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**NOT A HEARING LOSS, A DEAF GAIN:
POWER, SELF-NAMING, AND THE DEAF COMMUNITY**

by

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ABSTRACT

NOT A HEARING LOSS, A DEAF GAIN: POWER, SELF-NAMING, AND THE DEAF COMMUNITY

David James Thomas
Old Dominion University, 2013
Director: Dr. Dennis E. Gregory

Self-naming has long stood as the primary assertion of power for disenfranchised communities in the western world. While person first language (e.g. *person who is deaf*) has been the preferred language of disability and disability services for the last 20 years, members of the Deaf community have asserted their cultural capital, and indeed, their *Deafhood*, or defining the experience of being ‘deaf in the world’, through the power of self-naming. This research examines attitudes toward language, self-naming, and disability in the Deaf community and seeks to move toward a more attentive, sensitive, and responsive language policy in the academy.

Historically, Deaf students have been excluded to varying degrees from full participation in society and especially in higher education. The language we use reflects, in many ways, our perceptions of the world around us. Conversely, our perceptions and use of language also have observable real world effects (Linton, 2010). Our attention to the way we use language and the power that language can exert are important tools in examining the phenomenon of the language use and language policy in the academy.

A culturo-lingual model of disability was prevalent in most of the participant’s narratives. Deaf was constructed in opposition to deaf, although a certain amount of overlap with the disabled construction of deaf and disability did occur. The primary defining cultural artifact that was identified by participants was the centrality of ASL to

the Deaf experience as well as the respect and status of ASL as a language in the world-at-large. Intertwined with the primacy of ASL is the distinction between the visual world inhabited by Deaf people and the verbal world inhabited by Hearing people. Participants constructed Deaf pride as a strong primary identity in which participants simultaneously advocated sameness as well as a unique cultural identity.

The discussion of disability and its interaction with Deaf identity revealed four major categories of identity and association: participants outright rejected the classification of disability as pejorative; participants rejected disability as inaccurate and constructed disability as a trait of the other; participants accepted disability but still constructed their Deaf identity in opposition to the social construct of disability; and participants accepted disability only insofar as it provided for rights and protections under the law.

Although, perceptions of the language of disability have been studied among students and rehabilitation specialists, none of the existing literature examines the perceptions of this language in a way that takes into account the students whom such language is meant to describe. By examining how Deaf students view the language used to describe them, as well as how they use such language themselves, this study seeks to answer important questions that could influence the future of language policy in and outside of higher education.

Keywords: *Deaf, identity, disability, language ideologies, language policy, intercultural communication, higher education*

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This dissertation is dedicated, in loving memory, to my first teachers and the people responsible for opening my eyes to the limitless possibilities and wondrous peoples, places, and languages of the world:

My parents, Patricia U. Thomas (1944-2002) and James A. Thomas (1928-2009),

And my grandmother, Miriam W. Upham (1920-1992).

IN MEMORIAM

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NOMENCLATURE

Accessibility is defined as the degree to which the physical and instructional facilities, courses, administrative processes, and student activities, including distance learning portals and digital presences, of an institution of higher education are accessible to as many people as possible, particularly persons with disabilities.

Audism refers to the privilege afforded to Hearing people and the prejudices towards Deaf people associated with it.

Cultural Deafness refers to the common cultural artifacts, beliefs, behaviors, traditions, languages, institutions, arts, and literatures of the Deaf community. The primary defining characteristic of *cultural deafness* in the United States is the acquisition and use of American Sign Language (ASL) as a person's first language (L1). It is important to note that the *Deaf community* includes deaf and hearing people, sign language interpreters, the children of Deaf adults, and other family members. Although a person is clinically deaf, this does not necessarily make them culturally Deaf. *Cultural deafness* is recognized by the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006).

deaf refers to individuals who are clinically deaf or hearing impaired but do not identify as culturally Deaf. For these individuals, their experience is primary audiological and usually lose their hearing or are deafened later in life. Members of this category are primarily socialized in Hearing society and prefer to remain a part of the Hearing society that they have been socialized into (Ladd, 2003).

Deaf refers to individuals who self-identify as being culturally Deaf and actively participate in Deaf culture. Persons who identify as Deaf are those "for whom the

sign languages, communities, and cultures of the Deaf collective represents their primary experience and allegiance” (Ladd, 2003, p. xvii).

Deafhood is a term developed in 1990 by Paddy Ladd (2003) to effect a description of “the process of defining the existential state of Deaf ‘being-in-the-world’” (p. xviii) in order to differentiate it from and clarify the nuanced understandings of the medical term ‘deafness’, which had come to incorporate the culturally Deaf experience under the larger category of people with any degree of hearing loss, the vast majority of whom are elderly people.

Disability is defined as the result of social attitudes, beliefs, institutions, and physical structures that pose a barrier to access for individuals with a physical, psychological, or behavioral impairment (World Health Organization, 1980).

hearing is defined as a term used in the Deaf community to refer to any non-Deaf people, including those persons who are deaf or deafened (Ladd, 2003).

Hearing refers to individuals who self-identify as being primarily associated with a culture based in a spoken, non-signed language. *Hearing* can be understood to be an analog of *Deaf* as can the *hearing/Hearing* distinction be viewed as an analog of the *deaf/Deaf* distinction (Ladd, 2003).

Hearing impaired is a term used to describe clinical deafness or loss of hearing.

Impairment is defined as the underlying physical, psychological, or behavioral condition that substantially limits one or more major life activities (World Health Organization, 1980).

Individual with a disability is defined as a person with an impairment which substantially limits one or more major life activities for six months or more and who is generally regarded as a person with a disability.

Language variation and change is defined as the fundamental assumption that language changes over time and under social pressures, that language varies naturally within and between linguistic communities, and that language is a distinct part of regional and cultural identity. (Coates, 1993; Eckert, 2000; Labov, 1963; 1990;1994; 1966/2006; Wolfram & Schilling-Estes, 2006)

Oralist is defined as “the educational system imposed on Deaf communities worldwide during the last 120 years which removed Deaf educators, Deaf communities, and their sign languages from the Deaf education system. By replacing it with an exclusively Hearing-led system promoting the use of speech, speechreading, and hearing aids only, and advocating no fraternization between deaf children and Deaf adults, they hoped to remove the ‘need for’ Deaf communities to exist at all.” (Ladd, 2003, p. xviii)

Other(n.)/Other (v.) is defined in contrast to the same or the Self. *Othering* is the process by which cultural groups and societies exclude *Others* who either do not conform to the norms of the society or those whom such groups seek to subordinate. (deBeauvoir, 1949; Derrida, 1988; Foucault, 1986; Said, 1978)

Person first language is defined as a form of linguistic prescriptivism that has at its core the understanding that by making the person first in the noun phrase, there is a humanizing effect on the perceptions of persons with disabilities in society at large (i.e., *student with a disability*).

Student with a disability is defined as any student registered at an institution of higher education who has presented acceptable documentation of an impairment to a student disability resources and services provider and/or is covered under Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.

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Not A Hearing Loss, A Deaf Gain: Power, Self-Naming, and the Deaf Community

CHAPTER 1 - INTRODUCTION

With increasing numbers of Deaf students entering higher education *en masse* for the first time, we need to direct the attention of faculty and administrators to the cultural and linguistic issues that may arise when interacting with this unique population of students. Historically, Deaf students have been excluded to varying degrees from full participation in society and especially in higher education (Charlton, 2010, 1998; Linton, 2010). With the exception of Gallaudet University in Washington, D.C., the National Technical Institute for the Deaf at the Rochester Institute of Technology (NTID) in Rochester, New York, and the Deaf Center at California State University at Northridge (CSUN), the participation of Deaf students in higher education has been minimal and facilitated primarily through student disability services offices, and then only in the last quarter century. Previously, Deaf students were left to their own devices to navigate the world of higher education.

The language we use reflects, in many ways, our perceptions of the world around us. Conversely, our perceptions and use of language also have observable real world effects (Linton, 2010). Our attention to the way we use language and the power that language can exert are important tools in examining the phenomenon of the language use and language policy in the academy, which has evolved – sometimes gradually, sometimes drastically – to reflect changing attitudes toward language, perceptions of disability, and the interaction of Deaf culture and society-at-large. This study examines the perceptions, preferences, and experiences of Deaf students with the language used by higher education faculty, staff, and administrators in order to work toward a more student-centered language policy for higher education.

The language of disability has a long history, from euphemistic and medical to pejorative and oppressive. Person first language represents the latest in a chain of language forms reaching back through human history used to describe people with disabilities. Accepted by The Association for Persons with Severe Handicaps in 1988, person first language has been gaining greater acceptance and has been adopted as the primary accepted form of reference (Bailey, 1992). With the passage of *Rosa's Law* (S.2781.ENR, 2010) in 2010, person first language became the only accepted language of disability for the federal government.

While person first language (e.g. *person who is deaf*) has been the preferred language of disability and disability services for the last twenty or so years, members of the Deaf community have asserted their cultural capital, and indeed, their *Deafhood*, or defining the experience of being 'deaf in the world', in various ways through the power of self-naming, which has long stood as one of the primary assertions of power for disenfranchised and oppressed peoples that the Deaf community undeniably represents. This research examines attitudes of Deaf students toward language, self-naming, and disability and seeks to move toward a more attentive, sensitive, and responsive language policy in the academy.

In the last quarter century, the social, economic, and political status of persons with disabilities has changed significantly (Shapiro, 1993). Although perceptions of the language of disability have been studied among students (McCoy & DeCecco, 2011) and rehabilitation specialists (LaForge, 1991), none of the existing literature examines the perceptions of this language in a way that takes into account the experience and preferences of the students such language is meant to describe. Therefore, it has become

necessary to reexamine the status of this language, its use, and its perceptions in the academy.

Rationale

Social constructivism asserts that meaning is constructed by individuals through their understandings, perceptions, and worldviews (Patton, 2002). Knowledge is constructed through a negotiation of meaning between the researcher and research participants rather than through the preconceived constructs and beliefs of either. The guiding maxim for the research conducted under the social constructivist paradigm is known as Thomas's theorem: "What is defined or perceived by people as real is real in its consequences" (Thomas & Thomas, 1928, p. 572). In American Deaf culture, greater value is placed on personal experience and witness than on expertise, making social constructivism an appropriate approach for understanding the experience of Deaf students in higher education (Mindess, 2006).

Since the perceptions of Deaf students, administrators, and their Hearing counterparts represent multiple worldviews, and consequently, multiple views of the same world, the exploration of the phenomenon at hand must start from a place of neutrality. Since no one, including the researcher or the research participants, lives in a world devoid of the influence of language as a medium for the expression and representation of social constructions, we must acknowledge that not only do members of the Deaf and Hearing communities represent different social worlds, but that their worlds are also constructed through two differing linguistic traditions: visual ASL and spoken English.

