter. As such, Harrison was adamant about mentioning that if an interpreter is used in a healthcare setting, they absolutely must be qualified to do so.

Harrison went on to discuss his “ideal world” of healthcare for Deaf people. He told me,

Services need to be made more accessible for all. Ideally, it should not matter what kind of communication you use. The best solution would be for more healthcare professionals to know and use Sign Language and be more Deaf friendly. There needs to be more education about Deaf Culture during medical training. But if a doctor does not know ASL, then they need to have qualified interpreters readily available, especially for emergency situations. In this time, everything is available online so doctors’ offices should make vlogs in ASL to make sure Deaf people can learn more about well-being, health, and knowledge of nutrition (7/27/16 interview with Harrison).

Harrison is also adamant about spreading the use of ASL. He thinks learning ASL and Deaf cultural competency should be integral components of medical education. Otherwise, it is as if healthcare providers are disregarding an entire group of people. Again, he brought up the need for more qualified interpreters, especially since there is so little education regarding Deaf Culture in most medical education.

Daisy, the close-vision, Deaf-Blind woman I interviewed, told me some of her recommendations,

I want doctors to know that they need to have patience. They need to find a way to communicate clearly with us. Doctors need to allow for more time in an appointment with Deaf and Deaf-Blind patients. Most importantly, doctors need to learn more about Deaf and Deaf-Blind people, our Culture, and our various communication methods. They need to be willing to communicate with us in the way that works best for us (7/28/16 interview).

Similar to Harrison, Daisy focused on doctors allowing for more time in appointments with Deaf patients and having more patience when working with them. Daisy has had

experiences where doctors have become flustered and frustrated with her for not understanding something, or needing specific accommodations, such as an interpreter. She also mentions the need for doctors to become aware of different communication methods and be willing to try different things in order to accommodate the Deaf patient's communication preference.

Daisy went on to say,

I think the most important solution to improve healthcare situations is to have good interpreters. They have to be qualified! We [Deaf-Blind people] especially need more interpreters that are qualified to work with Deaf-Blind patients. Also, interpreters need to receive more training in healthcare settings and in interpreting medical language. They definitely need to have an RID [Registry of Interpreters for the Deaf] license. I have heard that many places accept and hire interpreters before they are qualified and officially licensed through the Registry. And this really is not acceptable, especially in healthcare. I have had too many experiences with unqualified interpreters and it is incredibly frustrating (7/28/16 interview).

A key element of Daisy's recommendations was about healthcare settings using qualified interpreters. As she said, she has had too many frustrating experiences with unqualified interpreters and she clearly does not want to go through another situation with one again, and does not want another Deaf person to have to go through it either. Daisy also feels as though there is not enough medical training provided for interpreters. Medical language is specific and can be difficult for the average individual who speaks English to understand, but it can be especially difficult to understand when there is a language barrier and something might not necessarily translate well.

Gwendoline, the fully blind, Deaf-Blind woman I interviewed, recommended,

To me, the biggest thing is for everyone to just be patient with us and have an open mind to different forms of communication. Do not pity us. There is nothing to pity. Let Deaf people live their lives the way they want to. And if that means a

person does *not* want cochlear implants, fine. If that means a person does want cochlear implants, fine. But it should be *that* person's decision. Nobody else's (7/28/16 interview).

Similar to Harrison and Daisy, Gwendoline thinks there should be more education about and training in Deaf Culture in medical education. The pity many hearing people have toward Deaf people stems from a lack of awareness about Deaf Culture and the Community. Gwendoline and other members of the Deaf Community do not want that pity because they do not see anything wrong with themselves. As Gwendoline said, they just want to be able to live their lives the way they want to.

Carrie, the hard-of-hearing woman I interviewed, told me,

The ADA needs to stay in place and really needs to be upheld. People have to follow it. I mean I do not know how it can be regulated but its implementation is of the utmost importance. I am a human being that deserves the rights that the ADA provides for me and others like me. Obviously, it needs improvement but so do a lot of other things. Things need to develop over time as things change so I think the improvement will come in time as long as people like us continue to fight for it.

As a hard-of-hearing woman coming to terms with her hearing loss, Carrie's recommendations focused more on being able to adjust more easily to such a lifestyle. She thinks that the ADA is not being upheld everywhere as it should be and that it does not help her as much as it should. She thinks it should be improved because the rights it claims to provide are basic human rights that she and other people like her deserve.

