A PURPOSEFULLY DESIGNED AMERICAN DEAF COMMUNITY:
A QUALITATIVE STUDY OF “SPACE” AND “PLACE”

by

AMANDA D. HAM

(Under the Direction of Larry Nackerud)

ABSTRACT

Deaf people have long argued for their identity as a visually oriented cultural and linguistic minority. In the United States, the predominant visual language of Deaf people is American Sign Language (ASL). Members of the American Deaf community, a heterogeneous and diverse population, share a commonality in that Deaf people are largely thought of and referred to as “disabled” by much of hearing society. An over-reliance on the disability orientation has eclipsed a more holistic, cultural understanding of this population, a situation applicable to and relevant for practicing social workers. This qualitative study will shed light on the Deaf cultural paradigm. The purpose of the study was to explore the perceptions and experiences of D/deaf persons living in a purposefully-designed Deaf community. Three research questions guided this study: (1) In what ways (if at all) have your experiences(s) with Deaf culture influenced your decision to live in a Deaf community? (2) What are the benefits of living in a Deaf community? (3) What are the challenges of living in a Deaf community? Participant interviews were the primary source of data collection; also used were participant observations and the collection of relevant artifacts. Over a one-week period, 33 interviews were conducted. Data were analyzed using a Constructivist Grounded Theory approach. Findings indicated that the benefits of living in a purposefully-designed Deaf community far outweighed the challenges, specifically regarding the importance of communication accessibility within the community, its opposite corollary described as loneliness and social isolation. For some, mostly those with previous Deaf cultural experiences, Deaf culture did seem to be an influencing factor for moving in. For others, it was the visual orientation of the building's design, particularly the visual safety features, that was the initial appeal and influence for moving in.

INDEX WORDS: Deaf community, Deaf culture, Deaf-specific apartment, DeafSpace, American Sign Language (ASL), Social work, Sign Language People (SLP)

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DEDICATION

This dissertation is dedicated to my family.

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"Alone we can do so little; together we can do so much." Helen Keller

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Again, this page is optional. You do not have to provide an acknowledgements section in your thesis or dissertation. You may use this section to express acknowledgements of those who have helped you with this document and your academic career.

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CHAPTER 1

INTRODUCTION

Deaf people create Deaf spaces by the very act of living lives with visual bodies rather than hearing bodies (Gulliver & Kitzel, 2014); however, these “Deaf spaces are often ignored, or treated as either non-existent or invalid by the hearing world” (p. 3). The concept of *Deaf-World*[1] is an example of Deaf space. Deaf people may use the term Deaf-World when referring to relationships with other Deaf people or to established social networks within the Deaf community (Lane, Hoffmeister, & Bahan, 1996). Deaf-World bears no relation to any specific geographic location, although geographic parallels have been used for centuries in discussing Deaf people and their unique relationship with space and one another (Gulliver & Kitzel, 2014). Regardless of national or ethnic borders, Deaf people share commonalities that include the biological and existential fact of deafness, the use of sign languages and experiences of oppression (Friedner & Kusters, 2015). In addition, the lives of Deaf people are influenced by both Deaf-centered spaces and the larger society.

The concepts of *space* and *place,* although connected and overlapping, have unique practical and theoretical conceptualizations. O’Brien, Stead, and Nourse (2017) differentiated: *Place* is defined as “an absolute location, with a specific material setting and to which people have an affective attachment” (p. 4). Places are where everyday life is situated. *Space* is viewed as the product of social interactions, such as the temporary deaf spaces that form when signing deaf people meet, using Gulliver and Kitzel’s (2014) example of in a bar or on the street. This

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[1] Sometimes written as DEAF-WORLD. All caps are indicative of the signed concept.

chapter is presented in the following sequence: introduction, affirming and navigating Deaf cultural research, the background of the problem, statement of the problem, the significance of the study, and definitions.

Affirming and Navigating Deaf Cultural Research

The word “deaf” can refer to both an audiological condition and a social identifier (Mitchell, 2006). This dissertation research follows the tradition of using a capital “D” for Deaf when referring to issues related to Deaf identity, Deaf culture, and the Deaf community, and a lowercase “d” for deaf when referring to the audiological condition or state (Woodward & Horejes, 2016). This “D/d” dichotomy is commonly used and accepted both in academic literature and with members of the Deaf community.

With no legal definition of deafness (Allen, 2015), it is generally understood to be the partial or total absence of the faculty of hearing (Ladd, 2003). The meaning and significance of this physical attribute vary greatly, however, between different groups of people and individuals within these groups. For many, the concept of deafness, or hearing loss, is associated with disability. This fits within the medical model. From a research perspective, the medical model implies a positivist research epistemology (Young & Temple, 2014) in which there is a true standard, to be hearing, and any deviation from the norm (being deaf) require amelioration. With the medical model, “knowledge is regarded unambiguously as knowable and reality is measurable” (p. 30).

Alternatively, deafness can be viewed from a social construction orientation (Holcomb, 2013) in which Deaf people are *self-defined* culturally and linguistically rather than from an audiological standpoint (Schein, 1989). In this paradigm, being Deaf is celebrated for its uniqueness and equal place in the range of human experiences (Wright, 2016). This dissertation research adhered to the social construction orientation of being Deaf, which encompasses Deaf culture and Deaf communities.

Described as highly visual (Dye, 2014) and inhabiting “a highly visual world” (Bahan, 2008, p. 83), it makes sense that much of Deaf culture is based on visual access to the world (Holcomb, 2013) while also explaining the importance of American Sign Language (ASL) to members of the Deaf community. ASL is considered one of the most distinctive marks of Deaf culture (Holcomb, 2013), and competence in ASL is at the core of Deaf identity in the U.S. (Lane, Pillard, & Hedberg, 2011). Deaf communities are broadly understood to consist of those Deaf people who use sign language (Woll & Ladd, 2003). Deaf culture binds the Deaf community together with its shared language, interests, traits, experiences, and history of Deaf people, and social groups and organisations comprise members who share the common denominator of deafness and language (Luterman, 1986).

Two additional concepts are important to discuss here. The first is *strategic essentialism* (Voronka, 2017). Although Deaf people are a varied and diverse group of people, just as hearing people are, there are times when essentialism can be used advantageously as an important intellectual and social tool (Bucholtz, 2003). Voronka posited that this is particularly true for groups where representation in academic knowledge has been produced *on* rather than *with* or within the group. Strategic essentialism is a way of promoting a shared universal identity among those marked different to achieve sociopolitical, economic, human rights or other equality gains. Although the concept of essentialism has become almost a pariah in contemporary cultural discourse, Ladd (2003) indicated that this is unfortunate for groups, like Deaf communities, who are struggling to conceptualize and advance their identities within the larger societal discourse.

Strategic essentialism is particularly "useful for minorities and ethnocultural groups in retrieving their place in society" (Burney, 2012, p. 186).

The second concept is that of *liminality* (Hart, Poole, Facey, & Parsons, 2017). Hart et al. explained this concept by stating that critical qualitative researchers ask questions that go beyond the prevailing assumptions and understandings and acknowledge the role of power and social position in the identified phenomena; as such, these researchers occupy and navigate *liminal* academic spaces and statuses. Rooted in anthropology, the concept refers to an in-between state where individuals are not easily categorized, e.g., an adolescent does not fit into either of the two categories of child or adult. More importantly, though, liminality also refers to a threshold between two states, as an evolving, dynamic, reflexive process. I would argue that the term *not* be applied to Deaf people, as they have had enough labels. Rather, liminality is a way of referring to the process of change that we, the social work profession, are going through as we traverse from the disability to the cultural understanding of what it means to be Deaf.

Background of the Problem

The concept of Deaf persons as a cultural minority is not new, although it is much less well known than the disability orientation. Until the late 19th century, Deaf people in the U.S. and Europe were viewed primarily from the cultural model perspective (Lane, 1999). The period from the 1760s until the early 1800s has been identified as the "golden age for deaf persons" in both the U.S. and France (Branson & Miller, 2002, p. 105). During this period, the Parisian Deaf community was renowned for its scholars and leaders (Mottez, 1993); deaf people held prestigious positions and jobs as educated professionals (Sacks, 1989); the field of deaf education was led and conducted primarily by deaf persons (Lane, 1999); deafness was considered a human variation, not a disability, by hearing and deaf persons alike (Groce, 1985);

and sign language was popular with both deaf and hearing Americans (Miller, K., 2008). Evidence of Deaf cultural orientation goes back hundreds and possibly thousands of years (Leigh, 2009).

The historic worldwide shift in thinking about D/deaf people, from the cultural model to the disability model, occurred late in the 19th century, as efforts from the domains of science, philosophy and politics converged to essentially *forbid* the use of sign language in the education of deaf students globally (Branson & Miller, 2002; Lane, 1999; Van Cleve & Crouch, 1989). Simultaneous to this outlawing of manual communication in deaf education was the promotion of *oralism*, a philosophy that advocates for auditory-verbal training (AVT) as the *exclusive* communication method used in the education of deaf children (McCullough & Duchesneau, 2016). The combined effect of these two historically situated factors has been identified as the most significant cause of the limited educational achievement of deaf men and women today (Lane, 1999).

By the mid-19th century, science was growing in popularity and influence. Much of society viewed progress, as well as science, as intrinsically good. With scientific progress came the conviction that nature could be mastered, and humanity transformed (Branson & Miller, 2002). Within this context, deaf people were constructed as people who could be "changed for the better" (Woll & Ladd, 2003, p. 156). Coinciding with both the suppression of sign language and the promotion of oralism, for the first time the education of deaf students came under the control of persons with no knowledge of sign language and no understanding of the Deaf community (Baynton, 1996, 1993). It was during this period that medical science began to objectify deaf people to the hearing public. Greenwald and Murry (2016) wrote:

> Early periodicals had praised the signing […] deaf people as autonomous individuals, implicitly assuming that deaf people had the same agency as their hearing counterparts. By contrast, the shift to talking about – rather than with – deaf people in what appeared to be scientific language resulted in denying them the status of autonomous individuals. (p. 12)

Today, for individuals who identify with a Deaf cultural orientation, being "Deaf" asserts a state of being that reflects completeness, demonstrated by the living of full, rewarding, Deaf lives (Leigh, 2009). In this paradigm, the issue of *loss* has no meaningful reality for sign language users who are born Deaf or become Deaf at an early age (Ladd, 2003). Researchers posit that the cultural model of Deafness stands not merely in *contrast to* but also as a *resistance against* the medical model of deafness (Obasi, 2008). Moreover, scholars suggest that many of the problems that D/deaf people experience are created not by deafness per se, but by the "parameters of expectations" for deaf people to function and communicate as hearing people within our society (Leigh, 2009, p. 13).

Deaf culture and Deaf communities are realities within the U.S. and throughout the world (Ladd, 2003), despite the limited empirical literature on Deaf culture and Deaf communities (Glickman & Pollard, 2013). Ladd suggested:

> When it comes to research in the Deaf domain, we find that because of the dominance of the medical model of deafness, only the barest minimum of resources have been made available to examine Deaf communities as communities…. Indeed it is only in very recent times that they have even been granted the status of communities. The idea of Deaf cultural research, then, is anathema to the majority who hold power and practice in those domains…. Moreover, there is almost no formal academic focus on linguistic

> minorities per se; thus bringing compelling Deaf linguistic and cultural evidence to their attention is extremely difficult. (p. 268)

It is also important to bear in mind the source of information when considering Deaf communities and Deaf culture. Szarkowski and Brice (2018) argued that Deaf communities have historically been studied by hearing investigators who constructed deafness through a deficit lens rather than a more appropriate strengths-based cultural orientation that validates the Deaf experience. Culturally Deaf people tend to view being Deaf as a positive attribute, not a negative one (Bauman & Murray, 2014), a quality that promotes resilience among individual community members when encountering various forms of oppression (Leigh, Andrews, & Harris, 2018). This is attributed to the concept of cultural capital (Yosso, 2005). "*Cultural capital* [emphasis added] involves the use of cultural knowledge, skills, abilities, and interactions to influence aspirations, socialization, language use, family patterns and resistance to disadvantages" (Leigh et al., p. 7). For those in the Deaf community, cultural capital wealth includes the use of visual language, visual learning, and connections with Deaf people who are leading full, self-actualized lives. Cultural capital lends support and provides "a protective factor when Deaf people work to maximize their opportunities even while experiencing lower expectations on the part of hearing people" (p. 7).

Statement of the Problem

Despite existing information and evidence of Deaf culture and Deaf communities being available, a general lack of awareness of the Deaf cultural paradigm persists (Ladd, 2003; Lane, 1999). Categorical assumptions of disability are regularly made by those outside of the Deaf community (Horejes, 2012), with little attention given to *accounts of the Deaf experience by Deaf people* [emphasis added] (Bauman, 2008). The dominance of the disability paradigm is evident within the social work profession as well, despite the foundational importance of diversity and social justice to the profession. An analysis of social work literature revealed a decidedly diagnostic approach to disability in social work education (Gilson & DePoy, 2002), with discussions and analysis occurring typically “through a deficit-treatment lens” (p. 153). Viewing deafness as a medical phenomenon to be understood and treated through specialized services places the locus of the disability within the individual, resulting in an interpretation of the individual as defective.

Without intentional and specific culturally oriented knowledge, Deaf people can easily be construed as “disabled by default” (Wright, 2016, p. 308), a label Wright argued is extremely hard to overcome. This perpetuates and maintains a system of paternalism and marginalization. Negative effects of this categorization occur and are felt throughout the lifespan. It often begins with delayed access to language during the early years of optimal language acquisition, and continues through the educational system, resulting in job and financial difficulties. Other serious negative consequences might include misdiagnosis and misunderstandings in medical and mental health settings (Tate, 2012); barriers to health care, health inequities, and difficulties navigating the health care system (Barnett, McKee, Pearson, & Smith, 2011), and underutilization of services and a mistrust of the mental health system and of healthcare professionals (Glickman, 2013; Steinberg, Loew, & Sullivan, 2010), For all these reasons, it is important that social workers develop a more holistic, culturally based understanding of members of the Deaf community.

Promoting a cultural understanding of deafness has the potential to increase the influence that Deaf people have over their own lives (Gertz, 2016). To date, no social work-specific research has been found specifically identifying Deaf spaces or Deaf communities. Moreover, previous social work research, to date, has not sufficiently provided the necessary foundational knowledge to understand Deaf persons from a Deaf-cultural orientation. By countering the pervasiveness of the disability model, this dissertation research fills a void in the literature, which will, hopefully, ultimately enable the profession to both better understand and better serve the needs of this population.

Purpose Statement

The purpose of the study was to explore the perceptions and experiences of D/deaf persons living in a purposefully-designed Deaf community. Three research questions were used to guide this study:

1. In what ways (if at all) have your experiences(s) with Deaf culture influenced your decision to live in a Deaf community?
2. What are the benefits of living in a Deaf community?
3. What are the challenges of living in a Deaf community?

Significance of the Study

Although discrimination occurs against all deaf people, “it is most intensely directed at those who practice Deaf culture. They have a different language, different values, traditions, and rules of behavior” (Fernandes & Myers, 2009, p. 25). There is a great need for improvement in the provision of services to persons who are D/deaf, including from members of the social work profession. The Deaf community has been identified as one of the most understudied health disparity populations in the United States (Anderson et al., 2018), with more than 90% of the deaf population’s mental health needs remaining unserved (Myers, 2010).

As a profession, social work has an ethical responsibility to work with clients and client groups in a way that honors self-determination and shows respect for cultural identity, as stated by the National Association of Social Workers (NASW) Code of Ethics (2017). A renewed effort is needed, however, to improve cultural responsiveness within the social work profession. This can and needs to be addressed on multiple fronts, particularly in the areas of social work education and practice. An exploration of social work curriculums from schools with predominately hearing student population bases revealed only one program[2] that included a Deaf culturally responsive course as a part of the curriculum. Given a general lack of Deaf cultural orientation within Council on Social Work Education (CSWE) curriculums combined with an emphasis on disability within published social work literature, it is conceivable that social work practitioners, educators, and students are not aware of the existence of Deaf culture and Deaf communities. Awareness of only the medical model of deafness places social workers in the cultural destructiveness range of Cross, Bazron, Dennis, and Isaacs' (1989) six-stage Cultural Competency Continuum (as cited in Lee & Zaharlick, 2013, p. 6). See Figure 1, pg. 11. A greater understanding of Deaf communities and the people who inhabit them will help to move social workers beyond the cultural destructiveness category.

Improving cultural responsiveness with this population is crucial because cultural insensitivity and a lack of Deaf cultural awareness on the part of hearing clinicians has been identified as the primary reasons that D/deaf people are not comfortable with hearing clinicians (Glickman & Harvey, 1996).

This dissertation research has the potential to increase the knowledge base that informs both social work practice and policy. On a practice level, a more holistic understanding of Deaf

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[2] The School of Social Work at the University of Texas at Austin offers a course is *Sign Language & Social Work Practice with d/Deaf Clients: Communication, Culture & Advocacy.* The premise of the course is that to do culturally competent mental health work with deaf clients, one must understand both their language and their culture.

persons will ultimately lead to better services by reifying the deaf individual as a complete person with a different language and a different culture, rather than as someone who is incomplete because of his or her hearing status. Given the diversity of deaf people in terms of age, gender, race, ethnicity, educational attainment, sexual orientation, and life experiences (Leigh, 2010), myriad potential opportunities exist for deaf persons and social work professionals to interface and work together throughout the lifespan, potentially at significant milestones and life stages.

Figure 1. Cultural Competency Continuum.

A paradigm shift toward a more holistic understanding of this population also has the potential to impact policy decisions. Lane (1999) contended that one of the major consequences of using medical parameters to define deafness as a disability is that it leaves the control of deaf lives largely in the hands of hearing persons, with little room for input from deaf people. Potentially relevant areas for policy implementation specific to this dissertation research could include housing, medical and mental well-being, and social isolation. The social work profession has identified social isolation as a critical social problem affecting persons throughout the lifespan (Laurio, 2016), and the eradication of social isolation has been identified as one of 12 Social Work Grand Challenges (SWGC) to be addressed in the coming decade (Williams, 2016).

Finally, this dissertation research will address and help fill the extensive gap in literature related to Deaf culture and the Deaf Community. This gap in the literature is not specific only to social work. This research may, therefore, also have relevance in other disciplines. What follows is a list of definitions germane to this dissertation research. The definitions are provided to achieve clarity and assist the reader.

Definitions

ASL: American Sign Language.

Audism: A term used to describe the sense of superiority of those who can hear and speak over those who do not. Audism can manifest and be seen on a number of levels, including, individual, institutional and subconscious levels (Gertz & Bauman, 2016). *Audist thinking*, therefore, is thinking that conforms to the principles of audism.

BSL: British Sign Language.

CODA: A child of deaf parents. CODA stands for “child of a deaf adult.” A CODA may have learned ASL as his/her first language with English as a second language. Holcomb (2013) states that CODAs “will have to negotiate between two cultures for their entire lives, the Deaf culture of their home, and the mainstream American hearing culture of which they are also a part” (p. 40).

D/deaf: Following convention, a “D” deaf denotes a cultural orientation to deaf people and their community, while a “d” deaf refers to a purely audiological perspective. “D/deaf” signifies a group of people that may encompass both cultural and audiological perspectives. Following the example of Padden and Humphries (2005), a lowercase “deaf” (p. 183) will be used when referring to schools or classrooms for the deaf because the standard for placement of children is by hearing loss. Uppercase “Deaf” (p. 183) will be used when referring to institutions built by Deaf people, such as Deaf organisations, clubs, and churches, as well as when describing those individuals who share in a collective and social history (Padden & Humphries, 2005, p. 183).

Deaf Studies: An academic field that comprises interdisciplinary approaches to the exploration of Deaf individuals, communities, and cultures as they have evolved within a larger context of power and ideology (Bauman & Murray, 2010, p. 210).

Deafhood: Represents a process, “the struggle by each Deaf child, Deaf family and Deaf adult to explain to themselves and each other their own existence in the world” (Ladd, 2003, p. 3). This dialogue also acknowledges and reflects different interpretations of Deafhood, of what being a Deaf person in a Deaf community might mean.

Dinner table syndrome: A concept in Deaf epistemology in which deaf children and adults are often left out of conversations with hearing family members and friends in many everyday settings, including at home and in school (Hall, Levin, & Anderson, 2017).

DOD: Deaf of Deaf. This is a deaf person with deaf parents.

DOH: Deaf of hearing. This is a deaf person with hearing parents.

Fund of knowledge deficit: (Also known as information deficits) gaps in knowledge due to an accumulated lack of environmental information (Hall et al., 2017).

Hard of Hearing: A hard-of-hearing person is a person who has *some* hearing. This person can either identify with the hearing majority and will rely heavily on voice and lipreading skills for communication or this person can identify with the Deaf community and will rely primarily on sign language for communication. The term *hard of hearing* (hearing perspective) and *HARD-OF-HEARING* (SIGNED; deaf perspective) have two very different meanings. Padden and Humphries (1988) explain that each is a deviation from the "norm" or central frame of reference – from both the deaf and hearing perspectives (p. 39-42).

H/hearing: "Hearing" (capitalized) is a cultural indicator and refers to a hearing-identified society, and by extension, mainstream society; "hearing" (not capitalised) is used to denote an audiological condition or ability (Senghas & Monaghan, 2002). May be used as a noun, as in "a hearing who lived next door to me" (Becker, 1980, p. 129).

Hearing world: Anything outside the Deaf community (Becker, 1980).

Language dysfluency: occurs when a person's best language is not considered fluent (Hall et al., 2017).

Langue des Signes Française (LSF): French sign language

Lip reading (speech reading): attempts to understand the spoken word through reading mouth patterns. A large amount of lip reading is guesswork because only a small proportion of speech sounds can be distinguished by these patterns (Corker, 1998, p. 148).

NAD: National Association of the Deaf. NAD proudly proclaims to be the oldest civil rights organization in the country, having "been in continuous operation since 1880 with the mission of preserving, protecting, and promoting the civil, human and linguistic rights of all deaf and hard of hearing people in the United States" (NAD, n.d., paragraph 1).

Sign Language Persons (SLP): SLPs include Deaf individuals and also some hearing people who are part of signing communities (Batterbury, 2012).

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

The purpose of the study was to explore the perceptions and experiences of D/deaf persons living in a purposefully-designed Deaf community. The central questions that guided this study were: (1) In what ways (if at all) have your experiences(s) with Deaf culture influenced your decision to live in a deaf community? (2) What are the benefits of living in a Deaf community? (3) What are the challenges of living in a Deaf community?

Initially beginning with social work specific sources, this literature review quickly expanded to other domains that included the fields of psychology, sociology, linguistics, history, Interpreter studies, Deaf studies, and eventually, Disabilities studies literature. Multiple databases were used, and ultimately help was elicited from a University of Georgia research expert to ensure that relevant resources were not being missed or overlooked. This chapter is a review and critical examination of literature germane to deaf people that are historical, socially, and politically relevant to the experiences and conditions that deaf people face today. Deaf history will be discussed within the hegemonic discourse of hearing society. This chapter shows how modern “advancements” in philosophy and science made it ultimately possible to systemically oppress and marginalize an entire group of people by redefining the essence of humanity as speech-based. This chapter also compares Deaf studies and Disability studies, examining areas of common ground and divergent ideologies. Deaf culture is discussed. This chapter describes how “the core of Deaf culture consists of solutions for effective communication, access to information, validation of the Deaf experience, and complete acceptance of being Deaf as a normal existence" (Holcomb, 2013, p. 102), both historically and present day. Next, this chapter examines various types of D/deaf communities. Deaf communities have generally been formed in two distinctly different ways, largely correlating with how deaf people and signed languages are viewed by the larger society. This chapter also examines issues of discrimination and housing concerns for persons who are deaf. Lastly, this chapter examines Deaf theory, the theoretical framework that guided this research.

Placing Deaf History within a Larger Historical Context

Historically, the opinions of the majority culture have played a dominant role in how deaf people are perceived and treated. Horejes (2012) posits that the concept of "what it means to be deaf" (p. 78) is, at any given time, based on the social constructions of language and technology to shape cultural identities. Understanding this is important for social workers, as researchers have advised that clinicians should never discuss psychopathology in deaf people until they fully understand "normality and health in deaf people" as well as "first understanding what hearing people *have done* [emphasis in original] to deaf people" (Glickman, 2013, p. 5). Attitudes regarding language and technology are driven by ideological philosophies of normalcy and deviance linked to a given historical time and place. Horejes (2012), for instance, wrote that during the period of European Enlightenment in the 18th century, sign language was "revered as a positive and remarkable component of language" (p. 75). During this period, scholars contended that written texts were forms of "nonhearing knowledge acquisition," but only sign language was viewed as *the* novel source of information in which the author was the sole authority of that information (p. 75). Predominant views about deaf people and sign language are quite different today, however, with the pervasiveness of the disability paradigm and the false belief that learning ASL inhibits oral language development in deaf children (Humphries, Kushalnagar, Mathur, Napoli, Padden, & Rathmann, 2014). What has not changed over time, however, is the power and sway held over deaf lives by members of the hearing majority. It is not possible to discuss the history of deaf persons without also including a discussion of the hearing population and the sociopolitical climate of the time. List (1993) maintained that

> The social problem of deafness – and with it also in large part the historical fate of deaf people – is treated, is decided, is even "produced" in a framework constructed by the hearing majority and defined by the paradigms (handicap, [etc.]…) they accord to the deaf minority. Any historical inquiry relating to deaf people therefore must encompass more than just a concentration of the history of deaf society as an isolated or autonomous historical phenomenon. The general history of hearing society, too, needs to be considered. (p. 115)

It could be argued that as recently as the 1970s, deaf history did not exist (Van Cleve, 1993). The only history available consisted of sketches of various hearing men, primarily teachers, who were credited with bringing knowledge and enlightenment to generations of deaf children. But in these scenarios, deaf adults have been ostensibly absent, as is the historical context for the events under discussion. History was written as though the world in which deaf people grew up, married, worked, procreated, and educated their children was somehow unrelated to the larger world inhabited by people who hear (Van Cleve, 1993). Ladd (2003) wrote that a century of linguistic oppression had left very few deaf communities able or inclined to present their beliefs and ideas in written form. The discipline of Deaf Studies, however, has been largely committed to the recovery and documentation of this forgotten Deaf history (Bauman & Murray, 2010).

Another consequence of more than a century of linguistic oppression is that for many years, even Deaf people who used ASL as their first and primary language internalized the assumption that ASL was something less than a “real” language (Schein, 1989). It was not until after the publication of Stokoe’s (1960) linguistic research that both deaf and hearing people realized that ASL was a true, legitimate, and *whole* language. This significant finding laid the groundwork that enabled deaf people to be seen from a sociocultural standpoint rather than from the pejorative medical model (Horejes & Anderson, 2016). Subsequent linguistic and psychosocial studies further developed the understanding that as a real language, ASL both nurtures and is, in turn, nurtured by culture (Roots, 1999). Language and culture are unequivocally linked. It is not possible to adequately address a culture without also addressing the language of the population under study (Horejes, 2012). Specific to the U.S. deaf population, ASL is the primary socializing agent of deaf Signers. ASL educates and conveys values, behaviors, and roles, both of its members and of others, including hearing society (Roots, 1999). The primary and crucial dimension of difference between Deaf and hearing cultures has been identified as the use of vision instead of hearing for accessing information, both vital and incidental (Stokoe, 1989).

To understand the disparity of public opinion about deafness and deaf people, from their prestige and perceived wholeness during the Enlightenment to their marginalization and social construction as disabled during the period of Industrialization, one must turn to areas of philosophy and science and the impact of both on the education system.

Philosophical Perspective

The period of the Enlightenment initially validated positive discourses about Deaf people (Ladd, 2003). One of its tenets, however, later proved to be a Trojan horse. Using the claim that nature could be improved by reason, some would advance that teaching deaf people to speak represented a necessary stage in their evolution to full human status. The first anthropological expeditions of the Napoleonic age were advised to employ people who knew sign language to act as interpreters. Ladd wrote that this powerful and apparent affirmation of Deaf people and their languages was later turned on its head, however. The fact that both Deaf and Native peoples used sign and gesture (albeit in different languages), and that neither could speak European languages, was used to construct essentialist similarities between the two groups. Both were described as "savages" in a belief system that constructed the "civilized Man" as the epitome of Western and modern advancement (Mirzoeff, 1995, p. 68). Sign language was devalued and placed among the "savage" languages, "supposedly forming a link between the animal and the human" (Baynton, 1993, p. 98).

Beginning in 1750 and through the next 100 years, interest in deaf people grew exponentially, as recorded in print. Deaf people and sign languages had become a touchstone for increased speculation about both the nature of Man and of language by philosophers emerging from the Enlightenment (Ladd, 2003). Increasingly, the construct of humanity became synonymous with one's ability to produce speech. Early philosophers whose work support this claim include Plato, Aristotle, Rousseau, and Husserl (Daylight, 2012). Saussure is credited with defining language as a strictly sound-based phenomenon, which set the stage for the 20th-century stance on languages (Bauman, 2008). Emphasis also shifted from the possession of an immortal soul to the possession of speech as a foundational criterion for the defining characteristic of humanity during the latter half of the 19th century (Baynton, 1993).

With the dominant view that language is derived *only* from the faculty of speech, those without speech were labelled as "mindless," less than human. Persons who were deaf were assumed to be not only incapable of learning language but also incapable of human understanding (Branson & Miller, 2002). In addition to this, the use of sign language was considered to be a grave danger to society, in that it encouraged defective individuals to socialize, form associations, intermarry, and ultimately to increase the numbers of “defective” individuals within the society (Bauman, 2008).

The link between language and humanity has played a vital role in the marginalization of deaf people because language, above all else, became defined as the one thing that separated the human from the animal (Branson & Miller, 2002). Brueggemann (1999) suggests that the difficulty of separating the rhetoric and theory of the last 2500 years has been and continues to be problematic for deaf people. Once the defining feature of humanity became oriented toward those who could speak, deaf people were excluded. The situation that deaf people face is summed up thusly: “*Language is human; speech is language; therefore deaf people are inhuman, and deafness is a problem*” [emphasis in the original] (Brueggemann, 1999, p. 11).

Branson and Miller (2002) suggest that, in many ways, deaf people of the 19th century were pawns in an intellectual “game” in the development of a new ideological approach to language and its potential. For deaf persons, their deafness was seen increasingly as the essence of their subjectivity. “The deaf” had become a category of humanity, pawns to be moved around to suit the strategies of the philosophical players. Deafness had become a human condition to be fixed, and “the deaf” was seen as a singular unit. Nonetheless, philosophical theorizing alone likely would not have been enough to wholly transform public opinion about deaf persons from viewing them as independent and capable to see them as incapable and in need of services, were it not for co-occurring scientific advancements. Science became the vehicle that would make the transformation of public opinion about deaf people possible.

Science

Using science to transform deafness became firmly identified with the progressive movement of the 19th century. Deaf people were caught up in the momentum of the progressive scientific discourses that looked to distinguish between the "normal" and the "pathological." In the ideological practice of scientism, the transformation of the pathological was to become a measure of humanity's control over its own destiny, a measure of the power of the scientific method. That human knowledge could overcome deafness and muteness and could teach deaf people to speak was seen as a triumph for human reason (Branson & Miller, 2002).

Evolutionary theory. Branson and Miller (2002) suggested that an abiding fascination of the 19th century was with evolution and the discovery of explanations for biological differences that were the consequence of natural laws rather than the work of God. These ideas had become so popular that when Charles Darwin's *Origin of the Species* was published in 1859, it became a best-seller, highly popular among the middle class. Darwin presented a scientific theory of biological progress that was interpreted as rationalizing the supremacy of humanity over animals and the supremacy of contemporary humanity over past forms. These theories soon turned to explanations of the supremacy not only of contemporary humanity over past forms but also of certain contemporary groups of people over other contemporary groups. Social scientists thought they had discovered the "living stone age" within the new world.

Darwin's theories of biological evolution generated a range of theories regarding social and cultural evolution as well. These theories sought to understand the stages through which societies passed in the process of "evolving" toward their present state. In addition, these theories sought to classify existing races and cultures in terms of the stages they had reached in the overall evolution of humanity (Branson & Miller, 2002). Scientists used the comparative method, rooted in the belief that contemporary “primitive” cultures were like “living fossils,” similar to early stages of currently advanced societies, to determine the stage of evolutionary development for a specific society or group of people. Thus, the evolutionary history of Western society was examined and documented within the context of the existing, contemporary primitive societies (Lee & Zaharlick, 2013).

Linguists of the late 19th century applied evolutionary theory to language theory and developed what is called “linguistic Darwinism,” arguing that inferior languages died out and were replaced by superior languages in the linguistic “struggle for existence” (Baynton, 1996, p. 40). Although early human languages could not be studied directly, anthropologists of the 19th century began to see the so-called “savage races” as examples of earlier stages of linguistic evolution. Africans, American Indians, Australian aborigines, and Deaf people came to be seen as “living fossils” left behind by more rapidly progressing cultures (Baynton, 1996, p. 41). Linguistic Darwinism ostensibly provided scientists with a way to study “early” human cultures and languages. Darwin himself wrote about sign language and gestures as a form of communication used by deaf people and savages. The use of sign and gesture was thought to be used in inverse proportion to general culture, and the most notable criteria for distinguishing between “civilized” and “savage” people were found in the “copiousness and precision of oral language” (Baynton, 1996, p. 42).