Linguistic Prescriptivism and Linguistic Descriptivism

Person first language can be classified as a form of linguistic prescriptivism that has at its core the understanding that making the person primary has a humanizing effect on the perceptions of society at large. Two paradigms exist when approaching language and language policy: prescriptive and descriptive. The prescriptive paradigm is generally understood to be what defines the traditional social conception of grammar while the descriptive paradigm attempts to present language as a phenomenon as it exists. A student-centered language policy needs to be based on a combination of prescription and description. It is necessary to set parameters on the discourse of academe in order to ensure that everyone is speaking the same language and to facilitate meaningful discourse. However, in order to arrive at a truly student-centered language policy, one emergent from the data and metalinguistic commentary, it is necessary to incorporate the students' own understanding about the language ideologies and the intersection of identities of students into that prescriptive language policy paradigm. The prescription of language forms as a means of social change for underrepresented groups has been well documented in the prescription of nonsexist usages, both in the academy and in society (APA, 2011; Coates, 1993; Cameron, 1998).

Disciplinary publication manuals and style guides are the primary vehicles for linguistic prescription in the academy. Linguistic prescriptivism slows down language change and can lead to a disparity between the role of language in the academy and that of parallel language in society at large (Baugh & Cable, 2002). Additionally, the prescriptive paradigm also reflects the often limited syntactic knowledge of the authors and editors of style guides and publication manuals (Pullum, 2009).

The descriptive paradigm acknowledges two core principles: that language is inherently varied and that language changes over time. The sensitizing questions of a descriptive approach include: What language do students use to describe themselves? What language do students prefer others to use when referring to them? How does the language used to refer to them matter?

Federal legislation and court rulings governing the treatment of persons with disabilities in higher education mandate that student needs be met on an individual basis. As such, it should follow that it would be necessary to carefully consider student perceptions of disability-related language when developing a student-centered language policy.

Any inclusive language policy that aims to be sensitive to the perceptions and preferences of students must incorporate aspects of description and prescription. This integration of language approaches allows for the flexibility that a descriptive approach provides while providing the structure, uniformity, and predictability of a prescriptive approach. This structure and predictability is necessary for academic discourse that requires specificity and a mutual agreement of forms.

Nomenclature: A Note on Language and Style

The focus of this study is the language of self-naming for Deaf students and its role in society and higher education. Person first language has become the accepted standard in scholarly publishing, clinical and therapeutic interactions, and governmental policy when referring to persons with disabilities. Indeed, the *Publication Manual of the American Psychological Association* (2011), which guides the style of this dissertation, prescribes the use of such language. Before person first language became the language of

choice, disability first language (*Deaf people*), disability group reference language (*the Deaf*) and disability only language (*deaf*) were the accepted standards for referring to persons with disabilities in the United States (Longmore, 1985).

Certain linguistic conventions are used throughout. The preferred language as defined by the research participants in the present study will be used. The editorial style of the Linguistic Society of America (2010) will be used for grammatical analysis, meaning, and to indicate citation forms of individual units of language.

A distinction is made in orthographic conventions between people who are clinically deaf and those who are culturally Deaf: *deaf* refers to people who are considered medically deaf or hard of hearing while *Deaf* is used to refer to people who are culturally deaf. For the purposes of this dissertation, *Deaf* is used to refer to all persons who identify as being culturally Deaf. Cultural deafness refers to those persons for whom American Sign Language is their first language and whose social beliefs, behaviors, history, and cultural artifacts reflect a shared Deaf experience (Ladd, 2003; Lane, 1999; Keller, 2004; Van Cleve & Crouch, 1989).

Empowering Deaf Students using a Student-Centered Language Policy

The original intention for the implementation of person first language was to emphasize a person's ability and individuality over their disability in language and thereby change the perception of persons with disabilities in society-at-large (Longmore, 1985). To date, there has been a significant gap in the literature concerning the perception of these language policies and the language they produce by the students such language is intended to describe and what they prefer. Person first language, while widely accepted by disability resources and services professionals and educators, is considered to

be offensive and overly cumbersome by some communities of people with disabilities, particularly in the blind and Deaf communities (Vaughan, 2009; Lane, 1999).

Throughout history, people with disabilities have been marginalized and deprived of social power. The power of self-naming is paramount to true equality, accessibility, and the standard of access on the basis of the individual (Longmore, 1985; Charlton, 2000). While person first language marked an important advance in language policy and respect for individuals with disabilities, the status of disability in society and the academy has changed drastically.

Research Questions

The present study was guided by four research questions:

- (1) What language is being used by Deaf students when discussing deafness with their professors, university staff, and administrators?
- (2) How do Deaf students feel about the language used by university faculty, staff, and administrators when discussing deafness?
- (3) What are Deaf student's perceptions of the term *disability* as it is used by faculty, staff, and administrators in higher education?
- (4) What major themes are present in the narrative experiences of Deaf students as they relate to language?

Research Design

The purpose of this study was to investigate the language used in the academy when discussing deafness and Deaf students in the professional practice of higher education and specifically, the perception of such language by Deaf students. By understanding how these students perceive such language, it will be possible for higher

education to move toward a more student-centered understanding of language policy. In order to effect a more holistic understanding of the phenomenon of the language of reference and its perceptions, a multi-phasic qualitative methodology was employed using an electronic survey and semi-structured interview protocol. This study was conducted under a social constructivist paradigm.

Participants in the study included students who self-identify as Deaf from higher education institutions across the nation and around the world. Participants were recruited using snowball sampling techniques and through targeted emails to higher education disability advocacy groups and student disability services offices as well as contacts in the Deaf community. An online survey consisting of open-ended questions was posted and responses collected for six weeks. A total of seven interviews were conducted with the total number of interviews needed ultimately being determined by the point at which data collection reached a theoretical saturation point and no new themes became evident in the coding (Guest, Bunce, & Johnson, 2006; Patton, 2002).

Participants were prompted by a series of open-ended interview questions to elicit their lived experiences as Deaf students. Students were asked about their perceptions and preferences related to the language used to talk about Deafness and Deaf people. Follow-up questions were targeted to elicit further responses from the student and to initiate natural conversation about such language and its place in the academy.

Researcher Bias and Assumptions

The primary researcher is a thirty year old Hearing Caucasian male doctoral candidate in higher education. He has a background in dramaturgy, applied linguistics, and sociocultural linguistics. He holds a bachelor of arts in individualized integrative

studies with an emphasis in dramaturgy and a master of arts in applied linguistics with an emphasis in Teaching English to Speakers of Other Languages (TESOL) as well as sociocultural linguistics. He has worked primarily as a college level English composition instructor and teaching English-as-a-Second-Language (ESL) at the graduate level. He currently serves as the ADA Coordinator and senior disability services officer in the Office of Educational Accessibility in a private, comprehensive Arts University, prior to that, he worked for two years as a graduate assistant in a counseling role at ODU. His work with OEA included working with Deaf students on English composition after noticing that many of the problems Deaf students were experiencing were similar to those experienced by ESL students. He also served as the primary organizer for a series examining Deaf culture co-sponsored by OEA and the Office of Intercultural Relations.

His interest in the Deaf community up to this point has been primarily academic and from a sociocultural perspective. While working with the Deaf community to organize a series of performances and lectures on Deaf culture, he became increasingly interested in Deaf culture and recognized the need for higher education to be more responsive to the needs of this community and sensitive to the perceptions and experiences of Deaf students as a linguistic rather than as a disabled minority. He is committed to social justice and is interested in how power is constructed using language.

He has been heavily involved with dialect studies and other sociocultural studies involving residents of the Tidewater region of Virginia and their speech patterns. He assumes that the language used to refer to Deaf students has an impact on student experiences at an institution and that this will be reflected in the narratives of their lived experiences.

Delimitations

Since language change is always occurring, the specific language of Deafhood and its perception will change. This study represents a snapshot description of language in time. As each person's experience is unique and each person's relation to significant social change is different, their recounting of an event or events will also be unique. There is no single or simple solution to the problem of accurately representing an inclusive, sensitive approach to the language of disability. Therefore, the aim of this dissertation is the description of language ideologies as they are related to impairment, culture, and perception to develop a method that moves us toward a more student-centered approach. Social perceptions of disability and the language of disability are also constantly changing (Aronoff, 2007; Eayrs, Ellis, & Jones, 1993; Jernigan, 1982; Lynch, Thuli, & Groombridge, 1994). As such, the primary outcome of this dissertation is to develop a model of language policy that is guided by a philosophy of inclusion, self-empowerment, and respect through self-naming rather than to prescribe specific language forms of reference.

Potential Contributions of the Study

The present study has the ability to contribute significantly to an area of emerging importance that has seen little in the way of formal scholarly inquiry. Although perceptions of the language of disability have been studied among students (McCoy & DeCecco, 2011) and rehabilitation specialists (LaForge, 1991), none of the existing literature examines the perceptions of this language in a way that takes into account the students whom such language is meant to describe. By examining how Deaf students view the language used to describe them, as well as how they use such language

themselves, this study seeks to answer important questions that could influence the future of language policy in and outside of the academy.

CHAPTER 2 - REVIEW OF THE LITERATURE

Introduction

Throughout human history, there have been people with medical and psychological conditions that have impaired their full participation in broader society, either physically, mentally, or emotionally. However, there are no impairments that are universally and inherently disabling across cultural contexts. While impairments, by definition, do limit certain abilities of an individual, the extent to which such limitations or disabling conditions exist varies by culture and context. There exist no impairments, no matter how severe, that disable an individual equally across cultures and cultural contexts.

In their seminal history of the Deaf community in the United States, Van Cleve and Crouch (1989) relate the story of Professor James Patterson, a hearing professor from Dartmouth College and congressman from New Hampshire, who came to the then National Deaf Mute College (now Gallaudet University) to lecture. However, since the sole mode of instruction and therefore, communication, at the school was American Sign Language and Professor Patterson did not sign, it became necessary for the school to provide for the services of a mediator, or a bilingual, bicultural interpreter. The conventions for ASL interpretation established at this event have persisted to the present (Van Cleve & Crouch, 1989).

In the instance of James Patterson, the social construction of *disability* shifted in an appreciable way. A Hearing person with full capacity of speech is disabled in the context of a signed-language-only culture if he does not sign. While Professor Patterson

would not have been considered disabled in any contemporary or modern popular conception of the construct, he was certainly disabled at Gallaudet.

In a Hearing culture, a deaf person is considered to be disabled because there is impairment to one or more of the four language skills: speaking, listening, reading, and writing, usually speaking and listening. In a signed only culture, a non-signing person is considered to be equally disabled because speaking and listening are equally impaired. *Speaking* and *listening* can be better understood in this context as ‘conveying information’ and ‘understanding received information’. As such, the conversational acts of signed conversation are equally effective at conveying information as their audible analogs.

Four Models of Disability

The Medical Model of Disability

The medical model of disability is by far the most straightforward and simplistic view of the four major models of disability and can be best understood as viewing disability primarily from an impairment perspective, taking impairment as a pathology that can and needs to be cured. In the past thirty years, including the era which preceded the Americans with Disabilities Act, persons with disabilities have fought to overcome a primarily medical, *biological deficit* (Shakespeare, 2010) view of disability and have argued that this is the primary barrier to full inclusion in society (Campbell & Oliver, 1996; Charlton, 1998; Driedger, 1989). Shakespeare (2010) directly addresses person first language and its relationship to the medical model: “Medical model thinking is enshrined in the liberal term ‘people with disabilities,’ and in approaches that seek to

count the numbers of people with impairment, or to reduce the complex problems of disabled people to issues of medical prevention, cure or rehabilitation” (p. 268).