A commonality among all of these conversations was that there needs to be more education about Deaf Culture and ASL provided in medical schools. As described in the Background Chapter, most physicians are not trying to discriminate against Deaf people. The problem is that they do not have adequate knowledge about Deaf Culture because

they are rarely, if ever, trained in Deaf cultural competency in their medical education. Another similarity among what my participants recommended is the need for more qualified interpreters, as well as more interpreter training in healthcare settings, to more properly interpret medical language. Along with this, is the need for doctors to allow more time in appointments with Deaf people because the present communication obstacles make it difficult for many Deaf people to understand what the doctor is trying to explain to them. A short appointment rushes things along and only makes things worse.

Since this study specifically highlights the detailed perspectives of four people involved with a Deaf advocacy organization, their views cannot be generalized across the whole Deaf Community. While there are similarities among other members of the Deaf Community, there are differences as well. While this study would be ethnographically stronger with more interview participants, the experiences of my four participants cannot be discredited, as they are underscored by the perspectives of many others with whom I interacted during many months of participant observation and at community events. Their experiences are real and their frustrations are legitimate. Their voices deserve to be heard; their signs deserve to be seen. Ultimately, this study can serve as a stepping-stone for further research. Any research regarding the health of Deaf people, or any other aspect of their lives, must be fully inclusive for Deaf people. Decisions cannot be made regarding their lives without their input, and their lives certainly cannot be improved without listening to their qualms and concerns by seeing what they have to sign.

APPENDIX A – DEFINITIONS

Three perspectives of deafness:

- **The Biomedical View:** Sees deafness as a deficit and the pathological absence of hearing. Deaf people are commonly regarded as disabled. It is called the biomedical model because medical professionals often recommend medical interventions, such as cochlear implants (DeVault, 2014, Fjord, 1996, Lentz, 2014, Senghas, 2002).
- **The Social View:** Focuses on individuals with disabilities gaining access into general society. This view provides advantages for Deaf people on certain levels but it does not address the central issues related to Deaf Culture and Sign Language. The view's ultimate goal of mainstreaming people into general society unwittingly isolates Deaf people (DeVault, 2014, Fjord, 1996, Lentz, 2014, Senghas, 2002).
- **The Cultural-Linguistic View:** Focuses on recognizing Deaf people as a minority cultural group with their own language and culture. In this view, deafness is regarded as just another human variation that becomes part of an individual's identity. Similar to other minority cultures, the Deaf Community has its own histories, traditions, values, and social norms that are passed down through generations (DeVault, 2014, Fjord, 1996, Lentz, 2014, Senghas, 2002).

History:

- **Thomas Gallaudet:** He was studying to become a minister at Yale University in the early 1800s. His neighbor's daughter was deaf and he tried to teach her to read and write a few words. His neighbor sent him to Europe to learn their way of educating deaf people and he learned French Sign Language in France. He returned to Connecticut with Laurent Clerc, a deaf man and instructor at the French school, and they established the first school for the deaf in America (Cokely, 1980, Lane, 2010, Nomeland, 2011, Padden, 2006, VanCleve, 1982, 1999, 2007.).
- **Alexander Graham Bell:** In the 1870s and 1880s, Bell was dedicated to teaching deaf people speech and lip-reading. He actively sought the "breeding out of deafness" because he saw deafness as an undesirable human trait (Baynton, 1996, Burch, 2004, Cleall, 2015, Fjord, 1996, Lane, 1992, Lentz, 2014).
- **1880 International Congress on the Education of the Deaf (ICED):** Originally called the International Conference on the Deaf and Dumb, the 1880 conference met in Milan, Italy. This group voted nearly unanimously to ban Sign Language

The Deaf Community:

- **Deaf:** Refers to the particular cultural group who shares a language and embraces the cultural norms, beliefs, and values of the Deaf Community (Cleall, 2015, DeVault, 2014, Munoz-Baell, 2000, Padden, 2000).
- **deaf:** Refers to the sensory inability to hear to the extent that one cannot understand speech for everyday communication purposes (Cleall, 2015, DeVault, 2014, Munoz-Baell, 2000, Padden, 2000).
- **Hard-of-Hearing:** Not able to hear well but still have some semblance of hearing remaining (www.lifeprint.com).
- **Late-Deafened:** Deafness that happens post-lingually, any time after the development of speech and language (www.lifeprint.com).
- **Deaf-Blind:** The absence of both hearing and vision (www.lifeprint.com).
- **Oral-Deaf:** The absence of hearing but the individual uses spoken language as opposed to signing, likely because that's how they were taught (possibly forced) as they grew up (www.lifeprint.com).
- **CODAs:** (Children of Deaf Adults). Children who can hear and were born to Deaf parents. They are considered bicultural because they have an awareness of both hearing and Deaf cultures (www.lifeprint.com).