Given the assumption that sign language was an earlier form of communication from which oral communication later evolved (Baynton, 1996), the move toward oralism was seen as a positive step in evolutionary development (Branson & Miller, 2002) and the use of sign language was seen as a step backwards. Baynton writes that society’s categorical acceptance of evolutionary theory made it possible for some to argue that since sign language *should have been* superseded by speech, it was deserving of extinction. This kind of thinking would impact deaf lives throughout the next century, namely through targeted changes made in the educational system for deaf children. Explicitly,

> Just as sign language had been supplanted by speech in the advance of civilization, so too was the use of sign language in deaf education – "like all the ideas of a cruder and less advanced age" – being rendered unnecessary by progress. (p. 45)

Through statistical science, the concept of *normalcy* emerged and replaced the earlier concept of the "classical ideal" to which humans should aspire (Bauman, & Murray, 2010). This change was accompanied by an understanding of the importance that the majority of the population should be part of the norm (Davis, 2006).

The creation of "normal." Creation of the ideology of normalcy was spearheaded by Auguste Comte (1798-1857), known as the father of scientific sociology (Branson & Miller, 2002). Once constructed, the identified *normal* organizes our understanding of all other variations by moving us to conceive all other outcomes as violations or variations of the norm (Simon, 1996). The power of *normal* lies in its ability to establish a difference and then to transform this difference into either deviance or variation. Branson and Miller (2002) attested that in Comte's positivism, the quality of the normative order in social and natural phenomena was a highly desired condition. As normality became equivalent with the "order of things," deafness was viewed as a deviation from the norm and a deficiency. Additionally, as the concept of normality entered the language of everyday life as well as the language of science, the distinction between normality and pathology became a vital source of social control. Branson and Miller (2002) argued, however, that no "pathological" population could exist until being culturally created. The concept of normality is always dependent on its opposite and in constant need of reaffirmation. It was also during this time that the focus of medicine changed. Scholars argued that whereas medicine in the 18th century had been focused on health, the medicine of the 19th century was more concerned with normality.

Education and the politics of "normal." As the full force of philosophical thought and scientific "advancements" focused on the deaf population, the goal to "normalize" deaf children through the mandatory use of speech within the existing school systems became common. It was believed that by doing this, science was "ensuring the evolution of humankind and its ascension to a higher order of life" (McCullough & Duchesneau, 2016, p. 723). The movement to remove sign language from *all* schools for the deaf, to be replaced *exclusively* with lipreading and speech, began in the 1860s (Baynton, 1993). In 1882, however, 93 percent of deaf students were still being taught via ASL in the U.S. (Van Cleve & Crouch, 1989). Additionally, almost half of all deaf educators were deaf, meaning that education still occurred in the students' native language, and it was still generally understood by those working within the school system that it was not possible to educate deaf children without a thorough knowledge of the students' primary language (Lane, 1999). The monumental task of removing sign language from schools for the deaf, which ultimately disempowered the deaf population, was made possible by two crucial events: 1) the second International Congress of Education of the Deaf in Milan in 1880 and, 2) the vigorous crusade of Alexander Graham Bell (Jankowski, 1997). These crucial events mark the shift from sign language to oralism in deaf education in both the U.S. and abroad.

Conference of Milan 1880. Lane (1999) identified the Milan Congress in 1880 as one of the most significant events leading to the marginalization of deaf individuals in modern society. To understand how this process occurred, it is necessary to look at events leading up to the Congress.

The worldwide movement to replace signed languages with majority spoken languages struggled to take hold until late in the 19th century. Lane (1999) wrote that the oralist movement gained momentum, however, when a group of 54 hearing, predominantly French, educators of deaf children met in Paris at the French Exposition in 1878. No deaf educators were included, even though at the time, in France and elsewhere, the majority of educators of deaf children were deaf. The group called itself the First World Congress to Improve the Welfare of the Deaf and the Blind and proclaimed that only oral instruction could restore deaf people to society. They further declared that "preference should be given to the method of articulation and lip-reading, rather than to sign language and fingerspelling, in the education of deaf children" (Van Cleve & Crouch, 1989, p. 108). Despite the group's small number, the meeting attracted attention to the growing debate and controversy over the best way to educate deaf students.

With a goal to conclusively resolve the oralism vs manualism debate, a second and larger meeting was scheduled for Milan in 1880. Oralists in both France and Italy began to lay the groundwork for the second congress (Van Cleve & Crouch, 1989). French oralists prevailed on the government to issue a report stating that sign language lacked grammar and that its use prevented deaf people from understanding French. The head of the Paris Institution, who supported sign language, was fired and replaced by a medical doctor who supported oralism and had no understanding of sign language. The Minister of the Interior ordered all schools supported by the French government to use oral French and not *Langue des Signes Française* (LSF) or fingerspelling. In Italy, Catholic clerics dominated the field of deaf education, where a concerted campaign to support oralism had been underway since the 1870s.

The Second World Congress, held in Milan in 1880, was larger than the first, both in the number of attendees and countries represented. A total of 164 delegates attended, primarily from

Europe. The Congress was little more than a partisan rally conducted by opponents of sign language (Lane, 1999). Most delegates were already staunch supporters of the oralist viewpoint prior to attending, with the atmosphere of the convention described as "rivalling religious fervor" (Gannon, Butler, & Gilbert, 2011, p. 359). As with the first Congress, deaf persons were both not invited and banned from attending (Lane, 1999).

The goals in Milan were twofold, to champion the benefits of oral education and to proclaim the dangers of sign language (Radutzky, 1993). The U.S. had the largest system of schools for the deaf in the world (Monaghan, 2016) but only five delegates in attendance. These five delegates "represented 51 schools with a total enrollment of over 6,000 students, more than the number of students represented by the other 159 participants combined" (Gannon et al., 2011, p. 64-65). The U.S. delegation stood nearly alone in the belief that sign language should be used as *an* instructional method (Van Cleve & Crouch, 1989). The Americans and one English delegate favored a combined system that utilized "both speech and sign language depending on the needs of the child" (Gannon et al., p. 65). Globally, the Milan conference was significant because nations *worldwide* honored the resolution, passed at the conference, to teach deaf students via *only* oral methods. This resolution read in part:

> The convention, considering the incontestable superiority of speech over signs, (a) for restoring deaf-mutes to social life, and (b) for giving them great facility of language, declares that the method of articulation should have the preference over that of sign in instruction in education of the deaf and dumb. (Monaghan, 2016, p. 173)

The worldwide shift and commitment to oralism with the accompanying commitment to the eradication of sign language in deaf education programs had been made. Supporters of oralism used the resolution as a major tool in their fight against sign language (Monaghan, 2016). Further, the Milan Congress seemed to give international approval to the idea that deaf children should be forced to communicate without sign language. The influential London *Times* newspaper asserted that there was a "virtual unanimity of preference for oral teaching" among teachers of deaf pupils (Van Cleve & Crouch, 1989, p. 110). Van Cleve and Crouch add that teaching deaf people how to talk "seemed a miracle of modern pedagogy," which reassured people that society was indeed progressing (p. 110). This sensationalism created a renewed push for oralism, which, unfortunately, was based on a general lack of knowledge about deafness.

The effects of the Milan Congress lasted for more than a century and were felt instantaneously in deaf schools and communities around the world (Lane, 1999). Many deaf teachers were forced to resign or retire immediately. Those not immediately forced out were ultimately replaced by people who had no knowledge of sign language or the deaf community. In 1867, the U.S. had 26 institutions for educating deaf children; ASL was the language of instruction in all of them. By 1907, there were 139 schools, and ASL was used in none of them. Other countries showed similar trends. In 1845, France had 160 schools for deaf children, all of which used LSF, but by the turn of the century, the use of LSF was not permitted in any of these schools.

With the oral mandate in place, it was deaf, signing teachers in schools for the deaf who were effectively handicapped and who became the linguistic outcasts (Lane, 1999). Milan marked a very clear change in the overall conceptualization of the education process as it applied to deaf people (Branson & Miller, 2002). Education that had previously been about the acquisition of knowledge was now focused primarily on the production of speech. The "vocal utterance" was seen "as a passport to the hearing world" (Branson & Miller, p. 168), and the entire goal of education was now focused "on the transformation of deaf people into pseudohearing people" (p. 173). Oralists sought to develop the social skills of deaf students that would make them as similar to hearing children as possible, allowing them to better fit into hearing American society. This goal replaced the traditional educational objectives of fact-based learning and the development of students' analytical skills (Van Cleve & Crouch, 1989).

Oralism and Alexander Graham Bell. Scientist and inventor Alexander Graham Bell became an ardent supporter of oralism. His reputation added credibility to the movement and helped play a role in its spread from the scientific and philosophical realms to a broader and more general population. Bell's prominence afforded legitimacy to his statements about deaf people that frequently had little to do with accuracy (Branson & Miller, 2002).

Bell, a native of Scotland, immigrated to Canada in 1870, and came to the United States in 1871 to teach articulation to deaf students using a system called "Visible Speech" invented by his father, Alexander Melville Bell (Moores, Miller, & Corbett, 2009; Van Cleve & Crouch, 1989). The invention of the telephone, which made Bell both wealthy and famous, was achieved in the pursuit of an amplification device for deaf persons (Roots, 1999). In addition to professional connections with the deaf community, Bell also had personal connections. Both his mother Eliza Bell (1809-1897) and his wife Mabel Hubbard Bell (1857-1923) were deaf to varying degrees. Bell's mother was generally able to follow one-on-one conversations and could play the piano, although her hearing was so weak that Bell grew up using the two-handed English manual alphabet (BSL) to communicate with her in situations where she could not hear conversations. His wife, a former articulation student, could not hear at all (Van Cleve & Crouch, 1989), although she was highly literate and excelled in speechreading in both English and German (Monaghan, 2016). Both of these individuals became Bell's role models for the "ideal deaf person" (Monaghan, p. 175): both were born hearing, became deaf in childhood, and retained some speech.

In the early stage of Bell's professional career, he did not believe speechreading to be effective with deaf students. Considered a fluent signer (Gannon et al., 2011), Bell communicated via sign language or in writing with his deaf students (Van Cleve & Crouch, 1989). As Bell's opinions about the use of sign language changed, however, he spearheaded the oralism campaign to have all deaf Americans educated through speech only methodologies. George Veditz, a prominent Deaf leader and two-time president of the National Association of the Deaf (NAD), described Bell as one who "comes in the guise of a friend, and [is], therefore, the most to be feared enemy of the American deaf, past and present" (Gannon et al., 2011, p. 77). Van Cleve and Crouch (1989) wrote:

> To hearing people Bell is best known for his invention of the first successful telephone, but to deaf people in the late nineteenth and early twentieth centuries he was best known as their strongest adversary in the controversy over sign language. (p. 114)

Bell further believed that deaf people weakened society genetically and that the growth of an American deaf community would be disadvantageous to the U.S. By the 1880s, Bell, who had both time and wealth, began to focus his efforts on discovering a means of preventing the birth of deaf children. At this point in time, "Bell specifically engaged the issue of eugenics and the deaf population" (Lane, 1993, p. 285).

Identified as "American's foremost oralist" and an extreme Darwinist, Bell believed that all social relations could be explained by evolutionary theory (Baynton, 1993, p. 97). He wrote and presented a paper entitled *Memoir upon the Formation of a Deaf Variety of the Human Race* to the National Academy of Science in 1883 (Gannon et al., 2011; Moores et al., 2009; Van

Cleve & Crouch, 1989), in which Bell noted that "man was able to modify breeds of animals by careful selection, and he reasoned that it should be possible similarly to modify the varieties of the human race" (Gannon et al., 2011, p. 75). In conclusion, the *Memoir* suggested that "the intermarriage of congenital deaf-mutes… should result in the formation of a deaf variety of the human race.... And that the production of a defective race of human beings would be a great calamity to the world" (Van Cleve & Crouch, 1989, p. 146).

To prevent the rise of this "deaf variety" of humans, Bell believed that it was important to minimize contact between deaf people (Greenwald, 2016, p. 164). Once isolated and separated from one other, deaf people would be forced to think and act like hearing people (Van Cleve & Crouch, 1989) allowing for the goal of integration into hearing society. To ensure success, contact between deaf people needed to be limited at several junctures, beginning with the school system (Kimura, 2016). Bell also actively worked to prevent deaf intermarriage.

In 1884, Bell published an article entitled *Fallacies Concerning the Deaf* (Moores et al., 2009) in which he suggested three "preventative measures": 1) eliminating residential schools, 2) prohibiting the use of sign language in the education of deaf pupils, and 3) prohibiting deaf adults from teaching deaf children. Bell argued that these steps would encourage deaf people to stop signing and to develop and use their oral skills, making them seem less deaf and more able to assimilate into the hearing community. These measures also had the advantage of appearing to be educational reforms, which fit "within the American tradition of using the schools to achieve social goals that could not be reached through coercion" (Van Cleve & Crouch, 1989, p. 148).

Bell contributed $25,000, an enormous sum of money in 1890, as an endowment for the American Association to Promote the Teaching of Speech to the Deaf (AAPTSD) (Van Cleve &

Crouch, 1989). AAPTSD became the vanguard of the American pure oralism movement. One of its projects was the construction of a journal created to counter articles published in the *American Annals of the Deaf*, a journal controlled by people in favor of the use of sign language. Originally called the *Association Review*, today it is called the *Volta Review.* Van Cleve and Crouch (1989) wrote:

> [Bell and the AAPTSD] willingly supplied information to parents of deaf children and to state legislators and journalists interested in issues related to deafness. In this way, oralist hoped to build broad public support for their policies and beliefs, and they were generally successful. (p. 122)

Van Cleve and Crouch (1989) identified that the most important external influence on deaf schools were the parents, and hearing parents of deaf children have been especially responsive to the arguments of oralism. Wishing their children to be "normal" and like themselves, many parents, even today, feel that oralism holds the best possibility for this. If their deaf children could learn to speak and read lips, parents reasoned that they could fit in with their family and would remain part of the culture and community that the parents understood. If, however, children grew up signing, they might not be able to communicate with their family and would potentially join a community that excluded the parents. "Whatever the objective truth of these ideas, they were widely held in the late nineteenth and early twentieth century. The AAPTSD, and Bell personally, made every effort to convince parents of their validity" (Van Cleve & Crouch, 1989, p. 126).

Bell's influence changed the course of Deaf education in the United States, resulting in the erosion of the use of ASL, the proliferation of oral-only methodology, and a steady decline in the number of deaf teachers (Moores et al., 2009). From the 1880s into the 20th century, teachers, school administrators, and others changed their attitudes toward the relative value of speech and sign language. Van Cleve and Crouch (1989) wrote that in 1882, only 7.5 percent of the 7,000 students in American schools for deaf children were taught orally. By 1900, this number had increased to 47 percent. The year 1905 marked the first time in American history that the *majority* of deaf students were educated without the benefit of sign language. By 1909, nearly 80 percent of all deaf students were receiving their education through speech, speechreading, and writing only.

Bell was correct in recognizing that institutions of the deaf community, such as schools, allowed deaf individuals, most of whom were from hearing families, to find one another, socialize, and marry. Without these organizational and cultural links, deaf Americans would have remained isolated (Van Cleve & Crouch, 1989). Specifically, sign language, deaf organizations, and residential institutions assisted deaf Americans in creating and perpetuating their own culture, "one in which their concerns and interests – rather than those of hearing persons – predominated" (p. 147).

Paradoxically, and despite his views on oralism, Bell was aware of the "benefits" of deaf people who live near to one another and who used sign language together. In the 1890 United States Census Special report on the Blind and Deaf, organized by Bell, it was noted:

> Deaf people from residential schools "are mainly responsible for the fact that the deaf from childhood no longer constitute a dependent class," and those deaf people who used sign language they had learned at residential schools were "more self-supporting than the deaf from adult life." (Greenwald, 2016, p. 165)

More than a hundred years later, Bell's influence is visibly evident in the medical model of education that prevails (Moores et al., 2009). Deaf students are educated primarily with hearing students; cochlear implants (CIs) are advertised as “cures” for deafness; there are relatively few deaf teachers and administrators in the public schools; and hearing parents are often still encouraged not to use sign language with their deaf children under the auspices of improving their child’s oral language abilities (Mauldin, 2016).

Scholars have been uniformly critical of oralism (Baynton, 1996), noting that there is little evidence that deaf people were unwilling to learn to speak but strong evidence to suggest that they were unwilling to communicate *only* through speech (Ladd, 2003). Baynton contends that many oralists were woefully ignorant of deafness, their faith in oralism based more on wishful thinking than evidence. Others, such as Bell, were more knowledgeable but motivated by eugenicist ideals and fears that intermarriage among deaf people, separate schools, and the use of sign language would lead to a formation of a “deaf variety” of the human species. Undoubtedly, Bell’s prestige, leadership abilities, financial support, and dedication to the cause provided a tremendous boost to oralism. Opponents of sign language believed that signing inhibited the learning of oral communication skills, and hearing parents, eager to believe their deaf children could learn to function like hearing people, supported its prescription. State legislators were persuaded by claims that oral education would be less expensive, and, finally, the fear of human diversity played a role. Baynton (1996) wrote that fear of diversity leads majorities to oppress minorities and that the suppression of sign language is yet “another example of the suppression of a minority language by an intolerant majority” (p. 6). Ladd (2007) also pointed out that during this 100-year period, there was virtually no nationwide research into the results of oralism policies until 1979.

Thus, we arrive at a state in which Deaf people are predominantly viewed as incomplete by people within the broader society. They are prescribed, viewed, categorized, and predominantly studied through a disability lens rather than a Deaf cultural lens.

Deaf vs Disability Categorization

The term disability encompasses a broad range of physical and mental conditions that are considered to be impairments by society and which inhibit or limit normal daily activities. One important defining characteristic of a disability is that it deviates from what is considered "normal" by mainstream society (Johnson & Nieto, 2007). Like disabled people, Deaf people dislike being objectified or viewed merely in terms of needing medical treatment (Padden & Humphries, 2005).

Lane (2005) explored the pros and cons of deaf vs disability categorization for persons who are deaf and argues that the overwhelming reason to reject the disability categorization of culturally Deaf people relates to how Deaf people view themselves. Specifically, there is no higher authority on how a group should be regarded than from group members themselves. Although people who have grown up Deaf and have become integrated into Deaf culture are naturally aware of their biological difference, they do not, as a rule, see that difference as a reason to consider themselves members of a disability group.

In the U.S., however, many services and rights of deaf people have been placed under the purview of disability. A fact which likely contributes to the general non-acknowledgment of the cultural paradigm by many. This is also problematic for Deaf people who must then decide whether to retain some important rights as members of society at the expense of being mischaracterized by that society or to surrender some of those rights in the hope of gradually undermining that misconstruction. Lane (2005) argued that embracing the disability label in hopes that it might assist Deaf people in gaining more of their rights is fundamentally flawed. Deaf people do not believe themselves to be disabled, to surrender to how others define them is to misrepresent themselves, yet another reason to reject the disability label. Holcomb (2013) explained:

> Deaf people have long considered themselves as independent and capable, and not defined by a deficit model. When they look in the mirror, they do not see disability. When Deaf people congregate among themselves, they do not feel disabled. Yet, society has consistently viewed deaf people as disabled. (p. 4)

It can be argued that deafness is categorized as a disability only if this condition runs counter to the sensory and physical expectations and demands of that society. Therefore, "deaf as disabled" is not a natural but rather a cultural construction (Branson & Miller, 2002, p. *xi*). Evidence of this constructed nature can be seen with the signing-fluent community of Martha's Vineyard (Groce, 1985), where for over 200 years sign language was used by everyone in the community, both hearing and deaf alike. Hearing and deaf people lived and worked together side by side in an integrated manner, with neither hearing status being more prestigious than the other. The hearing people on the island were bilingual in English and the Island sign language, and no one considered deafness to be a handicap (Whiting, 1985).

Official recognition of native sign languages has been an important precursor to the shift in perception of deaf people as people with a disability to members of a linguistic minority in parts of the world. British Sign Language (BSL) gained official full language status in 2003, and New Zealand Sign Language gained official status in 2006 (Komesaroff, 2008).

Corker (2000) argues that Deaf Studies and Disability Studies have little in common conceptually, and in many ways, their worldviews are in direct opposition to one another. There are, however, a few areas of similarity: 1) Within hegemonic discourse, both Deaf and disabled people are viewed as people with impairments; 2) Each discipline can be viewed from either the medical / pathological or the cultural / sociocultural paradigms (Paul & Moores, 2012); and 3) Both disciplines consider the "politics of visibility" to be important (Corker, 2000). The *politics of visibility* relates to the visibility the body has within a society and its value, or the importance ascribed to it by society at a given time. This definition occurs at both individual and corporate levels. Visible bodies are ones that are deemed important and are taken seriously by society, thereby providing them with both individual and institutional power. Conversely, bodies that are not visible and do not garner the same attention are left without power, leaving them vulnerable to erasure and marginalization. This bifurcation occurs when a society is stratified along the lines of gender, race, class, sexuality, age, disability status, citizenship, geography, and other areas of divide, such as one's hearing status (Casper & Moore, 2009).

The problem with incorporating deafness within the disability paradigm is that deaf people are conceptually distinct linguistically, socially and ideologically (Corker, 2000). Ladd and John (1991) argue that the disability label demonstrates a failure to understand "that we are not disabled in any way within our own community," adding that disabled people are viewed as "'hearing' people in that they use a different language to us, from which we are excluded, and [we] see them as being members of society's culture" (as cited in Corker, p. 24). To constrain Deaf Studies to the Disability Studies category results in fundamental ideological components of Deaf Studies being minimized or denied. The concept of inclusion is a prime example.

Inclusion

Problems with the concept of inclusion for deaf people occur throughout the lifespan. Two examples will be discussed: education and housing.

Education. Problems with the construct of inclusion are exemplified in the educational arena. Educational inclusion began in the 1970s when Congress passed legislation targeted at ending discrimination against disabled individuals. This included the Rehabilitation Act of 1973 and the Education for All Handicapped Children Act (Public Law 94-142), which was passed in 1975 and later became known as the Individuals with Disabilities Education Act (IDEA) (Fisher & Mattiacci, 2008). To ensure that students with disabilities were not discriminated against, Section 504 of the Rehabilitation Act of 1973 mandated that school provide “free and appropriate education” (FAPE) to all students identified as disabled. The IDEA mandated that children with disabilities be educated in the “least restrictive environment” (LRE) possible. The term “least restrictive” was defined by federal government legislation as follows:

> To the maximum extent appropriate, children with disabilities…should be educated with children who are not disabled, and…special classes, separate schooling, or other removal of children with disabilities from the regular educational environment should occur only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. (Fisher and Mattiacci, p. 77)

This legislation was claimed as a victory for disabled children, as the mandate for “inclusion” required that disabled children be included in the “mainstream” of education, rather than being segregated. For the deaf child, however, the problem with this solution is that in the educational setting, the deaf child has different linguistic needs from other children (Fisher & Mattiacci, 2008). Siegel (2000) explained:

> The law and policy that should open doors for deaf and hard of hearing children do quite the opposite. Under the LRE mandate of the Individuals with Disabilities Education Act

> (IDEA), a rich language environment is not required and indeed is often considered legally “segregated,” whereas a communication-poor environment is often viewed as legally “inclusive.” For many deaf and hard of hearing children, education is therefore a kind of Alice in Wonderland experience, where up is down and inclusion means exclusion. (p. 64)

This situation is not limited only to education, but rather occurs throughout the lifespan. Housing is another arena in which integration creates problems.

Housing. Housing that is “inclusive” creates an isolating environment for persons who are deaf. In an effort to effect change the president of NAD (2013), Christopher Wagner wrote to the secretary of the U. S. Department of Housing and Urban Development (HUD), Shaun Donovan. The letter stated in part:

> Due to the unique communication needs of deaf and hard of hearing people, many of them exist in isolation in inaccessible housing where there is no one else to communicate with in sign language. These residents therefore experience extreme loneliness and depression, and their quality of life is deplorable. (para. 5)

This letter was written partially in response to legal action attempting to integrate hearing people into a deaf specific community. Wagner continued:

> In a nutshell, your agency, HUD, is forcing deaf and hard of hearing individuals to only live according to an ideological vision of forced integration. The tragic irony is that such an ideology has punished deaf and hard of hearing individuals seeking a higher quality of life and a safer place to live and has actually resulted in the forced isolation of individuals who are deaf and hard of hearing. (para. 2)

Given that Deaf Studies and Disability Studies are frequently linked together, despite their differing views, it will be useful to deconstruct each. In the next section, the academic fields of both Deaf and Disability Studies will be discussed and compared.

Deaf Studies and Disability Studies

The academic field of Deaf Studies consists of interdisciplinary approaches to the exploration of Deaf individuals, communities, and cultures as they have evolved within a larger context of power and ideology (Bauman & Murray, 2010). The curricula include perspectives from anthropology, linguistics, literary theory, and bilingual education, as well as other cultural studies practices including gender, disability, and ethnic studies. Despite this wide diversity of disciplines and multiple perspectives, the field's fundamental orientation comes from the belief that "deaf people are not defined by their lack of hearing, but by linguistic, cultural, and sensorial ways of being in the world" (Bauman & Murray, p. 210).

Similarly, the field of Disability Studies encompasses a broad arena of theory, research, activism and practice (Goodley, 2016). It contests the view that disability is equated with human failings and places the concept of disability firmly in the social arena. Specifically, "disability becomes known when impairments interact with their environments" (Goodley, p. *xi*).

Corker (2000) extensively studied and compared established Deaf Studies and Disability Studies programs within the Academy. Table 1 is a partial representation of the findings.

The phrase "community of social practice" is used to describe academic work within each specific discipline. Corker reasons that academic work is collective in the sense that people within disciplines tend to adhere to a loosely defined set of common goals and ideas, and as such, academic disciplines can be described as communities. Furthermore, academic work is constituted in and through the social practice of academics and those whom they research and write about.

Table 1

Social Practice in Deaf Studies and Disability Studies

	Deaf Studies	**Disability Studies**
Language	Sign	Speech/ text
Discourse on the body (self)	The body is beautiful The fit, healthy body (Deaf)	Disabled
Community structure	Relational Collectivism	Aggregate Individualism
Community boundaries	Fixed	Fluid
Cultural	Visual-spatial	Auditory, oral, production
Relationship to 'society'	Social co-existence	Social inclusion
Ontology	Linguistic minority	Social category
Epistemology	Being *Deaf* is a natural occurrence	*Disability* is socially constructed

Note. Adapted from Corker (2000, p. 4).

Some of the Deaf Studies vs Disability Studies categories are self-explanatory, while several need a bit more elaboration. Regarding *language*, the difference between speech and sign is obvious. It is important to note, however, that ASL is unique in that it is not a written language. Crasborn (2015) describes that sign languages can be characterized as unwritten languages in the sense that there are no Deaf communities that have a written tradition. Additionally, the structure of ASL is distinctly different from that of the English language, making communication via written form potentially challenging. The *discourse on the body* category is related to the c*ommunity boundaries* category. People who identify as disabled generally want to "fix" the problem and rejoin the ranks of the "normal" or non-disabled. This makes their position fluid in that if the problem is fixed, the individual is no longer considered disabled. Deaf people, (although not necessarily all deaf people), conversely, have no desire to become hearing (Ladd, 2003). Being Deaf is considered very positive, to the extent that there is, in fact, a gain from being Deaf (H-Dirksen, Bauman, L., & Murray, 2014). Because of this, for many, there is no desire to become hearing, and thus the community boundaries are fixed. The *relationship to society* category relates to the desire of each group to assimilate into everyday activities. Again, mainstream education is a prime example. Disabled people have demonstrated a desire to integrate to the greatest extent possible. But because integration often leads to social and communication isolation for the deaf individual, social co-existence is seen as a much-preferred option. The category of *community structure* refers to the individualist and collectivist worldview. Hofstede (1991) defines these worldviews as follows:

> Individualism pertains to societies in which the ties between individuals are loose: everyone is expected to look after himself or herself and his or her own immediate family. Collectivism as its opposite pertains to societies in which people from birth onwards are integrated into strong, cohesive in-groups, which throughout people's lifetime continue to protect them in exchange for unquestioning loyalty. (p. 51)

In providing support for the collectivist nature of the Deaf community, Holcomb (2013) wrote that Deaf people are expected to be fiercely loyal to the Deaf community, be actively involved in community affairs, spend much of their time with Deaf friends and at community events. This expectation is true even among those deaf people who learned sign language at a later age or have never attended a deaf school.

In conclusion, deaf people have been understood and viewed predominantly from a disability perspective for many years, despite the foundational differences in Deaf and Disability orientations and despite the continued adherence to a cultural orientation from members of the Deaf community. Deaf culture will be discussed in the following section.

Deaf Culture

With hundreds of published definitions available for the term "culture" (Reeves-Ellington, & Yammarino, 2010), both defining the construct and conducting cultural research can be confusing (Hughes, 2010). At its simplest, however, culture is knowledge based on self-understanding, gained through engagement with people (Fisher, 2007). Cultural systems must have both a minimum degree of coherence and be able to make the argument that life is better for individual members because of their group association (Geertz, 1994). Culture is characterized by openness and is ever evolving (Fisher, 2007). Additionally, culture encompasses objects and symbols, the meanings attributed to these objects and symbols, as well as the norms, values, and beliefs that set the cultural boundaries and are recognized within the community and constructed by it (Reeves-Ellington & Yammarino, 2010).

The term "Deaf Culture" emerged late in the 1970s from hearing academic circles (Ladd, 2003), occurring after ASL was recognized as a legitimate language in the 1960s (Corker, 2000). The actual *concept* of Deaf culture itself has been around since at least the 1700s (Leigh et al.,

2018) and has long been recognized and understood by persons in the Deaf community (Humphries, 2008). In 1912, George Veditz, a Deaf man, wrote about himself and his community as “First, last, and for all time, the people of the eye” (Padden & Humphries, 2005, p. 2), indicating that the lives of Deaf people are heavily oriented toward the visual. Active engagement in practices associated with the visual is an important aspect of Deaf culture. Deaf people are guided by a central “core of seeing” that incorporates both visual knowledge and “seeing” and comes from a long history of interacting with the world in certain cultural ways (Padden & Humphries, p. 2).

The exact nature and constitution of Deaf culture have been described as “hotly contested and socially negotiable issue” (Horejes & Anderson, 2016, p. 914). It was the distinction between the audiological and cultural issues of deaf people that first created space for the Deaf internal life to be examined (Ladd, 2003). Without this “D/d” differentiation, Ladd argued that even sociological accounts tend to focus on audiological ways in which deaf people are outsiders, rather than giving full focus to what they have developed in their collective lives.

One model placed the core of Deaf culture at the center of four overlapping Deaf community membership criteria, each of the following areas playing an important role: 1) audiological, having a hearing loss; 2) linguistic, using sign language; 3) social, participation in Deaf social life; and 4) political, influence in community organization (Baker & Cokely, 1980).

American academic Deaf writers have since taken the *social* category and renamed it *cultural*, and have focused on examples of norms, values, and traditions (Ladd, 2003). The resulting model and its distinct and overlapping elements are illustrated in Figure 2.

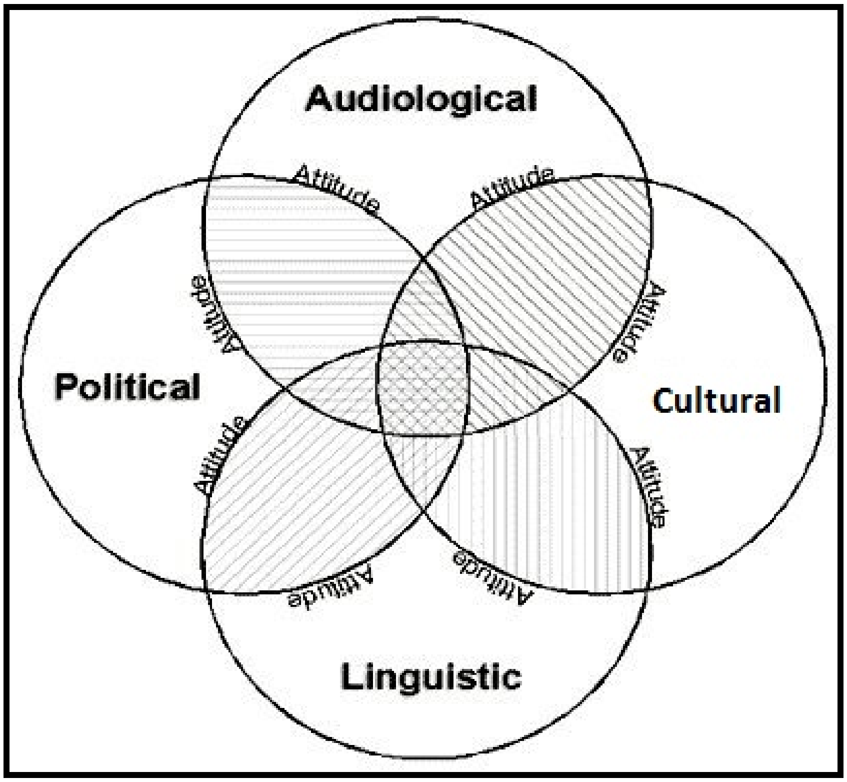

Figure 2. The core of American Deaf Culture.