The Social Model of Disability

The Social Model of Disability positions *disability* as a social construct that has an inherently oppressive effect on persons with disabilities. The social model has three major distinguishing elements: *Impairment* is distinguished from *disability*; the *social model* is distinguished from the *medical model*; and *disabled people* are distinguished from *non-disabled people*. This model has been an effective vehicle for improving the status of persons with disabilities politically, instrumentally, and psychologically (Shakespeare, 2010).

The social model assumes a distinction between *impairment* and *disability*. *Impairment* is the individual, private experience of a person, while *disability* is the structural, public barriers that impede a person’s full participation in society (Shakespeare, 2010). This dichotomy of natural expression and the socioculturally constructed norm was first introduced by early feminists (Garland-Thomson, 2010; Wendell, 2010). *Impairment* can be defined using the familiar legal definition of *disability* under the ADA as any physical or mental condition that impairs one or more major life activities. It establishes that physical or mental deviation from the socioculturally constructed norm, irrespective of its impact on major life activities, can have a disabling effect. *Disability* is defined as the barriers to participation that are created by or in response to an *impairment*. In this sense, the social construction of *impairment* into *disability* can be considered analogous to other natural expressions of difference which become social constructs. For the natural expressions sex, race,

sexuality, and impairment, there are the related parallel social constructions of gender, ethnicity, sexual orientation, and disability.

The social model also assumes a distinction between itself and the medical model of disability. Under the medical model of disability, the person with a disability is primarily viewed as a patient experiencing the effects of a medical impairment. The impairment under the medical model is taken as a cohesive set of symptoms that either can be or should be cured by medicine, therapy, or surgery. The person is removed from consideration and becomes a patient; no attention is paid to the effects of the impairment as experienced by the individual, rather it attempts to distill the individual, unique lived experiences of persons with disabilities into “issues of medical prevention, cure, or rehabilitation” (Shakespeare, 2010, p. 268).

The social model of disability has at its root the removal of social barriers to full participation in society. By removing such barriers, social model theorists attempt to remove the social cause of disabling conditions and therefore guarantee full participation in society.

Shakespeare (2010) criticizes the social model of disability for not taking the experience of the individual into account, specifically that the current social model ignores the very real individual and medical aspects of impairment which have a very real impact on the lived experiences of persons with disabilities (Crow, 1992). While the experience of a population may be greater than the sum of the experiences of its individual members, the experience of the individual is integral to understanding the phenomenon of the disabled experience. The lived experience of the individual is in some ways more authentic than the voice of the group, particularly in disability studies where

historic oppression and lack of agency may have prohibited authentic self-expression and because the range of possible experience can be so varied, it is necessary to examine the experience of the individual in order to provide for more complete contextualization of the types of experiences that may be encountered. The voice of the individual is just as important in understanding the experience of the group as the voice of the group is in understanding the experience of the individual (Johnstone, 1996).

Thomas (1999, 2004) attempts to modify the social model to include the *impairment effects* to acknowledge the limitations and difficulties which certain medical conditions inherently pose. Thomas argues that the reality of physical and mental impairment does not negate the oppressive nature of socially constructed disability. Consequently, any modified model should take into consideration both the lived experiences of individuals with a disability as well as the reality of the limitations and impacts of an impairment on an individual.

The Legal Model of Disability in the United States

While many members of the Deaf community do not view themselves as being disabled or having a disability, they are, nonetheless, covered under Federal legislation protecting individuals with disabilities. Indeed, most higher education professionals will encounter Deaf students under the auspices of the Americans with Disabilities Act (42 U.S.C. § 12102) and Section 504 of the Rehabilitation Act of 1973 (Pub. L. 93-112). Therefore, an understanding of how these pieces of legislation define disability and the accommodations provided, such as ASL interpreters and closed captioning, is important for an understanding of how Deaf and Hearing cultures intersect in the academy.

Under Federal law, a student must be recognized as having a qualifying disability in order to qualify for accommodations at an institution of higher education. Such accommodations seek to improve students' chances at success by mitigating the effects of a student's disability or disabilities on their ability to successfully complete a program of study. To meet the criteria for a disability under the law, a person's impairment must meet the conditions of the legal test as laid out in the Americans with Disabilities Act's threefold definition of disability: an individual must have "a physical or mental impairment that substantially limits one of more major life activities of such individual" (42 U.S.C. § 12102(1)(A)), there must exist a record of a qualified impairment diagnosed by a recognized and licensed medical professional (42 U.S.C. §12102(1)(B)) or the individual must be generally recognized as having a qualified impairment (42 U.S.C. §12102(1)(C)). And, the disability must impair, or be expected to impair, a major life activity for at least six months (42 U.S.C. 1202(3)(B)). For the purposes of the ADA, if any major life activity is limited, the disability is covered under the Act regardless of its impact on other major life activities, which are defined by the ADA as including, but not being limited to, "caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working" (42 U.S.C. §12102(2)(A)). Additionally, major life activities are also deemed to include major bodily functions and the functions of major bodily systems: immune, reproductive, digestive and excretory, nervous, and endocrine (42 U.S.C. §12102(2)(B)).

In higher education, the process for seeking accommodations is a three-step process. First, in order to qualify for accommodations, a student must supply the

institutional disability services provider with documentation or substantiation of a qualified impairment. Documentation must also demonstrate that the impairment is permanent in nature and meets the qualifying criteria as outlined in the ADA or Section 504 of the Rehabilitation Act.

After the student has provided the disabilities services office with this information, counselors determine, with the aid of documentation and disciplinary technical standards, which accommodations are reasonable and appropriate according to a student's individual circumstances. The student or the disabilities services officer, depending on the institution, is responsible for notifying the appropriate faculty, staff, and administrators of the accommodations as determined by the disability services office.

There exists a disparity among the definition of *disability* under the three major legislative acts that concern disability. The Individuals with Disabilities Education Act (IDEA) is far more specific in defining which disabilities fall under its purview than its sister pieces of legislation.

For students between the ages of three and twenty-one, IDEA defines thirteen different categories of disability for which a student might seek provision of services. These categories are autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, specific learning disability, speech or language impairment, traumatic brain injury, or visual impairment. It is important to note that children may not be defined as having a disability under this Act solely because they do not speak English as their native language or because they are functionally illiterate due to a lack of appropriate instruction in reading, writing, or math (NICHCY, 2009).

Under the Rehabilitation Act of 1973 (Pub. L. 93-112), disability is defined in multiple sections as applying to any individual who has “a physical or mental disability which for such an individual constitutes or results in a substantial handicap to employment” or who might benefit from rehabilitation services provided for under the Act (Pub. L. 93-112 §7(6)). Further defining disability, the Act defines the term “severe handicap” to include disabilities which require multiple covered services over an extended period of time which result from “amputation, blindness, cancer, cerebral palsy, cystic fibrosis, deafness, heart disease, hemiplegia, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia and other spinal cord conditions, renal failure, respiratory or pulmonary dysfunction” (Pub. L. 93-112§7(12)). These definitions are left open to revision by a provision which allows for the Secretary of Health, Education, and Welfare (now the Secretaries of Education and Health and Human Services) to specify covered disabilities in subsequent regulations (Pub. L. 93-112§7(12)).

The Americans with Disabilities Act defines *disability* in broader terms than either piece of preceding legislation. The Act employs a threefold definition of disability: an individual must have “a physical or mental impairment that substantially limits one of more major life activities of such individual” (42 U.S.C. § 12102(1)(A)), there must exist a record of a qualified impairment diagnosed by a recognized and licensed medical professional (42 U.S.C. §12102(1)(B)), or the individual must be generally recognized as having a qualified impairment (42 U.S.C. §12102(1)(C)). For a disability to be covered under the ADA, it must limit one or more major life activities. If any major life activity is limited, the disability is covered under the Act regardless of its impact on other major life

activities. Additionally, a disability covered under the ADA must impair, or be expected to impair a major life activity for at least six months (42 U.S.C. 1202(3)(B)). Major life activities are defined by the ADA as including, but not being limited to, “caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working” (42 U.S.C. §12102(2)(A)). Additionally, major life activities are deemed to include major bodily functions and the functions of major bodily systems: immune, reproductive, digestive and excretory, nervous, and endocrine (42 U.S.C. §12102(2)(B)).

Section 504 and the ADA protect the rights of individuals with disabilities regardless of age. In contrast to IDEA, which requires that students with disabilities be provided with an individualized education, Section 504 and the ADA only require that institutions not discriminate against a student because of their disability. Students with disabilities need to be informed of their rights under Section 504 and the ADA before they graduate from secondary education (Eckes & Ochoa, 2005). Section 504 protects qualified individuals with disabilities and mandates nondiscrimination and reasonable accommodation in federally funded programs.

The ADA mandates equal treatment and opportunity under the law for persons with disabilities. The ADA and Section 504 mandate that reasonable accommodations be provided so long as such accommodations do not fundamentally change the nature of or place an undue burden on the institution. ADA and Section 504 differ from IDEA in this respect: IDEA requires that accommodations be made to provide for a free and

appropriate public education, even if those accommodations fundamentally alter the nature of a program (Eckes & Ochoa, 2005).

The ADA prohibits intentional discrimination, as well as policies and procedures that have a discriminatory impact. For instance, while proof of a disability is a requirement for provision of accommodations under Section 504 and ADA, colleges and universities are not allowed to establish policies or procedures which are sufficiently complex enough to hinder a student seeking accommodation (*Abdo v. University of Vermont*, 2003, 263 F. Supp. 2d 772 (D. Vt. 2003)). However, according to the court's decision in *Stern v. University Osteopathic Medicine and Health Sciences* (220 F.3d 906 (8th Cir. 2000)), an institution is only legally responsible for providing accommodations that directly address a qualified disability (Eckes & Ochoa, 2005).

The ADA and Section 504 mandate that the provision of accommodations allows for integration not segregation of individuals with disabilities. Title II of the ADA prohibits state and local governments and their agencies from discriminating against *otherwise qualified individuals* and requires *reasonable accommodations* in the most integrated setting possible. The enforcement, procedure, and rights provisions are those laid out in Section 504 (Eckes & Ochoa, 2005).

The ADA and Section 504 both define an individual as having a disability if one (or more) major life activity is impaired. In *Toyota Motor Manufacturing v. Williams* (534 U.S. 184), the courts found that a disability impacting a major life activity is one which involves the inability to perform a variety of tasks central to most people's daily lives. As such, the courts found that major life activities include, but are not limited to

“caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working” (Eckes & Ochoa, 2005).

While Section 504 and the ADA may be less specific in detailing the services and accommodations to be provided than IDEA, their reach is equally as broad. When taken together, Section 504 and the ADA affect all aspects of modern American life except for healthcare.

The Culturo-linguistic Model of Disability

The culturo-linguistic model of disability is uniquely applied to Deaf students as it approaches culturally constructed disability from the perspective of the oppression and disabling of a linguistic minority rather than a disabled group. Deaf communities find that the legislative breakthroughs involving individual accommodations based on a social model approach do not meet their needs as a developed linguistic minority culture. While significant advances have been made through the use of the social model and alignment with the greater disability rights movement, many in the Deaf community view their struggles as more aligned with those of other linguistic minorities than with the disability rights community (Ladd, 2003).