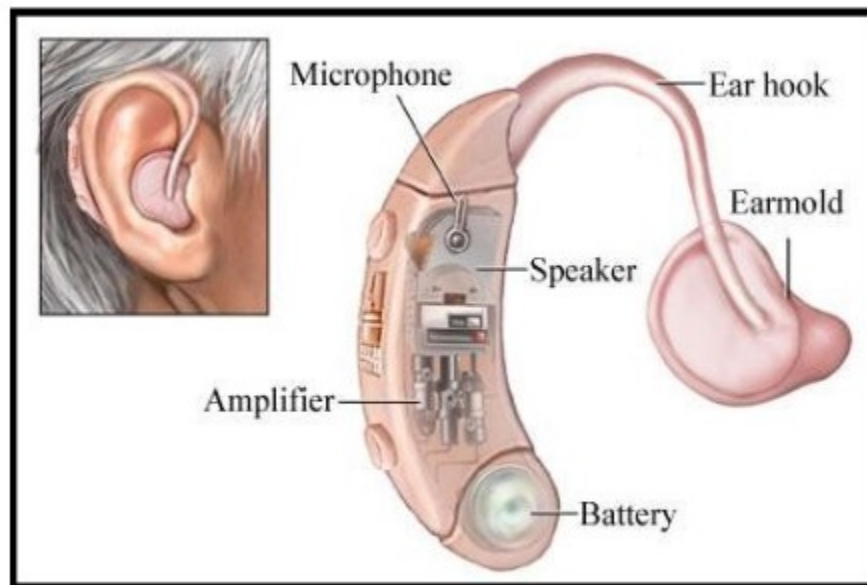
Communication:

- **Video-Remote Interpreting (VRI):** A video-telecommunication service that uses devices such as web cameras or videophones to provide sign language or spoken language interpreting services. Many Deaf people do not like to use it because they think it is unreliable and impersonal (DeVault, 2014, Hauland, 2014).
- **Registry of the Interpreters for the Deaf, Inc. (RID):** A national certified agency for qualifying interpreters. It has played a leading role in establishing a national standard of quality for interpreters (www.rid.org).
- **Cued Speech:** A type of sign language that uses hand movements combined with mouth shapes to communicate. (www.cuedspeech.org).

- **Lip-reading:** Observing a speaker's lip movements to better understand speech (www.lifeprint.com).
- **Tactile Signing:** A common means of communication used by people with both sight and hearing loss, which is based on a sign language or other system of manual communication. The individual puts their hands over the signer's hands to follow along with communication (Collins, 1998).
- **Protactile Signing:** The same as tactile signing but more fully supports Deaf-Blind culture, language, interpersonal relationships, politics, and has a true sense of empowerment (Collins, 1998).
- **Close-vision signing:** The Deaf-Blind individual still has some useable vision so they can usually see within two feet or less of their face (Emmorey, 2009).

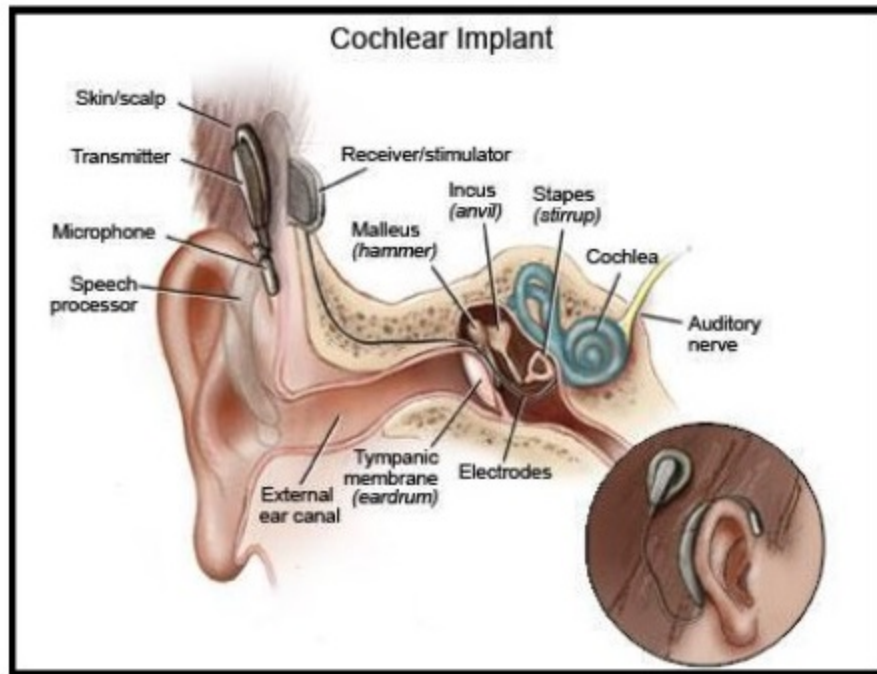
Assistive Listening Technologies:

- **Hearing Aids:** A small device that fits on or in the ear to amplify all sounds (Doyle & Dye, 2002).



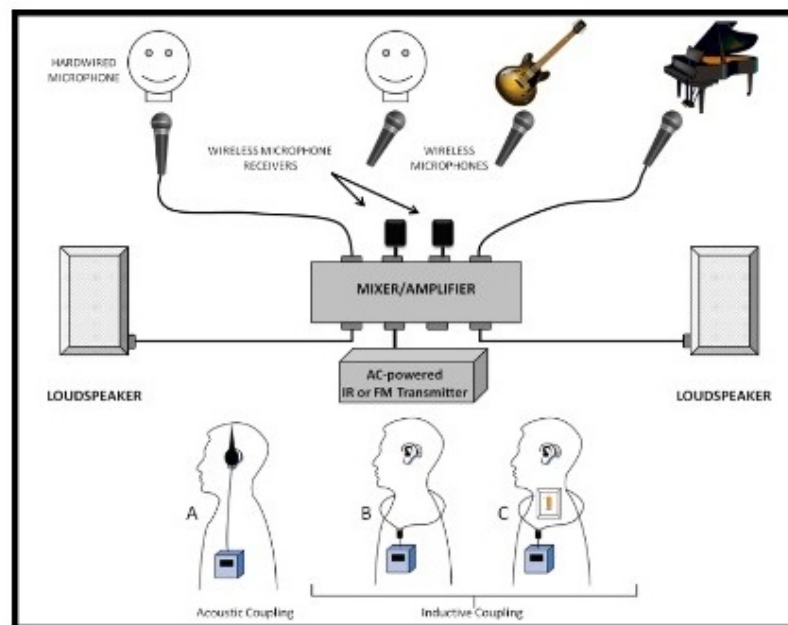
<http://www.zazbot.com/>

- **Cochlear Implants:** A complex device that can be surgically implanted into a person's cochlea to stimulate it to cause hearing. It consists of a tiny receiver which is placed under the skin in the bony part behind the ear (Doyle & Dye, 2002).



<http://kidshealth.org>

- **Infrared (FM) Systems:** One of the most common assistive listening technologies used in educational settings. Improves the speech to noise ratio by use of a remote microphone that can be placed close to the sound source (Doyle & Dye, 2002).



<http://www.comptonconleyconsulting.com>

Education:

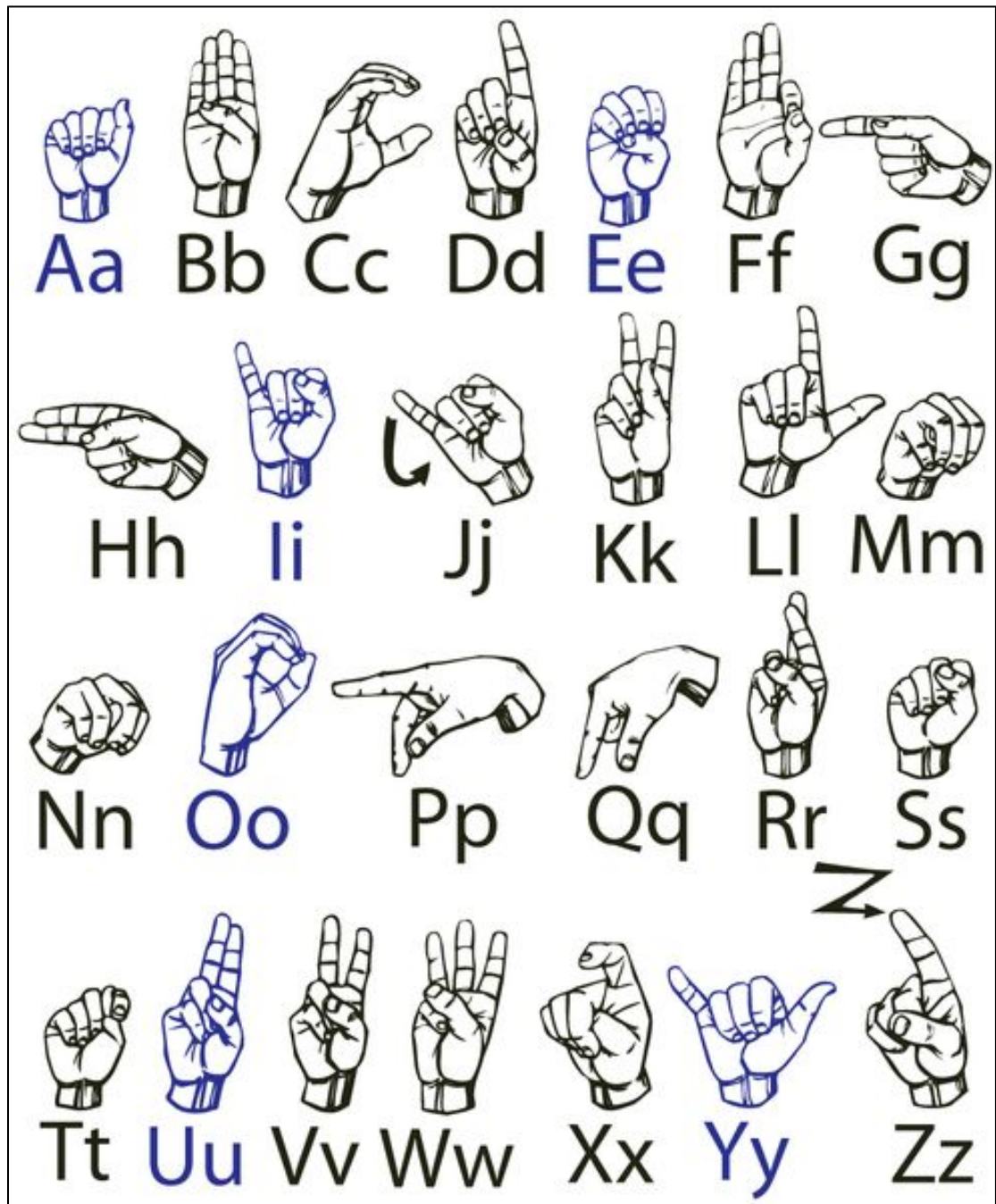
- **Oralism:** The system of teaching deaf people to communicate with speech and lip-reading, and forbidding the use of sign language (McKee, 2013).
- **Audism:** The notion that one is superior based on one's ability to hear and the belief that life without hearing is futile and miserable, which results in a negative stigma toward anyone who does not hear and their use of sign language (MacDougall, 2015).
- **Mainstreaming:** The process of educating students with special needs in regular classes (Doyle & Dye, 2002).

Retinitis Pigmentosa: A chronic hereditary eye disease characterized by black pigmentation and gradual degeneration of the retina. This inherited disease causes a slow loss of vision, beginning with decreased night vision and loss of peripheral vision. Eventually, blindness results. Unfortunately, there is no cure for it.

Usher's Syndrome: A condition characterized by partial or total hearing loss and vision loss that worsens over time. The hearing loss is classified as "sensorineural" which means that it is caused by abnormalities of the inner ear. The loss of vision is caused by an eye disease called retinitis pigmentosa (RP), which affects the layer of light-sensitive tissue at the back of the eye (retina). Researchers have identified 3 major types of Usher's Syndrome, designated as types I, II, and III.

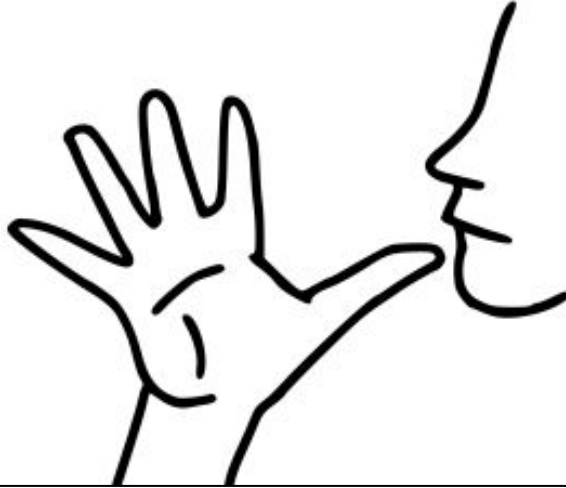
- Most individuals with type I are born with severe to profound hearing loss and progressive vision loss caused by RP becomes apparent in childhood.
- Type II is characterized by hearing loss from birth and progressive vision loss that begins in adolescence or adulthood.
- Type III is characterized by experiencing hearing loss and vision loss beginning somewhat later in life. Usually associated with normal hearing at birth.