On the surface, there may seem to be little to demarcate Deaf culture from other cultures, as Deaf people dress, eat, and worship just like their fellow citizens who hear (Holcomb, 2016). Yet, when the experiences of Deaf people are examined on a deeper level, many unique cultural aspects become apparent. Holcomb elucidated that while traditional definitions associated with Deaf culture have included prerequisite experiences for the individual that comprise residential school experience, prominence of Deaf clubs, and the importance of sign language, many deaf people today do not grow up with these experiences. Presently, deaf children are more likely to attend public school, which limits both contacts with deaf peers as well as exposure to sign language, and many Deaf clubs have ceased to exist.

Rather than being obsolete, however, Deaf culture is now more important than ever before (Holcomb, 2016). As true of all cultures, Deaf culture is rich with historically created solutions for effective living that are passed from generation to generation. Holcomb (2013) argued that without access to the Deaf community, deaf children are devoid of resources and strategies that can be used to navigate and survive in a world populated with people who are different from themselves, stating that "the core of Deaf culture consists of solutions for effective communication, access to information, validation of the Deaf experience, and complete acceptance of being Deaf as a normal existence" (p. 102). Although the educational and social environments have changed for deaf persons over the last century, the historically created solutions for effective living vis-à-vis Deaf culture remain the same (Holcomb, 2016). These include full access to communication, information sharing, health identity formation, and self-determination.

Cultural solutions for effective living can be delineated into three categories: explicit, tacit, and emblematic. Holcomb (2016) describes each category and advances specifics relevance to Deaf culture within each. Explicit solutions reveal the group's values and expectations clearly and explicitly. They may be stated in formal documents and voted on by members. Examples of explicit solutions might be found in a group's constitution or by-laws, which reflect the values of the community. Most cultural norms are not stated explicitly, however. Rather, members of the culture tacitly understand the expectations. The final category involves behaviors that are typically associated with a culture or those that are considered emblematic of the group. Although emblematic behaviors are strongly associated with the group, members of the community do not universally practice these actions.

Holcomb (2016) suggested that in the case of Deaf culture, there is little explicit demarcation of cultural values. One clear exception, however, is the value of self-determination. Specifically, Deaf people have found it necessary to assert their political voice to ensure that their needs and issues are addressed; "otherwise, Deaf people face the consequences of dealing with ill-conceived policies imposed on them by well-meaning people who have limited understanding of the Deaf experience" (p. 163). The consistency of this problem over the last two centuries has given rise to the value of self-determination among Deaf people.

Because Deaf people have continually found it necessary to assert that the best solutions for effective living come from themselves, many Deaf-run organizations have by-laws that explicitly limit leadership opportunities to Deaf people, while welcoming hearing people to the organization's general membership (Holcomb, 2016). It is not unusual to see policies requiring that an organization's officers be Deaf or that a 51% Deaf majority be maintained on boards that serve members of the Deaf community.

Athletics is another area within the Deaf community where expectations and hearing status are explicitly stated (Holcomb, 2016). In most situations, the specifics of a Deaf person's hearing levels (e.g., decibel loss) is not seen as relevant to their identities or daily lives. Instead, one's ability to sign is much more important. However, at events such as the Deaflympics or the annual Deaf Basketball Championships, where athletic completions are taken very seriously, participants must verify that they are deaf enough by showing their certified audiograms. The reasons for this explicit requirement are two-fold. It ensures that Deaf athletes are not denied opportunities to compete and can enjoy the experience of being in a barrier-free environment. It also prevents outstanding hearing athletes from competing in Deaf events.

Most Deaf cultural rules are tacitly understood by Deaf community members. They are largely associated with the core values of full access to communication, information sharing, and healthy identity formation among members of the Deaf community (Holcomb, 2016). Full access to communication is made possible *only* by sign language for many Deaf people (Holcomb, 2013, 2016; Ladd, 2003; Padden & Humphries, 2005), which is why ASL continues to be an enduring cultural value. Information is often difficult for deaf people to access due to persistent communication and linguistic barriers between deaf and hearing people, providing a rationale for the importance of information sharing among group members (Holcomb, 2013; Corker, 1998; Mindess, 2014). Matsuoka, Morelli, and McCubbin (2013) suggest that collective cultures, or those oriented toward group behaviors, exist because group members rely heavily on each other for their survival. Holcomb (2016) adds that deaf people have largely assumed the responsibility of filling in gaps for each other by supplying as much information as possible. This action is necessary because most hearing parents either do not know how to sign or have failed to establish an effective communication system at home. Difficulties and limitations associated with speechreading and hearing are additional communication barriers. Consequently, many deaf people miss out on incidental learning, such as information casually shared at dinner tables, in hallways, or in other places outside the formal classroom environment. Information deprivation trauma (IDT) emerged as a recurring theme among deaf participants in a recent, large-scale trauma study conducted within the Deaf community (Schild & Dalenberg, 2016). While IDT can be traumatic in and of itself, it can also lead to an enhanced vulnerability for further traumatization.

Another factor that speaks to the importance of information sharing is that many deaf people leave school with relatively poor English skills, often attributed to the inability of teachers and parents to communicate effectively (Holcomb, 2016). Accordingly, accessing information via printed materials is difficult for many. With limited access to communication in the home and school settings accompanied by weak English skills, Deaf people have made it a habit to support one another by exchanging information as extensively as possible. Deaf people routinely share minute details of everyday life with one another, e.g., details of a medical exam or income tax information. This same information, if shared outside of the Deaf community, might be considered gossip. Within the Deaf community, however, this information serves a definite purpose. The information exchange might include topics related to behaviors that have the potential to cause public embarrassment that is often encountered by deaf people, with the objective to help others avoid being humiliated. For example, bathroom tales are often told and retold in a hilarious manner, reinforcing the need for Deaf people to acquire such minor yet critical information.

Another core value that is tacitly shared by Deaf people is that of healthy identity formation. Holcomb (2016) contended that most deaf people are intolerant of self-pity or sympathy relevant to their hearing status and choose instead to celebrate their Deaf essence. This attitudinal celebration serves as a powerful affirmation for newcomers to the Deaf community who are, perhaps for the first time, being embraced for who they are regardless of their hearing or speech abilities. As Holcomb noted, “no longer do they need to apologize for their deficiencies, but rather they are now celebrated for who they are and what they are capable of doing” (p. 166).

Pride in being Deaf, along with the desirability of Deaf children, is emblematic of Deaf culture (Holcomb, 2016). For many, a deaf child is a cause for celebration, not pity. Also emblematic of the culture is the tendency of deaf people to be blunt, or to engage in what may be described as participating in "straight talk" (p. 166). Given that information sharing is an important cultural value, Deaf people often reveal information in a straightforward manner, rather than "beating around the bush" in conversation as is often done by non-Deaf people. Holcomb posited that the need for straight talk could be traced to Deaf people's frustrations with trying to obtain information as clearly as possible, especially from non-signing people. For example, given the challenge of lipreading, the difficulty for many associated with reading the written English language, and the added challenges associated with the tendency of many hearing people to hedge on an issue, to seem polite, can make trying to obtain information quite frustrating for deaf people. The tendency to practice straight talk in the Deaf community is a source of comfort and is welcomed by Deaf people. Straight talk should not be equated with being rude, however, which is not a Deaf cultural value.

The minimal level of social interaction required to constitute a culture has been identified as the *community* (Anderson, 1983). A comprehensive understanding of culture, therefore, needs to include a discussion of community, both in terms of its members and the spaces they occupy (Reeves-Ellington, & Yammarino, 2010). These aspects will now be discussed, as well as the distinction between Deaf culture and the Deaf community.

Deaf Communities

Community is defined as a feeling of acknowledged fellowship with others that is expressed in structured ways within communal structures (Anderson, 1983). Community requires self-awareness, fellowship within the community, tacit acceptance of ambiguity by not requiring total shared values and experiences, and experiences that are shared in organized ways through agreed structures. They can be tiered within both formal and less formal complex structures. Community members integrate for two purposes: for socialization and for the business of the community (Reeves-Ellington & Yammarino, 2010).

Ladd (2003) posited that the hegemonic construction of a continuum of hearing impairment has resulted in the absence of clear-cut boundaries around the Deaf community. Consequently, attempts to define Deaf communities and Deaf culture have often become circular, e.g., Deaf communities are those which have Deaf culture and Deaf culture is a defining characteristic of a Deaf community. For the sake of specificity, the term *deaf community* has demographic, linguistic, political and social implications (Padden, 1980). There is a national "community" of deaf people who share certain characteristics and may react to events around them as a group, and there are smaller deaf communities in cities and towns throughout the country. Although the phrase "the deaf community" is commonly used (Leigh et al., 2018, p. 12), it is important to note that many communities make up the larger Deaf community (Van Cleve & Crouch, 1989), with much racial and ethnic diversity (Ladd, 2003; Leigh et al.; Woll & Ladd, 2011). When distinguishing between a community and a culture, Padden suggests that "a *culture* is a set of learned behaviors of a group of people who have their own language, values, rules for behavior, and traditions," and a community is a social system in which a group of people live together, share common goals, and carry out certain responsibilities to one another (p. 344). Thus, a person's belief system and actions may be primarily influenced by *culture,* and work and social activities are carried out within the *community*. Using these parameters, a deaf community can include persons who are not Deaf but who actively support the goals of the community and work with Deaf people to achieve these goals.

Padden (1980) suggested that the culture of Deaf people is more closed than that of the deaf community. Members of Deaf culture "behave as Deaf people do, use the language of Deaf people, and share the beliefs of Deaf people toward themselves and other people who are not Deaf" (p. 345), whereas the characteristics of deaf communities include location, language use, and community goals. Each individual deaf community is uniquely affected by its location. For example, the deaf community in Washington, D.C., is influenced by its surrounding political and educational institutions. Deaf people can move from one geographic location to another and enter a new deaf community with relative ease. They carry with them the knowledge of their culture to help them establish new community ties and learn the specific issues and operations of that community. Thus, while there are many different deaf communities across the U.S., there is but a single American Deaf culture with members who live in different communities.

Since a deaf community comprises people from different cultural groups, language use within the community is different from language use within the cultural group (Padden, 1980). For example, in the U.S., variations in ASL have been noted among Black and White deaf sign-language users (McCaskill, Lucas, Bayley, & Hill, 2011). Such dialects naturally develop in languages when people are separated by geographic or social barriers (Rickford, 1999). Padden (1980) suggested that language use at the community level is more flexible than within the cultural group, where it is more restricted. This distinction between *community* and *culture* allows for an understanding of how some Deaf people may accept, respect and use the language of the majority group in community activities, while still preferring the language of their cultural group.

A community is generally understood to be a group of people in a geographic location who share common goals. Yet "Deaf communities do not have their own land or live (or even choose to live) as geographically intimate communities" (Ladd, 2003, p. 175). Padden (1980) posits that the primary goal of the national deaf community is to achieve public acceptance of deaf people as equals, particularly regarding employment, political representation, and control of institutions that involve deaf people, such as schools and service organizations. Prime examples of this include the foundation of the National Association of the Deaf (NAD) in the U.S. in 1880 and of the British Deaf Association (BDA) in 1890 (Woll & Ladd, 2011). Both organizations were founded in response to oralism, and both are still in existence today.

Differing from the Deaf community in a fundamental respect, a s*igning community* is operationally defined as a community where Deaf people use sign language to communicate with either deaf or hearing *co-inhabitants* (Kusters, 2016). These communities differ from mainstream communities where deaf people are mostly surrounded by hearing, nonsigning people.

A great deal of variation exists when considering Deaf communities worldwide. In general, however, these communities appear to be formed in two distinctly different ways, correlating largely with how deaf people have been treated and how signed languages have been viewed by hearing society (Bahan & Nash, 1996). A Deaf community conceptual model will help to clarify this distinction.

Deaf Community Conceptual Model

To make sense of the literature and "to situate the full range of community types" (Woll & Ladd, 2011, p. 161), Woll and Ladd created a multi-dimensional conceptual model of Deaf communities based on attitudes toward sign language, social choices, and size of the Deaf community. Figure 3 is an adaptation of this model.

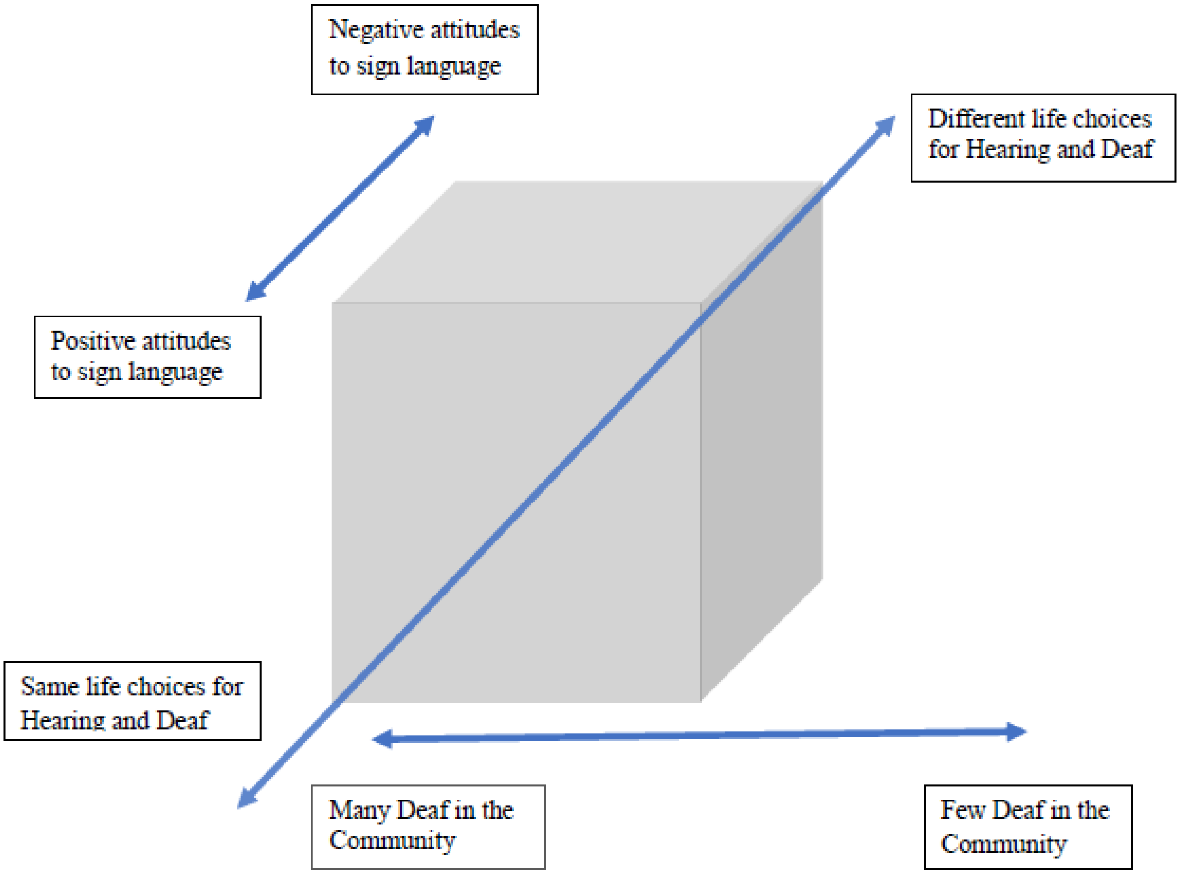

Figure 3. Model of Deaf communities. Adapted from Woll & Ladd, 2011.

Deaf communities have been broadly grouped into two categories, each explaining the typical social and linguistic characteristics of the respective community. Although various names have been used to identify and differentiate these groups, this paper will utilize the terminology put forth by Fenlon and Wilkinson (2015) of macro-communities and micro-communities.

Macro-communities. Other terminologies found in the literature for the macro-community concept include suppressing communities (Bahan & Nash, 1996), differentiating communities (Lane et al., 1996), sign language communities (Padden, 2011), and oppositional communities (Woll & Ladd, 2011). Using the conceptual model, a macro-community is a majority community with few deaf people, negative attitudes toward sign language, and different life opportunities for deaf and hearing people. Therefore, it occupies a position in the upper right rear of the model. In a macro-community, a person's hearing status determines their access to society, resulting in proportionately lower socioeconomic status and educational achievements for deaf persons.

Several characteristics have been identified that contribute to the formation of macro-communities (Fenlon & Wilkinson, 2015). Their emergence is typically spontaneous, largely independent of spoken languages, and often occur against a changing socio-political background. Macro-communities are described as large, stable signing communities that emerged from the European tradition of bringing deaf children together in residential schools (Fenlon & Wilkinson). Schools play an important role in the origin of sign languages in these macro-communities because, typically, in these communities, only 5 – 10 percent of deaf children, those born to deaf signing parents, will acquire sign language in the home (Mitchell & Karchmer, 2004). Because most deaf children are born into hearing, non-signing families, Deaf schools have typically provided the first point of encounter of widespread sign language use for many deaf children. This experience is quite different from the process of language acquisition for hearing children learning to speak. In macro-communities, sign languages are transmitted primarily through peers at school or are learned later in life. These signed languages are minority languages surrounded by the majority, spoken languages. In America, the modern Deaf community can be traced back to the formation of the first schools for the Deaf in the northeastern U.S. in the first half of the 19th century (Rosen, 2016).

Sign languages from macro-communities generally refer to sign languages used across nation states (Fenlon & Wilkinson, 2015). These include, among others, languages such as ASL, British Sign Language (BSL), French Sign Language (LSF, Langue des Signes Françaisе), Japanese Sign Language (NS, Nihon Shuwa). This category may also apply to sign languages located in large urban centers, such as Hong Kong Sign Language and Hausa Sign Language.

The American Deaf community meets the criteria for a macro-community. The American Deaf community came into being over two hundred years ago (Padden & Humphries, 2005). As the 19th-century residential schools brought deaf students together, Deaf people realized that "they were often happiest and most successful among persons who shared their language and perspective" (Van Cleve, & Crouch, 1989, p. 60). Therefore, Deaf signing communities formed because of school ties, where communication occurred freely (Monaghan, 2003). As students finished school and entered the workforce, they often chose to live in areas with other deaf people so that they could maintain social connections (Leigh et al., 2018). Deaf people have created communities based on three factors: deafness, communication, and mutual support (Woll & Ladd, 2011). Deaf people then connected within these communities through friendship, the use of a common visual language, and social gatherings sponsored by religious institutions, sports areas, and deaf clubs. Leigh et al. (2018) posit that it is the rich culture that strongly encourages a sense of community, with sign language as the unifying factor that draws Deaf people together, forming social, psychological, and language bonds. Primary reasons identified for the existence of the Deaf community include the desire for effective communication, acceptance, and socialization opportunities (Holcomb, 2013; Bauman, 2008; Lane et al., 1996).

Micro-communities. Other terminologies found in the literature for the micro-community concept include assimilating communities (Bahan & Nash, 1995; Lane et al., 1996), sign language villages (Padden, 2011), and single communities (Woll & Ladd, 2011). Applied to the multi-dimensional conceptual model, micro-communities occupy the front lower left section.

These deaf communities are viewed as inseparable from the hearing communities. There are more deaf people in these communities than in macro-communities, positive attitudes about sign language predominate, and the same life opportunities are available for both deaf and hearing persons.

Sign language micro-communities are characterized as small, labor-intensive economy-based communities, with a higher-than-average incidence of deafness as compared with macro-communities (Fenlon & Wilkinson, 2015). Although the percentage of deaf individuals is higher in micro-communities than in macro-communities, Kusters (2016) explained,

> Rather than a particular percentage of deaf people in a community, it is the communities' social atmosphere that creates the possibility for a shared sign language to emerge and to be spread and passed on throughout the community, especially when the deafness exists for a number of generations. (p. 889)

Deafness in micro-communities can typically be traced back for centuries, leading to a higher number of deaf and hearing signers living near one another who are related by blood or marriage. This setting affords deaf children the opportunity to learn sign language in a natural environment, from signing parents and extended family, as well as neighbors and others who sign. Because of the considerable knowledge of sign language by hearing persons in these communities, the lives of deaf and hearing individuals are more closely interwoven than typically seen in macro-communities (Woll & Ladd, 2011). Thus, these are true signing communities. An additional characteristic of deaf micro-communities is that the socioeconomic status and educational achievements of deaf members are thought to be largely equivalent to those of hearing members.

Martha's Vineyard is both the quintessential and best-documented example of a deaf micro-community. Other deaf micro-community studies have been almost exclusively linguistics oriented (Kusters, 2010). Yet these communities are important as they are examples of deaf and hearing people within communities that do *not* operate from a deficit perspective of deafness. Table 2 is a compilation of deaf micro-community studies. Each of these studies describes a unique population and setting in a non-industrial environment with an increased incidence of deafness. Kegl, Senghas, & Coppola (1999) highlighted the importance of viewing each community as a dynamic, fluid entity, with each community susceptible to social and political changes in their respective environments. Rapid changes were noted among both Bali and Nicaragua communities, and the Martha's Vineyard community is no longer in existence. The introduction of formalized deaf education altered the linguistic and social dynamic of the Desa Kolok community of Bali (Woll & Ladd, 2011). In addition, Woll and Ladd also noted limits on social integration in both the Israeli Bedouin and the Yucatan Maya communities, placing each community in a more intermediate position on the deaf community model.

Having language, ethnic identity, and solidarity common to both hearing and deaf people, micro-communities have often been perceived as representing an idyllic opposite to the Deaf communities of Europe and North America (Woll & Ladd, 2011). It can be argued, in fact, that the construct of a Deaf community *only* applies to macro-communities where deaf people are marginalized from mainstream society (Fenlon & Wilkinson, 2015). This idea is supported by Johnson's (1994) study in which deaf villagers in the Yucatan Mayan community did not identify with deaf people from other villages.

Martha's Vineyard, with its idyllic environment of sign language used by all, has become a powerful part of the collective memory of the international Deaf community (Kusters, 2010;

2016). As one hearing study participant explained, “those people weren’t handicapped. They were just deaf” (Groce, 1985, p. 5). The power and appeal of this type of community come from the reality that most deaf people grow up in hearing nonsigning families and then later need to comply with a predominantly hearing nonsigning society (Kusters, 2016).

Table 2

Deaf Micro-Community Studies

Location/ Group	**Date**	**Author**	**Publication location**
Grand Cayman Island	1981	Washabaugh	*Sign Language Studies*
Providence Island off the coast of Colombia	1978	Washabaugh, Woodward, & DeSantis	*Anthropological Linguistics*
Urubu of Amazonia, Brazil	1984	Ferreira-Brito	*Sign Language Studies*
Yucatan Maya	1994	Johnson	Chapter in *DeafWay*
Enga of New Guinea	1980	Kendon	*Semiotica*
Martha’s Vineyard	1985	Groce	*Everyone Here Spoke Sign Language: Hereditary Deafness on Martha’s Vineyard*
Desa Kolok on the island of Bali	1996	Branson, Miller, Marsaja, & Negara	Chapter in *Multicultural Aspects of Sociolinguistics in Deaf Communities*
Israeli Bedouin	2004; 2008	Kisch	Chapter in *Genetics, Disability, and Deafness; Medical Anthropology*
Hausa tribe of northern Nigeria	2000	Schmaling	*Maganar hannu: “Language of hands;” A descriptive analysis of Hausa Sign Language.*
Nicaragua	1999	Kegl et al.	Chapter in *Comparative Grammatical Change: The Intersection of Language Acquisition, Creole Genesis, and Diachronic Syntax*

Groce's (1985) ethnohistoric study of Martha's Vineyard community was a four-year project, funded with a grant from the National Institute of Mental Health (NIMH). The study drew from the fields of genetics, deaf studies, sociolinguistics, ethnography, and oral and written history, with a heavy emphasis on oral history. It sought to learn how people affected by the recessive genetic trait of deafness functioned within their society and how they perceived their roles in the community.

At the time of the study, no individuals with the inherited form of deafness that had existed for several centuries on the Island were still alive (Groce, 1985), the last hereditary deaf person on the Island died in 1952 (Whiting, 1985). Groce wrote that the first recorded case of deafness on Martha's Vineyard occurred in 1714, and "all deaf Vineyarders had some direct ancestral tie to a group of families who settled on Martha's Vineyard between 1642 and 1710" (p. 23). These settlers had all come to the New World from the same area of the English county of Kent known as the Weald.

Groce (1985) attempted to interview every person old enough to remember the Island's deaf inhabitants. Special attention was given to persons in their eighties and nineties, and who remembered the deaf residents as active members of the community. More than 200 Islanders were interviewed, with a majority of information coming from a core group of about fifty Island elders with a "vast knowledge of Vineyard people and events" (p. 6). All information was then substantiated with written documents, and all stories came from more than one source.

Groce's (1985) account showed a remarkable degree of integration of deaf and hearing people essentially equal in all regards. One exception is that deaf people may have attained a higher level of education than their hearing neighbors, and at times were called on to help with either legal documents or the writing of letters. Only two of the deaf Islanders were described as handicapped. One had lost a hand in an accident, and the other was described as "limping badly" (p. 128) as the result of a foot injury. One of the strongest indicators that deaf people were completely integrated into all aspects of society is that each deaf person remembered was thought of and described as a unique individual. Deaf Islanders were never thought of or referred to as a group. Here is an example from one of the participant interviews:

> "Do you know anything similar about Isaiah and David?"
>
> "Oh yes!" she replied. "They both were very good fishermen, very good indeed."
>
> "Weren't they both deaf?" I prodded.
>
> "Yes, come to think of it, I guess they both were," she replied. "I'd forgotten about that." (p. 4)

Whiting (1985) wrote that with the influx of new residents from off-Island, in the twentieth century, "the incidence of hereditary deafness on the Vineyard declined and finally ceased altogether" (p. *vii*).

Other Deaf community types. Occupying other points along the multidimensional conceptual model are Deaf communities integrated to greater or lesser extents with hearing communities. These are referred to as *integrated* (Woll & Ladd, 2011) or *cohesive* (Kusters, 2016) communities. There are also sub-communities of deaf and hearing signers in certain locations such as Fremont, CA and Rochester, NY in the U. S., and Wolverhampton and Preston in Britain (Woll & Ladd, 2003). These types of communities represent a "third culture" (Napier, 2002), in recognition of the fact that Deaf and hearing people come from different cultures, but that sign language interpreters have a foot in both worlds. The third culture concept allows for Deaf and hearing cultures to "meet in the middle" (Bienvenu, 1987). It is also worth noting two additional types of Deaf communities, *imagined* communities and *planned* communities (Ladd, 2003). Signing Deaf people have been described as "constituting a geographical diaspora, yearning to be together and to use sign language whenever they want to, leading them to imagine ideal places where this is possible" (Kusters, p. 888). These imagined Deaf communities have become actual planned Deaf communities in several instances. In France, a "deaf-mute nation" was conceptualized, which was to consist of 23,000 Deaf French citizens (Ladd, p. 112). This idea was defeated in part by the failure of the Revolution of 1848. During this same period, similar efforts were being made in the U.S. to create a Deaf state. The idea, proposed by John Flournoy in 1850, was for the Deaf state to be both self-governing and have its own land (Bauman, 2014a). Kusters described England's proposed colonization of Canadian land for deaf people, a plan that came to fruition between 1884 and 1885 when groups of deaf people were relocated to Canada, took employment as farmers and brought their families over. A more recent example was the plan to establish a town for sign language users in South Dakota. Plans began in 2004, with the goal that Deaf people could start moving in 2008. Ultimately, the project went bankrupt.

Deaf Housing Concerns

NAD (2014) published a statement on the state of housing for persons who are deaf and hard of hearing (HoH). Extensive testing had revealed rampant discrimination from apartment complexes in the treatment of deaf and HoH renters when compared to hearing renters. Specifically, when providing information to prospective tenants: 86% gave less information to deaf individuals, 56% informed deaf individuals that further background and financial checks would be necessary to determine qualification, and 40% hung up on deaf callers at least once. Ultimately, antidiscrimination suits filed against 715 apartment complexes in seven different states.

The report also described a severe lack of *accessible* housing for deaf people in the U. S. (NAD, 2014). Accessibility refers to the modification of auditory notifications such as doorbells, intercoms, and smoke alarms. Without which,

> Most [deaf and HoH] live in fire-traps because the smoke alarms do not alert them visually or in other non-audible ways. Even if they do have a stand-alone smoke alarm that visually alert them, this alarm is typically not connected to the other smoke alarms in a housing complex (NAD, 2013),

a fact which negatively impacts its effectiveness.

Another issue for deaf persons living in standard housing communities is the isolation and loneliness that results from communication barriers associated with living among non-deaf, non-signing persons. NAD (2014) wrote that many deaf people who communicate in ASL want to be able to "live among others who share their language. To counteract such loneliness, many groups […] in various parts of this country have sought to create housing facilities where they can live together and enjoy ease of communication" (par. 6).

This dissertation research took place in the largest of these apartment communities, with 75 units, created specifically so that deaf people can live near one another with full communication and environmental accessibility, Visions of Home, located in the southwestern part of the United States. This research explored the perceptions and experiences of deaf individuals who live there. The community itself does not fit all criteria for either macro- or micro- community categorizations. The research will contribute to the small yet growing body of deaf community literature.

Theoretical Foundation

When positioning qualitative research among other forms of research, one must consider both the nature of reality (ontology) and the nature of knowledge (epistemology). Interpretive research, which is the most common form of qualitative research (Merriam & Tisdell, 2016), assumes that reality is socially constructed and that there is no single observable reality. Instead, there are multiple realities, or *interpretations*, of a single event; and researchers *construct* knowledge rather than find it. Hence, the terms constructivism and interpretivism are often used interchangeably.

The social constructive paradigm developed as part of the post-modern philosophical movement that began in the 1960s that challenged the objectivist roots of science and the post-enlightenment belief in a knowable world (Dean, 2012). It has greatly influenced the field of cultural studies, with some researchers attributing the rise in cultural studies directly to this theoretical framework (Galbin, 2014). Social constructionism is concerned with the ways that knowledge is both historically situated and embedded in cultural values and practices.
This paradigm helps define how seemingly natural social phenomenon are socially and culturally created (Mercadal, 2016). Phenomena that may be viewed as normal and which are widely accepted are, in fact, a product of the culture, thereby causing most of its members to adopt the same worldview. In time, these interpretations of reality may change as other ideas and beliefs are introduced into the culture and its institutions.

Burr (1995) noted that “there is no one feature” (p. 2) used to identify a social constructionist position, rather it is any approach that has at its foundation one or more of the following key assumptions: (a) a critical stance towards taken-for-granted knowledge, (b) historical and cultural specificity, (c) knowledge is sustained by social processes, and (d) knowledge and social action go together. Explanations offered by social constructionists are frequently in terms of the dynamics of the social interactions. "The aim of social enquiry is moved from questions about the nature of people or society and towards a consideration of *how* certain phenomena or forms of knowledge are achieved by people in interaction" (p. 8). Key concepts include:

- Human consciousness and the sense of self is shaped by continual social interaction;
- Social reality is created when people, in social interaction, develop a common understanding of their world;
- Social interaction is grounded in language and customs, as well as cultural and historical contexts;
- People can modify meanings in the process of interaction;
- Society consists of social processes (particularly language), not social structures (Butler-Kisber, 2010)

In addition to a socially constructed epistemological stance, this research utilized Deaf theory (Bienvenu, 2016) as its theoretical framework. Theories help us to understand the experienced world and provide the researcher with a chance to highlight certain aspects of the phenomenon being studied (Tavallaei & Talib, 2010). Deaf theory is situated firmly within the critical theory framework. Critical traditions are characterized as a set of intellectual positions that examine social arrangements through the lenses of power, domination, and conflict (Prasad, 2005). While convinced of the socially constructed nature of all reality, Prasad posits that critical theorists are far more *skeptical* than interpretivists with respect to the role of interests governing individual and collective action. Researchers in the critical traditions are simultaneously committed to both critique and change of oppressed groups, “for one without the other is not considered very meaningful” (p. 109).

Bienvenu (2016) explained, “Deaf, in all its complexity, is at the center of a growing body of texts that can be grouped under the category of Deaf theory” (p. 282). The body of knowledge known as Deaf theory is still developing. Bienvenu, however, indicated that the ideas *within* Deaf theory have been discussed by Deaf Studies scholars for decades. Deaf theory is an identity-based theory established on the premise that *Deaf* is neither a deficit-based concept nor can it be easily reduced to a fixed and stable experience. Its theoretical traditions are rooted in identity, critiques of power relations, and emancipatory struggles (e.g., feminist theory, critical race theory, and queer theory). Each is based on the premise that (a) identity matters, (b) power relations structure our experiences in the world, and (c) theory is not divorced from political struggles but rather holds the potential to support emancipatory movements.