Part of the culturo-linguistic model is based in the differences between low-context, individualistic cultures, such as the Hearing population of the United States, and high-context, collectivistic cultures, as represented by the Deaf community. The Deaf sense of belonging, both within the Deaf community and the community-at-large, is largely rooted in American Sign Language and the ability to effectively communicate widely in ASL. While ASL is the third most widely used language in the United States, it has not achieved the level of recognition that English and Spanish have. When the

majority fails to learn signed languages to effective communicative levels, it falls on the Deaf community to move between two cultures, often with a degree of difficulty, having to rely on Hearing sign language interpreters to effectively communicate and participate in social activities. In this sense, the experiences of the Deaf community are identical to those of other minority language users in all cultural contexts.

Since a majority of deaf educational programs until recently have relied on an Oralist tradition and have discouraged the use of ASL, often to the point of suppressing its use, these educational programs have in effect been doubly oppressing their students. This is achieved by not only failing to teach them the skills and abilities to effectively function in a Hearing world but also by failing to teach them the skills and abilities to function in their own world. This, in turn, damages the Deaf communities by failing to teach students to read, write, and by keeping them unaware of the Deaf community-at-large. Therefore, it is the aim of the culturo-linguistic model that Deaf students should be afforded a Deaf-centered appropriate education in their own language. It is not the aim of proponents of the culturo-linguistic model to supplant English with ASL, rather it is their aim to include sign language in national curricula so that not only Deaf students may benefit, but also to create a bi-lingual, bi-cultural citizenry which can move seamlessly between the Deaf and Hearing worlds (Ladd, 2003).

The Language of Disability

Person first language is the latest in a chain of language used to describe people with disabilities reaching back through human history. First adopted by The Association for Persons with Severe Handicaps in 1988, person first language has been gaining ground and has been adopted as the accepted form of reference (Bailey, 1992). With the

passage of *Rosa's Law* (S.2781.ENR, 2010), person first language became the only accepted form of the language of disability for the federal government.

Person first language has been accepted as the standard in language policy for disability services professionals since it was first proposed at the inception of the Americans with Disabilities Act. However, in the intervening quarter century, the social, economic, and political status of persons with disabilities has changed significantly. It has become necessary to reexamine the status of the language of disability and its perceptions in the academy.

Language and Disability: From Medicine to Colloquialism

Language can be likened to a living organism, it grows, changes, and adapts in response to internal and external stimuli (Baugh & Cable, 2002). Many of the pejorative terms of disability, such as *idiot*, *moron*, *imbecile*, *mongoloid*, and *mentally retarded* entered the lexicon as terms with legitimate and distinct clinical connotations. For instance, *idiot*, which entered the English language during the Middle English period (1150-1349), originally held the meaning: 'a person with extremely low intelligence'. In the Late Middle English period, the term entered the social lexicon maintaining a related, however pejorative or negative, meaning: 'of a stupid person, a fool, a blockhead'. Finally, in the period between the early sixteenth and early eighteenth centuries, *idiot* came to mean 'a person of weak intellect maintained as an amusement' (OED, idiot). Such terms only acquired a pejorative meaning when they entered the social lexicon being separated from the presumed objectivity of medicine. However, once a term acquires a pejorative meaning, such meaning becomes primary in the social consciousness, and the original clinical meaning is obscured. This social change in turn

has an effect on the medical establishment, which changes its diagnostic terminology in response to societal pressure.

Since the process of language change is ongoing, changes enter at a varying rate and seldom happen all at once (Baugh & Cable, 2002; Eckert, 2000). For instance, some terms, now considered outmoded, held clinical and official status long after the advent of person first language in 1990. *Retarded*, now considered highly offensive, was only officially removed from federal legislation on October 6, 2010 when President Barack Obama signed *Rosa's Bill* into law. The legislation changed *mental retardation* to *intellectual disability* and *mentally retarded individual* to *an individual with an intellectual disability* (S.2781.ENR, 2010).

Retarded entered the medical lexicon in the late Middle English period (1350-1469) with the meaning 'the action or an act of retarding; the result of this; specifically backwardness in mental physical, educational, or social development'. *Retarded* maintained its primarily clinical meaning until the late twentieth century when it acquired the pejorative meaning 'a person with learning difficulties, used as a term of abuse' (OED, retard, retardation). Blaska (1992) prescribes *people with retardation* and *has retardation* as person first alternatives to *the retarded* and *is retarded*, demonstrating that linguistic change is incremental and moves in fluid phases.

While the language of disability has changed generally, the specific language of reference and conceptions of Deaf people have changed as well. The current preferred language as stated by the Publications Coordinator of the National Association for the Deaf is either *deaf* or *hard of hearing*. The World Federation of the Deaf adopted *deaf* and *hard of hearing* as the preferred forms of reference in 1991. The three most

commonly used forms considered outdated and offensive by the Deaf community, but which regularly appear in the Hearing discourse, are *hearing impaired*, *deaf and dumb*, and *deaf-mute* (Creighton, n.d.).

The first mention of *deaf-mutes* appeared in the *Code of Hammurabi*, the Babylonian code of law dating back to the eighteenth century B.C.E. While the modern English usage dates to the early eighteenth century, it is technically inaccurate. *Deaf-mute* refers to silence and the absence of voice (OED, mute); however, deaf people tend to have perfectly functioning vocal folds. While Deaf people use sign languages to communicate and many Deaf people do not use their voices, they are not truly *mute* (Creighton, n.d.).

Deaf and dumb dates to the fourth century B.C.E. and the Greek philosopher Aristotle, who discusses the differences between the deaf and the blind in *On Sense and the Sensible* (J.I. Beare translation). Aristotle believed deaf people to be incapable of intelligent thought, lacking the ability to learn or be taught, because of the inability to communicate effectively through spoken language: “for developing intelligence ... hearing takes the precedence... it is hearing that contributes most to the growth of intelligence. For rational discourse is a cause of instruction in virtue ... since it is composed of words, and each word is a thought-symbol” (Aristotle). Therefore, Aristotle understood that to be able to speak was equivalent to the ability to develop cognitive abilities (Gannon, 1981). *Deaf and dumb* is considered offensive to Deaf and hard of hearing people because not only are deaf people not *dumb* in the modern sense of ‘stupid’ (OED, dumb), but as discussed earlier, they are not ‘mute’ (OED, dumb) in the Middle English sense of the word either.

The third term generally considered offensive, yet frequently used in the Hearing community, is *hearing impaired*. This term is largely viewed as a more recently adopted alternative to *deaf*, *Deaf*, and *hard of hearing*; however, it is largely an audist term which implies that there is an *impairment* or that there is something fundamentally wrong with a person who cannot hear. However, since Deaf people regard their culture, language, and community, as well as their lack of hearing as just as fulfilling as those experienced by the Hearing world, the term *hearing impaired* is viewed as offensive and demeaning (Creighton, n.d.).

Language in the Academy: Publication Manuals and Style Guides

Disciplinary style guides and publication manuals govern the style and editorial decision-making processes of academic publishers. Indeed, the importance of academic publishing is reflected in the publication requirements for promotion and tenure within the faculty ranks of most universities. (American Association of University Professors, 1940/1970) Thus, the scope of influence of the language policy and practice of by editors and professional associations is truly far reaching. This influences not only scholarly discourse but also the discourse of disabilities services providers, faculty, staff, administrators, parents, and students.

The work of the academy is to create and spread knowledge as well as training future generations of researchers. The primary medium for scholarly discourse is the peer-reviewed journal. In order to effect a meaningful discourse, it is necessary for academics to respect and employ the language prescribed by the editorial policies of these journals when producing and publishing research findings. That is to say, it is necessary for members of academic disciplines and subdisciplines to speak the same

language in order to minimize confusion and ambiguity. As novice researchers acculturate to their specific discipline of study, they are taught to accept the specific language and epistemologies of those disciplines. As such, the language policies of professional academic societies from which peer-reviewed journals draw their editorial policies have a profound influence on not only what is discussed but also how it is discussed. Therefore, it is in the academy where changes in language policy must start.

As the primary means of conveyance of academic discourse, academic publishing is at the locus of the research responsibility of the scholar. In a 1993 memorandum to staff in the Department of Education's Office of Civil Rights, the Acting Assistant Secretary for Civil Rights mandated that person first language be the standard for all OCR communications (Lim, 1993). The *Publication Manual of the American Psychological Association* includes a section on removing bias in language for all APA publications specifically aimed at "non-handicapping language"(APA, 2011).

The language of the academy is that of person first. However, accessibility is determined by the acceptability and perception of such language by students. This study seeks to examine language policy and use as it relates to higher education with sensitivity to the individual needs and preferences of students in an effort to construct a more student-centered model of language policy.

Legal and Cultural History of Disability

By examining the cultural and political events surrounding the entry of the concept of *disability* into the English lexicon, we can understand the origins of the concept in the collective consciousness of the English-speaking world. We can look to language to understand when a concept first entered the collective consciousness of a

society. The written record of a society holds not only the content of its records but also the social and philosophical history of the society held within its language. Similarly, the laws of a society reflect the collective morals, values, and ethics of a society.

The ways in which we define legal concepts point to our collective cultural understanding of them. The drafting of legislation is a collective effort achieved by consensus and, as such, legal concepts often lag behind current cultural trends reflecting past understandings of a phenomenon. However, the language of law and policy also has the ability to shape such understanding especially with regard to historically disenfranchised and subjugated groups. Due to the real world consequences of legal definitions, it is important that we understand how they function and how they interact with society to produce real consequences for those they classify. In the case of disability, we must look to the federal and state anti-discrimination statutes to examine this phenomenon, specifically those which apply directly to education: the Rehabilitation Act of 1973, the Individuals with Disabilities Education Act, and the Americans with Disabilities Act of 1990.

The legal history of disability rights in the United States begins with the Social Security Act of 1935 (42 U.S.C.A. §§301 to 399) which provides for the identification and provision of medical and therapeutic services for *crippled children*. This was the first mention of any disability in federal legislation. In 1943, the LaFollette-Barden Act (Pub. L. No. 78-112, 57 Stat 374) provided for the training of persons older than fifteen for the purposes of increasing their employability. A little more than a decade later, the Vocational Rehabilitation Amendments of 1954 (29 U.S.C.A. §§31 to 42) expanded the

amount of federal funding available for rehabilitation services established under previous legislation.

However, in 1968, with the passage of the Architectural Barriers Act (ABA)(42 U.S.C.A. §§4151 to 4157), the federal government entered into a period of rapid expansion of rights for persons with disabilities that continues to the present day. The ABA represented the first far-reaching piece of federal legislation extending rights of access to the disabled. The ABA requires that all buildings constructed with federal funds, leased by the federal government, or maintained for the purpose of providing public services must be accessible by persons with physical disabilities. The Urban Mass Transportation Act (49 U.S.C.A. §§1601 to 1618) expanded access requirements outlined in the ABA to public transportation authorities.

In 1971 and 1972 respectively, the courts held in *Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania* (334 F. Supp. 1257) and *Mills v. Board of Education of the District of Columbia* (348 F. Supp. 866), that establishing educational systems for students with disabilities or treating them differently within the education system was a denial of equal protection and due process under the Fourteenth Amendment to the Constitution. These cases apply the principle of equal educational opportunity as set forth in *Brown v. Board of Education of Topeka, Kansas* (74 S.Ct. 686) to disabled Americans. This led the way for one of the landmark pieces of legislation that made use of the federal purse strings to advance the rights of disabled Americans.