APPENDIX B – ASL SIGNS



ASL Alphabet (www.pinterest.com)

mother/mom

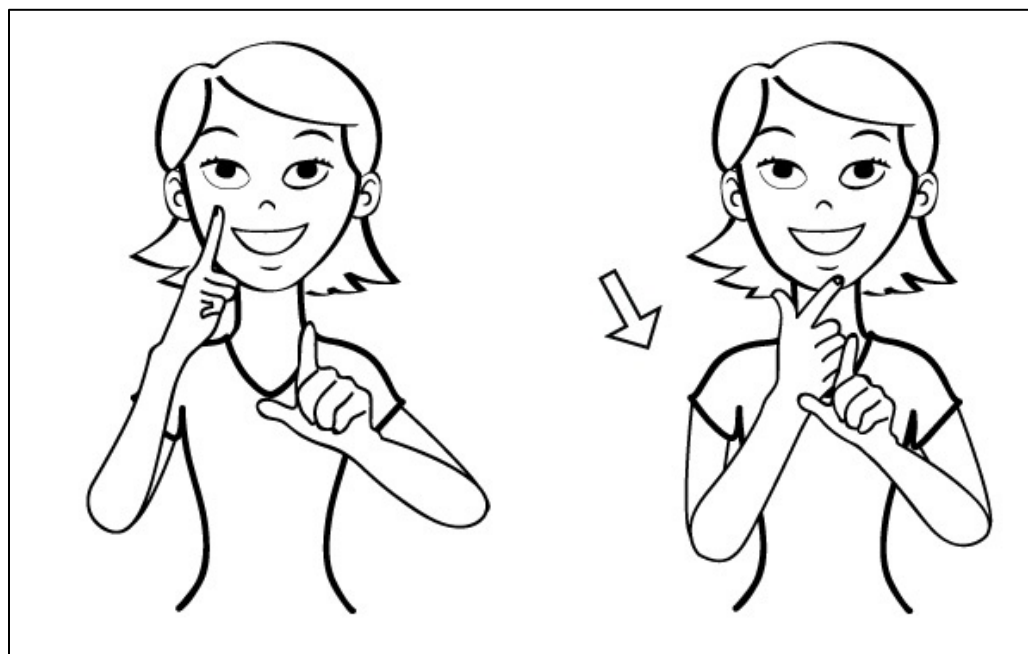


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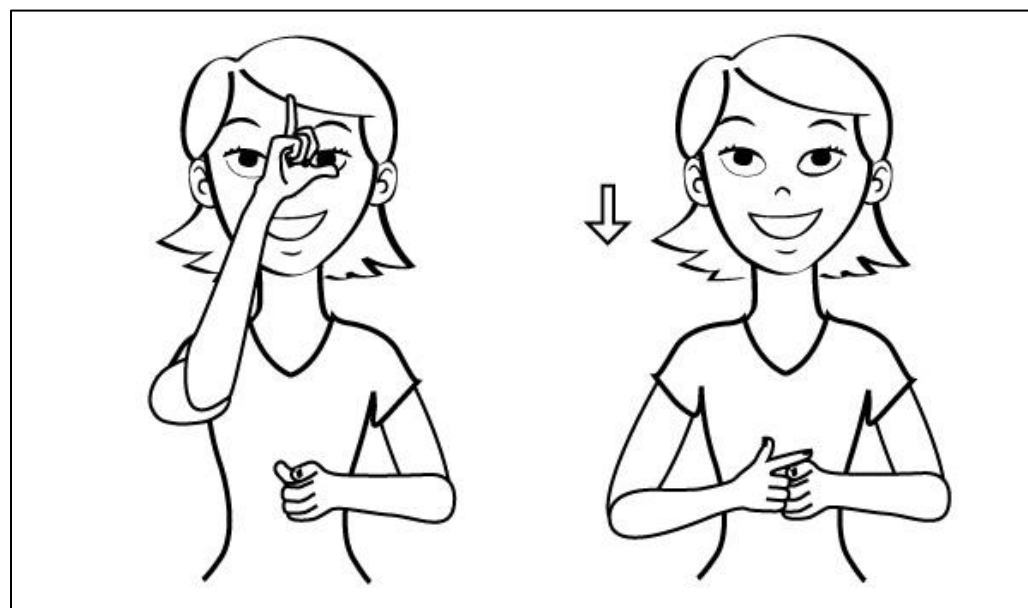
father/dad