Bienvenu (2016) identified four issues or concepts central to Deaf theory. First, *Deaf world* is a radical concept that rejects the supposition that a person is required to have all five senses to be considered a “normal.” Historically, Deaf people have been defined by their “deafness,” not seen as whole people but rather viewed in relation to their audiology. Deaf world fundamentally rejects this worldview and seeks to reinforce the place of Deaf people in a world where deafness is understood as a source of cultural and linguistic gain. Second, *linguicism* is a form of discrimination based on language or dialect. In the U.S., linguicism operates in relation to the English language. The assumption is that anyone who fails to communicate fluently in English, the language of power, is less worthy. Like other linguistic minorities, Deaf people have often struggled to assert themselves in the face of linguistic dominance. Deaf theory explores linguicism as a powerful ideology that continues to negatively impact the lives of deaf people. Third, *identity* is associated with the concept that a deaf person also has the right to also be a Deaf person. Bienvenu argued that mainstream education, under the auspices of integration and acceptance, has effectively stripped deaf children of their ability and opportunity to develop a unique identity as a Deaf person. Mainstream policies have drastically restricted deaf children's access to the Deaf world and robbed them of their Deaf identity. Bienvenu wrote:

> It is important to bear in mind that deaf people are hearing until proved Deaf. Professionals will make any effort to make the child hearing – oral training, the invention of sign systems, cued speech systems and the use of hearing aids. Ultimately, in the end, they are still deaf. (p. 283)

Deaf theory provides a philosophical framework from which to explore the concept of the power of Deaf as an identity position and locus of collective power. Fourth, and finally, *phonocentrism* is the belief that speech is superior to everything else, and therefore, sign language and writing are secondary. This concept was advanced by Derrida (1998) who used the works of Plato, Aristotle, Rousseau, Saussure, and others to reinforce the universal privilege of the spoken language over all other communication forms (Daylight, 2012). Bienvenu contends that phonocentrism is one of the most damaging and volatile ideologies that deaf people encounter, even more than linguicism, as it leads to the false belief that to succeed, one must speak.

The literature demonstrates that deaf people have a distinctly different way of knowing and experiencing the world, based on their visual nature, that is distinctly different from the hearing majority. *Deaf* and *deafness* are two distinctly different social constructs. Both constructs influence and are influenced by language choice modalities. NASW (2015) declared:

> Language is a source and an extension of personal identity and culture and therefore, is one way that individuals interact with others in their families and communities and across different cultural groups. Individuals and groups have a right to use their language in their individual and communal life…. Linguistic diversity should be preserved and promoted. The essence of the social work profession is to promote social justice and eliminate discrimination and oppression based on linguistic or other diversities. (line 1378 – 1388)

With this in mind, it is important to understanding the social construction of deafness from the perspective of the Deaf population, rather than the hearing majority. Deaf theory provides the framework for this greater understanding.

Summary and Conclusion

In conclusion, this chapter reviewed and critically examined literature germane to deaf people that are historical, socially, and politically relevant to the experiences and conditions that deaf people face today. "Advancements" in philosophy and science made it possible to redefine the essence of humanity as speech-based, thereby excluding deaf people from possessing all the necessary attributes. This led to the categorization of deaf people as disabled, creating a systemic backdrop for ongoing oppression and marginalization.

Through Deaf culture research, we learn that there is a different *center* for persons who are deaf and that it is visually oriented (Padden & Humphries, 1988). It is through Deaf culture that historically created solutions for effective living can be found and passed from one generation of Deaf people to the next (Holcomb, 2013). Deaf communities are where the transmission of this cultural knowledge occur and where communication happens most freely. This chapter reviewed literature relevant to alternative social constructions of deaf individuals and deaf communities. This chapter also discussed specific housing concerns for deaf people in the U.S. Finally, Deaf theory was identified as the theoretical lens that guided this research. Deaf theory encompasses the vast, overarching and systemic socio-political and historical context of the deaf persons and the Deaf community.

CHAPTER 3

METHODOLOGY

Introduction

The purpose of the study was to explore the perceptions and experiences of D/deaf persons living in a purposefully-designed Deaf community. This qualitative inquiry sought answers to the following research questions:

1. In what ways (if at all) have your experiences(s) with Deaf culture influenced your decision to live in a Deaf community?
2. What are the benefits of living in a Deaf community?
3. What are the challenges of living in a Deaf community?

In this chapter, I provide a description of the research site, the process of site selection, a description of qualitative methodology and the rationale for its use in this study. I also discuss sample selection; data collection and analysis; validity and reliability; limitations of the study; and researcher bias and assumptions.

My first exposure to Visions of Home was from a local Deaf person who announced a desire to move to Visions of Home, so she could live with other Deaf people. I was unfamiliar with Visions of Home at the time, so I looked it up online and read that it was in the process of being sued for discrimination by a group of hearing people who wanted to live there. I feel certain now that this was probably an oversimplification of the facts, but at that time it was my introduction to Visions of Home. The more I learned, the more fascinated I became.

Design of the Study

The paucity of Deaf cultural research combined with the abundance of disability and medically-oriented deaf research presents a skewed, and therefore, biased image of the Deaf community. This imbalance contributes to the “disabled by default” (Wright, 2016, p. 308) representation of Deaf people. The dearth of Deaf-specific, culturally-oriented literature prompted my decision to use a qualitative research design. Because the goal of this research was to explore individuals’ perceptions and experiences of living in a purposefully designed Deaf community, a qualitative research methodology was best suited to this objective.

Qualitative research is an umbrella term that encompasses a number of philosophical orientations and methodological approaches (Merriam & Tisdell, 2016). Yet despite this range and diversity, all qualitative research shares certain characteristics. Merriam and Tisdell identified four characteristics that have been recognized by most as key to understanding the nature of qualitative research:

1. *The focus of qualitative research is on process, understanding, and meaning.* The overall purposes of qualitative research are to achieve an understanding of how people make sense of their lives, delineate the process of meaning-making, and describe how people interpret what they experience. It is important to understand the phenomenon of interest from the participants’ perspectives, not the researchers. This is the *emic* or insider’s perspective, versus the *etic* or outsider’s viewpoint.

2. *The researcher is the primary instrument for data collection and analysis.* Since understanding is the primary goal of qualitative research, the human instrument is the ideal means for collecting and analyzing data. This is due to the researcher’s ability to be both immediately responsive and adaptive during the research process. Additional benefits are that

the researcher can expand his or her understanding through nonverbal as well as verbal communication, process information (data) immediately, clarify and summarize material, check with respondents for the accuracy of interpretation, and explore unusual or unanticipated responses.

Conversely, the human instrument also has shortcomings and biases that can have an impact on the study. Rather than attempting to eliminate all biases, it is important for the researcher to identify and monitor them, as well as to make clear how they might impact and shape the collection and interpretation of data. Without the awareness that comes from monitoring one's own biases, Peshkin (1988) admonished that "untamed subjectivity mutes the emic voice" (p. 21). Subjectivity can be virtuous as well, however, "for it is the basis of researchers' making a distinctive contribution, one that results from the unique configuration of their personal qualities joined to the data they have collected" (p. 18).

3. *Qualitative research is an inductive process.* Qualitative studies are frequently used when there is a lack of theory or when existing theory fails to adequately explain a phenomenon. Because qualitative research is an *inductive process*, researchers gather data to build concepts, hypotheses, or theories rather than deductively testing hypotheses, as occurs with positivist research. Theory is built from observations, and intuitive understandings gleaned from being in the field. Information from interviews, observations, or documents is combined and synthesized into larger themes as the researcher works from the particular to the general. Findings from the data are typically in the form of themes, categories, typologies, concepts, tentative hypotheses, and even theory about a particular aspect of practice.

4. *The product of qualitative inquiry is richly descriptive.* Words and pictures are used instead of statistics and numbers to convey what the researcher has learned about a phenomenon.

Studies are likely to include descriptions of the context of the study, the participants involved, and other activities of interest. Data are generated in the form of quotes from participant interviews, field notes, documents, electronic communication, or a combination of these. Data are included to support the findings of the study. In addition, this data adds to the descriptive nature of qualitative research.

In addition to these four primary characteristics, Merriam and Tisdell (2016) identified several characteristics common to most forms of qualitative research. Ideally, the design of the study is *emergent and flexible*, so that the researcher can respond to changing conditions of the study as it progresses. This is not always possible, however, as dissertation committees, funding sources, and human subjects review boards often require the study design to be specified ahead of time. Sample selection is usually nonrandom, *purposeful*, and small, as opposed to larger, more random sampling in quantitative research. Finally, the qualitative researcher often spends a substantial amount of time *in the natural setting* of the study, often in intense contact with participants.

There are various reasons for choosing a qualitative methodological approach. Padgett (1998) identified six reasons, although these are not mutually exclusive nor are they exhaustive:

1. The qualitative researcher wants to explore a topic about which little is known.
2. The qualitative researcher is pursuing a topic of sensitivity and emotional depth.
3. The qualitative researcher wishes to capture the “lived experience” from the perspectives of those who live it and create meaning from it.
4. The qualitative researcher wishes to get inside the “black box” of programs and interventions.

5. The qualitative researcher has reached an impasse in data collection or in explaining findings.
6. The qualitative researcher is seeking to merge activism with research.

Because the purpose of this study was to explore the perceptions and experiences of D/deaf persons living in a purposefully designed Deaf community, qualitative research methodology was the most appropriate fit. Little is known about this group of Deaf people who chose to live together in a designated place. This research sought to capture the lived experiences of D/deaf participants and the meanings created from their shared experiences.

Sample Selection

The two basic types of sampling are probability and nonprobability sampling. The strength of probability sampling comes from allowing the researcher to generalize the results of a study to the population from which it was drawn (Patton, 2015). However, since generalization in a statistical sense is not a goal of qualitative research, probability sampling is not necessary or even justifiable (Merriam & Tisdell, 2016). Nonprobability sampling is the method of choice for most qualitative research, and the most common form of nonprobability sampling is purposeful sampling. *Purposeful sampling* assumes that the investigator wants to discover, understand, and gain insight and, therefore, must select a sample from which the most can be learned. Patton posited that the logic and power of purposeful sampling is derived from the emphasis on an in-depth understanding of specific *information-rich cases*. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term *purposeful sampling*.

There are numerous types of purposeful sampling. Patton (2015) identified forty types, and Marshall and Rossman (2011) identified sixteen. To begin purposeful sampling, the researcher must first determine what selection criteria are essential in choosing participant or site selection (Merriam & Tisdell, 2016).

I used criterion-based purposeful sampling for this study. In criterion-based sampling, the selection of participants is based on specified criteria (Patton, 2015). The criteria for participant involvement was that each person was a resident at Visions of Home.

Data Collection

Predetermining a sample size in qualitative data can present a challenge. As Lincoln and Guba (1985) indicated, in purposeful sampling, the size of the sample is determined by informational considerations. Specifically, "sampling is terminated when no new information is forthcoming…. Thus *redundancy* [emphasis in the original] is the primary criterion" (p. 202). Saturation occurs when continued data collection produces no new information or insights (Merriam & Tisdell, 2016). It is impossible to know in advance, however, when the point of saturation will be reached. This is problematic when submitting a proposal to a funding agency, dissertation committee, or other oversight board. In such cases, Patton (2015) recommended researchers "specify *minimum samples* [emphasis in the original] based on expected reasonable coverage of the phenomenon given the purpose of the study and stakeholder interests" (p. 314). Unsure of what to expect when I arrived at Visions of Home, my initial proposed sample size for this study was 8 -50 participants.

"Data are nothing more than ordinary bits and pieces of information found in the environment" (Merriam & Tisdell, 2016, p. 105). Auerback and Silverstein's (2003) suggestion to keep the purpose of the study and research questions on a single sheet of paper and available at all times was useful. The data collection techniques used, and the specific information considered to be data are determined by the researcher's theoretical orientation, by the problem and purpose of the study, and by the sample selected. Qualitative data are most commonly collected through interviews, observations, and documents. Merriam and Tisdell indicated that interviewing is the most common form of data collection in education and applied fields of study. Patton (2015) described qualitative interviews as open-ended questions and probes that yield in-depth responses about people's experiences, perceptions, opinions, feelings, and knowledge. The data consist of verbatim quotations with sufficient context to be interpretable.

Interviews are generally grouped into categories along a structure continuum (Roulston, 2010). I used semi-structured interviews for data collection. With semi-structured interviews, the researcher asks participants a series of predetermined but open-ended questions using an interview guide that is based on the research questions (Ayers, 2008). Although the questions are predetermined, the order in which they are asked is not. This allows for a more conversational flow during the interview. Interviews were the primary source of data for this study. Following a pre-site engagement period in October, the interviews occurred over a one-week period in November 2018. Throughout the week I made observations and collected data artifacts that included photographs of the building, brochures, and notes from participants (See Appendix D). Observations were recorded in journals and memos during my time in the field, and artifact data were used to support what I saw and learned.

Cross-cultural interviewing can add complexity to the already-complex interview process. Patton (2015) identifies ten examples of variations in cross-cultural norms that can affect qualitative interviewing and fieldwork. Several of these areas have the potential to be relevant to this study. See Table 3.

Table 3

Cross-Cultural Norm Variations

Cultural Norm	**Cross-cultural variations**
1) Attention to time and being "on time"	Some cultures value being on time as a matter of respect. In others, people routinely show up late, sometimes by a considerable amount.
2) Engaging in pre-interview "small talk"	Some cultures value getting right down to business. In others, it would be impolite to begin an interview without first discussing the weather, exchanging family information, or having coffee or tea together before getting on with the task at hand.
3) Eye contact	Some cultures value direct eye contact; others consider direct dye contact invasive.
4) Physical proximity	Norms vary greatly about how near to sit or stand when interacting.
5) Nonverbal gestures	Behaviors such as shaking hands, crossing one's legs while sitting, head nodding, and other nonverbal behaviors can be welcome or offensive depending on the cultural norms.
6) Appropriate topics for inquiry	Cultures vary greatly in what issues can be addressed in interviews.
7) What words can be used	In many languages, there is no word for "interview," "research," or "evaluation." Describing and explaining the process of gathering data, for what purposes with what uses, can be among the most challenging aspects of cross-cultural communications.

Adapted from Patton (2015, p. 482)

Data Analysis

Once data collection was complete, it was important to create an inventory of the dataset. Merriam and Tisdell (2016) have suggested that it needs to be organized and labeled in a way that makes sense to the researcher so that data can be accessed at any time. The object of data analysis is to determine the categories, relationships, and assumptions that inform respondents' view of the world in general, and of the topic in particular (Basit, 2003). It is the process of making sense of the data (Merriam & Tisdell, 2016). Ideally, this process begins while the researcher is still in the field. Bogdan and Biklen (2007) provided several suggestions to accomplish this. They include writing "*observer's comments*" (p. 163) about ideas, writing memos to yourself about what you are learning, and planning data-collection sessions in light of what you find in previous interview sessions.

The process of making sense of the data is essentially the process used to answer the research questions(s). Merriam and Tisdell (2016) explained that this begins by identifying segments of the data set that are responsive to the research question(s). This unit of data can be as small as a word a participant uses to describe a feeling or phenomenon. According to Lincoln and Guba (1985), each unit must meet two criteria. First, it should be heuristic, that is, aimed at some understanding the researcher needs. Second, the unit should be the smallest piece of information about something that can stand by itself. It should be interpretable in the absence of any additional information other than a broad understanding of the context of the inquiry. Ryan and Bernard (2007) added that although themes can often seem to be fuzzy and abstract constructs linked to texts, "You know you have found a theme when you can answer the question, 'What is this expression an example of?" (p. 87).

I used constructivist grounded theory (Charmaz, Thornberg, & Keene, 2018) for data analysis, which has been identified as a powerful method in social justice inquiry. Social justice refers to the condition whereby all people are afforded fair opportunities to enjoy the benefits of society (Miller, P., 2008). Charmaz et al. identified four reasons for this. First, grounded theory methods widen the scope and depth of analysis of social justice research, beyond what has been largely macro and quantitative. Bringing micro and meso analysis into the foreground, grounded theorists are able to show their connections to institutionalized macro structures and practices. Second, grounded theory fosters showing how inequities and discriminatory practices are enacted. Consequently, these methods can produce interpretive analysis of how structural inequality is played out in individuals' meanings and actions and how individual agency and action affect larger social structures. Third, grounded theory supplies the tools to discover the ideological roots of implicit meanings, actions, and larger social processes of which people may be unaware. Fourth, the flexibility associated with grounded theory permits studying hidden unjust practices and policies as well as observed inequities that arise during research.

The term grounded theory (GT) refers to a theory developed from successive conceptual analyses of empirical materials (Denzin & Lincoln, 2018). GT is a method of qualitative inquiry in which data collection and analysis reciprocally inform each other through an emergent iterative process. The process of iteration occurs as the researcher continually reconsider what is being done in light of what has already occurred so that the individual parts of an analysis develop together as a whole (Woolf & Silver, 2018). Merriam and Tisdell (2016) likened this process to moving between the big picture or the "forest" (p. 207) and the particulars or the "trees" (207). Attride-Stirling (2007) suggested, "Data analysis is a complex procedure that involves moving back and forth between concrete bits of data and abstract concepts, between inducting and deductive reasoning, between description and interpretation" (p. 202).

GT coding addresses what people do and look at, which actions their stated views perform or imply (Denzin & Lincoln, 2018). Constructivist grounded theorists realize that their understandings, use of language, and interactions with participants and data shape their definitions of what fragments of data to include. Denzin and Lincoln wrote that constructivist grounded theory (CGT) consists of at least two phases of coding, initial coding and focused coding. Initial coding is very close to the data. During the initial coding process, the researcher will identify the most significant or frequent initial codes that make the most analytic sense. Focused codes are more directed, selective, and conceptual than most initial codes. During the focused coding process, the researcher will sift through large amounts of data to capture and synthesize what is happening in the data. Conceptual categories will develop from the focused codes.

Validity and Reliability

All research is concerned with producing valid and reliable knowledge in an ethical manner (Merriam & Tisdell, 2016). Given that qualitative research is based on assumptions about reality that are different from those of quantitative research, the standards for rigor are necessarily different. Because the terminology for discussing and assessing the trustworthiness and rigor in qualitative studies is in flux, (Denzin & Lincoln, 2011), I followed the example of Merriam and Tisdell (2016) who reference issues of trustworthiness with the traditional terminology of validity and reliability.

In traditional quantitative research, the trustworthiness of a study was measured in terms of its internal validity, external validity, and reliability (Lincoln & Guba, 1985). In quantitative studies, *internal validity* focuses on the measurement instrument (Patton, 2002). Does the instrument measure what it is supposed to measure? In qualitative inquiry, however, the researcher is the instrument. Internal validity, or *credibility*, in qualitative research, addresses the question of how the research findings match reality (Merriam & Tisdell, 2016). How credible are the findings with the information provided? Merriam and Tisdell discussed five strategies for ensuring the internal validity of a study. They include triangulation, member checks, adequate engagement in data collection, the researcher's position or reflexivity, and peer examination or peer review. My dissertation research used three of these strategies: member checks with participants during the interview, data triangulation (Mathison, 1988) from multiple participants and sources, and researcher reflexivity, which is demonstrated and included in the next two chapters.

External validity is concerned with the extent to which the findings of a study can be applied to other situations (Merriam & Tisdell, 2016). How generalizable or *transferable* are the results of a study? Merriam and Tisdell have suggested that the question of generalizability has plagued qualitative investigators for some time. Although generalizability in the statistical sense is not possible in qualitative research, there are a number of understandings of generalizability that are more congruent with the qualitative research worldview. One such understanding is that we should think in terms of "working hypotheses" that reflect situation-specific conditions within a particular context. Another understanding is that of "concrete universals" which are arrived at by studying a specific case in great detail and then comparing it with other cases, also studied in great detail. Probably the most common understanding of generalizability in qualitative research, though, is that of the *reader or user generalizability*. This involves leaving the extent to which a study's findings apply to other situations up to the people in those situations. It is the person who reads the study who decides whether the findings can apply to his or her particular situation. The use of rich, thick descriptions enhances the external validity, which I provided in the description and details of this study. Thick descriptions involve providing enough description and details to contextualize the study such that readers will be able to determine the extent to which their situations match the research context (Merriam & Tisdell, 2016).

Reliability, from a quantitative standpoint, refers to the extent to which research findings can be replicated (Merriam & Tisdell, 2016). In other words, if the study was repeated, would it yield the same results? Replication is not possible in qualitative research because human behavior is not static, and people's experiences vary. Therefore, a more important question to ask in qualitative research is whether the results are *consistent* with the data collected. Marshall and Rossman (2011) referred to this as *confirmability*. Merriam and Tisdell stated, "Rather than demanding that outsiders get the same results, a researcher wishes outsiders to concur that, given the data collected, the results make sense – they are consistent and dependable" (p. 251). Strategies used to ensure reliability, consistency, and dependability, in this qualitative dissertation research include are triangulation from multiple participants and sources, researcher's reflexivity, and an audit trail.

Study Limitations

Several study limitations have been identified for this dissertation research and are discussed in this section. First, my status as a hearing person and researcher may have caused internal discomfort with research participants. In turn, this might have made the sharing of information difficult with me. It is possible that my hearing status made people feel reluctant to discuss hearing people in any less than positive context. As one person said, *"I am not criticizing hearing people, but…."* Merriam and Tisdell (2016) have suggested,

> Participants in studies of marginalized groups […] are often suspicious of those who are members of the dominant culture doing research *on* [emphasis in original] people of oppressed groups. They often worry about what the researcher's agenda is and how they will be portrayed as participants. (p. 64)

I also want to acknowledge, as a hearing person, an awareness for potential implicit hearing bias. Implicit biases are described as automatic or stereotypical associations that have “gone underground” (van Nunspeet, Ellemers, & Derks, 2017, p. 207) yet still impact interpersonal interactions.

Any linguistic translation errors that occur are a study limitation (Sutrisno, Nguyen, & Tangen, 2014); as is the short amount of time spent at Visions of Home. Kirkhart (1995) has suggested that imposed time constraints may work against sound cultural appreciations, especially when conducting cross-cultural research. Indeed, even in the short amount of time, I was at Visions of Home, my understanding of some of the cultural nuances was far greater at the end of the week than they had been at the beginning of the week.

A final identified study limitation is that, at present, I have yet to figure out the best way to dissemination study findings in an ASL friendly format. Harris et al. (2009) wrote that if research information is less accessible to deaf participants than it is to hearing participants, this imbalance constitutes a form of deception by the researcher.

Researcher Transparency and Bias

“We believe that hearing researchers do not need to defend their doing Deaf Studies work per se, but it’s vital that they think and write about their positionalities” (Kusters, De Meulder, & O’Brien, 2017, p. 23). I will, therefore, now share personal and professional experiences that seem relevant. On a personal level, my introduction to the Deaf community happened by chance. My best friend in high school wanted to learn ASL, and she had a car. So, literally, I went along for the ride. I continued learning, however, because of a deep love that developed for the beauty of American Sign Language and its users. I entered the Interpreter Training Program for the sake of language development when I took my first job as a counselor and advocate working with Deaf persons. At this point, I had no intention of ever interpreting, but I did want to be able to effectively communicate in a clinical or advocacy setting.

I acknowledge both my hearing status and the power associated with it. I realize that there have been times when I entered the periphery of the Deaf community as someone working in and with the community. I am fortunate to have had these opportunities. In each of these situations though, my hearing status meant that I could also leave when it suited me.

Professionally, my second job after receiving an MSW was working with deaf persons in the newly developed Georgia Council for the Hearing Impaired (GaCHI)[3]. As a newly minted social worker, I had a job I loved with much to learn. This is where I first experienced the subtle (and sometimes not so subtle) cultural differences with Deaf and hearing people.

Several years later and a move to Kansas brought me to a community mental health center where I was hired as an outpatient clinician. Because of my previous experience with deaf clients, I was offered the option of splitting my job into working half of the time with deaf clients and the other half of the time with hearing clients. This job, like in Georgia, involved a great deal of advocacy on behalf of deaf clients, which entailed a great deal of educating on behalf of the hearing parties involved. I have since expanded my professional repertoire to include NAD (CI/CT) sign language interpreter certification.

I believe that the goal now is for us, hearing people, and especially practicing social workers, to stop being the part of the problem. An important way to do this is to ask Deaf people what it means to be Deaf rather than to rely on professions that have a financial interest in defining Deaf as disabled. I want to state clearly that I am not speaking for Deaf people, nor do I presume to know what it is like to be D/deaf. The knowledge and information I have learned

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[3] Now the Georgia Center of the Deaf and Hard of Hearing (GCDHH).

about Deaf people and the Deaf community have been as an H/hearing person; I speak from this perspective. As a hearing person, I have seen many misunderstandings and false beliefs from hearing people who are aware only of deafness as a disability.

Fellinger, Holzinger, and Pollard's (2012) illustration (Figure 4) resonates with me. It depicts the burden of mental problems on deaf people. The burden of mental health problems is symbolized by rucksacks, which everyone carries and from which they seek relief. The rucksacks of deaf people are bigger, but the entrance to services is smaller because accessibility is poor. This resonates with me because I have seen this to be true, but not just with the mental health system. It also applies to the educational system, basic housing, employment, language accessibility, and many other basic human rights.

The ultimate, long-term goal of this research is to encourage the widening of the accessibility door for persons who are Deaf.

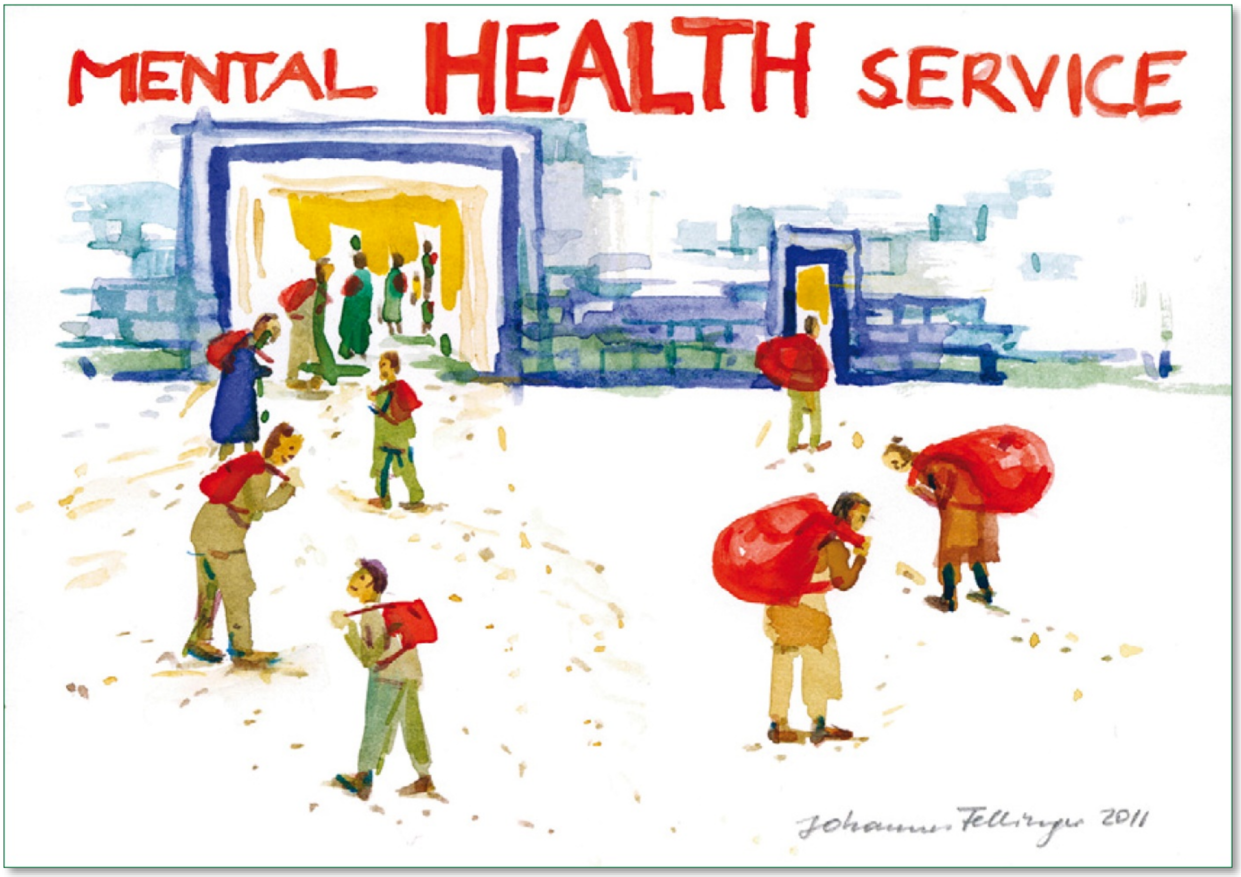

Figure 4: Burden of mental health problems on deaf people

CHAPTER 4

SITE ENGAGEMENT AND DATA COLLECTION

Introduction

The purpose of the study was to explore the perceptions and experiences of D/deaf persons living in a purposefully-designed Deaf community. The following research questions guided this study:

1. In what ways (if at all) have your experiences(s) with Deaf culture influenced your decision to live in a Deaf community?
2. What are the benefits of living in a Deaf community?
3. What are the challenges of living in a Deaf community?

The data collection process included interviews, observations, and document analysis, which took place between October and November 2018, to Visions of Home, a 75- unit, free-standing, Deaf apartment community located in the western region of the U.S. Increasingly, Deaf communities are being referred to as Sign Language Peoples (SLP) (Young & Temple, 2014). This chapter describes the place, Visions of Home, and the spaces within. This chapter chronicles the researcher's journey from entering the field, the process of establishing trust with community members, and the recruitment process for study participants. In addition, this chapter includes a discussion of ethical consideration when conducting research in a Deaf community, participant demographics, interview methodology, and research design challenges. This chapter also explicates data analysis, study findings, researcher transparency and bias, study limitations, and a conclusion.

Entering the Field

The reality of doing [qualitative] research is that it is a complex, insecure and unanticipated endeavor, not an entirely analytical journey. (Salovaaro, 2018, p. 315)

Coordinating and conducting successful research 2000 miles away necessitated making two distinct trips to the field site. The "field" refers to space, or setting, where data collection takes place. (Naveed, Sakata, Kefallinou, Young, & Anand, 2017, p.782). Patton (2015) has suggested that entry into the field for research involves two separate parts: 1) negotiation with the gatekeeper about the nature of the fieldwork to be done and 2) actual physical entry into the field setting to begin data collection. Each of my two trips to Visions of Home served a distinct purpose and corresponded with Patton's two-part entry.

I had three goals for my first trip into the field, which was scheduled after obtaining University IRB approval. The first goal was to establish a rapport with the Property Manager, who was also the community gatekeeper. Prior to this visit, all communication had taken place via email, Skype, or Google Hangouts. A second goal was to gain a better understanding of the building itself, its history, and the actual physical space(s) that comprise Visions of Home. The third goal of this trip was to work out the logistics of a future, more extended trip, that would involve both participant recruitment and interviews.

Three goals were successfully achieved during the first trip to Visions of Home. The first goal, to establish rapport, with the Property Manager, was critical. Without the Property Manager's permission and assistance, this research would not have been possible. Over the time span of both trips, my appreciation and respect for the Property Manager grew as did my awareness and understanding of her role and responsibilities in the community.

My second goal, which was to gain a better understanding of the building itself and its history was accomplished through information obtained, both verbal and written, from the Property Manager. I was also given an in-depth tour of the property, which included an apartment unit and other spaces within the building. Each apartment is equipped with a flashing light notification system, in which different colored (red, yellow, blue, green) lights are used for each of the following: front door of the building notification, back door of the building notification, individual apartment doorbell, and fire alarm. This provides visual access to information that hearing people receive auditorily. Another feature of the building specifically geared to visually oriented communication is the presence of videophones (VP). They are in each apartment, and there are several in common areas of the building. There is also a workout room available on the first floor for residents to use. Impressive, too, are the spaces in and around the building, *not* affiliated with Visions of Home, but whose proximity offers residents an array of services via sign language. These include a beauty salon with a sign fluent hair stylist and several counselors' offices.

I noticed that many, if not all, the staff at Visions of Home are Deaf and communicate using ASL. This includes the Property Manager and the Assistant Office Manager. Other jobs held by deaf persons include housekeeping and maintenance positions. A few participants mentioned that a former employee had been hearing, but that "he left because he didn't like Deaf people." Upon his departure, a Deaf person was hired to fill the position.

Individual places within the apartment building and the use of space discussed further in the Site Description section of this paper. Importantly, during the initial site visit, I learned where the Participant Information meeting/ luncheon would be held as well as all the participant interviews. I left with a much better understanding of the building itself, the use of space, the history behind the creation of Visions of Home, and it's plans for the future.