The Rehabilitation Act of 1973 (29 U.S.C.A. §§790 to 796) applies disabilities protections to any recipient of federal financial assistance, including educational

institutions directly receiving federal dollars through grants or indirectly through student financial aid. Section 504 mandates nondiscrimination and reasonable accommodation. In 1974, Congress passed a series of amendments to the Rehabilitation Act that changed the definition of a *person with a disability* from a person who had the potential to benefit from rehabilitation services to an individual who “(A) has a physical or mental impairment which substantially limits one or more of such person’s major life activities; (B) has a record of such an impairment; or (C) is regarded as having such an impairment”(29 USCA 706 (8)(B)). In 1978, the addition of Section 505 provided that the remedies, procedures, and rights under Title VI of the Civil Rights Act would be extended to persons entitled to Section 504 protections. These amendments substantially increased the reach of the act making it the most far-reaching piece of federal disability legislation until the passage of the Americans with Disabilities Act seventeen years later.

In 1975, Congress enacted the Education for All Handicapped Children Act (EAHCA) (20 U.S.C.A 1400 *et seq.*), which is a federal grant statute that established a steady base of federal funding for states that successfully established a free appropriate public education for children with disabilities in the least restrictive environment. In 1990, the EAHCA was superseded by the IDEA. IDEA began the transition from the use of *handicap* to *disability* in all federal documents and legislation. IDEA added new definitions for coverage and expanded special education services to include transitional programming to either higher education or post-education life. The greatest significance of IDEA is the provision that states are not immune from lawsuits for violations. In 1997, IDEA was again amended to add new provisions relating to services in private schools and student discipline.

In 1990, Congress passed the Americans with Disabilities Act (ADA), which broadened the coverage of protection for individuals with disabilities by extending the provisions of the Rehabilitation Act to a much broader group of employers, public accommodations, public services, transportation programs, telecommunications, and public opportunity providers. The receipt of federal funds is not required to be subject to ADA nondiscrimination mandates.

The most recent expansion of disability rights came in the form of the Civil Rights Act of 1991 (Pub. L. 102-166) which amended and expanded the landmark Civil Rights Act of 1964 (Pub.L. 88-352, 78 Stat. 24). The new act provides for compensatory and punitive damages in cases of intentional discrimination. Damages are provided for claims filed under the Rehabilitation Act and the employment sections of the Americans with Disabilities Act.

Deaf History and Culture

Deafhood, or “the process of defining the existential state of Deaf ‘being-in-the-world’ ... is not seen as a finite state but as a process by which Deaf individuals come to actualize their Deaf identity, positing that those individuals construct that identity around several differently ordered sets of priorities and principles, which are affected by various factors such as nation, era, and class” (Ladd, 2003, xviii). Ladd developed the concept of *Deafhood* in order to differentiate the experience of the culturally Deaf individual, both in their experience as an individual and as a member of the larger Deaf community, from the sometimes broadly and misapplied understandings of the medical term *deafness*. In common usage, *deafness* had come to incorporate the Deaf experience under the larger

category of 'hearing-impaired', the vast majority of whom are elderly people with a hearing loss (p. xviii).

As there are many different clinical definitions of deafness and varying degrees of hearing impairment, identifying the number of Deaf individuals in a given population is difficult for researchers. However, according to an analysis of available federal statistics compiled by the Gallaudet Research Institute, the number of Deaf persons in the United States was identified according to three main criteria. Of the two to four out of every 1,000 functionally deaf adults in the United States, fewer than 1,000 people became deaf before the age of 18 years old. When considering persons with a severe hearing impairment, that number increases to nine to 22 out of every 1,000; however, most reported initial hearing loss after the age of 64 years. Finally, if the number of persons with any degree of hearing loss is taken into account, the number rises again to 37 to 140 out of every 1,000, with a plurality, if not a majority, of those reporting initial hearing loss after the age of 65 years (Mitchell, 2005).

According to Blanchfield, Feldman, Dunbar, and Gardener (2001), educational participation and success by individuals with a "severe to profound hearing loss" was significantly lower than that of their hearing counterparts. Approximately 19% (18.7%) of the population in the United States did not graduate from secondary education; however, for persons with severe to profound hearing loss those numbers represented 44.4%. While 12.8% of the hearing population graduated from a postsecondary institution, only 5.1% of the Deaf or hard-of hearing population did. Finally, while those who went on to or completed post-graduate study represented 9.2% of the hearing population, the corresponding proportion of the Deaf population is only 4.8%.

Cultural Deafness is understood to refer to those persons for whom American Sign Language is their first language and whose social beliefs, behaviors, history, and cultural artifacts reflect a shared Deaf experience (Ladd, 2003; Lane, 1999; Keller, 2004; Van Cleve & Crouch, 1989). Deaf with a lowercase d, *deaf*, is used within the Deaf community to refer specifically to those individuals who are clinically deaf or hard of hearing but do not identify as culturally Deaf. For these individuals, their lived experience is considered to be primarily audiological and verbal. They have been primarily socialized in Hearing society and generally prefer to remain a part of the Hearing society they have been socialized into (Ladd, 2003). In addition to the *deaf/Deaf* distinction, members of the Deaf community also refer to many non-Deaf people, including those persons who are deaf or deafened as *hearing* (Ladd, 2003). These terms may be used interchangeably in discourse.

Whereas *deaf* refers to an individual's experience that is mainly a loss of hearing with little to no identification with any cultural experience, *Deaf* refers to individuals who self-identify as being culturally Deaf and actively participate in Deaf culture. Persons who identify as Deaf are those "for whom the sign languages, communities, and cultures of the Deaf collective represents their primary experience and allegiance" (Ladd, 2003, xvii). The primary experience of the Deaf individual tends to be visual. For purposes of clarity and simplicity in this dissertation, this distinction is used; however, as will be discussed in greater depth later, the experience of any individual d/Deaf person is unique and incorporates to varying degrees aspects and cultural artifacts of both Deaf and Hearing cultures.

Deaf culture includes the common cultural artifacts, beliefs, behaviors, traditions, languages, institutions, arts, and literatures of the Deaf community. American Sign Language forms the center and the primary defining characteristic of *cultural deafness* in the United States. For members of the Deaf community, ASL is recognized as a person's first language regardless of the age or order of acquisition. As with any cultural group, shared experiences in Deaf culture include participation in Deaf cultural events, social organizations, and most importantly Deaf schools. While the Deaf community may be viewed as an insular group by some, it is important to note that the *Deaf community* can include deaf and hearing people, sign language interpreters, the children of Deaf adults, other family members, and many others, and that a person who is clinically deaf is not necessarily culturally Deaf. Cultural Deafhood and the rights of signed language users have been recognized and codified by the United Nations in the U.N. Convention on the Rights of Persons with Disabilities (UN, 2006).

Language forms an integral component for the formation and transmission of culture and, therefore, cannot be considered apart from culture. Deaf people and, by extension, Deaf students and administrators live simultaneously in and constantly cross between two cultures: Deaf and Hearing. It is the intersection of these two cultures which forms the basis for the lived experiences of the Deaf community.

The Oralist movement and the Oralist attempts to remove Deafness from the education of Deaf students have been regarded by many in the Deaf community as cultural genocide (Ladd, 2003). The Oralist movement, during the last 120 or so years, imposed on Deaf education a system that not only deemphasized the use of signed languages, but banned their use. Deaf educators, Deaf communities, Deaf cultural

institutions, and their signed languages were systematically removed from the deaf education system and were replaced with a system led by the audist notion of *passing* in which students were taught speech, speechreading, and through the use of hearing aids only. The Oralists sought to remove the need for the existence of Deaf community to the point that deaf children were isolated and kept from interaction with Deaf adults (Baynton, 2010, 1993; Edwards, 2010; Ladd, 2003; Lane, 1993, 1999, 2010).

The importance of community in Deaf culture is reflected in its collectivist nature. In such a collectivist culture, the concept of semantic distancing found in Person First Language to emphasize that one aspect of a person's experience does not define them common in American Hearing discourse, i.e. *I'm not a Deaf person, I'm a person who is Deaf*, has no cultural meaning as far as deafness is concerned. Identification with the Deaf community and Deafhood is primary. If a person were to distance themselves from their Deafness in such a way, it would be seen as an insult to all members of the Deaf community (Mindess, 2006; Padden and Humphries, 2010). Such distancing happened when Marlee Matlin, a Deaf actress used her voice rather than ASL when presenting at the Academy Awards. While the Hearing community may have viewed her use of spoken English rather than ASL as overcoming adversity, the Deaf community viewed this as rejecting a primary aspect of her Deafhood (Mindess, 2006).

Truth in this cultural context is constructed through personal experience rather than relying on perceived expertise as demonstrated by achievement or education (Mindess, 2006). ASL is understood in Deaf culture as the great unifier and the great equalizer (Padden and Humphries, 2010). Respect for self-naming in Deaf culture is well established. Many members of the Deaf community, one that is focused intensely on its

past and reveres its history and heroes, have moved away from using traditional ASL signs for cultural groups (Mindess, 2006).

Decision-making in collectivist cultures means that buy-in must be undertaken by the community as a whole and any threat to the community posed by an outsider must be minimized and clearly communicated to gatekeepers and community members (Mindess, 2006).

Toward a Student-centered Model of Language Policy

Language policy, which often carries a cultural weight similar to law, can have a constraining or defining effect on how we use language and, consequently, how such language affects the way we live our lives. Language policy in higher education has a more profound influence than in other venues.

Since the findings of researchers throughout academe influence the world around us, whether directly or indirectly, the manner in which such discourse is conducted has the power to be an agent of social change. Congress relies on the expertise of members of the academy and the professoriate when drafting legislation and making decisions as to its implementation and implications. Governmental agencies and institutions of higher education also look to the language policies of the academy when making decisions concerning the crafting of policy and the development of their own language policies. As the language used at the level of policy takes hold, eventually the language used socially also begins to change. By taking the concept of the influence of language policy to its logical conclusion, the decisions made about language use in the academy will eventually determine the ways in which a society uses language to describe any given phenomenon.

Because of its influence on how we view and understand the world around us, a

change in language has the power to change the way we perceive and interact with the world and each other. By developing a language policy that is centered on the needs and perceptions of Deaf students, the academy can help to advance their status in the world, how the world perceives them, and how they perceive themselves.

One of the defining principles of student affairs is that our primary focus as educators should be on developing the whole student as an individual. Additionally, in the realm of disability, the law mandates that we treat each person as an individual. As such, any policy in higher education should have the needs of the individual student as its primary focus. By recognizing the uniqueness of each individual's experience and by creating a student-centered language policy, higher education professionals have the ability to influence social understanding and effect change at the ground level. In order to meet the student on an individual level with regards to language, it is necessary to first understand the lived experiences of the individual and how the language of disability in the academy is perceived.

Throughout history, people with disabilities have been marginalized and deprived of social power. The power of self-naming is paramount to true equality, accessibility, and the standard of access on the basis of the individual (Longmore, 1985; Charlton, 2000). While person first language marked an important advance in language policy and respect for individuals with disabilities, the status of disability in society and the academy has changed drastically.