(www.pinterest.com)



ASL sign for SISTER (www.pinterest.com)



ASL sign for BROTHER (www.pinterest.com)

Gwendoline used these signs on page 96

APPENDIX C – INTERVIEW GUIDE

Consent Statement:

“As an individual who identifies with the Deaf community, you are being invited to participate in a research study on the experiences of Deaf individuals in receiving health care in the Greater Boston area. Specifically, this research seeks to better illuminate how Deaf people perceive the “hearing-dominated” health care system and how this impacts their overall health and well-being. The purpose of this research is to use the personal experiences of Deaf individuals in their own language to hopefully improve respectful overall collaboration between health care providers and Deaf individuals. Your participation is completely voluntary and you can choose not to answer any questions that you wish and you may stop the interview at any time. Interviews can be as long or as short as you like, but will probably take between 30-60 minutes. There is no payment for participation. Your participation in this research is completely separate from the services offered by DEAF, Inc. and will not affect any services available to you. If you choose to participate, your confidentiality will be protected by using only a pseudonym or nickname of your choice to identify your answers, recordings, transcripts, and notes about our conversation(s), rather than your real name. To facilitate transcription of this interview for later analysis it will be video recorded. All recordings will be maintained securely to protect your confidentiality and destroyed at the end of the study. The student researcher and possibly the Boston University School of Medicine Institutional Review Board (IRB), which oversees research ethics, will be the only people who have access to information that you share, until or unless the findings are published. If you have any questions, you can contact me, Charlotte Kelleher, at chkell17@bu.edu (860-634-4715) or the principle investigator, Dr. Bayla Ostrach, at ostrachb@bu.edu. If you have questions about your rights as a research subject/participant, you can contact the committee that oversees research ethics at Boston University School of Medicine at medirb@bu.edu or 617-638-7207. Thank you very much!”

ASL is not a written language. I will sign (in ASL) the above statement according to the syntax and grammar of ASL.

As the student investigator, I Charlotte Kelleher, attest that I signed (in ASL) and/or showed the above consent statement to Deaf individuals who volunteered to be interviewed for this study. I obtained consent, confirmed ‘verbally’ (in ASL) as indicated by my listing of their pseudonyms below.

Pseudonym: _____ Date of Interview: _____

Pseudonym: _____ Date of Interview: _____

Pseudonym: _____ Date of Interview: _____

Pseudonym: _____ Date of Interview: _____

Pseudonym: _____ Date of Interview: _____

Pseudonym: _____ Date of Interview: _____

Pseudonym: _____ Date of Interview: _____

Interview Guide: *(Questions will be adapted for ASL grammar and syntax at the time of the interview.)*

- How old are you?
- Where are you from?
 - If not from Boston, when did you come here?
 - If not from Boston, why did you come here?
- How did you get involved with DEAF, Inc.?
- Were you born Deaf or did it happen later in life?
- Were your parents Deaf?
- What does being Deaf mean to you?
- Can you tell me a bit about your experiences growing up? (schooling, healthcare, etc.)?
- Are you aware of the 3 predominant current views toward deafness- the medical view, the social view, and the cultural-linguistic view?
 - If not, explain: Medical view- deafness is a “loss” and needs to be fixed, social view- mainstream Deaf people into the hearing world, and cultural-linguistic view- focuses on recognizing Deaf people as a minority cultural group with their own language.
 - Can you tell me how you feel about the medical view?
- Do you find it difficult to receive adequate health care?
 - What sort of barriers have you faced in getting health care?
 - What would you like a doctor (hearing) to know about the way you wish to be treated at an appointment?
 - Have you ever felt like you could not trust a doctor you went to? Can you provide an example?
- Could you tell me how you feel about Video Remote Interpreting (VRI) systems?
- Could you tell me how you feel about cochlear implants?
- Can you explain some of the things that DEAF, Inc. has helped you with?