An unintended and unexpected benefit to come from my initial visit is that when I was being shown around the building, this generated curiosity from residents who saw me with the Property Manager. As we walked through the building, I saw people asking questions about me such as, "Who is that?", "Is she moving in?", "Is she deaf?" Granted, I did not see much beyond these brief snippets of conversations as I was busy looking in rooms and around the building. This situation differs from 'hearing conversations', where one can be involved in a conversation and still 'overhear' what is happening in the background. With visual language communication, the conversation ceases and becomes inaccessible when one's back is turned from the speaker (Oliva, 2004). I hoped this interest would later translate into participant interviews during my next visit.

The third goal of the first site visit was to logistically work out the necessary details for the longer and more extensive return trip that would involve participant recruitment and data collection. This goal was met. Property Manager and I identified a few optional weeks that data collection could occur and not be too disruptive to the community. I left with catering information for the Information Meeting Luncheon and learned which grocery stores the community van drives to each week. Each Wednesday there is a van that drives residents who want to go shopping at a different store each week. In a month, the van goes to one of four grocery stores on a rotating basis; a schedule is posted in a community area. I used this grocery store list as the basis for purchasing gift cards that would be given to research participants.

At the end of my first site visit, I left for home feeling excited and eager to return. The subsequent return trip for data collection was scheduled to take place three weeks later. Patton

(2015) has suggested that there is an evolutionary process to fieldwork and that it generally goes through three stages: the entry stage, the routinization of the data-gathering period, and the closing stage. This was my experience as well. As I reflect on the process of data gathering, my mind instinctively divides the time into three segments corresponding with the week. At the beginning of the week, there was a focus on introduction and relationship development within the community. By midweek the focus had shifted to task completion of data collection and interviewing. By midweek, I felt that we – the community and I – had hit a stride. I was no longer such a novelty, and I had already interviewed many of the people I saw in the lobby or even out on the street near Visions of Home. A few people still looked at me with wariness (which I still completely understood!), but many more were now smiling and helpful, friendly faces. By the end of the week, it was time to wrap up and say goodbye.

Qualitative literature has much to say about unforeseen events that happen while a researcher is in the field, a great deal of which seems to be directed to novice researchers and doctoral students. Therefore, when what can be described as an 'unforeseen event' happened early in the second site visit journey, I was able to fall back on the literature and say to myself, "*Yep. This is what they were talking about.*" These unexpected events and challenges in the field often require the researcher to modify their initial research design (Naveed et al., 2017). Rather than glossing over these challenges and design changes, Naveed et al. have argued for the importance of recognizing the organic nature of the research project, thereby making researcher reflexivity paramount. In the context of researcher reflexivity, I share my unforeseen event:

Even though I was flying from a warm climate to an even warmer climate, the first major challenge came in the form of a blizzard in Chicago that prevented planes from flying. Thankfully, I eventually arrive at my destination, but by the time I did, I had been awake for more than 24 hours and would have only a four-hour window to sleep before it was time for the scheduled Participant Information Meeting. I changed my original plans, therefore, and decided to sleep in instead of arriving early at Visions of Home in the hope of generating interest in the meeting. Ultimately, I arrived on site at 10:30, providing me with an hour to set up the food and the Community Room. As I sat for hours in an airport, it had become clear that parts of the research process would indeed be out of my control (Salovaaro, 2018). I also had time to reflect on the idea that I was in control of my mindset. I, therefore, made a firm commitment to myself that no matter what else happened on this trip, I had two non-negotiables: 1) I was going to do quality research, and 2) I was going to be open, respectful, and transparent with members of the Deaf community. All other decisions would be filtered through these two lenses. Transparency was especially important to stay mindful of, as secrecy can be considered antisocial in the Deaf community and Deaf people often find hearing people's attitude toward privacy "infuriating and perplexing" (Mindess, 2014, p. 47). Regardless, staying mindful of these two non-negotiable self-commitments proved to be very helpful throughout the week. Even though being open, respectful, and transparent with research participants is a component of quality research. It was important to keep these two issues of equal importance, because as Aneas and Sandin (2009) wrote, "when it comes to setting up a qualitative research process involving study participants from different cultures it is important to be aware of the anxiety which, even if unconsciously, can affect all those involved" (p. 8).

Site Description

Qualitative research requires that the researcher be precise in relation to the environment, as it is important to be responsive to the context in which the study phenomena occur (Salovaara, 2018). Since all the fieldwork took place at Visions of Home, and most of the activities took place in the Community Room, I will now describe these spaces in more detail.

The Building

The building itself was unique in many ways, designed specifically to respect the visual orientation of Deaf people. Moreover, communication rules of hearing and Deaf people are different (Mimoun, 1994). Hearing rules about conversation function on an exclusively verbal level, while for Deaf persons, they operate on physical and visual levels. Also, deeply embedded in Deaf culture is the desire to take possession of space where deaf people can dwell rather than merely use the space (Bauman, 2014a). Dwelling "implies the establishment of a meaningful relationship between 'man' and a given environment" (p. 375). Regardless of how brief or ephemeral, these places of dwelling serve as liberators of language and cultural functions. Throughout history, Deaf people have developed exceedingly practical and elegant means of adapting their surroundings to reflect their unique way of being. This concept is now identified as *DeafSpace*. "The DeafSpace concept and its origins are broadly defined in terms of daily acts of cultural customization focused toward building connection – visual, spatial, social and symbolic" (p. 377). These cultural customizations were inspired by and developed through Deaf collectivist social sensibilities.

Linguistically, ASL incorporates an element of *space* in all aspects of language production, as compared to the auditory signals of speech-based languages (Fekete, 2017). Thus, the personal space around a signer is a fundamental part of their ability to communicate. Specifically,

> ASL requires an adequate amount of space because the language is expressed with the hands, with movement, and within an area defined by the current type of conversion. As such, the space surrounding a Deaf person is an extension of his or her body. (p. 138)

Visual language, communication through movement in space, leads people to see the world around them visually. “The act of creating a visual diagram showing relations of objects produces a type of 3-D imagery space quite different from descriptions in non-signing languages” (p. 139). In this way, to be Deaf “is not defined by a lack of ability to hear the environment, but rather as being able to see one’s surroundings more fully” (p. 139). Fekete also suggested that ASL works to actively create spaces, as opposed to passively existing in prefabricated spaces.

Visions of Home was designed by a Deaf architect and exemplified the DeafSpace concept. Signed conversations can take place comfortably at much greater distances than spoken conversations (Mindess, 2014). The communal areas at Visions of Home were well lit and spacious. These features are important so that Sign Language People (SLP) (Batterbury, 2012) can both have room to communicate expressively, i.e., using sign language, and receptively, i.e., visually receiving the signed communication. Hallways in the Visions of Home building are spacious. They were built wide enough to accommodate groups of signing people, so that conversation can proceed unimpeded as people and groups move from one area of the building to another. Figures 5 illustrates the space needed for a small group, from two to four people to communicating via a visual/ gestural language.

Another DeafSpace feature of Visions of Home is the unimpeded sight lines from one area of the building to another. These unimpeded sightlines include spaces both inside and outside of the building, creating an open concept that has a lot of windows. This open concept allows for easy communication both within the space, and between spaces, e.g., a person in the Community Room can easily communicate with another person in the lobby or even outside the building through the glass doors or one of the many windows. Figure 6 provides an example of communication space and lines of sight for an 8-person visual conversation. From this, one can see the importance of unimpeded sight lines in a Deaf specific environment. Bauman (2014b) explained:

> A conversation between two signers (A and B) begins with a straight line; when a third party (C) joins in, a three-way triangular conversation begins. Every new interlocutor maintains a triangular building block so that each person can clearly see the others. (p. 240)

Conversations in a visual language also require “enough light in the right place and an absence of visual distractions” (Mindess, 2014, p. 92). The numerous windows throughout the communal space within the building provided great natural lighting for communication.

Providing more than just light, Bahan (2014b) explained that windows carry a different meaning for Deaf people than they do for hearing people. Bahan is referring to the fact that Deaf people can easily communicate through a closed window; hearing people cannot. Conversely, hearing people can easily communicate through a closed door; Deaf people cannot. Visions of Home was built with many windows. Essentially an entire wall in the Community Room is one large window. It was not uncommon to see someone outside the building, perhaps smoking, having a conversation through the window with someone inside the building.

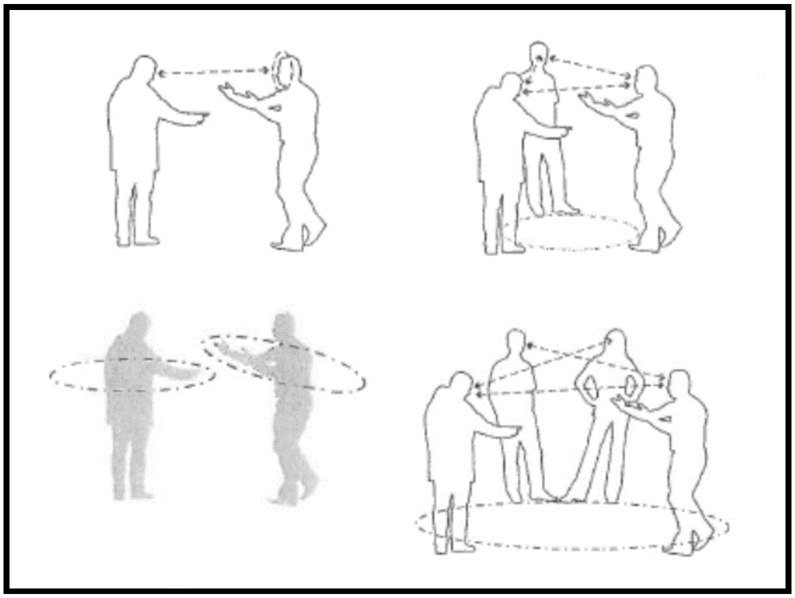

Figure 5. The space of the conversation circle is defined by the distance between signers and the signing range. The circle expands with each additional participant to provide visual access to everyone. (Bauman, 2014a, p. 383)

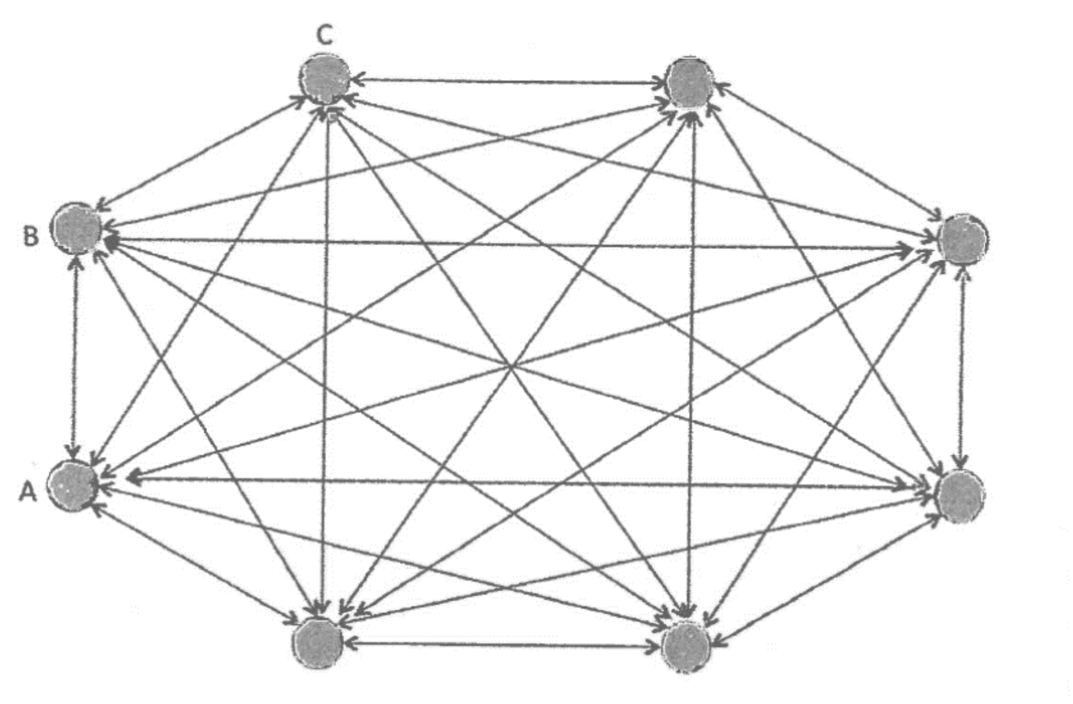

Figure 6. Circular proxemics. Bauman, 2014b, p. 240.

The Community Room

The Community Room is the largest gathering room in the building. It is used for many activities and functions. Some of the activities include holiday parties, pot luck dinners, game nights, organized crafts, Coffee Chats, and various meetings. The Community Room space essentially became my “home” in the field for a week during the data collection. The Participant Information Meeting and all participant interviews were conducted there. The room was well-lit and was visibly accessible to other areas in and outside of the building. Sightlines, so advantageous to DeafSpace, proved somewhat problematic at times during private interviews. This will be detailed in the research design challenges section of the dissertation. As the design of the room, particularly with respect to privacy, had an impact on research methodology, a rough sketch drawing of the Community Room is provided. See Appendix A. Note the many windows. Each window is floor to ceiling, except for the three in the kitchen area. These windows provided wonderful lighting for all the interviews, regardless of the time of day.

Participant Recruitment

The primary tool for participant recruitment was a catered lunch that all Visions of Home residents were invited to attend. During this Information meeting / luncheon, I explained the purpose and goals of the research, as well as the process involved to take part in the study for those who wanted to participate. At the close of the meeting, those people who were interested in being interviewed were then asked to provide additional information.

Residents were notified of the recruitment meeting through a Participant Recruitment Flier distributed to each resident by the Property Manager. The manager was exceedingly clear, however, that this would be the extent of her involvement in my recruitment efforts, and that all decisions about whether to participate in the study would be left entirely up to the residents.

The Recruitment Flier asked for people willing to share their experiences of living in a Deaf community and indicated that this would be confidential, Deaf-friendly research in ASL. I included a photograph of myself, so people could identify if they knew me or not. I also included my interpreter qualifications, which indicated a certain baseline competency to communicate via ASL. The Recruitment Flier also indicated the dates that the research would be conducted over a one-week period. It asked for an hour to an hour and a half of the residents' time. To compensate for participants' time, a $15 gift card was offered from a list of local grocery stores. Logos from the stores were found on the internet and included on the flier. The Participant Recruitment Flier was designed for simplicity, bearing in mind that it would be seen predominantly by people for whom English was a second language (ESL). See Appendix B.

Information Meeting Preparations

The primary tool for participant recruitment was a meeting where I served lunch and explained the research. This was open to all residents. After the meeting, anyone wanting to participate in the study was asked to fill out a Participant Background Information form. See Appendix C. The Participant Background form asked about the length of time living at Visions of Home, where the individual moved from, gender, age, race / ethnicity, religious affiliation- if any, type of education as well as the highest level of education attained, type of employment (past or present), and the hearing status of the participants' parents. Some of this information is self-explanatory, and other categories require some explanation. Education situations for deaf people can vary greatly, from residential schools, Deaf day schools, Oral only education programs, to mainstream programs where the individual is educated alongside hearing people, this might occur with or without interpreters. The hearing status of the participants' parents is important since the literature indicates that only a small proportion of deaf children are raised in households where sign language is the primary means of communication (Ortega, 2016). "As a result, most deaf children lack constant exposure to a sign language, and instead receive delayed and intermittent linguistic input" (p. 548), which affects the child in a myriad of ways throughout life. Furthermore, Barclay and Yuen (2017) have reported that the majority of Deaf family research has focused on hearing families with one Deaf Member. Yet the culture, values, and dynamics of this type of family are very different from an all-Deaf family. It was also noted that this question was the only one that consistency caused confusion for research participants. The form stated: "Parents were: Deaf / Hearing / Both". I had become so accustomed to the confusion that this caused, that it caught me by surprise the first time someone said that they really did have Deaf parents.

Hoping for a large turnout to the Information Meeting, I solicited advice from the Property Manager regarding the best time to serve lunch. A time of 11:30 was suggested. I walked in the building with the caterer and a large cart of food at 10:30. This caught people's attention! Not knowing how many people to expect, I had ordered lunch (of sandwiches and sides) for 32. After lunch was set up, I prepared the rest of the room by putting business cards on each of the tables. I also left a resume out and accessible if anyone was interested in my background. I placed many Participant Background Information forms, clipboards, and pens around the sides of the pool table. Unbeknownst to me at the time, the many windows in the room, as well as the collective nature of the Deaf community, were working in my favor, as people began to gather and watch to see what I was doing. When I arrived, there had only been a handful of people in the lobby; one hour later, the lobby was full of people waiting and ready for lunch.

As I was setting up, people came into the room one or two at a time to ask questions; (e.g., "If I come to lunch, do I have to agree to be interviewed?" *Of course not! Come and enjoy! I don't care if you want to be interviewed or not! Truly. Just come and have lunch.* There were a few sentences that started with, *"My friend wants to know…"*) Also, during this time, I was handed two notes from different people who were delivering messages for friends who could not attend the meeting. Both notes indicated an interest in participating in the study. See Appendix D.

I opened the door at 11:30 to find a large group of people in the lobby; a good estimate would be the mid to upper 30s. Wanting people to be able to enjoy their food and friends, I waited to explain my research until a majority had finished eating. Too nervous to eat, I became a bit of a server – assisting as needed. Like before, several people either walked up to me or called me over to their table to ask a question. I politely gave each person a brief answer, but most of the questions were going to be answered in the meeting, so I would then ask the person to hold on for just a bit. I was very aware that when someone asked a private or individual question during lunch, there were *many* sets of eyes watching my answers. Patton (2015) wrote that researchers would do well to remember that "regardless of the nature of the fieldwork, during the entry stage more than at any other time, the observer is also the observed" (p. 397).

People seemed both curious and skeptical about who I was and what I was doing. I knew that how I conducted myself at this first meeting would have a huge impact on people's decision to participate or not. Therefore, my focus was on honesty and transparency both with who I am as a person and with what and why I wanted to do this research. I stayed mindfully of the fact that "sharing personal information is such a basic value in Deaf culture that to decline to do so can be seen as rude" (Mindess, 2014, p. 260). This meeting felt like one big test where I was being judged on my intent, character, and ability to communicate. I had come expecting to be evaluated, and I respectfully understood this to be an important part of the process, staying ever mindful of what Glickman & Harvey (1996) have described as a "healthy paranoia" (p. 127) toward hearing people. I also realized this meeting would set the tone for the week, making it a high stakes meeting. I knew the importance of making a good first impression, and, at a minimum, not making a bad impression, aware that people would discuss both what they saw and what they thought of me.

Before the meeting started, someone came in and asked where I planned to stand when I talked. She stated that she was deaf and oral and needed to be able to see my lips clearly to know what was being said. She also said that Visions of Home is very good about hiring an oral interpreter for her for meetings, but that I had not provided enough advance notice for this to happen. She was both excited to learn about the research and wanted to participate in the study. She said that as long as I spoke clearly, she would be able to understand me fine. This was not a scenario I had contemplated or planned for but turning her away felt wrong. Including this person would necessitate a methodological adjustment in how the meeting would progress.

Because ASL and English are distinctly different languages with markedly different grammatical structures (Leigh et al., 2018), simultaneous signing and speaking, also referred to as SimCom, was not an option. Moreover, "SimCom is harder for Deaf people in general to understand because people who SimCom often resort to speaking in English clearly and drop essential ASL signs and grammar while trying to speak and sign two different languages" (Leigh et al., p. 100).

I decided, therefore, that the information at the meeting needed to be conveyed in two different languages, ASL and spoken English, consecutively. First, I explained to everyone why consecutive communication would be used. To explain this process, I took the first segment of information and proceeded to convey the information via ASL; then I took the same information and conveyed it verbally. I then took the next segment of information and signed to the group… and so on, until all the information was covered. As I reflect on the experience, the message did get conveyed in two modalities, although I am not sure how equal the access really was. I remember that at one point I realized that I had completely forgotten about the oral woman. I signed something to the effect of, *"Oops! I forgot that woman. I should catch her up now."* There was a lot of laughter in the room at this. I saw a person sign, "*I like her. She's funny!*"

Content

I began the meeting by introducing myself and sharing my background, paying special attention to areas of interest and intersection with the Deaf community. Patton (2015) explained that in cross-cultural research, "the usual explanation is some variation of 'I'm here because I would like to understand you better and learn about your way of life because the people from my culture would like to know more about you'" (p. 395). As I explained the research and the reasoning behind it, I also acknowledged my bias that the social work profession, as a group, needed to improve our understanding of Deaf people beyond the limited medical paradigm. The response to this was a lot of head nodding and agreement. This is a bit of a conversation I observed as one person explained to another, the point of what I said: *"You know how social workers are bad because they don't understand DEAF [people/culture/ community]?" "Yes." "That is who she wants to help – social workers to understand us better." "Oh Good!"*

I explained the concept and process of Informed Consent. I also explained that although they would not benefit from the research directly, I hoped that the research would ultimately help Deaf people in the future. As I discussed who would benefit from the research, I added that although it had not been written in the Informed Consent paperwork, I hoped to personally benefit. I explained that my goal was to finish the dissertation, get out of school, and get a job, which is how I would benefit. I said, “While that is not really important to you, I just want to be very upfront and honest about the fact that I hope to benefit from this research as well.” This statement and the honesty that went with it seemed to be appreciated, as people nodded in acknowledgement. While this is not something I would have said to a group of hearing people, the high value of information sharing within the Deaf community made this appropriate. After all, “if there is value in sharing information, it follows that withholding information is considered rude” (Mindess, 2014, p. 89). As the meeting progressed, people relaxed somewhat and began to intact more freely. I explained that interviews would last no more than one and a half hours and that I hoped to videotape the interviews. People would still be able to participate if they did not wish to be videotaped, in which case I would take notes during the interview. I explained that the video recordings would be destroyed at the completion of the research study. Next, I explained the process for those who wanted to continue further and to be involved with the dissertation research study. Lastly, I answered questions. One of the final questions and natural segue into the next phase of the meeting was, “What do we do if we want to participate?” I directed everyone to the Participant Background Information forms that had been placed around the pool table and explained that interview times would be scheduled after the completion of this form. Many people went to fill out paperwork, while others continued to ask questions.

As the Participant Background Information forms were completed, people then came to schedule an interview time. There was enough interest that a line formed. My system of scheduling involved asking each person when they wanted to come. As long as the preferred day and time were available, that became their appointed interview time. I then wrote the weekday and time of interview on the top corner of the Participant Information form, which I kept. I wrote the same day and time on the back of one of my business cards and gave it to the individual, which served as an interview reminder. Interviews were generally scheduled about 1 ½ hour apart. Each form was then placed in a pile corresponding with the day of the week chosen. This made it easy to see at a glance when there was and was not time available.

Assistance from the Community

Two individuals from the community were especially helpful during the scheduling process and with ongoing participant recruitment.

The assistant. Much commotion and activity accompanied the interview scheduling phase. At one point while in the middle of doing about three things, I looked up and realized that one of the people who were among the first to get an interview time had taken up position near me and was helping, quite effectively. She did not take over, but for example, when I ran out of business cards and was using torn paper to use as interview reminders, she made sure that the stack didn't run out. When she saw that I saw her helping she asked if I wanted her to stop. I said, "*No. You're hired!*" She replied, "S*orry, I only work for free.*" I noticed that a few people in line asked her, for example, if Wednesday morning was free. She would then glance at the piles and give a reply. If the answer was no, the person then had time to consult their schedule to come up with an alternative time. I started to think of this person as the *assistant*. Yes, it helped me, but it also helped the group by making the process go smoother and faster. With the assistant's help, I scheduled 30 interviews throughout the week. Other than for an interview, I did not see the assistant again at all during the rest of the week.

The recruiter. This is also a person that I interviewed, although it took a few days to realize the impact that this person was having on recruitment efforts. This person was often found in the lobby encouraging others to participate. One time, when I was going to get the next person being interviewed, I saw the recruiter ask someone else if they were next. The person said, no, and that he did not know what he was talking about. At the time, I was entering a conversation with the next interviewee, but as I turned back around, this new person said that yes, he did want to be interviewed. That encounter was the direct result of the recruiter’s actions.

As the week quickly filled up, I kept a running waiting list of names of people that still wanted to be interviewed until it became obvious that there would not be enough time to talk with everyone. By the time I left for home, I had conducted 33 interviews and had 5 people on a waiting list. During the initial Information meeting, 30 people signed up, although not all those people were interviewed. If a person was scheduled for a time slot but did not show, after a waiting period of approximately 15-20 minutes, the time slot was often given to someone else.

In summary, the Participant Information Meeting lasted about an hour and a half. People ate and talked for about 30 minutes. I explained the study and answered questions for another 30 minutes, and scheduling took about 30 minutes. By 1:00, I was conducting the first of six interviews on my first day in the field.

Ethical Cross-Cultural Research with Deaf Persons

A primary goal of qualitative research is to understand the phenomenon from the participants’, or *emic*, perspective, rather than the researcher’s, or *etic*, perspective (Merriam & Tisdell, 2016). Patton (2015) has proposed the distinction between “emic” and “etic” is, in part, related to the classification systems based on (a) the language and concepts used by the people in the culture studied, the *emic*, from (b) concepts and categories of the researcher, based on the analysis of important cultural distinctions, the *etic*. The challenge, Patton noted is to do justice to both perspectives.

An additional challenge when conducting qualitative cross-cultural research is that the researcher needs to keep in mind the diversity of elements and ways in which culture can manifest itself (Aneas & Sandin, 2009). Crossing cultural and linguistic borders in research intensify the inherent complexities of understanding and interpreting, and therefore, requires even greater attention to the need for continuous reflexivity from the researcher (Rubinstein-Avila, 2013). Moreover, this dissertation research is also "cross-modal" (Palfreyman, Sagara, & Zeshan, 2015) in respect to the fact that it ultimately crosses between visual/ gestural and auditory/ oral channels.

Given these complexities, the hearing-dominated research world will have better research to inform policy by engaging with Deaf researchers (Ladd, Gulliver, & Batterbury, 2003). Furthermore, Ladd et al. added:

> We would suggest that whilst there is a place for hearing-led research, it is imperative that Deaf people be involved. However, this emic-interpretation and advisory role can only be valid for situations where the research has no implementational effect on Deaf people. Research effecting Deaf people and their lives must be Deaf-led. (p. 23)

This dissertation research is hearing-led, with advisory role support from a Deaf committee member. The goal of this research is to explore the perceptions and experiences of D/deaf persons who live in one specific Deaf community, attached to one specific place, Visions of Home. It is hoped that through this exploration, an emic perspective of this Deaf community can be achieved and shared with the social work profession so that we, as a group of professionals, can become better allies with and to Deaf community members. This is a way of essentially staying in our own lane, with the implementational effects of this research geared toward the social work profession.

Design Changes

Ideally, the design of a qualitative research study is "*emergent and flexible*, responsive to the changing conditions of the study in progress" (Merriam & Tisdell, 2016, p. 18, italics in original). Because dissertation research requires both committee and University IRB approval, any design changes would need the approval of both parties before permission could be granted. After arriving on site and becoming more familiar with the environment, residents, and daily flow of Visions of Home, it became evident that a few minor design changes would greatly strengthen the study by, among other things, providing triangulation to some of the issues. Therefore, during the first half of the week, I maintained almost daily contact with both my committee chair and University IRB representative. In this situation, the two-hour time difference seemed to work in my favor. My daily routine consisted of interviews and fieldwork each day, with preliminary analysis, writing, organizing, and preparing for the next day each evening. At the very end of the day, I would email my committee chair with my ideas about the minor changes I wanted to make, the reasoning behind the request, and how this would ultimately strengthen the study. Invariably, by the time I woke up, I had a supportive and affirmative response. I then emailed the same request to the University IRB representative, and also received a timely and affirmative response each time, usually within the hour. This seamless flow of communication allowed me to respond to events in the field, in almost real time, and to make the necessary adjustments to strengthen the study. Ultimately, I identified and requested to make three changes: 1) to interview an Oral, non-signing, deaf person; 2) to interview a hearing resident; and 3) to accommodate those few individuals who had requested to be interviewed together.

Deaf Specific Research Ethics

There are several principles to consider when conducting ethical research with Sign Language communities (Harris, Holmes, & Mertens, 2009). These include 1) "Investigators should acknowledge that Sign Language community members have the rights to have those things that they value to be fully considered in all interactions" (p. 115); and 2) "Investigators should consider the worldviews of the Sign Language community in all negotiations or dealings that impact on the community's members" (p. 115). It is also critical to acknowledge that hearing and deaf people have different funds of knowledge due to differences in access to information. "Researchers who do not consider this when collecting data are participating in yet another form of deception" (p. 121).

Singleton, Jones, and Hanumantha (2014a) published the first empirical study addressing ethical concerns of research with deaf participants. Issues were examined from the perspective of three stakeholder groups: Deaf research participants, researchers, and Deaf studies experts. Confidentiality was high on the list of concerns. On the one hand, the use of video recordings preserves the participants' signed language production, including facial expressions for linguistic meaning, important for data analysis. On the other hand, however, it is not possible to deidentify video data to protect the participants' identity. Meaning that if, for example, a researcher wants to show a video example from the data, "they are *de facto* showing the identity of the participant" (Singleton et al., 2014b, p. 5). All participants expressed a lack of trust with hearing researchers who could not sign and who showed cultural insensitivity. Participants also voiced concern with feeling unsure of how to best handle cultural insensitivity from the hearing researchers and felt powerless to change uncomfortable situations during the research process. In addition, both researchers and Deaf Studies experts expressed "frustration with the lack of a

Deaf-centric perspective in the scientific community" (2014a, p. 63). It is also important that the researcher "provide information about their qualifications to use ASL" (2014a, p. 60).

Several steps were taken to address these issues. I shared my background as an LCSW clinician who has formerly worked with Deaf people in two different states, as well as a nationally certified interpreter with CI/CT. I left a copy of my resume out and visible on a nearby table for those who were interested or wanted more information on me or my background. Several people did. The resume served as a starting point for a few people to ask questions, which I answered honestly. Video recordings were made optional. All but three people consented to the video recording; and many agreed, only after specifically clarifying that the video would not be shared with anyone else. In addition, I clearly stated that I wanted the participants to stop me and ask for clarity if I said or signed something they did not understand. Likewise, I asked when I did not understand something. I tried to be transparent and honest, especially with what I did and did not know (e.g., I have never used a videophone; and I learned many new signs specific to Thanksgiving and the Southwestern region of the U.S.).

Establishing Trust

Establishing trust, especially when working in cross-cultural research, is critical. Therefore, trust will be discussed in the two contexts. First, I will discuss establishing trust with Deaf research participants in general and then more specifically; I will discuss how I worked to gain the trust of Deaf persons at Visions of Home. I will then discuss trust within the context of the trustworthiness of the study.

Deaf Research Participants

Aneas and Sandin (2009) argued for the importance of being aware of the anxiety that can result, even if unconsciously, of qualitative research participants and researchers who come from different cultural backgrounds. Not only is it essential to be aware of such potential anxiety, but one must also anticipate its influence, and to incorporate strategies for reducing its impact, thereby facilitating mutual confidence and making the communication process more effective. Moreover, Stone and West (2012) have argued that

> 'Trust' is a tricky concept, hard to quantify, and one which rests largely on our acknowledgement that, for many years, decades even, Deaf people have been viewed and treated as 'subjects' of largely hearing-led research…. Power imbalance, lack of consultation and an absence of community participation in research 'on' Deaf people has led to an inherent mistrust of non-Deaf researchers who 'come here, get what they need, then leave'. Hearing researchers in Deaf Studies should, therefore, be guided by a reflexive, culturally-sensitive imperative to work alongside Deaf people, colleagues, and participants on a footing that attempts to be more equal. (p. 647).

Staying mindful of both the power imbalance and the historical abuses inflicted on the Deaf community in the name of research, there were several strategies I used to try to gain trust within the Visions of Home Deaf community. Regardless of whether people chose to participate in the dissertation research study or not, I stayed mindful of the fact that I was a guest and visitor in their home. I also focused on being transparent and honest. If someone asked me a question, I answered it to the best of my ability. I was also careful not to simply answer and then move on to something else. I tried to make sure that I really did answer what was being asked. For example, at the end of each interview, I asked each person if they had any questions for me. One woman asked about the study. I answered completely and honestly, but I could tell she still had questions. We continued back and forth for a few minutes, but I felt like something else was needed. I then showed her a copy of the Interview Guide which included the purpose of the study and the research questions. After thoroughly reading the entire paper, she said, *"Oh, I get it! That's why you went back and forth with those questions. Okay, thanks."* The point here is that I tried to answer all questions in a way that would be understood; and to the best of my ability, I stayed with each question until the answer was satisfactory.