CHAPTER 3 - METHODOLOGY

Introduction

The purpose of this study is to investigate the language used in the academy when discussing deafness and Deaf students, to examine the interactions it fosters¹, and specifically, the perceptions of the students such language is meant to describe. By understanding how these students perceive such language, it will be possible for higher education to move toward a more student-centered language policy. In order to effect a more holistic understanding of the phenomenon of the language of reference and its perceptions, a multi-phasic qualitative methodology was employed. This phenomenological study was conducted under a social constructivist paradigm.

Rationale

Social constructivism asserts that meaning is constructed by individual discourse participants through their understandings, perceptions, and worldviews (Patton, 2002). Knowledge is constructed through the negotiation of meaning between the researcher and research participants rather than through preconceived constructs and beliefs. The guiding maxim for research conducted under the social constructivist paradigm is known as Thomas's theorem: "What is defined or perceived by people as real is real in its consequences" (Thomas & Thomas, 1928, p. 572). In American Deaf culture, greater

¹ It is important to note when referring to d/Deaf people, a distinction is made in orthographic, i.e. written, conventions between people who are clinically deaf and those who are culturally Deaf: *deaf* refers to people who are considered medically deaf or hard of hearing while *Deaf* is used to refer to people who are culturally Deaf. Cultural deafness refers to those persons for whom American Sign Language is their first language and whose social beliefs, behaviors, history, and cultural artifacts reflect a shared Deaf experience (Ladd, 2003; Lane, 1999; Keller, 2004; Van Cleve & Crouch, 1989).

value is placed on personal experience and witness than on expertise, making social constructivism an appropriate approach for understanding the experience of Deaf students in higher education (Mindess, 2006). The Sapir-Whorf hypothesis (Whorf, 1956/1997), or the theory of linguistic relativity, is the understanding that the language we use, both structurally and lexically, shapes our understanding of the world around us, and informs what we define as *real*. Taken together, Thomas's theorem and the theory of linguistic relativity form the complementary theoretical basis for the examination of the perception of the language of reference in the academy examined in this study.

Since the perceptions of Deaf students, administrators, and their Hearing counterparts represent multiple worldviews, and consequently, multiple views of the same world, the exploration of the phenomenon at hand must start from a place of neutrality. Since no one, including the researcher or the research participants, lives in a world devoid of the influence of and on language as a medium for the expression and representation of social constructions, we must acknowledge that not only do members of the Deaf and Hearing communities represent different social worlds, but that their worlds are also constructed through two differing linguistic traditions.

Research Questions

The present study was guided by four research questions:

- (1) What language is being used by Deaf students when discussing deafness with their professors, university staff, and administrators?
- (2) How do Deaf students feel about the language used by university faculty, staff, and administrators when discussing deafness?

- (3) What are Deaf students' perceptions of the term *disability* as it is used by faculty, staff, and administrators in higher education?
- (4) What major themes are present in the narrative experiences of Deaf students as they relate to language?

Research Team

To ensure the highest rate of interrater reliability, the analysis of qualitative data was facilitated through consensus coding by a team of researchers. The primary researcher was the author, who has been trained in higher education administration and language policy, sociocultural linguistics, discourse analysis, and language and identity. The coding of qualitative responses was performed by a team consisting of three researchers with experience and expertise in higher education administration and policy, sociolinguistics, and disability services. Additionally, the final audit trail, including the transcripts of interviews, data collected via electronic survey, reflexive journals, and other research materials were evaluated by an outside auditor without prior knowledge of the research design or the phenomenon under investigation. While all members of the research team are Hearing and do not sign, they reflect the majority of higher education administrators and professors who will form the core audience of these findings. The primary researcher as well as the Deaf consultants ensured that culturally and linguistically likely conclusions were derived from the participants' responses.

The primary researcher is a thirty year old Hearing Caucasian male doctoral candidate in higher education. He has a background in dramaturgy, applied linguistics, and sociocultural linguistics. He holds a bachelor of arts in individualized integrative studies with an emphasis in dramaturgy and a master of arts in applied linguistics with an

emphasis in Teaching English to Speakers of Other Languages (TESOL) as well as sociocultural linguistics. He has worked primarily as a college level English composition instructor and teaching English-as-a-Second-Language (ESL) at the graduate level. He currently serves as the ADA Coordinator and senior disability services officer in the Office of Educational Accessibility in a private, comprehensive Arts University, prior to that, he worked for two years as a graduate assistant in a counseling role at ODU.

The additional research team members included the following:

1. A hearing White female postdoctoral researcher with a Ph.D, M.A., and B.A. in linguistics.
2. A hearing White female with a Ph.D. in higher education. She holds a master of science in counseling psychology with a concentration in college student personnel and a bachelor of arts in English with a secondary education certification.
3. A hearing Asian-American female Ph.D. candidate in higher education. She holds an educational specialist degree in higher education, a master of arts in applied linguistics and a bachelor of arts in French.

The author was responsible for overseeing all aspects of the study, including the development of the research questions, structuring of the research team, selecting the target population, recruiting participants, designing the interview protocol, collecting data, debriefing the participants and functioning as the leader of the research team. The research team members were not part of the interviewing process.

Participants

Participants were drawn from self-identified Deaf students. The level of educational attainment of participants ranged from students at community and technical colleges to students and professors at four-year doctoral-granting institutions.

While Deaf students are underrepresented in higher education, this study will focus on those students who are attending institutions of higher education and their lived experience and perceptions. It is the aim of this study to develop a more responsive language policy concerning Deafness in the academy to help create a more welcoming and fulfilling experience for Deaf students in primarily hearing institutions of higher education.

Participant solicitation. Student participation was solicited from national and international institutions through listservs targeting disability student services professionals, disability studies researchers, and contacts in the Deaf community: members of the Deaf Culture Initiative, the Standing Committee on Disability of ACPA: College Student Educators International, the Society for Disability Studies of the Association for Higher Education and Disability (AHEAD), Disability Studies in the Humanities, the Working Group for Performance and Disability of the International Federation for Theatre Research, and the Disabled Student Services in Higher Education Listserv at the State University of New York.

Electronic survey. A link to an electronic, open-ended, qualitative survey was distributed to faculty and staff who work with Deaf and Hard of Hearing students for distribution to their students. Since written English is the primary means of written communication for members of the Deaf community in the United States, the survey was

provided in English. However, participants were also provided with a link to a videotaped ASL version of the survey and had the option of recording an ASL response and uploading it to a secure cloud computing server accessible to the researcher. The survey remained open for six weeks to ensure maximum opportunity for students to respond. Approximately 58 surveys were started, of these, 50 respondents self-identified as Deaf or Hard of Hearing, the majority of respondents completed the demographic information form; however, only 18 provided answers to the open ended questions which constitute the survey instrument.

Individual interviews. Participants were selected for inclusion in the study using snowball sampling techniques. Seven individual interviews of Deaf students from across the nation were conducted. The total number of interviews conducted was ultimately determined by the point at which a theoretical level of saturation was reached. Due to the location of the participants and the primary researcher, in-person interviews were not possible. Interviews were conducted via Skype, Google Chat or a similar video-conferencing or chat programs. Accommodations were made to conduct the interviews according to the preference of the individual participants. Individuals who participated in the electronic survey phase of data collection were not eligible to participate in the interview phase to prevent cross-contamination of the two populations.

Measures

Multiple sources of data were collected: an open-ended, qualitative survey distributed electronically and individual qualitative interviews. Data from these collection efforts were used to triangulate responses and increase the internal and external validity of the results. Data collected during the survey phase of the study were analyzed

and used to inform the development of the interview protocol. Detailed information on how these data were analyzed and how they inform interview protocol development will be discussed later in this chapter.

Functional Equivalence. In order to achieve functional equivalence, or the ability to function and elicit similar responses across cultures, it is necessary to adjust the language used by the researcher so that it is equally meaningful in both Hearing and Deaf culture and requires the least amount of cultural clarification by the interpreter (Jones, Lee, Phillips, Zhang, & Jaceldo, 2001; Pollard, 2002).

The ASL version of the survey was interpreted by a Certified Deaf Interpreter to ensure that the highest level of functional equivalence was achieved. Certified Deaf Interpreters are certified by the Registry of Interpreters for the Deaf and are Deaf or Hard of Hearing. The CDI is a member of the Deaf community and has demonstrated knowledge and understanding of deafness, Deaf culture, and is a native or near-native signer. (RID)

Electronic Survey Instrument. The survey consisted of open-ended questions allowing for free response from participants. Students had the option of linking to an ASL version of the survey and responding via video file uploaded to a secure cloud server through a provided link or responding in written English through the survey platform. Responses from the survey were used to develop, clarify, and finalize the interview protocol used in the second phase of data collection.

Before being deployed via SurveyMonkey®, questions were reviewed by Deaf consultants serving as instrument auditors to ensure that functional equivalence had been achieved and cultural sensitivity maintained (Sheppard, 2008). The survey was piloted

for a week with a small group of volunteers to test for instrument validity before it was opened for responses.

Table 1

Correlation of Survey Questions and Research Questions

	RQ 1	RQ2	RQ3	RQ4
1. How do you talk about being Deaf with your professors? Examples?	X			X
1a. What language do you use? Examples?	X			X
2. How do you feel about the language your professors use to describe Deaf people?		X		X
3. How do you feel about the term <i>disability</i> when it is applied to Deaf people?			X	X
4. Describe an experience with faculty, staff, and administrators at your institution.		X		X
5. What language would you prefer your professors. Staff, and administrators use when talking about Deaf people?		X		X
6. What other issues concerning the language your institution uses to talk about deafness would you like to talk to us about?		X		X

Interviews. A semi-structured interview protocol was used. Due to the variant nature of data collected in this manner, the interview protocol was continually reexamined, renegotiated, and revised to reflect the changing directions of the research project. Participants were initially prompted by a series of open-ended interview questions guiding their responses to the topics under investigation; however, regardless of the questions asked in a sociolinguistic interview, interview participants will reveal, in terms of relative talk-time, topics of greater saliency. The interview protocol was comprised of a number of primary questions and related follow-up questions designed to elicit further data from participants. Sub-questions were used only to prompt further responses from the participant for the purposes of clarification.

Based on the coded and analyzed data collected during the survey phase of the study, a semi-structured interview protocol was developed using the questions posed by the survey as a basic framework; the interview protocol directly addresses all four of the primary research questions. A similar review with Deaf consultants as used in the development of the electronic survey was used to develop the semi-structured interview protocol. Three questions were added to the interview protocol due to their overwhelming presence in the survey data.

Table 2
Correlation of Interview Questions and Research Questions

	RQ 1	RQ2	RQ3	RQ4
1. How do you talk about being Deaf with your professors or other Hearing people?	X			X
2. How do you talk to your professors about the logistics of having a Deaf student in class?	X			X
3. How do professors word their sentences in their discussion about Deafness? How do you feel about the language your professors use to describe Deaf people?		X		X
4. How would you describe your overall experience with faculty, staff, and administrators at your institution? Examples?		X		X
5. How do they behave (body language, facial expressions, hesitation)?	X	X	X	X
6. Do they ask you about intimate aspects of Deafness as well, or simply avoid those aspects?	X	X	X	X
7. How do you feel about the term <i>disability</i> ?		X	X	X
8. How do you feel about the term <i>disability</i> when it is applied to Deaf people?		X	X	X
9. How do you feel when you are described as <i>a person with a disability</i> or <i>a person with a hearing impairment</i> ?		X	X	X
10. How do you feel about Deaf people as a <i>linguistic minority</i> ?	X	X	X	X
11. What language would you prefer your professors, staff, and administrators use when talking about Deaf people?	X	X		X
12. What common misconceptions do Hearing people have about Deaf people?	X	X	X	X
13. Do you feel that Hearing people should be educated about Deaf identity, history, and culture? Who should do the education?	X	X	X	X
14. Is there anything else that you would like to discuss about your experience as a student?	X	X	X	X

Demographic data collection. At the beginning of each data collection event, participants were asked to provide detailed demographic data. Participants were asked to

provide information about their age, year in school, major field of study, native language, and whether or not they had attended a residential Deaf school. Participants were also asked to provide information about the higher education institution they attended: public or private; religious affiliation, if any; size of the institution; and geographic location of the institution (state), and whether ASL or another signed language is the primary language of instruction.