APPENDIX D – ASL TRANSCRIPTION EXAMPLE

- Interview from 7/28/16 with “Daisy”
- 00:07:34 to 00:09:56.
- Based off the “Transcription Teaching Symbols” from *American Sign Language, A Student Text Units 1-9; Dennis Cokely and Charlotte Baker-Shenk; T. J. Publishers, Inc. 1980; xv-xxiii.*
 - This is a teaching technique used in this book to explain how a sign is supposed to look, what sort of inflections should be made, and if any non-manual signals should go along with it.
 - We are taught this as a way to practice writing dialogue and it is usually no longer used the farther you get into learning the language.
 - This serves as an example as to why I chose to transcribe my interviews in written English.

Student Researcher: YOU KNOW (2h)MEDICAL (2h)PERSPECTIVE (2h)ABOUT
____y/n
DEAF

Daisy: ME DON’T-LIKE (2h)VIEW. (2h)MEDICAL (2h)alt.TALK-ABOUT DEAF ME
DON’T-LIKE. NO*. COCHLEAR-IMPLANTS GOOD FOR SOME (2h)alt.PEOPLE
(2h)SPECIFICALLY (2h)alt.PEOPLE (2h)WITH R-P.

____wh
Me: WHAT THAT

Daisy: R-E-T-I-N-I-T-I-S...

(gaze-up, mouth open)
Me: OH-I-SEE. ME KNOW THAT.

Daisy: #IF HAVE R-P DEAF HARD-OF-HEARING (2h)NO VISION COCHLEAR-IMPLANTS (2h)HELP (2h)alt.MAYBE (2h)MORE (2h)BUT ME DON'T-LIKE. (2h)MEDICAL (2h)alt.PEOPLE (2h)FORCE. (2h)SPECIFICALLY (2h)CHILDREN ME DON'T-LIKE THAT. A-T A-L-L. NO*.

Me: YES. AGE 2 #OR 3 YOUNG* CHILDREN COCHLEAR-IMPLANTS. HARD...

Daisy: SHOULD* EASY MOST PARENTS LEARN ASL. KIDS CAN LEARN WITH LIPREAD BUT* NOT BEST.

- An English word in capital letters represents an ASL sign, this word is called a “gloss.”
- When more than one English word is needed to gloss an ASL sign, the English words are separated by a hyphen.
- A triangle with a letter inside is used to indicate a name sign.
- When an English word is fingerspelled, the letters are separated by a hyphen.
- When two glosses are joined by curved lines, it indicates that two signs are used in combination. Generally when this happens, there is a change in one or both of the signs so that the combination looks like a single sign.
- When the # symbol is written before a gloss, it indicates the sign is a fingerspelled loan sign.
- When a plus sign follows a gloss, this indicates the sign is repeated. The number of plus signs following the gloss indicates the number of repetitions.
- An asterisk after a gloss indicates the sign is stressed.
- A comma indicates a grammatical break, signaled by a body shift and/or a change in facial expression (and usually a pause.)
- Double quotes around a gloss indicate a gesture.

- The symbol (2h) is written for two hands to indicate that the sign is made with 2 hands.
- The symbol 'alt' means that the hands move in an alternating manner.
- The symbols '*rt*,' '*lf*,' and '*cntr*' indicate 'right,' 'left,' and 'center.' When a sign is made in or toward a particular location in space, that place or direction is indicated after the gloss. If none of these symbols appear, the sign is produced in neutral space.
- When a sign is followed by the symbol '*arc*' it means the sign moves in a horizontal arc from one side of the signing space to the other side.
- CL signifies classifiers and is written after the symbol for the handshape that is used in that classifier.
- An arrow pointing upward indicated that the palm is facing upward.
- Single quotes around a lower case word or words is used to help describe the meaning of the classifier in the sentence.
- The @ symbol indicates a particular type of movement that is often used when giving something a spatial location.
- When a sign is made with the non-dominant hand, it is written in italics.
- A line on top of a gloss or glosses means that a certain non-manual (eyes, face, head, body) signal occurs during the time period shown by the line. At the end of the line, there is a letter(s) which indicates what the non-manual signal is.
 - 'wh' for a question that begins with wh and indicates the eyebrows go down, and the head tilts down.
 - 'y/n' for a yes or no question and indicates the eyebrows go up, and the head tilts up.
- Words in parentheses on top of a gloss are used to indicate other movements of the eyes, head, and body.
 - Like the word (gaze) would refer to where the signer looks.

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