Another strategy for gaining trust included giving participants gift cards at the beginning of the interview rather than at the end. This was to equalize the inherent power imbalance and to make it clear that the gift card was in appreciation of the participant's willingness to participate in the study. It was not, in any way, contingent on the content or substance of the interview. Even so, I sensed a general desire, at times, of the participants to give me what I wanted and not to offend me. This was evidenced by questions such as, "*Is this what you want?*", and "*Am I doing okay?*" early in the interview. One person who moved in with a spouse stopped mentioning the spouse in all subsequent activities. When I inquired about the spouse's status, (I thought maybe the spouse had died.), I was told that the spouse did not want to participate in the interview. I reinforced that this was absolutely, and completely okay with me, but I wonder if the person's answers would have been different if he/she had not (potentially) been concerned for my feelings.

Also, I left my resume out on one of the tables during the Information meeting and throughout the week. It was not pointed out or discussed, but it was available for transparency. A few people looked at it, and one or two made a comment or asked me a question. It stayed on the table that had various piles and paperwork throughout the week, available if someone wanted to see it or ask about my background information. After one interview, a participant picked it up and looked at it. My sense though was that the English was a bit of a barrier. I said, "This just shows my background. For example,…" and then I pointed out which jobs I had worked with Deaf people and what those jobs entailed, and which jobs worked with hearing people.

I hope that my respect for Deaf people was in evidence. Here is one example. On the first day, one man came up and mentioned that he has a graduate degree. Then he said, "*I bet you're surprised.*" I replied, "*I'm not surprised. That's awesome! But it doesn't surprise me.*" He held my gaze, checking for sincerity, and then he left.

Another strategy is that I was often the first to bring up the subject of hearing people. Because of my hearing status, this might have been a taboo subject had I not brought it up first. I also demonstrated, and at times initiated, a viewpoint of the 'hearing perspective' in less than glowing terms. This was not done to highjack or direct the interview, but rather it served to acknowledge an awareness of the vast power differential between deaf and hearing persons.

As the week progressed, I feel that I did earn a degree of trust and respect from some community members. This is evidenced by comparing my journal entries of time spent in the field from the beginning of the week to later in the week. Here is a journal entry excerpt from day 1:

> *As I was wrapping up the first day and organizing my paperwork and equipment, etc., a man came in and asked if I planned to clean up the mess that had been made from lunch. I affirmed that I would as soon as I packed up all my other stuff. He looked at me quite skeptically and said, "We'll see."*

The following verbatim journal entry excerpt was written at breakfast the morning after my first day in the field:

> *Description of participants (in general): Polite and respectful, but wary-*

I believe that the number of people who agreed to participate in the study is another indication of trust. Journal and memo entries reflect this progression of trust as well. By midweek people were joking with me and laughing. Here is one of my favorite examples, recreated from a journal entry:

> *As I passed through the lobby on the way to the restroom between interviews, I was stopped by someone I had previously interviewed. He very seriously and gruffly told me that we had scheduled an appointment together, but that his twin brother had taken his appointment. He wanted to know what I planned to do about it since I didn't have any more time slots left. I froze and thought through a host of potential solutions. Then noticed a twinkle in his eye, and I busted out laughing – not a little laugh either – a big laugh, from the gut. (I clearly needed that!) He laughed too! Honestly, he looked a little bit proud of himself. He said, "I got you for a minute!" That he did!*

By the end of the week, I really felt a lot of acceptance. The following memo was taken verbatim from my journal:

> *Fri AM Reflection Memo:*
>
> *The first day I was there people were / seemed protective of their space and themselves. But by yesterday I felt very included in the "bubble of protection" (i.e., Uber, lunch, meeting, etc.)*

To explain: '*lunch'*- Wednesday had been a very busy day, and I had not had time to eat. One of the participants knew that, and on Thursday asked if I had lunch. I said that I did, but the person replied, *"If you don't, I'll go upstairs right now and make you a sandwich. Everybody needs to eat!"*

To explain ‘*Uber*’: It had just gotten dark as I waited outside the building for my ride back to the hotel. Two gentlemen from the building were standing outside smoking and talking. One I had interviewed, one I had not. We all acknowledged each other, and I moved away, not wanting to intrude on their conversation. A few minutes later, the person I had interviewed came over to me (sans cigarette) and asked if it would be all right if he could wait with me until my ride arrived. He said that he wasn’t sure it was safe for me to be standing by myself on a street corner in the dark. He hastily added that he knows that I would be fine, but that he would feel better waiting with me anyway. I gratefully accepted! My gratitude was not about safety; I felt safe. My gratitude stemmed from this person going out of his way to be kind and to show concern for my safety. We chatted as we waited. He told me that he had never used Uber and did not know how it worked. I told him that I had learned specifically for my trips to visit Visions of Home. I shared with him what I had learned and how the app worked. We could see the driver’s name, license plate number, the number of rides provided, customer service rating, present moment location, and the number of minutes until pick up. As the car pulled up, my new friend said, “*Okay. No- wait!*”, as he quickly scanned the driver’s face and license plate before nodding a definitive and firm “*OK.*” I had long since learned that ‘deaf eyes’ are so much better than my own! Science is now starting to catch up to what deaf people, and those familiar with deaf people, have known for years about the increased visual acuity of deaf people. See Dye (2014).

To explain the ‘*meeting*’: This refers to the fact that I was invited to one of the Visions of Home’s coffee chat socials in the Community Room. Someone came to talk with me about Friday morning time slot, and I said that I could not see anyone as the Community Room was being used. He replied, “*I know. But I want to make sure you know that you are invited to come.*”

Research

Trustworthiness has been defined as the quality of an investigation and its findings (Schwandt, 2007). To ensure trustworthiness, I engaged in researcher reflexivity throughout the process and included parts of this in the final research analysis. Furthermore, I wrote copious journal entries and analytical memos. These served as a starting point of analysis as I focused on what was most important and relevant to the purpose of the study. I used memos and journal entries to record my thoughts, experiences, feelings, and questions throughout the week. Memo categories included analytical, descriptive, methodological, and sometimes they were identified simply as musings. Here is one paragraph of a two-page memo written the first day; this took place during the lunch part of the meeting:

> *For the guys – The UGA Dawgs football team SEC matchup next Sat. was a good conversation starter. (I even met an Alabama fan… I just looked at him and shook my head. All his friends laughed.) Light mood.*

Another method used to ensure trustworthiness was the use of thick descriptions in the reporting of the study and study findings. A thick description in the final reporting provide the details necessary to essentially re-live and contextualize the research process (Roller, 2018). In this way, the reader can then evaluate the transferability of the research design, i.e., how well it might be used in a comparable context.

Data triangulation was another method used to ensure trustworthiness. I used multiple sources of data that included participant interviews, observations, and artifacts. Two of the requests made to the University IRB for study design changes related specifically to strengthening the study design by enhancing data triangulation sources.

Participant Interviews

A total of 33 residents were interviewed. However, only 31 fulfilled the audiological requirement of Baker and Cokely's (1980) core of American Deaf Culture diagram. Despite an intent to conduct only one hearing participant interview, a methodological misstep resulted in two hearing interviews. Therefore, all findings and discussions, unless otherwise noted, will pertain only to those 31 people who meet the basic audiological assumptions.

Demographics of All Participants

The age range of persons interviewed was 48 – 90 years, with an average age of 67. Demographic statistics change very little with the inclusion of the two hearing participants. Women outnumbered men 24 to 9. Individuals came from all regions of the U.S., from coast to coast. More people came from the West than any other region, and California was the most heavily represented state. Four people were born outside the U.S. The majority of participants were White; followed by Asian and Hispanic ethnicities, with three individuals in each category. Thus, approximately one-tenth of the study sample immigrated to the U.S., one-tenth was Asian, and one-tenth was Hispanic. "Black" was also identified as a category but had fewer than ten percent. An observation and anecdotal comment on the population sample is that although there were people who walked with the assistance of a cane or walker, there were also many who were very physically fit as evidenced by reports from one person of playing golf all day, another who enjoys going in to the nearby University football stadium to walk laps and climb the stairs as a form of exercise, and another who reported enjoying walking miles a day.

Regarding the question "Highest level of school?", including all participants, the range was 4th grade through graduate school. The two hearing participants were at both ends of the range: fourth grade and graduate school. Removing the hearing sample resulted in an educational range of 7th grade to graduate school for the 'deaf only' sample. A vast majority of the participants had at least a high school education with only a very small percent of people who did not finish high school. The reasons for not finishing high school were varied, although one commonality was noted among participants. Each of these people described their parents in similar ways: overprotective, low confidence in their deaf child's ability to function apart from their parents, and/or frustration with and dislike of sign language. The following example is an excerpt from an interview transcript:

> *When they figured out that I couldn't hear, they sent me to the Oral Only*[4] *School. The point of going there was to learn to talk. It was hard. To go there, I had to move away from home and stay in the dorm. I started at the age of 6 and stayed. Really, we communicated by writing though. They didn't let you sign at all. NOTHING. There was zero sign language! ... [Anyway], I was at the Oral Only School from age 6 to 11. Then I went to the Deaf school. So, there I learned sign language when I was 13. Then when I went home that Christmas, I was signing. My family was shocked! They said, 'Who taught you that?!" They refused to learn how to sign. I tried to teach them, but they wouldn't even try to learn. My father didn't want me to sign, and he wasn't going to sign either. I was so frustrated! I tried to explain that it would be so simple if he would just try to learn. But he refused and would only communicate with me by writing notes. Then I had to quit school to come home and help my mom with work around the house. From that point on, I was just homeschooled by my momma. Anyway, I never graduated. Then later, I got married. My husband is Deaf.*

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[4] Name redacted.

More than half of the participants' education went beyond high school. This included those who had some college (many have 1 – 2 years), college degrees and graduate school. One issue with the Participant Background Information form (see Appendix C), is that although it asked about the educational setting history, there were few options listed and little room to write in a more complete answer. Moreover, Oral education was not included as an option. I realized the mistake as, time after time, regardless of how participants identified their educational background, the majority of people interviewed had spent many years in an Oral education setting. Below is a segment from an analytical memo written during the transcription phase of research:

> *Most people who identified that they went to a residential or Deaf school, first had many years of oral education. It is interesting that these people identified that the actual education began when sign language was included, rather than at the beginning of the formalized education process.*

As Hoffmeister (2008) wrote, for those in the Deaf world, "to become Deaf" (p. 195) has no relation to when hearing loss actually occurred, but rather when the individual learned to accept and use a signed language. In support of Hoffmeister's concept, here is a redacted, interview excerpt from someone who was first exposed to ASL in college:

> *I started learning sign language in 19xx. I met a Deaf group in (City, State). I picked up sign language fast, and I became Deaf fast.*

In a similar way, education was identified as beginning with learning, which most associated with information via ASL, rather than the beginning of formalized, Oral education. Here is one of many similar stories:

> *I went from struggling to understand at oral school - when I went to Deaf school I 'took off' and became top of my class.*

Here is one of many examples of closet sign language users:

> *I went to an oral school. Most of my friends were at the Deaf school. I moved to the Deaf school when I was 14! I blossomed there. I was very happy. I had to hide sign language when I was at the oral school.*

Here is a description of the problem with oral only communication:

> *My mother used to read to me. I just watched her lips move. That's all it was. What is the point of oral (communication)? It is so crazy and easy to misunderstand mouth movements. It is hard to distinguish words by mouth movements. With oral communication, I had no idea what anything meant!*

Holcomb (2013) has suggested that "90% of Deaf signers were former oralists, making the Deaf populace a community of converts" (p. 39). I found this to be true. Because the number of people who experienced Oral education is so large, it bears further mention. The continuum and range of experiences in the Oral education setting were vast. One person described a positive experience, several described physical and emotionally abusive practices. The worst of these experiences involved being placed in a small dark closet for an extended period of time after corporal punishment methods to deter sign language were unsuccessful. At a minimum, most described the experience as ineffective and a complete waste of time. Gratitude for speech was also noted by several people, who mentioned that it was helpful in navigating the Hearing World. However, the consensus was vehemently opposed to oral *only* methods of education, with no sign language, at the expense of learning.

Family attitudes toward sign language also had a strong and lasting impact on life trajectories, both positive and negative. On the positive side, those who had a family member, such as a parent or grandparent, who was Deaf and were exposed to ASL at birth, excelled academically and socially. Here is a verbatim, signed and voiced, interview excerpt:

> *I have noticed that Deaf children with hearing parents are much farther behind in class than kids with Deaf parents. I am not saying that I am better than anyone else, but I have noticed that. Same thing in my daughter's class. She was way ahead in class, and that was because of having a Deaf family.*

On the opposite end of the spectrum are those families so opposed to the use of sign language that the deaf individuals never learn to sign. Despite wanting to learn ASL, two people waited until they were in their 30s to take ASL classes at a community college. One waited until her mother died before enrolling.

Participants worked at a variety of jobs including accounting, drafting, welding, warehouse work, housekeeping, chef, automotive technician, office work, electrical assembly, maker of prescription eyeglasses, teachers, and RV driver for Hollywood Studios. One commonality among participants though was that finding a job suited to their education level was often difficult. One person moved 24 times, all over the U.S., for various jobs. Another commonality could only be described as blatant discrimination, much of which I hope would not be tolerated today. For example, one woman was hired to teach ASL in a public-school system. Later, she was informed that the decision had been made to change her duties. She was then required to teach Signing Exact English (S.E.E.), which is not a real language, but rather is manually coded English on the hands. When she indicated that she was not comfortable with doing that, she was fired. The job was then given to a hearing, non-signing person, and the participant was offered a position as a substitute teacher. Another person described having difficulties in various job situations. Here is a part of the interview transcript:

P: The Way that I look at it is that I am a person. I am a being. I'm not my ears.

AH: Is part of the problem isolation?

P: I don't know if it's ever had to do with isolation. I think it had to do with people are not comfortable with the fact that I have trouble hearing.

Interview Methodology

Interviews were conducted in the modality that the participant felt most comfortable using. American Sign Language was the most common communication modality. Before beginning the interview, the Informed Consent procedure was thoroughly discussed, and all questions were answered to the participant's satisfaction. This process included asking permission to video record the interview. Three people declined the video process. I then explained that I would need to take notes during our interview. If the participant consented, I started the recording. Interviews were recorded using a 9-inch iPad facing the participant. At the conclusion of the paperwork process, the participant was given a choice of $15 gift cards for either Safeway, Fry's, or Walmart, all places that the Visions of Home shopping van visits.

At the beginning of the interview, I reviewed the Participant Background Information form. This served a few purposes. First, it was an opportunity to make sure there was no confusion with the written communication. The question that proved most problematic was the parents' hearing status. In addition to resolving confusingly worded questions, reviewing the Background Information form served as a natural departure point that often led straight to the Interview Guide questions used during each interview. See Appendix F. For example, when reviewing background information, I might say, “I see you have lived here 4 years, is that right?” And the person might reply with, “Yes. I moved here (exact date provided) because…”

As previously stated, each participant was given the appointment time that he or she requested, as long as that time was available. Initially, I scheduled each day to begin at 8:00 a.m., however, after scheduling the entire week, I was realized that I had made a mistake. The building, and therefore, the Community Room was not available until 9:00 a.m. each morning. After realizing my mistake, the Property Manager was very helpful and notified all 8:00 a.m. interviewees, via VP (which I have still never used) that there would need to be a time change. The scheduling all worked out. I include this information to illustrate how one of the many Deaf / Hearing cross-cultural issues were negotiated; in this case, the issue was time and time management. Mindess (2014) wrote that there is a cultural difference regarding timing associated with greetings and leave-taking behaviors. Moreover, hearing Americans often view time as a precious commodity “that we can save, waste, buy, spend, find, lose, make, pass, take, spare, run out of, and kill” (p. 50-51). There is a different perspective on time in the Deaf community; however, due to the importance of communication and face to face interactions. Mindess explained,

> If Deaf people are involved in a discussion, cutting it off arbitrarily because the clock says it’s getting late is almost unheard of. These moments of face-to-face communication and fellow Deaf people are so precious that there is minimal value placed on being ‘on time’ to the next appointment. (p. 51)

Throughout the week, there were two times that I was late to begin the next appointment, even when using “Deaf Standard Time (DST)” (Mindess, p. 51). I made a point to arrive on site using a hearing standard of time, and I tried to keep a general awareness of the time, otherwise, however, my focus was on the individual and our interaction rather than the clock. When one person expressed frustration that the interview was starting late, I apologized and then explained that 1) although I thought I would start interviews at 8:00 in the morning, I had been wrong about the time I could start, and by starting at 9:00, I was already a little bit behind; and 2) although I usually caught up with the correct appointment times each morning, each of the previous interviews that particular day had gone longer than expected. She was completely satisfied and mollified with this answer. Her reply back was *"Oh, that makes sense. Okay. Don't worry…"*

Ensuring understanding. The University IRB consent documents require a very specific language. For linguistic accessibility, these documents need appropriate modification for the possibility of a Deaf reader who is not highly fluent in English. Singleton et al. (2014b) wrote that "ASL translations of the English consent document may be one pathway to meeting the spirit of informed consent" (p. 4) while retaining cultural and linguistic access for research participants. Repeated efforts were made to secure a Certified Deaf Interpreter (CDI) over a three-week period in November 2018, for the purpose of signing, in ASL, the Informed Consent form for this dissertation research study. These efforts were not successful; however, and therefore, I communicated the Informed Consent information via ASL at the Participant Information Meeting and before each interview, each time staying mindful to ensure that the information was conveyed in a way that made sense to the participant as well as making sure that all questions were fully and completely answered.

The first thing I did with each participant was to thoroughly discuss the Informed Consent procedure and to answer all questions. English is a second language for most deaf people (Ladd, 2003), and possibly a third or fourth language. For this reason, the Informed

Consent form was written to be as clear as possible, omitting or replacing as much of the academic jargon as was feasible, and thereby making the form easier to read and less intimidating. See Appendix E. Throughout the process, conscientious effort was made to ensure that each participant fully understood the Informed Consent information. I stayed vigilant to fund of knowledge deficits, also known as fund of information deficits, which can best be described as gaps in knowledge due to an accumulated lack of environmental information that is not always accessible to deaf individuals (Hall et al., 2017), information that a hearing person might acquire passively through such avenues as radio, television, or overhearing a conversation. I stayed vigilant to my own potential knowledge deficits as well, given my unfamiliarity with the people and the environment. Even if the person nodded affirmatively during this process, I checked to make sure that this information was truly understood. Ultimately, I began to color code parts of the informed consent paper. For example, my contact information was highlighted in yellow. In one instance someone kept nodding, but I was not convinced that the information was actually being conveyed or sinking in. I picked up a business card, and we established that it was my information on the card. Next, I showed the person the same information on the Consent Form. The person said, "*Oh! That's you. Okay.*" I then took a yellow marker and highlighted the information, at which point, I felt confident that that piece of information had been clearly conveyed. In addition, the Principal Investigator's contact information was marked as well, but in a different color. I did not start this initially. But once started, the practice continued throughout as an additional way to make sure the information was conveyed completely and accurately.

Only three people did not permit the interviews to be video recorded. A majority of those who did agree to video recording did so only after verifying that no one else would see the videos. If a researcher wants to show a video example of the data, they are de facto showing the identity of the participant (Singleton et al., 2014b).

Research design challenges. I had established a basecamp of sorts for conducting the interviews in the Community Room. As people came in at the appointed interview time, I would ask each person if the seating was all right, or if he or she would like to move to a different spot. Several people took me up on the offer to change seating. This was done for various reasons including privacy and vision issues. Changes had to be made on the two occasions that more than one person was being interviewed. This was necessary to capture multiple participants on video. Normally, I sat with my back toward the window and the person being interviewed was able to see out the window.

American Sign Language was the most common communication modality. There were some exceptions. In two instances, participants who typically communicate via ASL opted to answer interview questions using their voices only. Sign language was reserved for instances when I needed clarification of a word or concept. Each person who chose this communication method stated that their decision was based solely on potential confidentiality concerns of people being able to look through the windows. I still signed since this was necessary for communication, but confidentiality was maintained by sitting with my back toward the window. This worked only because I am hearing and can rely on the auditory language. My part of the interview was still signed, however, as both of these participants relied on visual language. I kept my back to the windows, thereby preventing anyone from seeing my half of the conversation.

Another unique situation and design challenge happened when I interviewed an oral deaf person who did not know or use any ASL. A meeting had just taken place in the Community Room prior to our scheduled interview time, and there were still clusters of Deaf people engaged in various animated conversations. The Oral participant suggested that we go ahead with the interview, stating that privacy was not a concern since the interview would not be signed, and therefore, not visible to other people in the room. I was told that, in fact, I did not need to use my voice at all, since it was the shapes of my words that were most important. I was told that I have "good lips" and am easy to understand. Here was the dilemma though. It is rude to be *able* to sign, but not to sign, when in the presence of Deaf people. Therefore, starting the interview with Deaf people in the room did not seem like a good idea. On the other hand, Deaf people are well-known for their extended leave-taking practices (Mindess, 2014), which meant that it might be a while before the room cleared. This, too, was less than ideal. While this was certainly not the only time during the week that I needed to negotiate conflicting priorities between Deaf and Hearing cultures, it was hopefully one of the few times that I willingly allowed the Hearing cultural standards to take precedence. So, we sat at a table and began the interview. Admittedly, it felt both very rude (to the Deaf people) and very strange (to me) to be engaged in a private conversation while surrounded by people having conversations.

Interviews were recorded on a 9-inch iPad, once consent was given. A few notes were taken as well as a backup system. This proved both beneficial and somewhat distracting. All videos resulted in high-quality data. However, when people adjusted their seats to get out of a line of sight, for example, I did not always readjust the camera. This means that there were several instances when fingerspelled words were just outside of camera range. Another methodological issue is that as I watched the videos, there are times when I am signing that I have no idea what I said. The video is of the participant who is watching me and then responds to my question or comment. Although I have been able to figure it out, next time two cameras will be used.

Another challenge, especially initially, was the frequent interruptions during the interviews. Here is a partial list:

- Participant says to someone through the window, *"Go away! I'm trying to talk! This is private. Go smoke over there."*
- *"They're looking at me. We need to wait…."*
- A person is engaged in the interview and then sees something out the window and says, *"Oh look! Wait. I want to see what's happening…."*
- I almost always had my back to the window, and therefore, rarely saw what was happening. However, one time I was the one who stopped the interview, *"Hey, what's that news crew doing out there?!"* The person replied, *"I don't know. It's probably somebody who wants to know about sign language or Deaf people or something."* This was said with a shoulder shrug in a very blasé manner.
- There were interruptions for various other reasons as well, such as someone walking through the room from the hallway to an exit. This happened once or more daily.
- Several people walked in and asked, *"Hey! When is my interview?"*
- Or, *"I want to sign up to be interviewed…"* There were several of these as well.
- Someone came in to drop off food – to donate to whoever wanted the food.
- People came in to pick up the dropped off food…
- Someone left a card for a sick friend (a resident of Visions of Home).
- People came in to sign the card that has been left for the sick friend.
- Someone walked over to us and then said, *"Oh, I'm sorry! I thought you were doing crafts. DARN."*
- People chatted through the windows.

- Or, *"Oops! Sorry! But…. While I'm here, can I just ask you one question?"*

As the week went on, interruptions became less of a problem. In addition to being less of a novelty, I adopted more of a "go with the flow," attitude, and the interruptions seemed to become just another part of the fabric that made up the data gathering experience.

In the next section, the subject of hearing people will be discussed. "The cultural status of a hearing person exists only in juxtaposition to the cultural status of a Deaf person, and vice versa" (Glickman, & Harvey, 1996, p. 58). Hearing people who live at Visions of Home are in the unique position of being both members of the dominant, more powerful society, as well as people who are living in a space and place where they are the cultural and linguistic minority. The Cambridge Academic Content Dictionary (2009) advanced the concept that "the elephant in the room" (p. 298) is an idiom for an obvious problem that no one wants to discuss or talk about. Since this seems to be an apt description of the situation with hearing residents at Visions of Home, I will make use of this metaphor in the discussion that follows.

Discussions of the Hearing Elephant in the Room

I had not initially planned to interview anyone hearing at Visions of Home. But with the presence of hearing people in an established Deaf space, it seemed to be a bit like having a hearing elephant in the room that no one talked about. So, I asked about the elephant. In asking *about* the elephant, it also seemed only right to talk *with* the elephant.

There are a few reasons that the discussion of hearing people is relevant. First, much of the American Deaf experience is related, directly or indirectly, with hearing oppression (Lane, 1999). Also, Visions of Home had been involved in Federal litigation which, when resolved, resulted in a percentage of the units at Visions of Home going to hearing residents. Also important, I brought up the topic of hearing people, in part, to indicate that it was okay to discuss the topic of hearing people with me, in whatever context they wanted. My feeling was that without me being the first to bring up the topic, “hearing people” would have stayed a taboo subject that few, if any, would have discussed with me – a hearing researcher.

When asked how they felt about hearing people living at Visions of Home, the replies varied. There was a consensus; however, that to increase the number of hearing people would negate many of the positive aspects of Visions of Home by replicating the societal structure where hearing people take control of too many aspects of Deaf lives. Here are a few interview excerpts:

> *AH: Does it bother you that hearing people are here?*
>
> *P: No. it’s fine. Some are eager to learn to sign language. That’s fine. But if they kept adding hearing people, I would not like that! It would be talking only. “blah blah blah blah…….” Not good! It’s fine with no ears, but not with so many people here – just talking only.*

This individual’s first exposure to ASL was in college.

> AH: *So, the communication (with other residents) – even though it is tough, is it easier than in the Hearing World?*
>
> P: *Yes. I would recommend this place for hard of hearing and Deaf people. I’m not criticizing hearing people. They are fine. But still, I recommend this place for Deaf and hard of hearing people only. But mostly, I recommend it for Deaf and hard of hearing – ONLY. I mean, these hearing people moved in here, and then they act like they are surprised [that we are Deaf]! I don’t even understand why they are here. These people aren’t Deaf or hard of hearing, and I can’t communicate with them. Why did they move*

> *here in the first place? The hearing people can't communicate with Deaf people. They have to write things out on a pad. It is harder.*

In the next example, I had just asked the participant if he/she thought that hearing people should not live at Visions of Home.

> *No. That would be discrimination! But hearing people thought that for all Deaf people to move here is dumb. That thinking is wrong!*

I asked this next person if there had been any surprises they had found from living at Visions of Home. The reply:

> *I thought this was a place for Deaf – not hearing. I think it would be a better design if they kept the hearing people separate. (Proceeds to tell me all the hearing people's apartment numbers. It seems that a hearing person has one of the best apartments.)*

The next excerpt is from a participant who mentioned both Deaf and hearing specific accommodations:

> P: *Finally, after much discussion and debate, it was decided that some hearing could live here. That was to be fair. There were a few hearing people here then, but some hearing people couldn't stand Deaf people, so they move out. They don't like all the noise and the lights, and all those things don't help them anyway. So, they move out. For example, Deaf people have like to have TVs loud, so we can feel the vibration. Hearing people don't like that. Then they complain and yell, "Turn that TV down!" They complained to the manager too, who told us that we had to be quiet by 8:00. We were shocked! We said, "But this building is for Deaf people, and we welcomed hearing people! This isn't right!" That caused a big uproar and a lot of complaining.*

> [After an interruption from someone entering the Community Room, the participant continues.]
>
> Y*es. They asked us to be quiet. ...And we had welcomed them [hearing people]! Some of them were eager to learn [how to] sign; some weren't. Which was fine. I think there were about seven hearing people at that point. But I noticed that they seemed to all stay in a group to themselves. And they would just kind of look at us.... which was fine. Some of them, one or two, wanted to join in with us and learn sign language. And that was fine. But when they complained about the noise! That is not something we can help. Now we have to be quiet by 8:00 or 9:00 and for sure by 10:00 and then all night until the morning.*

Hearing Residents

Intending to interview only one hearing person, I mistakenly interviewed two. In addition to these two interviews, this section includes the description of an unsolicited encounter with a hearing resident.

Intended hearing interview. Initially planning to interview only D/deaf residents at Visions of Home, I requested a change from my committee and the University IRB, after arriving on site and realizing that the 'hearing element' was a factor in the environment whether we discuss their presence or not. The interview I have identified as the 'intended hearing interview' is with a hearing resident who approached me with an expressed interest in participating in the study. The methodological justification for including this interview is that it provided a triangulation component (Mathison, 1988).

Normally part of the majority culture, this hearing participant voiced feeling left out when Deaf residents communicated by sign language only, without using their voices. As she talked through the issue, however, she concluded that even though she enjoys living at Visions of Home for its location, affordability, and the exposure it has afforded her to learn about a new group of people, she is not sure that living with hearing people is what is best for Deaf people. Here is a verbatim excerpt:

> *Maybe in the future, around the country, if they make more of these places, they should talk to the government about letting it be a total Deaf community. Which I see nothing wrong with that. And I think they [Deaf people] would like that. I really think they would like that. You know, let's be politically correct, but let's be understanding and kind, too. And try to see from everybody's viewpoint, what is needed.*

Unintended hearing interview: A methodological faux pas. The second hearing person I interviewed was a mistake. On the one hand, it would be easy to simply 'forget' this interview and not discuss it. However, as Naveed, et al. (2017) posited, complications that happen in the field, which initially seem to be detrimental to the research, can instead enhance the study, especially if the researcher is willing to be both reflexive and transparent. Therefore, in the spirit of reflexivity and transparency, I acknowledge my blunder and admit that, indeed, it caused a great deal of introspection.

Let me first explain that at the time I was approached by the individual who ultimately became Participant #25; I already had a waiting list of Deaf residents who wanted to be interviewed. As she handed me a completed Participant Background Information form, she apologized that she was not better at the written English language. The form indicated a fourth-grade education, construction work history, and her ethnicity was listed as "Aian". She handed me the form as I was completing a very long, full day of interviews. In addition, this was the only day that I had worked through lunch, the result of a scheduling error combined with and several longer than expected interviews. So, tired and hungry, I looked over the Participant Background Information form. It was the Asian ethnicity that tipped the scale in this person's favor, as I thought of my committee, who had expressly mentioned the importance of interviewing participants from diverse backgrounds. Therefore, in pursuit of maximum variation, I made a split-second decision to interview this person, putting her ahead of all others who were already on the waiting list. Below is an excerpt of the transcribed interview when I realize my mistake, which occurred @ 2:44 minutes after starting the recording.

P: Do I have to write it too? (insecure) …. I don't know how to do that.

AH: No, that is fine. If I am communicating, and it is not clear what I am saying, let me know. Do you want me to voice and sign at the same time? Is that what is best?

P: I am not a signing.

AH: Okay. So, just talking is good?

P: Yes.

AH (reviewing the background information): All right. So, you have lived here for 5 years?

P: Almost 5 years. I love everything in here.

AH: What do you love about this place?

P: It is quiet and the social. When we have Coffee-chat, that is what I love…. talk to the people.

AH: Are you deaf? Hearing?

P: No, I am not deaf.

AH: Ok. You're not deaf.

Yes, it was embarrassing and frustrating, but there are also a few points worth noting from this experience. First, I felt a little bit like this person had cheated the system. After all, I had already started a waiting list, and she took a slot that a Deaf person could have used. I also felt a little bit angry. But when I watched the video, I saw that she did not deceive me or lie to me; rather I am the one who made an erroneous assumption. This caused me to really consider the question, what does a Deaf (or hearing) person look like? I wondered what factors contributed to my reading the situation so wrong? I need to acknowledge the fact that this hearing person presented herself in a manner that was less secure and less confident than any Deaf person I interviewed.

Ultimately, though, I was able to make an interesting connection from having two hearing participants that would not have been possible with only one. Sutton-Spence and West (2011) have suggested that Deaf people's distinction between Deaf and hearing is first an identity issue, but when discussing someone else, this distinction is more of an indication of *how* the person communicates. Is it visual or on the mouth? Deaf people communicate manually; hearing people communicate orally. Interestingly, each of the two hearing people I interviewed had lived at Visions of Home – a Deaf space and place – for 4 to 5 years each, and neither person referred to themselves or other hearing people as “hearing”, but rather “speaking”. They both seem to have come to the same conclusion as Deaf people, which is that “hearing” and “deaf” have less to do with one’s audiological acuity and more to do with the mode of communication used. Here is an interview excerpt:

AH: Are you saying that some people don’t like you because you are hearing?

P: No. I am saying that some people don’t like me because I am speaking.

Also, interesting, the hearing person who had struggled with English for much of her life, stated definitively that communication was easier and better with Deaf Property Manager at Visions of Home than with almost anyone else. Here is an interview excerpt:

> *P: I love it, to live here. It is quiet and peaceful and friendly. Especially Property Manager. I like about her because she understands me more than anyone else. I love the building. I love Property Manager. If you need something, you just say what you need. You tell her (Property Manager) what you need, and she does it.*
>
> *AH: How do you and Property Manager communicate?*
>
> *P: She want me to write down, and I write down to communicate.*

As mentioned, at times there seemed to be a lot of interruptions and commotion going on, in and around the Community Room, during interviews and transition times between interviews. This next encounter fits into that category.