No identifying information was reported; however, some of the data that were collected could be used to identify a participant. All identifying information was redacted from transcripts and was not included in the materials provided to the research team. Participants were not asked to identify themselves or to provide directly identifiable information about their institution; however, in the course of an interview such information may have been revealed by the participant; all reasonable efforts were made to mask this information. Participants were asked to choose their preferred form of reference, i.e. pseudonym, in written manuscripts resulting from the data during the interview process, those chosen names are used throughout the data when referring to data collected during the individual interviews. Demographic data were presented in aggregate form to protect the anonymity of participants.

Validity and Reliability

To ensure credibility of data and results, a number of measures were used: triangulation of responses using multiple sources of data and multiple participant groups, consensus coding of qualitative data, and bracketing of researcher assumptions and bias. Data collection instruments were reviewed by Deaf consultants prior to use to address

any threats to credibility and validity. Both the survey instrument and interview protocols were piloted before implementation in the primary study.

Threats to external validity

Only Deaf students' perceptions were examined in this study in order to keep the scope of the study focused; further research should include a comparative study, which examines differences in how Hearing students perceive the language used to describe deafness versus how Deaf students perceive such language.

Threats to internal validity

Since the Deaf community is very close-knit, the possibility of participants communicating with other potential participants about their interview experience is a concern especially since participants will be identified through snowball sampling. This is a cross-sectional design that is concerned with the perceptions and opinions of a small group of participants when describing the phenomenon at hand and is not concerned with establishing a causal relationship of language and experience.

Integrating multiple sources of data

The research design implements three of the four types of triangulation identified by Patton (2002) to increase the validity and verification of study data: triangulation of sources, analyst triangulation, and theory/perspective triangulation.

Triangulation of sources. Data collected from the electronic survey were used to further inform the stories related by interview participants. The scope of the electronic survey gives context to individual interviews. Additionally, the manner of responses was examined on a micro-level to ascertain discursive functions. Data and codes, in an aggregated form, from both the electronic survey and individual interviews were

examined for overarching emerging themes which were present in both phases of data collection.

Analyst triangulation. Data were analyzed by a variety of research team participants: the primary researcher, the research team, and Deaf instrument auditors. Since the primary objective of phenomenological inquiry is the accurate representation of the lived experiences of individual participants, the engagement of these participants in the development of the final analysis is paramount. This is especially important considering the linguistic and cultural factors at play in the present study. The research team represents a wide cross section of academic disciplines which each have their own perspectives and epistemologies, each contributing to a greater and more holistic understanding of the data and their contexts, place in higher education, and understandings across the academy.

Theory/perspective triangulation. Data were examined with the perspectives of a number of stakeholders taken into consideration. The primary stakeholders in the present study are the members of the Deaf community and the primarily Hearing administration of higher education institutions in the United States.

Procedure

Electronic Survey

An email was sent to the listservs of disability service providers and researchers in disability studies as well as to contacts in the Deaf community for dissemination containing a solicitation letter and a link to a SurveyMonkey® survey. The survey link remained open for six weeks to allow participants ample time to respond. A reminder email was sent twice over the course of the period the survey was open to ensure a

maximum response rate, once every two weeks after the initial solicitation. Responses were collected using the software available on the SurveyMonkey® website.

Interviews

Interviews were conducted online using a variety of online chat programs. Transcripts of the interviews were used to facilitate analysis. Transcripts were not altered from their original state, other than removal of identifying information, to avoid any bias imposed by the researcher. Any personally identifiable information pertaining to the participants was redacted from any publicly available presentation of the data. Student information was masked to protect confidentiality and is presented in an aggregate form wherever possible.

The interview event began with a reading of the informed consent form. Participants were provided with an electronic informed consent form in written English. The written version of the informed consent form was approved by the University Institutional Review Board as well as undergoing checks for functional equivalence by Deaf consultants.

Participants were prompted to answer a number of demographic questions, including age, year in school, educational background, and primary cultural identification. Participants were then prompted with the first question of the interview protocol. Subsequent responses from the participant guided the rest of the interview so as to interfere with the participant's narrative as little as possible. If at the end of the interview, any of the primary questions included in the interview protocol had not been addressed, the researcher asked them at that time.

Data Analysis

Survey Data Analysis

Data collected from the survey were aggregated and coded according to the metathemes and themes that each member of the research team identified during the data analysis process. Research team members were instructed to code according to their own perception of salient and structural themes and metathemes present in participant responses and interview transcripts. These themes and metathemes will be discussed in full detail in the next chapter. Coding was checked for any embedded cultural cues and for clarification on any ambiguous responses by the Deaf instrument auditor. Coding and coding categories were adjusted based on the input of the instrument auditor. The researcher developed a brief addressing any of the points identified by the instrument auditor for distribution to the research team along with the initial participant responses.

Data from each of the survey sections were aggregated to identify any metathemes which were present. The codebook represents core structural and salient themes. Following each interview event or the addition of coded documents to the corpus, the codebook was renegotiated to ensure that the codebook reflected the emergent nature of the data. Information from the codebook was used to inform organization and analysis of participant responses in aggregate to create a unified narrative of the effects and perceptions of social change on the institution.

Interview Data Analysis

Data collected from participant interviews were analyzed individually and were presented and examined as individualized case studies and as aggregated codes. Interview transcripts were coded according to the metathemes and themes present in each participant's narrative. Coding was checked for any embedded cultural cues and for

clarification on any ambiguous responses by the Deaf instrument auditor. Coding and codes were adjusted based on the input of the instrument auditor.

Transcripts, which were coded by the researcher and the research team, served as the basis for developing a codebook establishing the criteria for inclusion and exclusion of responses in certain codes. Each member of the research team was provided with an equal number of interview transcripts to code chosen at random. Codes were developed for the interview data separately from the codes developed for the survey phase. Following the receipt of the interview coding from the research team, codes were aggregated to create a master codebook.

Thick description

The language of the participants is presented in a holistic manner making heavy use of description and direct quotation, only employing the interpretation of the researcher when necessary to explore themes and metathemes. Codes were defined and exemplified using the language of the participants wherever possible. While data from the electronic survey phase of data collection were presented only in aggregate form, the data collected from the interview phase are presented using a case study approach. Case studies are holistic and context sensitive approaches to the interpretation and presentation of findings (Patton, 2002). The case study approach allows for a fuller, more holistic understanding of the lived experience of the individual after parsing the data into discrete units for a cross-case approach to extract themes and metathemes.

Data collected from the electronic survey further inform the stories related by interview participants and data collected during individual interviews helps to further clarify responses gathered via the electronic survey. The scope of the electronic survey

gives context to the individual interviews. Data and codes, in an aggregated form, from both the electronic survey and individual interviews were examined for overarching themes which are present in both phases of data collection.

Journals and reflections

The primary researcher was sensitive to reflexivity in the process of data analysis and presentation. The three areas of reflexivity identified by Patton (2002) include self-reflexivity, reflexivity about those studied, and reflexivity about audience.

Self-reflexivity. All members of the research team kept reflexive journals throughout the research process. Additionally, all members of the research team disclosed initial perceptions and background factors that may influence not only their perception of the data being analyzed, but also their personal perceptions of the phenomenon under investigation. Members reflected on their perceptions of the Deaf community and their initial understanding of the phenomenon of self-naming. Members of the research team reflected initially and at the conclusion of the study on the following questions:

1. What do I now know about the phenomenon of Deaf perception of the language of disability? How do I know what I know?
2. Has my perspective changed since I last engaged with the data?
3. What shapes and has shaped my perspective? Has this changed since beginning this study? If so, how?
4. How have my initial perceptions of the phenomenon under investigation and my background affected the data I have encountered?

5. How do I perceive the Deaf community? Has my perspective changed since my initial engagement with the data?

Reflexivity about those studied. The researchers also continually reflected on the perceptions of the participants. This information was used to bracket and examine researcher biases since these reflections examine perceptions of perceptions. The researchers' reflections included responses to the following questions:

1. How does the interview participant know what they know?
2. How do they represent their understanding of the phenomenon under investigation? How do they represent their expertise, through lived experience, of the phenomenon examined?
3. What shapes and has shaped their worldview? How do they communicate this to the researcher?
4. How do they perceive me, the inquirer? Why? How do I know? How might this effect the study of the phenomenon under investigation?

Reflexivity about audience. Each member of the research team was asked to reflect on his or her understanding of higher education and impact of the phenomenon under investigation on language policy and the academy at the outset of the study and after the completion of the data analysis. Each member of the research team answered the following questions with regard to the intended audience of this study:

1. How do higher education professionals and policymakers make sense of the present data?
2. What are the perspectives that hearing professionals and policymakers in higher education bring to the initial reading of these findings?

3. How does the intended audience of these findings perceive me? How do I perceive them?
4. How do these perceptions affect what I report and how I report it?

Participant Protections

Multiple relationships

There were no instances in which the primary researcher or any member of the research team had multiple relationships with any of the research participants.

Participants

The questions asked during all interview events were limited to the participants' experiences and, primarily, their use and perceptions of language. Participants were reminded prior to the commencement of each interview event that their participation was voluntary and that they could refrain from answering any questions they felt uncomfortable with and that they were free to end the interview at any time. Participants were informed that they were free to withdraw from the study at any time by providing written notice to the researcher.

Participants are not personally identifiable in any reports or publications which may result from this study. However, some participants, only at their prompting, requested that they be identified by name; their wishes have been respected. The researcher never requested that any participant identify themselves by their real name. The participants had the right to choose the pseudonym to be used in any presentation of the data. If the participants failed to select a pseudonym, one was chosen by the researcher. Pseudonyms are used only to facilitate the readability of the resulting presentation and analysis of the data in the next chapter.

Data

To mitigate any risk to the participants, all participants were provided with an informed consent document and research was conducted in accordance with the guidelines established by the Institutional Review Board for this study. Data collected through the electronic survey were aggregated and any identifying information removed prior to analysis and incorporation into the master codebook and corpus. These data were maintained, along with the transcripts from the interview events as part of a corpus included in the audit trail prepared by the researcher as part of the research process. Only the researcher, the instrument auditor, and the dissertation committee had direct access to the information provided by the participants. All other members of the research team were only provided with transcripts produced from individual interview events. Transcripts resulting from original interview events will be maintained for further analysis unless their destruction is requested by individual study participants.

CHAPTER 4 - FINDINGS

A Note on Language and Style

Due to the nature of the data being presented here, certain linguistic conventions were used. The actual language as used by the research participants is used wherever possible. The editorial style of the Linguistic Society of America (2010) is used to indicate meaning and citation forms of individual pieces of language. The quoted language of respondents and participants as well as the use of cited language forms are indicated using *italics*.