One person's opinion. The following is a verbatim observation memo written immediately after the encounter:

> *Observation memo. 11/29/18 @ 2:13*
>
> *Hearing woman barged in and said WAY TOO LOUDLY, "Tell your people to stay away from this place!!"*
>
> *AH: Who are you??*
>
> *R: I'm one of the hearing people who live here. It's way too loud. It's awful here. HEARING PEOPLE SHOULD NOT MOVE HERE!!!!*
>
> *AH: Would you like to say that on camera?*
>
> *R: No!*
>
> *AH: It's confidential.*

R: You say that!

[She then turned and quickly walked out, and I began the next interview.]

The topic of noise came up regularly. Both hearing participants interviewed described Visions of Home as an exceptionally quiet environment. Deaf residents also frequently described the environment as “quiet” or “noisy”, although these descriptions often related more to “tone” and “commotion” than actual physical sound. There were also a few reports of a “crazy hearing man” that liked to yell sometimes. Yet, others expressed worry and frustration that sound had become a problem to and with the hearing residents; these Deaf people did not want to get into any trouble. As one person said, “*That [noise] is not something we can help.”*

What Does It Mean to Be “Hearing”?

The term “hearing” refers to members of the majority population whose values, conventions, or behavior departs significantly from those practiced and supported by the Deaf minority (Holcomb, 2013, p. 47). Andrews, Leigh, and Weiner (2004) have posited that the question “Are you Deaf or Hearing?” is a powerful inquiry that is really asking, “Are you with us or with the other?” It represents the greatest deviation from “Deaf”, and therefore, can be used in less than complimentary ways. Holcomb gave the example that during sporting competitions between two Deaf schools, it was not uncommon to see students calling rival team members “hearing” (p. 48) during the competition. Holcomb also explained that there is an ASL term used in the Deaf community, “HEARING-BUT”, for hearing allies, people who have a deep respect for Deaf culture and a positive attitude toward Deaf people.

The Deaf/Hearing cultural binary arises for many reasons. Sutton-Spence and West (2011) advanced that the emancipatory agenda of Deaf Studies makes use of strategic labeling “to discover and recover Deaf histories of oppression maltreatment, patronage, and discrimination by naming, from within a unified, political, essentialized space, the Hearing Other" (p. 422).

Until recently, the idea of 'hearing' was defined strictly as a person's audiological status (Sutton-Spence & West, 2011). Like any identity concept, hearing is socially constructed (Bauman, 2008). Bauman advances the concept of H/hearing, thereby addressing both the cultural and audiological aspects as does D/deaf. Researchers have suggested that many Deaf and Hearing cultural tendencies can be broadly divided into collectivism and individualism (Mindess, 2014).

The following poetic expression was written by "hearing, sign-language-using researchers" (Sutton-Spence & West, 2011, p. 422). Used here, it has been taken out of context and not in its totality. Regardless, it delivers a powerful message:

Something Somebody Wrote. And published.
Something a Deaf person wrote. And published. Hearing people have a "hands off attitude"
[….]
But somehow
Hands Off is the cruelest of terms
(p. 430, italics in original)

CHAPTER 5

DATA ANALYSIS AND RESEARCH FINDINGS

Data Analysis

The process of qualitative data analysis transforms data in the field into research findings. The challenge lies in making sense of massive amounts of data (Patton, 2015). There is general agreement that analysis should begin while the researcher is still in the field (Patton) and that whenever anything significant happens or comes to mind, “stop whatever you are doing and write a memo about it immediately” (Saldaña, 2016, p. 42). Patton suggested the researcher note and record emergent patterns and possible themes while in the field. Confirming cases can then be added that will deepen the analysis and possible disconfirming cases can be used to test thematic ideas while in the field. I did both. I kept a notebook and pen within reach throughout the process and was able to record events, thoughts, and observations as they occurred. Each evening, I wrote, journaled, and worked through preliminary analysis ideas with the data collected thus far.

Another recommendation that proved useful was to keep a copy of the research goal and guiding questions on a single page in front of you at all times (Auerback & Silverstein, 2003). I read this before each interview; it helped me stay focused on the information I wanted to capture. It was also helpful during the preliminary analysis writing sessions at the end of each day, by helping me to identify what data were most relevant. Saldana (2016) identifies several strategies for checking the progress of analysis while still in the field. The two strategies that I used were to 1) to check your interpretation developed thus far with the participants, or member checking, and 2) to maintain a reflective journal on the research project with copious analytic memos. An analytic memo is described as a reflexive freewriting, a narrative that sets in words your interpretations of the data.

Knowing that organization is paramount (Merriam & Tisdell, 2016), upon returning home from the field I created a hard copy master file notebook with all Participant information organized and numbered 1- 33. For the remainder of the analysis, each person was identified only with their assigned number of P1-P33. The identifying Participant numbers were removed in the final writing of the research study as an additional measure to protect the confidentiality of the participants.

The next phase of the analytical process involved processing, which is the transformation of raw data into a data set that can be used for analysis and often involves converting audio or video recordings into a written transcript (Roller & Lavrakas, 2015). There are challenges to representing signed utterances that occur in four dimensions, on paper, a two-dimensional format (Young & Temple, 2014). Another challenge is that “qualitative data in signed languages cannot be archived in its raw form without breaches of confidentiality” (p. 66). I, therefore, developed a system of processing the data that involved watching each video recorded interview while simultaneously making notes in a Word document, also identified as P1 – P33. See Appendix G for examples of transcribed interview data. All Participant numbers, ages, locations, and other identifying information has been removed. Parts of the interview transcripts are in English, providing “a ‘flat’ English rendering of what was signed” (Ladd, 2003, p. 290). Words written in all capital letters represent ASL gloss words. In some instances, the English and ASL gloss are both included, side by side. Parenthetical body language and other useful information are also provided. Some parenthetical information was included for the benefit of hearing, academic readers, who might need additional context. Video timestamps are also included. These are in brackets so that data can be retrieved and reviewed in its original signed format. This process developed and evolved somewhat organically as I figured out what did and did not work.

The abundance of raw data obtained in qualitative research is overwhelming (Patton, 2015). Therefore, the first challenge in data analysis is to make sense of the complexity. Patton wrote that developing some manageable classification or coding scheme is the first step of the analysis. “Content analysis, then, involves identifying, coding, categorizing, classifying, and labeling the primary patterns in the data. This essentially means analyzing the core *content* (emphasis in original) of the interviews and observations to determine what’s significant” (p. 553).

During the transcription process, copious analytical memos and code development ideas were recorded and stored using ATLAS.ti, a computer-assisted qualitative data analysis system (CAQDAS) (Woolf & Silver, 2018). As a supporting visual tool, I used a white board and note cards that could be easily be moved and adjusted as themes merged and ideas coalesced. I used a constructivist grounded theory (CGT) approach (Charmaz et al., 2018) to data analysis. CGT has a minimum of two phases of coding, initial coding and focused coding. The initial coding phase stays very close to the data. It is during the focused coding phase that conceptual categories are developed.

After the initial phase of coding was completed, I had 50 categories of codes and other information captured. Not all the information would be included in the findings, however, as, for example, I had a category for things I could not discuss due to the specificity of the information which might reveal the identity of the participant. I also realized that there were many ways that the information could be categorized. For example, isolation was noted as a recurring theme in many contexts, including the family of origin, school, and work environments. Initially, this was coded in each context. In subsequent rounds of analysis, these codes were brought together to become a theme that isolation, as the result of a lack of language and communication with others, occurred throughout the lifespan, when an individual was not around others who also communicated via sign language. Ultimately, this theme was incorporated into the larger category of the importance of communication, which was described as the antidote for isolation. At the end of the focused coding phase, there were three primary conceptual categories / primary research findings. Two additional secondary conceptual categories / secondary research findings are worth noting, but they were mentioned less often than the primary three conceptual categories / primary findings.

Research Findings

Introduction and Impressions

This research study took place in one location. One specifically created Deaf space. The people interviewed were a diverse group from different backgrounds. Initially, I was surprised that some of the people who work at Visions of Home lived there as well, although it makes sense. As vacancies opened, qualified residents were offered jobs. This is an example of Deaf people helping Deaf people. It is also indicative of respect for language and communication.

This was a very positive group of people, for the most part, despite life adversities. Although not quantifiable, many people looked much younger than their chronological age as well. The importance and love of animals were evident. I was surprised at the strong and very close connection to WWII from residents born in other countries, although in retrospect, that too makes sense.

At the end of each interview, I asked each person if there was anything else they wanted to share with me or wanted to ask me. Several people had a message that they wanted to share with those who live outside the Deaf community, specifically with members of the Hearing community:

- *"I want the government to see that the education at the Kendall School is much higher than it is in (state). It's not right that Deaf kids don't get a better education, because it is possible!"*
- *"I'm hoping that this is able to help others. I have worked with social workers in the past, and I had to work really hard - and with doctors too, especially - I had to work really hard to get them to understand me. And I'm hoping that this will help them to understand that it's not that hard to get along with us. I assume.*
- *"I hope my daughter in law reads your book. She doesn't understand Deaf [people]. It's been five years, and she still hasn't invited me for Christmas. It hurts me a lot."*

Constructivist Grounded Theory Primary Categories/Findings

Three primary conceptual categories / primary findings that emerged from the focused coding phase of data analysis were 1) the importance of communication, 2) family, and 3) Deaf help Deaf. These categories are presented as the findings of the dissertation research. In addition, two secondary conceptual categories / secondary findings emerged: 4) independence and safety, and 5) and identity, labeling, and ontology. Primary and secondary conceptual categories were determined based on frequency.

The importance of communication. The importance of communication was singled out as the number one primary conceptual category /finding to emerge from constructivist grounded theory coding. Without a doubt, the importance of accessible communication throughout the lifespan was identified as paramount. The need for communication accessibility was conveyed explicitly, as was its opposite, the absence of communication, and the ensuing loneliness and isolation. Holcomb (2013) wrote that many deaf people suffer an impoverished linguistic home environment largely due to the fact that family members do not sign. Deaf epistemology has noted a "dinner table syndrome in which deaf children and adults are frequently left out of conversations with hearing family members and friends in many everyday settings, including at home and in school" (Hall et al., 2017, p. 767). The dinner table syndrome was frequently described by participants:

> *My parents are both hearing, so our communication was only oral. We did some writing. At the dinner table, I was completely left out of conversations. I would ask, "What did they say?" They would tell me, "Oh, never mind." It was a tough experience.*

Here is another example:

> *Communication with my family was oral only - by lip-reading. My family always left me out. They all talked and left me out of the conversation. Sometimes when they left me out, I would ask my Mom what they were talking about. She would tell me just a little bit. I knew what she was saying was not enough information for everything they said.*

One person reflected:

> *I felt like a visitor in my home.*

Communication isolation is a ubiquitous fact of life for many deaf people. Mindess (2014) pointed out, however, "being deaf is a communication handicap only when deaf people are around hearing people" (p. 81). The next two people compare hearing and Deaf apartment living environments:

> *I feel this place is a very good idea for Deaf people or hard of hearing people who can't communicate and have no friends. It's very hard. I was shocked to find out about this place, but it's wonderful! Especially for Deaf people who have lived for years in an apartment alone. Now they can communicate without barriers. You don't have to be lonely. You can have a social life.*

Also,

> *Communication accessibility is so much easier here! Hearing people have such limited ability to communicate. There is no communication really. But it is very different here. Very different! Out there, hearing people on the outside world don't communicate. So, there is no communicating with your neighbors. But here, (big smile) there is communication with your neighbors because most of the people sign. This place has good communication accessibility, and that keeps me from being lonely. There are no barriers to communication like there is outside of here. If I were to move out, I would have no idea what was going on again because I can't hear, and hearing people don't know how to communicate in ASL.*

This statement speaks to two important issues: incidental learning in the Hearing World and information sharing in the Deaf World. Incidental learning can be described as informal or unintentional learning that regularly occurs throughout the day outside of formal educational or work-related situations (McKee & Hauser, 2012). Because this same information is very difficult for deaf people to access, Holcomb (2013) explained that deaf people have learned to help each other by filling in gaps of knowledge whenever possible. Thus, information sharing in the Deaf World helps to compensate for information not acquired through auditory channels.

The hearing status of participants' spouses or partners was not included as part of the Interview Guide or Participant Background Information; therefore, this information was not consistently gathered. If someone mentioned a spouse or getting married, however, I often inquired about the individuals' hearing status. Deaf people have one of the highest intermarriage rates among all social groupings (Ladd, 2003). Of the participants I specifically asked, the percentage who married someone Deaf was 100%. For many, a marriage or partnership seemed to be the first truly accessible communication with family. One person said,

> *I did not like living with my parents. They ignored me, and they controlled me – that kind of thing. I felt very isolated when I lived with my parents. Then I got married and left.*

This period of adulthood, the time when people chose their friends, spouses, and life partners, seemed to be, generally speaking when participants experienced communication compatibility at home. Following this period, however, as life circumstances changed for whatever reason some found themselves, once again, to be isolated while surrounded by hearing, non-signing family members. For instance, *"The problem is my son's wife. It is hard for her to understand about Deaf culture."* Also,

> *My family is all hearing, and there is no communication. My son signed, but no one else did. They used him to communicate with me. No one talked with me. No one paid attention to me at all. I became very depressed from being so isolated. Deaf people at the apartment here are nice. They have been very accepting of me. I also like that it is nice and quiet here. It's very peaceful, much better than with my family [no squabbles; no communication]. I am tired of all that. I'd much prefer to be here. I'M DEAF! It is important to look at me when you talk to me. My family doesn't do that. Some do look at me to communicate, but I'm tired of being excluded from family communication. I like it*

> *here. In the back of my mind, I think that my son and his family might think that Deaf means dumb. Because I am Deaf, they think I'm dumb. I'm not! Oh, no, no, no, no! That isn't right. I feel like they won't communicate with me because they think I'm stupid. I'm not! I'm Deaf. There is a difference between Deaf and stupid. But they're hearing. They're hearing, and they don't want to know. They don't respect me. I decided to show respect to myself, and I moved here. I'm done with that negative attitude toward Deaf people. I'm done. But that's the reason I moved here.*

Not all participants described difficult family situations, but rather conveyed only happiness at living at Visions of Home. Note the Deaf / Hearing space binary:

> *I am happiest here than at any other time. Even my daughter noticed that. It's because of communication. You don't get that out there.*

Finally, in this instance, I had asked the individual to share an example of something they missed from before moving to Visions of Home. Here is their answer:

> *Nope. I don't miss anything. I have always had Deaf friends; I went to Deaf schools. I have always been with and around Deaf people. When I got married (to a Deaf person), then I was with my family. Now my family has all grown up and moved away. I didn't want to sit around with nothing to do in my life, so I moved here to keep me busy. I am so much happier here with other [Deaf] people than I would be sitting alone with no one to communicate with. I don't want to sit around bored all the time. No thank you!*

Family. The importance of family was identified as the second of three primary conceptual categories / primary findings to be derived from constructivist grounded theory coding. The importance of family was mentioned often. The definition of family, however, varied. For some, family meant children, grandchildren, spouses, siblings, generally the more traditionally defined family roles. Two participants had moved into Visions of Home, moved out, and then moved back in again. In each case, the reason for moving out was related to a family member being sick or needing help. When each family situation resolved, both people put their name on the waiting list to return.

The caveat to the importance of family is that, for many, the Deaf community is family. Lane et al. (2011) explained,

> The Deaf-World is a surrogate family; it offers many ASL signers (those with hearing parents) what they often could not find at home; a positive identity, a language model to emulate, easy communication, and lives they can image leading. (p. 9)

One person definitively stated, *"The Deaf community here feels like family."* Interview Guide question #5 asks, "Growing up, how did you communicate with your family? Several people responded to that question with a burst of laughter. Another participant explained,

> *The Deaf community here – it feels like family. We see each other every day, we talk. It is good for all of us. I have had many people tell me that without this place they would be at home alone with no one to talk with. That is not a good life. It's not good for your mind or your physical health. But here - it is good. We have each other. We can socialize and talk, and that keeps our minds working, and all that.*

Someone else said, *"I have learned a lot more here from Deaf people than I ever did from hearing people before."* Also,

> *I come from a big family. I when to the Deaf school when I was 5 years old, and I stayed there for 10 months. I came home at Christmas, but I was just so isolated. I couldn't wait to get back to school! I just kept wanting the Christmas break to be over, so I could get back to school. I was so happy then. During the summertime, I had nothing to do. I'd*

> *ride my bike around, but I was so bored. My family talked to each other, but I wasn't included. They didn't sign. For example, if I wanted a 7-Up drink, I needed to point to something green. 'Green' meant 7-Up to my family, but really it wasn't communication. It was very confusing. They just used home (made up) signs, but it wasn't real communication. I don't feel very connected to my brothers and sisters because we didn't communicate very much at all growing up.*

As opposed to the experience of very little communication from their biological family, this person explained:

> *I love hearing about the different experiences of other Deaf people from all over the U.S. and other countries. I have learned so much from them! And we like to do many things together and have fun as a group.*

The next excerpt is from someone describing group advocacy efforts when residents were worried that Visions of Home would cease to be Deaf-specific.

> *We thought they believed that all Deaf people are dumb and that they were trying to get rid of us. But they said no, you've got the wrong idea. We know that Deaf people help each other. And when Deaf people get together as a group, they have a more enjoyable life than when Deaf people are scattered all over and live alone without other Deaf people. Together, we can help each other and enjoy each other's company. Deaf people help each other. Being together will help us to build our minds up, too. Because when Deaf people get old, some might have to move in with their families. Then they are all by themselves, completely isolated. Then they just sit there with nothing to do, and their mind deteriorates – and they die much faster. I don't want that. No thank you! I am going to stay here.*

Thus, the importance of family was evident regardless of whether it was family by blood or community. As one person said, "*My son ignores me, but I had to let that go. I haven't seen him now for 8 years. It's sad, but now I needed to make myself happy.*"

Deaf help Deaf. The importance of Deaf people helping other Deaf people was the third of three primary conceptual categories / findings to emerge from constructivist grounded theory coding. This was more than simply learning from and enjoying the company of other Deaf people. There was a premium placed on the concept of Deaf people helping other Deaf people. Signed (gloss) DEAF HELP DEAF, with one English translation of Deaf people help other Deaf people, I have chosen to use a hybrid version: Deaf help Deaf. Simply stated:

> *I am so happy to be here. This place is awesome! It's perfect for me. I love it – hanging out and socializing with other people. Here, we can talk with each other; otherwise, I would be lonely and isolated. But here we get together. We help each other.*

A lot of people volunteered in the community; several people are involved with Deaf-Blind organizations, animal rescue, and others. In addition to these more formal volunteer activities, there were accounts of helping a younger Deaf person figure thing out, almost in the role as a "second mom". There were also stories from people who were helped by an older Deaf person; some were related by blood; some were not. One person explained by saying, *"My second mom is Deaf."* Another person said,

> *I am the only Deaf person in my family, except for my grandparents who lived out in the country. They helped me a lot! I loved to go visit them. My hearing brothers and sisters did not, but I loved it! They taught me all kinds of things, and that helped me to get a job.*

The next excerpt is important from the perspective of Deaf helping Deaf, but also, has relevance to the profession of social work, as the individual expressed frustration with counselors who lack Deaf cultural awareness:

> *One of the things I learned back in (state), is that it depends on the counselor. Because sometimes the counselor is not doing a good job. Sometimes the counselor does not know anything about it because they don't know anything about Deaf culture. You've got to understand Deaf culture because some Deaf people use sign language and that is difficult because they don't want to help you. So, what is going to happen to the Deaf? What will happen to the Deaf (people)? You need to get some Deaf counselors who know how to help. It is very important! Deaf need to help the Deaf. Yes. Deaf need to help the Deaf.*

I had asked this next interviewee about what activities he or she enjoys:

> *My favorite thing to do is puzzles. It takes time, but when a group of Deaf help each other, we can put it all together. Sometimes we will have 7 Deaf people, all together, working on the same puzzle. Together we can do all things.*

That was a powerful message that typifies what I saw and heard from people throughout the week. *"Together we can do all things."* The help and support that the residents showed to one another were noted numerous times in memos throughout the week. This verbatim observation memo was one of the first, written as interviews were being scheduled, Monday, November 26, 2018.

> *Positive note:*
>
> *People are helping other people sign up to be interviewed!*

Next will be a discussion of the secondary conceptual categories / secondary findings that emerged from the focused coding phase of analysis.

Constructivist Grounded Theory Secondary Categories/Secondary Findings

Each of the two secondary categories / secondary findings discussed is a compilation of related ideas.

Safety and independence. Safety and independence were identified as one of two secondary conceptual categories / secondary findings to emerge from constructivist grounded theory coding. For some, largely identified as hard of hearing and oral deaf individuals, the visually oriented safety features were the primary identified the reason for moving to Visions of Home. It has been suggested that there is no oral deaf community because oral deaf people do not want to live together (Woll & Ladd, 2003). There was evidence, however, that some friendship groups had developed along communication preference lines. Regardless of the initial reason for moving in, individuals from each group, e.g., Deaf, hard of hearing, and oral deaf, indicated feeling safer at Visions of Home than at any other place or time. Here is an interview excerpt:

> *AH: Can you share an example of how your life is different here?*
>
> *P: This place is the safest I have ever felt, and that even includes when I was growing up with my parents. It is the safest I have ever felt! So, I'm not as nervous like I was at other places - because I know I can't hear.*

Also, from interview transcripts:

- *The main reason I moved here was for safety.*
- *I can sleep soundly at night because I know I'm safe.*
- *I like the fact of the light flashing for the doorbell. Of course, there's already light flashing for the alarm, but there's a lot of safety features - and that's why I moved here.*

- *I feel safe because of the two locked [outside] doors. Really, I do have good neighbors. There is really no trouble around here, not much. It's good people here.*
- *I feel much safer here. I really like that I can communicate with the manager and the assistant manager in ASL. That means I can take care of my own business and do what I need to do. It is also nice to be able to talk with neighbors.*
- *I feel safe here. I like the security here. People from the outside can't just walk in the building. Each resident must let their guest in.*

This memo was written during the transcription phase of data analysis:

> *Memo:*
>
> *This is a recurring theme in a variety of situations. P10 [@26:30] is discussing the doorbell safety feature in detail. I will note from my personal observations, that people DID NOT open the door for me. Period. Even if I knew the people and could see them sitting around the sofas and chairs in the lobby. It was as though I did not exist until the CORRECT person let me in. (Truthfully, it was as though I was almost invisible. And I KNOW that deaf people have the best eyes! Therefore, the only thing for me to conclude is that the rules were being followed explicitly.)*

A few safety concerns were mentioned as well, the vast majority of which were directed outside the building to the surrounding area. For example,

> *I [want] someplace that I can walk outside and feel safer, something closer to a grocery store. Here I don't feel that safe walking around outside the building. And the sidewalks seem uneven. You hear a lot – like this whole street used to be motels a long time ago – and old trailer parks. And they got rid of them all, and now they are apartment buildings. Women will not walk their dogs at night here. It's too dark outside.*

In addition, there were several mentions of a homeless population in the area with panhandling in the immediate vicinity of the building, particularly at night.

For several, independence was identified as most important. Visions of Home became a place that independence was made possible, in large part due to the Deaf specific safety features. Here is one transcript example:

> *I didn't want to live with my parents. I didn't want to live with my brother. I wanted independence!! I want to be independent. I don't want to live with my parents. They can't sign so we can't communicate! I don't fit in there. It's very isolating for me! I don't want that. I've experienced that my whole life. After 24 years of marriage, I got a divorce. I started going to church some. Then I moved in here. And here we are. That's all.*

Although related, an important distinction was observed between the safety and independence categories. In one category, *safety*, the safety features brought a sense of peace, security, and well-being to D/deaf residents. In the *independence* category, however, these same safety features were described as putting their hearing family members, e.g., parents, adult children, siblings, at ease, and in that way providing freedom for the D/deaf person who would not have to move in with hearing, non-signing family members.

Identity/Labels/Ontology. The second secondary category / secondary finding to emerge from constructivist grounded theory coding was that of 'Identity / Labels / and Ontology.' How a person identified themselves was not something that I made a point of asking everyone. Some people offered this information**;** I ask others. This topic was discussed enough to realize though, that a person's 'Deaf Identity' is personal and there is no uniformity among the 'typically' used labels. Several people told me that they were "one-half Deaf, and one-half hearing", and each of these people explained the concept differently. Still another person came up to me at the Information Lunch Meeting and explained that they would not participate in the study because I was asking about Deaf people, and this person was only "*one-half Deaf*", and the other half was "*hearing.*" Of the people I interviewed, a person that I would have identified as culturally Deaf explained their *"half Deaf / half hearing"* cultural status:

> *Really, Hearing culture and Deaf culture are different - very different! But I associate with both cultures because I have a hearing family, and my child is hearing. So, I learned both. It's not just Deaf culture for me. No, I have learned both ways of being in the world.*

Another person who identified as both explained:

> *I have noticed that there are groups of friends here. I don't really fit in any of the groups though. I don't know how to explain it. I guess I feel half Deaf and half hearing. That makes me different from other people. At first, I didn't understand the groups until one man explained it to me in confidence. There are some Deaf people who grew up in the dorms, and that is one group. Then there are some hard of hearing people that act hearing, and that is one group. We really need to all just be nice to each other here. It is not everyone, but just a few people like to stay only with their own group. But that's why I feel like am only one half in each group. I don't fit completely in either. I can understand and talk with the hard of hearing group some, but also, I understand the Deaf group. I really do feel like half of me fits in each group. I am fully Deaf, but I can understand each perspective. That leaves me feeling a little bit left out.*

Another thing to consider with using an identity label with someone is the fact that ontologically deaf and hearing people are different (Padden & Humphries, 1988), and therefore, identities and identity labels carry different meanings. "Central to explorations of Deaf ontology is a focus on the sensory orientation of Deaf people as primarily visual and kinesthetic" (Temple & Young, 2014, p. 18). Several participants explained that *"hard of hearing means that you can hear some."* Padden and Humphries elucidated that in both languages, ASL and English, the phrase to be "hard of hearing" (or "HARD-OF-HEARING"), signifies deviance from the norm, i.e., of being either hearing or DEAF. Therefore, from a Deaf perspective, "VERY HARD-OF-HEARING is someone who departs from the center greatly, thus someone who can hear quite well" (p. 41). One participant explained a similar concept: *"When you say, 'I didn't hear you' to Deaf people, what you really mean is I didn't see what you signed."* Another person explained the Visions of Home living space similarly.

> *It is different when all Deaf people live here. When you live out there (indicating Hearing space), it is one or two Deaf people only. But here, it is the opposite situation. Here, it is like the hearing people who can't hear.*

The consideration of ontology explains how, even for the hearing residents, 'hearing' becomes 'speaking.' It is more about how one communicates than auditory acuity.

Several people talked about problems that can happen when others, and in particular hearing people, make assumptions based on identity labels. This occurred in a variety of forms such as, "Why can you hear some things, but you can't talk? Or "Why can you talk and not hear?" In work situations, some Deaf people found hearing colleagues trying to test their hearing and thereby the honesty of the Deaf individual. In one situation, someone pulled an alarm to prove that the Deaf person was lying and was then surprised when the Deaf person did not react.

Attention will now be given to each research question. Research questions will be addressed in the order of saturation attainment, meaning that all research questions will be addressed in reverse order, beginning with research question 3.

Answering the Research Questions

The purpose of the study was to explore the perceptions and experiences of D/deaf persons living in a purposefully designed Deaf community. The following research questions were used to guide this study.

1. In what ways (if at all) have your experiences(s) with Deaf culture influenced your decision to live in a Deaf community?
2. What are the benefits of living in a Deaf community?
3. What are the challenges of living in a Deaf community?

Addressed in the order of saturation attainment, in which saturation is identified as the point in data collection when no new or relevant information emerges (Patton, 2015).

Research question 3: What are the challenges of living in a Deaf community?

Gossip and negativity among community members were the most often identified problems. One person explained that the sharing of information feels very different in a predominantly hearing space, where only 1 or 2 Deaf people live than it does in a predominantly Deaf space with many Deaf people. Also, comparing predominantly Deaf and predominantly hearing living environments, one person said, H*earing people gossip too, but at least I can't see what they are saying, so it doesn't bother me."* One person explained communication misunderstandings and gossip as being similar to the "*game of telephone"*:

> *It is a little bit of a sticky situation, but the thing you have to be careful of is gossip. Also, sometimes there can be challenges when there is confusion or a mix-up with*

> *communication. It is like [the game] phone to phone. For example, I have a story, and I tell it to the person next to me, and then they change it a little bit, and they tell the person next to them…. And it goes all the way around the people. This is called phone to phone. As the story goes around and gets changed a little bit each time, by the time it gets back to me… It's like…No! I did <u>not</u> say that!*

There were different opinions as well. Several people said that there were no problems associated with living in a Deaf community; still others said that the positive attitudes of people who live at Visions of Home are one of its best features. From an observational standpoint, people conveyed that negativity can be a factor. What I witnessed and experienced throughout the week, however, was an overwhelming amount of positivity and positive attitudes from the group as a whole and from individuals. There were two exceptions from individuals who, I felt, used the interview as an opportunity to vent frustrations and to complain. With both, the complaints did not seem to match the reality of what is feasible, e.g., *"I want to pay less money every month, but I want to live in a gated community with a nice swimming pool."* Everyone else who mentioned that negativity could, at times, be a problem, did so in a Deaf culturally appropriate way (Holcomb, 2016) of providing enough information that I was able to ascertain a clear understanding of the whole situation and by providing solutions of how one might navigate such a situation. This is evidenced by these statements:

- *You have to know how to avoid negative people!*
- *The most important thing in my life is to keep positive.*
- *I like to communicate with positive people.*
- *If there are gossip and conflict, I will avoid it by spending time with my dog instead.*

Numerous people stated that their community volunteer involvement helped them to avoid negativity. There were many examples of people "taking a break" from community activities when faced with too much gossip or negativity, before rejoining and resuming involvement. This is illustrated in the next two examples:

- *If something bad happens, for example, and there is gossip, then I will take a break from everyone for a while until I have calmed myself down. Then I will go back, and everything is fine. But if there is a whole lot of negativity going on, I don't want to be around it. So, I will stay away, and take a break from the group. I have learned how to take care of myself and stay away from negative situations.*
- *If something happens and people gossip, then I decide I need to stop hanging out with the community for a short time until I can calm myself down again.*

Other challenges identified, seemed to have less to do with *living* in a Deaf specific community than it did with *moving*, sometimes great distances, to live at Visions of Home. Moreover, some people identified challenges associated with getting older and learning a new and different environment. One person explained that getting older is tough enough, but when one also moves to a new part of the country to live, this adds difficulties. *"Before I moved [to Visions of Home], I knew where everything was – doctor, etc. But to figure all that out again, when I'm older now, is tough."* Another person said, *"I like to walk, but the sidewalks around the building aren't even, and I don't want to fall."* Also, many people identified that having to leave their home, i.e., described as an area or part of the country they loved, to be able to live in a place where they can communicate with others, was tough. For example:

- *I miss the mountains.*
- *I miss the cold weather.*

- *I miss the foliage and plant life of (state).*
- *I miss the seasons.*

Research question 2: What are the benefits of living in a Deaf community? The benefits of living in a Deaf community comprise the majority of the findings section of this chapter. Living in a Deaf community was described as both validating and liberating. To distill the benefits of living in a Deaf community to its most basic, living in a community where communication is possible makes life easier. A number of people explained the benefits of living at Visions of Home by illustrating its opposite corollary: what their life and future would look like if they did not live there. They described a bleak, lonely, isolated existence, which led to mental and physical deterioration, and ultimately, an earlier death. Here is a condensed excerpt of this sentiment: *“If we didn't have each other, we would all be alone, at home - and then we would deteriorate and die.”* Thus, Visions of Home was perceived as an antidote for loneliness, isolation, and the dinner table syndrome. Also, when I asked participants if they would ever leave Visions of Home, I received quite a few very similar answers, as typified by this example: *“Yes. When I am dead and cremated. Then I will return to (state) and be buried beside my (spouse).”*

Research question 1: In what ways (if at all) have your experiences(s) with Deaf culture influenced your decision to live in a Deaf community? Various factors were identified as influencing participants’ decisions to move to Visions of Home. Some people, notably those who identified as hard of hearing and oral deaf, moved to Visions of Home specifically for the visual safety features of the building. Others came for the opportunity to get to know other deaf people. This included those who were raised and communicated primarily orally in many areas of their lives. For example, AH: What motivated you to move here?

> P: *I moved to many different places, and I heard about this place. I wanted to get to know other Deaf people. It is important to get to know other people and talk to them, so we can get to know each other. Deaf people need other Deaf people. For example, if I get old what is going to happen? If I am alone, well yes, I can talk, but I am still alone. I am still half a Deaf person. My ears aren't going to open, and I am not able to hear. So, I can communicate with Deaf people in sign language. Sign language is very important. I don't want to lose that language. Mostly when I grew up, it was with talking.*

The traditional route of individuals into the Deaf community has typically been through contact with other Deaf people at school, with only a small percentage of people entering through family contact (Padden & Humphries, 2005). Ladd (2003) wrote, "In the last 30 years, however, those numbers of mainstreamed Deaf children placed in hearing schools and belatedly finding their way to the Deaf community after their schooldays constitute a growing third route" (p. 42). Indeed, this was evident at Visions of Home.

The majority of people interviewed had previous experience with Deaf culture, either through family or school experience. I interviewed many of the first residents to move in. Several people described watching Vision of Home be built from the ground up and waiting with excited anticipation. One person said, *"I have been dreaming of moving here since I heard it opened in 2011."* Yet another person said,

> *When I heard about Visions of Home, I moved here and waited 10 months for this place to be finished. I was ecstatic when this place opened! I am so happy to be here with other Deaf people and to have Deaf fellowship. It's absolutely wonderful!*

Another individual moved to their home country in Europe when their apartment lease was up to await the completion of the Visions of Home building. Indeed, those who had previous Deaf cultural experience seemed most adept at navigating the intricacies of living in a visual space and finding an acceptable balance between communal and personal life.

When answering the research question, I compared what participants told me with definitions of Deaf culture and learned: Yes, Deaf people do marry Deaf people. Yes, Deaf people want Deaf children (Hauser et al., 2010), and there is a great deal of excitement and enthusiasm with the birth of a Deaf child. Yes, athletics were an important part of Deaf lives. In fact, I interviewed two Deaf Olympians. There were many examples that illustrated how Deaf culture helped individuals to navigate the Hearing world. The problem though is that the early definitions of Deaf culture, based largely on a Deaf / Hearing binary used to explain a cultural understanding to those who only had a medical understanding of deafness, were not big enough to encompass what I saw and experienced at Visions of Home. In hindsight, the Deafhood concept would have been a better, more appropriate fit. This model was not chosen, however, due to the pervasiveness of the disability paradigm within the social work profession. Another problem with earlier Deaf cultural discourses is that ideologies concerning Deaf people were characterized by the medically oriented term 'deafness' (Ladd, 2003). To create a space within which Deaf people's own self-conceptions could be situated and examined, another term was needed. Ladd, therefore, created the term *Deafhood*. Ladd wrote,

> In so doing, one is essentially in search of a *Deaf epistemology*, [emphasis in original] that is, Deaf ways of being in the world, of conceiving that world and their own place within it (both in actuality and in potentiality). It will emerge that a crucial aspect of that

> epistemology is that it is not simply oppositional, but that it examines and presents the nature and significance of Deaf people's relationships with each other. (p. 81)

Deafhood is not a monolithic concept, although it does make use of strategic essentialism. Ladd explained that in order to examine minority group narratives, there must be an academic space established which "recognizes the existence of 'counter-narratives' in themselves, a pole around which resistance thinking can even be organised" (p. 81). A Deafhood framework would permit a more thorough understanding of study participants.

Conclusion and Summary

By the end of the week, my thoughts about the Community Room had changed. There were disruptions and interruptions, to be sure. In some ways, it was not an ideal interview environment. In other respects, however, it could not have been better. I was both a witness and a participant in the space. I am very grateful that the Property Manager said no to my initial request that I be allowed to use a small, closed off, windowless office for interviews. My week-long use of the Community Room space provided me with a much greater understanding and appreciation of the space and place that interview participants called home.

In the next chapter I will discuss moving forward, and the implications of the study findings to the field of social work.

CHAPTER 6

DISCUSSSION

The vast majority of people in our society, including practicing social workers, seem to have wholeheartedly accepted the disability framework of deafness. Consequently, Deaf people are viewed and understood to be broken versions of hearing, and thus whole, people. Yet the majority of people in mainstream America, including practicing social workers, have never met a Deaf person or have had very limited exposure to or contact with Deaf people (Glickman & Pollard, 2013). Ladd (2003) posited that those who perceive Deaf people negatively "seem only to be aware of *isolated Deaf individuals*" (p. 92, emphasis in original) who lack a peer group with which to communicate. Conversely, "those who perceived Deaf people positively appear to be aware of their *existence as a group*" (p. 91, emphasis in original). Intuitively, this makes sense. One deaf person, in isolation, is viewed as a deviation from the norm, which people have tended to want to fix. Yet when viewed in groups, Deaf people can be seen living full, self-actualized lives with no communication barriers, since all communication is visible and therefore accessible. In this scenario, it is the very definition of 'normal' that needs further scrutiny. Indeed, until language is understood by society as more than just speech-based communication, Deaf people will continue to be marginalized.

I share this next experience, which happened early in the week of data collection, as it illustrates both the need for and importance of this research: At the end of each day, I generally spent 2-3 hours journaling, writing memos, conducting preliminary analysis, and preparing for the next day. Much of the writing took place at the same restaurant, where I would sit each night with pens, notebooks, and something to eat. The first day, I had not realized that the restaurant was right next door to a large university campus and was a local hangout for university students and faculty. So, when I heard an animated "study design" discussion going on behind me, I paid attention, (a prime example of incidental learning.) Anyway, I apparently made a noise in support of the person struggling to get their research design right, because immediately all conversation stopped. I turned to see what had caused the disruption in this somewhat interesting conversation, only to see seven sets of eyes looking at me. Based on conversation content and the general age range of the group, I concluded that these people were probably university professors. I replied, "*Oops, sorry. I'm just sitting here working on my own dissertation, and apparently, that caught my attention.*" A brief conversation ensued that included a short description of my research. One comment from the group stayed with me: "*Wow. My grandparents were Deaf*[5]*. It is strange to hear you talk about Deaf people the same way they talked about themselves."* This remark identified the crux of the problem and why this research is important. Deaf people have been claiming a cultural identity for years; but we, the Hearing majority, have failed to listen.

Why is it so hard for hearing people to understand a Deaf-centric perspective? Deaf-centric refers to the language and culture of the Deaf community (Holcomb, 2012). Reflecting on this question, four possible reasons were identified. First, when hearing people reflect on deafness, they generally begin by imagining themselves without hearing, which is, of course, to have a disability but not to be Deaf (Lane, 1999). Another barrier is that 'hearing' is so strongly associated with the 'norm', that hearing people have a difficult time conceptualizing and understanding a visual orientation and way of being, or ontology. Yet, most research in the field

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[5] He used the term "deaf-mute", but this term is both incorrect and disrespectful.

of deafness has been conducted by hearing people who have few to no cultural or linguistic ties to the Deaf community (Komesaroff, 2008). Third, the individualistic nature of the American culture makes understanding a collective culture within our society very difficult, despite the fact that 70 percent of world cultures can be identified as collectivist or group oriented (Mindess, 2014). Finally, and importantly, separate but equal in education and special education in the U.S. has been described as "immoral" (Siegel, 1994, p. 3). While there are valid historical reasons for this, it needs to also be noted that for a deaf individual, education inclusion becomes communication exclusion (Olivia, 2004). At the very minimum, it is important to both realize and acknowledge the co-existence of "exclusion as the counterpart of inclusion" (Haualand, 2017, p. 319) for Deaf individuals in mainstream education settings. Moreover, educational inclusion becomes both a sentence and a life trajectory of communication exclusion for many deaf individuals. After seeing and hearing participants' stories at Visions of Home, Ladd's (2003) argument for bilingual, bicultural education seems almost Utopian:

> Imagine that all children with a hearing loss on a scale that inhibits meaningful interaction with mainstream societies were brought up bilingually and biculturally; that they were told throughout their childhood *'By learning both spoken and sign languages, you can learn to navigate your life path in and around two cultures and two communities, selecting whatever you wish for from either in order to build your own lives.'* Is this not culturally-centred perspective a more healthy social philosophy than the medical one which stresses the shamefulness of association with signing communities? (34-35)

Addressing and fixing the educational system of deaf children is certainly beyond the scope and intent of this research. At the same time, however, ignorance of major issues that impact the lives of Deaf people in our society is one of the reasons that the social work profession has been, at best, ineffective, and at worst, part of the problem when working with this population.

Granted, the political, social, and educational climate for Deaf people today is markedly different than it was when many of the study participants were growing up. Moreover, as numerous study participants pointed out to me, there are great variations from state to state within the U.S. regarding Deaf services, accessibility, and educational quality. It would be misleading to assume that the situation is drastically better today. Prejudice and discrimination, although diminished, have not disappeared; rather, they have “gone underground, into the subconscious of many hearing people who would probably strenuously deny having any prejudice at all” (Jacobs, 1994, p. 684). Furthermore, although education is compulsory for children in the U.S., for deaf children, communication and language are still “a discretionary matter” (Siegel, 2002, p. 265). Siegel elucidated that it is this absence of communication and language that has had a crushing effect on the development of basic education and life skills, which in turn has affected the high rates of under- and unemployment among deaf and hard of hearing adults. Gertz (2008) reported that the oppression of Deaf people still appears to be omnipresent and everlasting. Several Deaf adults of Deaf parents were told that “sign language would ruin their chance for succeeding in American society” (p. 221). Groce (1985) wrote that “the difficulty in communicating along with the ignorance and misinformation about deafness that is pervasive in most of the hearing world, combine to cause difficulties in all aspects of life for deaf individuals – in education, employment, community involvement, and civil rights” (p. 4). Indeed, to function in predominantly hearing society, Deaf people make enormous adaptations to be understood and to understand (Temple & Young, 2004). Improving our cultural understanding of this population could only help.

People of today cannot be held personally responsible for the historical Oralism that marginalized and disempowered groups of Deaf people worldwide by the systematic eradication of signed languages everywhere. However, our acceptance of the status quo and complacency with the present situation shows the same ignorance and prejudice as before (Ladd et al., 2003). Freire (2000) wrote:

> The truth is, however, that the oppressed are not “marginals,” are not people living “outside” society. They have always been “inside” – inside the structure which made them “beings for others.” The solution is not to “integrate” them into the structure of oppression, but to transform that structure so that they can become “beings for themselves.” (p. 74)

Members of the American Deaf community, although small in numbers are a diverse and heterogeneous population. There is a great deal of misunderstanding about the Deaf people, Deaf culture, and the Deaf community by much of the hearing majority, including from practicing members of the social work profession and within social work education. As previously stated, numerous reasons for this have been identified. The fact remains that hearing people project their own understanding of deafness onto a group of people who have a very different world experience, ontology, and viewpoint. While discrimination occurs against all deaf people, “it is most intensely directed at those who practice Deaf culture. They have a different language, different values, traditions, and rules of behavior” (Fernandes & Myers, 2009, p. 25). It is, therefore, incumbent upon the social work profession to invest the resources and effort necessary to learn about Deaf people and Deaf culture from the experts, members of the Deaf community. To this end, Ladd (2003) has suggested,

> Perhaps instead of continuing to see them as objects to be pitied or 'cured', we might begin taking our first baby steps in the process of developing our new cultural literacy by actively seeking out what it is they have to teach us. (p. 25)

However, "even good intentions by the dominant group are not always sufficient to enable their ears to hear and *therefore* [emphasis in original] for the other to speak" (Jones & Jenkins, 2008, p. 478). It would, therefore, be incumbent upon the social work profession to incorporate a cultural paradigm shift into the social work education curriculum.

Social Work Education

To make a serious and legitimate change in direction toward a cultural orientation, changes would need to happen with social work education. Partnering with the Deaf community would be paramount. Mindess (2014) wrote, "acknowledging our differences is the first step" (p. 36). It will be critical that the focus is on *difference* [emphasis added] rather than deficit (Hauser et al., 2010). Other areas that can be developed and addressed within the Council on Social Work Education (CSWE) curriculum is a more robust awareness and knowledge of collective cultures, the history of Deaf Sign Language Peoples and the effective and systematic disempowerment campaign of the 19th century. Hauser et al. have suggested:

> Deaf epistemology should be the lens through which auditory learners seek to expand their understanding of visual learners, in order, ultimately to enhance learning and strive to create environments that value visual beings as much as auditory beings – environments that, in other words, embrace Deafhood and deafness as much as they embrace hearinghood and hearingness. (p. 490)

Aspects of the Deaf episteme (Hauser et al., 2010), not caused by deafness but by Deafhood, things that have a positive impact on how Deaf individuals learn, stay mentally healthy and navigate the Hearing World need to be included.

Ladd (2016) explained that two features underpin the initial development of the term Deafhood. First, was the need expressed by Deaf communities for a more positive term that would accurately reflect the nature of their collective existence. The second originating impulse was the need to develop a formal analytical framework that validates the concept of "Deaf culture," which has been either disputed or misunderstood by wider society. On the individual level, the Deafhood process serves as a tool for individuals to understand and strengthen their own Deaf identities and to actualize these in both majority and SLP (Sign Language Peoples) societies. On the collective level, the Deafhood process serves as a tool for re-envisioning of SLP collective lives, in relation to both majority societies and the shaping of future SLP communities and organizations themselves.

In order to bring together Deaf commonalities and differences, Deafhood theory makes use of strategic essentialism (Ladd, 2016). Despite the critiques to essentialism, it is sometimes necessary to identify certain commonalities in experiences and cultures to construct a larger, idealized selfhood, which then empowers them toward re-envisioning of their societies.

> Deafhood theory has two constituent elements – the sum of all meanings of what "deaf" might be *and t*he journey undertaken by each Deaf person to understand and define himself or herself. There is therefore no place for assumptions of superiority regarding any one individual perspective – each Deaf person can be said to be engaged in a lifelong journey to locate, develop, and maintain the largest sense of Deaf self that is possible. (p. 291)

In addition to being more open to learning from the lived experiences of Deaf experts rather than relying primarily on hearing professionals, we need to acknowledge, and then rectify, the role that the social work profession has played in relegating the cultural paradigm to the margins.

The Next Step in Moving Forward

There is no value neutral education (Scaull, 2000). It either functions as an instrument "used to facilitate the integration of the younger generation into the logic of the present system and bring about conformity to it" (p. 34) or it becomes "the practice of freedom" (p. 34) and means by which people participate in the transformation of their world. So, despite the social work profession values of cultural diversity and self-determination, Deaf specific literature is primarily found in disability journals (Leake & Skouge, 2014). This gives both power and credence to the deafness as a disability paradigm since one must first make the mental shift to *disability* before being able to access *Deaf* within the social work literature. Thus, Deaf culture is incorporated under the disability umbrella, making it, for all intents and purposes, invisible, seen only by those with interest in Disability Studies. As Ladd (2003) has argued, to be able to examine minority group narratives, "an academic space must be established which recognizes the existence of 'counter-narratives' in themselves, a pole around which resistance thinking can even be organized" (p. 80-81). Ironically, this is one situation where Deaf people would benefit from being in the mainstream, i.e., mainstream social work culture-specific literature.

Social work supports the right to self-determination. Moving forward, therefore, it is important to keep in mind that the "culturo-linguistic discourse" (Ladd, 2003, p. 35) was led by Deaf children of Deaf parents, for whom the degree of deafness is very much secondary to their heredity cultural influences. Albeit slow, there is some evidence of a shifting paradigm. Lane (1999) wrote:

> Deafness-as-disability is increasingly replaced by Deaf as linguistic minority. To quote the former secretary-general of the United Nations: “For me and my colleagues, Deaf people are not a disability group [but] a linguistic minority. And I understand that recognizing Deaf people as a linguistic minority goes, hand in hand with respect for the Deaf community. (p. xv)

In 2010, I. King Jordan, the first Deaf president of Gallaudet University, co-authored a social work article, with Janet Pray, entitled ‘The Deaf Community and Culture at a Crossroads: Issues and Challenges’, which can be found in the *Journal of Social Work in Disability & Rehabilitation*. I suggest that, likewise, the social work profession is also at a crossroad. We have two options, which are to either maintain the status quo or preferably, we can become a profession of Deaf allies.

This study demonstrated that Deaf collective life was an antidote for the dinner table syndrome. In Deaf discourses, Ladd (2003) informed us that it is *the “fact of coming together as a community*, [that] is the all-important humanising quality” (p. 108-109, emphasis in original). Yet, Ladd has also pointed out that there is an “*almost total absence of any academic research into Deaf collective life* on its own terms” (p. 171, emphasis in original).

One of the current “Grand Challenges for social work: research, practice, and education” (Williams, 2016) is to eradicate social isolation. Visions of Home clearly demonstrated having a positive effect on the social isolation of Deaf individuals who live there. Yet Deaf mental health research is 40 years behind that of hearing mental health research (Glickman & Pollard, 2013). This is another area where social work could partner with Deaf mental health experts and explore research opportunities.

Ultimately, “we change the world by the way we make it visible” (Denzin, 2000, p. 266). It is time that we become aware of and increase our knowledge about Deaf culture and Deaf communities by partnering with experts such as the Deafhood Foundation. “The Deafhood Foundation is dedicated to achieving economic and social justice for all Deaf people” (www.Deafhood.org). As one participant told me, *“Hearing people really don’t know how to communicate at all.”* This statement was not sign language specific. There are a lot of cultural factors that have contributed as well.

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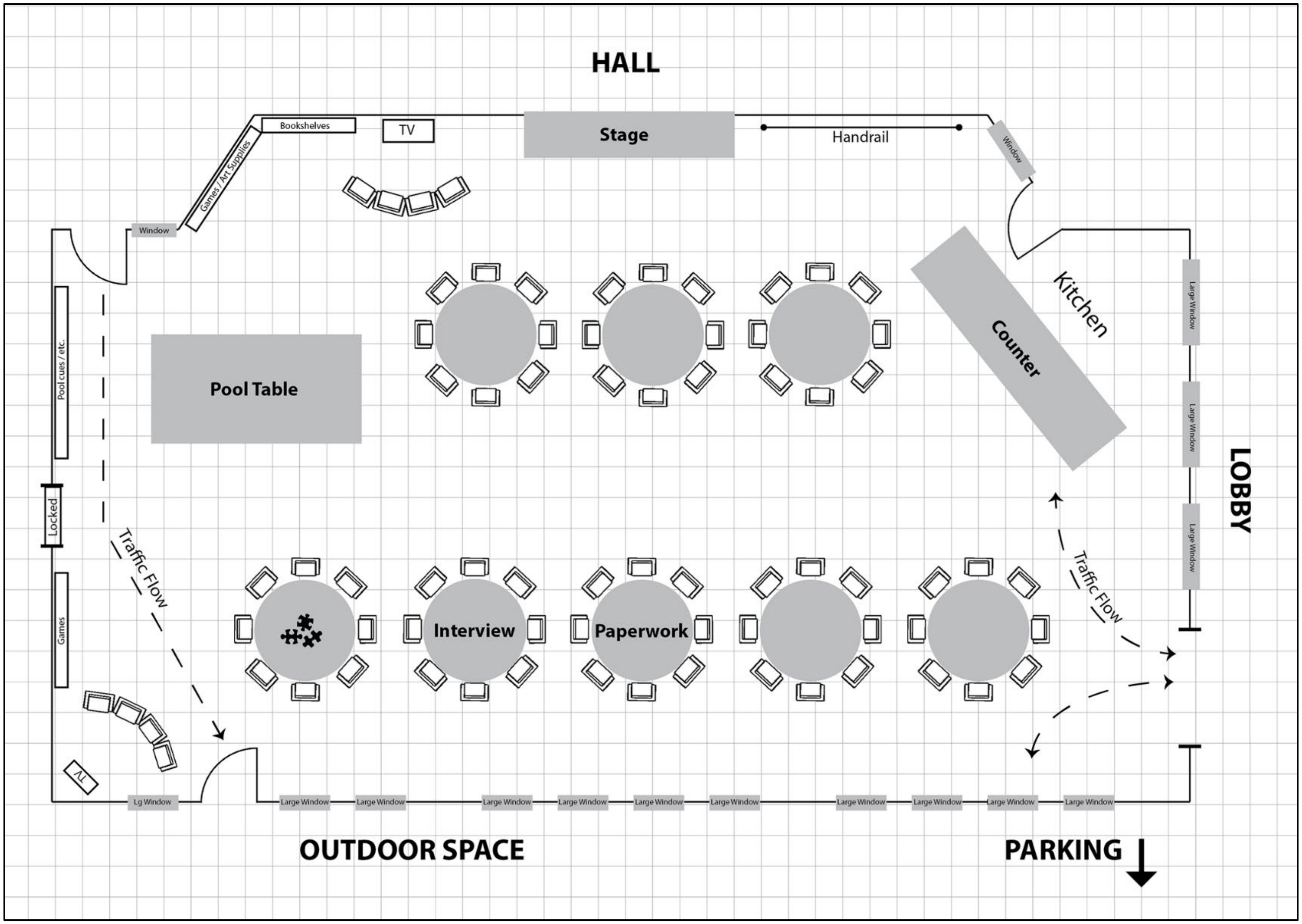
APPENDICES

APPENDIX A

COMMUNITY ROOM FLOOR PLAN



APPENDIX B

RECRUITMENT FLIER

Research at Apache ASL Trails
Sponsored by
UNIVERSITY OF GEORGIA
School of Social Work

Wanted:

People willing to share their experiences of living in a Deaf community.
CONFIDENTIAL, Deaf friendly research in ASL

When?

November 26 – 30, 2018

Where?

Apache Trails Community Room

Who is the researcher?

Amanda Ham, CI/CT

How long will this take?

An hour to an hour and a half of your time.

Will I be paid for my time?

Yes. Each person interviewed will receive a $15. gift card to one of the following:

SAFEWAY fry's Marketplace Walmart

(You may choose *which* gift card- while supplies last)

APPENDIX C

Participant Background Information Form

Name: ____

Address/ Unit # ____________________

How long have you lived at Apache Trails? _________________________

Where did you move here from? (State) _____________________________

Gender: Male / Female / Other

Age: ________________

Race/ Ethnicity: _______________________________________

Religious Affiliation (if any): _______________________________

Parents were: Deaf / Hearing / Both

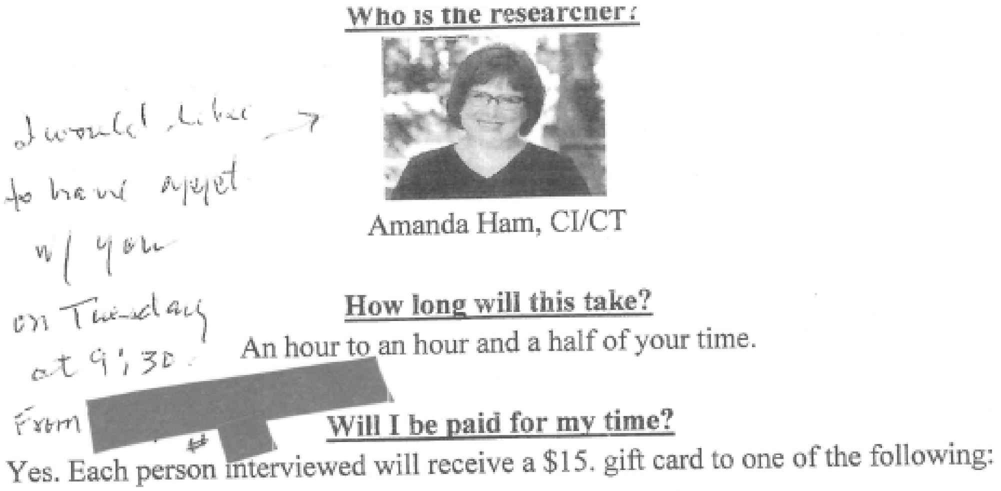
Education:

- ➢ Residential / Mainstream with interpreters/ Mainstream without interpreters/ Other? ____________________________________
- Highest level of school? _____________________

Type of employment (past or present): ____________________________

APPENDIX D

INTERVIEW REQUESTS



Who is the researcher?

Amanda Ham, CI/CT

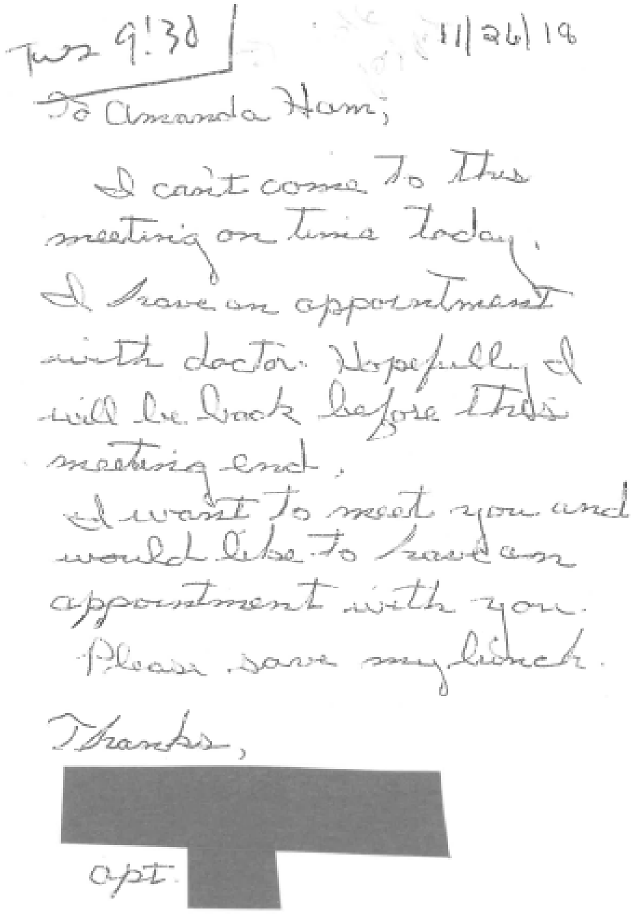
How long will this take?

An hour to an hour and a half of your time.

Will I be paid for my time?

Yes. Each person interviewed will receive a $15. gift card to one of the following:

I would like →
to have appt
w/ you
on Tuesday
at 9:30.
From [redacted]



Tues 9:30 11/26/19

To Amanda Ham;

I can't come to this meeting on time today.
I have an appointment with doctor. Hopefully I will be back before this meeting end.
I want to meet you and would like to have an appointment with you.
Please save my lunch.

Thanks,

[redacted]
apt.

APPENDIX E

INFORMED CONSENT FORM

UNIVERSITY OF GEORGIA
CONSENT FORM
A Purposefully Designed American Deaf Community: A Qualitative Study of "Space" and "Place"

Researcher's Statement

I am asking you to take part in a research study. This form provides information about the study, so you can decide if you want to participate or not. Please ask me if there is anything that is not clear or if you need more information. When all your questions have been answered, you can decide if you want to be in the study or not. A copy of this form will be given to you.

Principal Investigator:	Larry Nackerud
(Amanda Ham's supervisor at UGA)	School of Social Work
	nackerud@uga.edu

Purpose of the Study

Many (mostly hearing) people understand deafness as a disability and are not aware of the cultural aspect of being Deaf or of the existence of the Deaf community. The goal of this study is to help hearing people, especially hearing social workers have a better understanding of Deaf culture and Deaf communities. You are being asked to participate in this study because you live at Apache Trails, a community designed specifically for deaf people.

Study Procedures

If you agree to participate, you will be asked to …

- Sit down with me for an interview. I will ask you a few questions to get to know you and your community a little better. This will take about an hour.
- I will video record our conversation so that I can remember what is said. I will not show this to anyone, and I will destroy the video when the study is complete.
- If later, I have another question or need clarify something you said, I would like to be able to contact you. This can be via email, telephone or Skype, whichever is best for you. This communication will be brief, lasting no more than 15 minutes.
- I will take photographs of the Apache ASL Trails building, but not of the people who live there.

Risks and discomforts

- I do not anticipate any risks to you for participating in this research. However, I know that the Deaf community is small, and confidentiality is very important! I will be very careful to remove any information that can identify who you are. All video recordings and personal information will be destroyed when the study is complete.
- I am a hearing researcher. It is possible that some people will question my motives. I will be open and honest about my background and interest in deaf people, also, a deaf person is working with me and my committee throughout this process.

Benefits

- You will not benefit directly from participating in the study.
- Other people might benefit from this study. This includes hearing social workers, who learn more about deaf culture. Other deaf people might benefit, if similar places are built in the future.

Incentives for participation

You will receive a $15. gift card for participating in this study.

Audio/Video Recording

I will audio record our session to help me remember exactly what you tell me. I will not show this to anyone else, and I will keep it locked in a secure area of my home. I will destroy the video recording when the study is finished. If you would like to participate in the study but are not comfortable being videotaped, I will need to take notes during our conversation.

Please provide initials below if you agree to have this interview video recorded or not. You may still participate in this study even if you are not willing to have the interview recorded.

_______I do not want to have this interview recorded.
_______I am willing to have this interview recorded.

Privacy/Confidentiality

Initially I will get your personal information. This includes your name, age, where you are from, and your contact information. I am the only person who will see this information. I will keep this information strictly confidential and stored in a locked place. Before I write about what I have learned, I will change any information that can be used to identify you or anyone else. This means that I will change people's names, where they are from, and anything else that can be used to identify you. If there is anything I am not sure about, I will contact you and ask before including this information.

Taking part is voluntary

It is completely your decision if you want to participate in this study or not. If, for example, you start the interview and you want to change your mind, just tell me and we will stop. Or if you do not want to answer a specific question, just tell me. That is fine. You will still receive your gift card. I will not be mad. I want you to feel comfortable and answer what you are comfortable answering.

If you have questions

The main researcher conducting this study is Amanda Ham, a graduate student at the University of Georgia. Please ask any questions you have now, or you can email Amanda at amdeeham@uga.edu or text or video relay Amanda at (678)463-4582. Amanda's supervisor for this research is Larry Nackerud. He can be reached at nackerud@uga.edu.

Research Subject's Consent to Participate in Research:

To voluntarily agree to take part in this study, you must sign on the line below. Your signature below indicates that you have read or had read to you this entire consent form and have had all of your questions answered.

_________________________	_______________________	_________
Name of Researcher	Signature	Date
_________________________	_______________________	__________
Name of Participant	Signature	Date

Please sign both copies, keep one and return one to the researcher.

APPENDIX F

INTERVIEW GUIDE

The purpose of the study is to explore the perceptions and experiences of D/deaf persons living in a purposefully-designed Deaf community.

1. In what ways (if at all) have your experiences(s) with Deaf culture influenced your decision to live in a deaf community?
2. What are the benefits of living in a Deaf community?
3. What are the challenges of living in a Deaf community?

Interview Guide

1. **What motivated you to move here?**

2. **Can you tell me about your life here?**
    - **Your experiences?**
    - **What are you involved in?**

3. **Can you share an example of how your life is different here?**

4. **Can you share an example of something you miss from before you moved to Apache Trails?**

5. **Growing up, how did you communicate with your family?**

6. **Tell me about your first exposure to ASL?**

7. **(A): Can you tell me about a time before you moved here that you were the happiest?**

    (B): Can you tell me about a time *since* moving here that you have felt the happiest?

8. **Have there been any surprises that you found from living here?**

9. **Now that you live here, what are the benefits?**

10. **Now that you live here, what are the challenges?**

11. **Can you tell me about your involvement with the Deaf community outside of Apache Trails?**

12. **Tell me about your involvement with the Deaf community where you lived before?**

APPENDIX G

EXAMPLES OF TRANSCRIBED INTERVIEWS AND NOTES

Excerpts from Transcribed Interviews and Notes

I am fully Deaf now. I became fully Deaf when I was __, and I am __ now. Hard of hearing means you can hear some. [11:28]

Growing up, I didn't communicate with my parents much. I would watch tv. But one day we got a new tv with CC (closed captions), then I watched! [35:36]

You've got to understand the Deaf culture [33:02] because some Deaf use sign language and that is difficult because they (counselors) don't want to help you. So, what is going to happen to the Deaf people? What will happen to the deaf (people)? You need to get some Deaf counselors who know how to help. It is very important. Deaf needs to help the Deaf (in this instance, P voiced "help" but signed MANAGE). Yes. Deaf needs to help the Deaf.

Communication accessibility is so much easier here! Hearing people have such limited ability to communicate. There is no communication really, [16:22] but it is very different here – very different!

I thought this place was all Deaf. It surprised me [SHOCK] [21:45] that there were hearing people here.

[27:11] Deaf education is wonderful! So many Deaf teachers and supervisors. But today… it's all hearing (public) schools and now deaf are THINK-HEARING. Now, also, they put those oral (hearing) things in their heads. It's awful. It's just terrible. Those kids are going to grow up writing notes to people to communicate.

[25:3] Deaf community - friends that are awesome. Communication: it is easy to contact each other. Out there (indicating hearing space), DIFFERENT. This is where my heart is! [26] Before it wasn't a senior center. Now it is. (This person is 74)

[34] I love the VP! (video phone) There was nothing like this when I was growing up.

(Face beamed!): "It's taken 3 years to learn all the people. At first knew only a few, but now I know (them) all!"

Do you have any questions for me???

How did you learn SL? ….. (f/u) Did you take a sign class? ….. Where? …. [45:26] That's wonderful. I'm impressed. …. How many years did you learn SL? …. I love your country. America is wonderful! In most states in the US, people can learn SL. That's impressive. That's not like __________. It's wonderful here. You have good services for deaf here, interpreters, VP. You (Americans) are all "spoiled"- very, very spoiled! (smiling) [46:39] ….