All cited and quoted language forms have been preserved in the original language of the respondents and participants. For the respondents and participants in this study, American Sign Language is their native language or the language they communicate most fluently in and may not follow the conventions of standard Written American English.

Findings: Electronic Survey

Respondents and Demographics.

Only 18 people completed the full survey; however, 50 completed the demographic portion of the survey for a total of 58 responses recorded during the six week window the survey was available. This demographic information provides helpful insight into the distribution of Deaf students in higher education. 50 (86.2%) identified as Deaf or Hard of Hearing; 8 (13.8%) did not. Only those participants identifying as Deaf or Hard of Hearing were asked to continue with the demographics and survey questions. Of the remaining 50 participants, 48 (98%) of the participants were over the age of 18, and of those, 41 (95.3%) agreed to participate in the study. The total number of participants who completed the demographic portion of the survey was 38 (65%). The

geographical locations of participants responding to the online survey were not documented to preserve anonymity; however, based on the responses of participants, data were collected from the United States, Peru, the United Kingdom, and Italy. Participants were recruited using snowball sampling techniques using a variety of contact methods including Listservs, social networking, and personal contacts in the Deaf community.

The demographics of the survey sample are representative of the broader world of higher education. A plurality of participants were traditional age college students, 18-25, representing 31.6% (n=12) of the study population. The next most prominent age group was those aged 30-39, representing 23.7% (n=9). Students in their forties comprised 21.1% (n=8) of the sample, students in their late twenties, 25-29 (n=7) represented 18.4%, and students in their fifties 5.3% (n=2).

More than half of the participants were enrolled in an undergraduate program with 2.6% (n=1) enrolled in a certificate program, 13.2% (n=5) in an associate's degree program, and 42.1% (n=20) enrolled in a bachelor's degree program. A total of ten students were enrolled in a master's degree program (26.3%) and eight in a doctoral level degree program (21.1%). Of the total number of participants, six (15.8%) were enrolled in a community college, fourteen (36.6%) in a four-year college or university, and eighteen in graduate school. The vast majority (81.6%, n=31) of participants attended a public institution while seven (18.4%) attended a private institution.

While American Sign Language (ASL) Studies and related disciplines, such as Deaf studies, formed a plurality of the responses with four majors and one minor, these numbers only represent approximately 8% of the total sample. The rest of the majors represented the full gamut of academic and professional disciplines. After ASL Studies,

the most common majors among respondents were psychology, linguistics, accounting, and special education, each representing approximately 3.5% of the total sample. The remaining 78% of students were distributed across the range of disciplines and include the liberal and fine arts, the natural sciences, the social sciences, computer science, business and public administration, education, and medicine and the allied health professions.

The majority of participants did not attend a residential Deaf school (n=26, 64.9%), while 27.0% (n=11) did, and only four students (10.5%) were currently attending a school for the Deaf or a school where ASL or another signed language is the primary language, while the majority (n=34, 89.5%) did not.

Structural Themes Present in Survey Responses

A number of structural themes emerged from the survey responses. Chief among these were a sense of Deaf identity and how that identity is constructed; metalinguistic commentary on cited language forms, commentary on pragmatic aspects of Deaf-Hearing interactions; and commentary on *disability* and its intersection with the Deaf world. These themes, taken in the aggregate, will give context to the individual case studies presented later in this chapter.

Deaf Identity Metatheme

The Deaf identity metatheme is comprised of a number of distinct subthemes. The most striking of these is the role of the dichotomy created between the visual and the verbal language paradigms, which forms a key distinction between the Deaf and Hearing worlds. This is particularly exemplified in the discussion of *deaf* and *Deaf*: '*Deaf*' or '*deaf*' (*sounds the same in spoken English!*). ASL and recognition of its legitimacy

played a strong role in the intersection of aspects of Deaf identity, often forming the core of the discussion and defining feature of a Deaf identity:

We have a beautiful language, which is severely under appreciated by many, an amazing, lively culture, and a powerful sense of identity and community.

(R19)

Recognizing that the most salient characteristic of the community is using BSL 'British Sign Language', not having less hearing ability. (R56)

Deaf pride, in part signified by the distinction between *deaf* and *Deaf*, also played an important role in the construction of a Deaf identity as did the discourse around the distinction between *Deafhood* and *Deafness*.

deaf, Deaf and the Visual versus the Verbal Language Paradigms

The discourse surrounding the distinction between *deaf* and *Deaf* was a highly salient one in the responses of the students in this study, whether positive, negative, or neutral value was assigned to the difference. Generally, in the Deaf community and for the purposes of this dissertation, *deaf* refers to 'individuals who are clinically deaf or hard of hearing but do not necessarily identify as culturally Deaf'. (Ladd, 2003). *Deaf*, on the other hand, refers to individuals who self-identify as being culturally Deaf and actively participate in Deaf culture. People who identify as *Deaf* are those "for whom the sign languages, communities, and cultures of the Deaf collective represents their primary experience and allegiance" (Ladd, 2003, xvii). It should be noted that these definitions of *deaf* and *Deaf* are used in part to convey the dichotomy of the medicalized *deaf* and the cultural *Deaf*. As the data show, each individual's experience with the concepts conveyed by *deaf* and *Deaf* are complex and unique to the individual.

Signed languages are inherently embodied languages. While voices can be disembodied from their speakers, signs cannot be disembodied from their signers. (Sacks, 2000). In fact to discuss the distinction between cultural Deafness and clinical deafness becomes increasingly awkward when you move from the visual to the verbal language paradigm. The distinction between the concepts conveyed by *deaf* and *Deaf* as well as the metapragmatic discourse about it is efficient, even elegant in ASL or in Written English, the difference between the *Deaf community* ‘culturally Deaf’ and a *deaf individual* ‘an individual with hearing loss’ is immediately clear through the visual distinction and recognition of the significance of the capitalization of languages and nationalities in Written English. However, once the discourse moves to the verbal language paradigm, the distinction becomes sloppy, an awkward string of modifiers resulting in phrases like *big d Deaf*, *little d deaf*, or *culturally Deaf* and *clinically* or *pathologically deaf*, since spoken English does not have a lexical equivalent of the *deaf* and *Deaf* distinction.

The dichotomy of the visual vs. verbal language paradigms was a reoccurring theme:

[Our] *language is visual which is new for other people. Some people do not understand what it means. I had to use my body language, my hands, arms, legs to show the buildings relationship. I had to make hand modelings and explain everything in visual. That is my language. I do not have to use verbal or anything.* (R53)

One student recounted an experience in a class in which the teacher corrected each instance of *Deaf* and replaced it with *deaf* when the student had used the distinction

appropriately to convey the difference between cultural Deafness and clinical deafness. The student took the opportunity as a teachable moment and educated the professor on the distinction and its significance.

There was one time when I typed a paper for [a] B.S. course about Deaf ... I would used capitalized "D" for every word "Deaf" that I used in my paper. Teacher made red "x" marks on every "D" and gave me lower grade. I had to find an article explaining about the difference between small "d" and big "D" and give to my professor. (R37)

American Sign Language and Its Place in Deaf Culture

American Sign Language and other signed languages are recognized, and the rights of signed language users are protected by the United Nations in the U.N. Convention on the Rights of Persons with Disabilities (UN, 2006). The recognition and position of ASL in the academy as a fully fledged language played a major role in participant responses:

I noticed that many college begin to accept ASL as a foreign language. However, I noted that some colleges use the term, "sign language", not "American Sign Language" in their curriculum. ASL [has been] recognized as a full-fledged language for a while. Colleges should update. (R21)

ASL forms a central place in the lived experience of Deaf people, and hence, the discussion of the Deaf world, Deaf culture, and Deaf life. Participants identified four categories of language use in their narratives: signed language only, a combination of signed and written language, a combination of signed and spoken language, and signed language with an interpreter.

Some responses were nuanced indicating a distinct preference for ASL with written English as a secondary means of communication and spoken language reserved for an emergency when it would be necessary to interact with a rescuer:

I use American Sign Language (ASL). ASL is my primary language. It is how I communicate daily. When I am communicating with someone who is not a signer, I would use written English... If there is an emergency, I would use my voice. For example, if I get injured badly and need to interact with a person who comes to my rescue, I would definitely use my voice and use gestures if needed. (R21)

ASL was the primary salient characteristic in constructing Deaf identity and Deaf pride:

I am proud of us – fiercely proud. We have a beautiful language, which is severely underappreciated by many, an amazing, lively culture, and a powerful sense of identity and community. (R19)

This extended to feelings of protectiveness and nurturing for ASL:

If the professors mock about American Sign Language [that] Deaf people use in Spoken English, I would not be okay with that. (R21)

Deaf as a Linguistic Minority

The construction of the Deaf community as a linguistic rather than a disabled minority, reinforcing the notion of a culturo-linguistic model of disability, was a prominent theme: *It is extremely important for [professors] to view deaf people as a cultural minority.*

There was, however, nuanced and varied discourse about the intersection of *disability* and a Deaf identity. Some participants flatly rejected the classification of the

Deaf experience as a disabled one: *Deafness is not a disability. Period. I have never viewed myself or other Deaf people as disabled.* Others defined the Deaf experience as inextricably linked with a disabled experience; however, each instance of this inextricable construction of identity framed *disability* in terms of a linguistic minority or a minority language group and in opposition to *disability*. Participants acknowledged that they were communicatively disabled in Hearing society, but they viewed this *disability* as a social construction which shifts contextually. There is no such *disability* for a Deaf person interacting in the Deaf community. Participants framed Deaf-Hearing interactions with the Hearing, non-signing discourse participant as the *person with a disability*, it is the Hearing person who cannot understand what is going on, not the Deaf person:

We are a minority language group, but unlike other minority language groups, we cannot learn to use the language of the majority community (e.g. spoken English in the U.S. or U.K.). So in that way, the physical difference (not hearing as hearing people do) can be considered a disability in hearing society. (R56)

Well, I would be idiotic if I refuse to admit that deafness is a disability where the society is dominated by hearing people. However, if the society is dominated by deaf people, then deafness is not a disability. The term disability does not make sense. The term should apply to hearing people, if they are part of a deaf community. Honestly, I don't like the term, disability, because I don't consider myself disabled and have to be fixed. (R21)

Deaf Pride

Deaf pride was a prominent theme, and strongly expressed among participants. The concept of sameness and similarity as Hearing people was prominent, as was the rejection of pejoration:

Deafness is not a horrible thing. We are human beings too. We can do anything we want, except hearing everything. (R12)

I just wish that they think that deaf people are really human instead of disability. Why? Deaf and Hearing are the same human period! (R36)

Honest with that disability ... I don't think it should be called disability because I am deaf and they are hearing so we are human. (R36)

Deafhood versus Deafness

Another structural theme surrounding Deaf identity was the discourse about the distinction between *Deafhood* and *deafness*. This discourse intersected with the d/D distinction and the construction of a Deaf identity through a culturo-linguistic model of disability, that of “being Deaf in the world”:

I don't like the word deafness, whether D/d. “Deafhood” seems culturally appropriate, “deafness” so clinical. If you mean not being able to hear, maybe “being deaf” would work. (R56)

Should you use Deafhood instead (R37)

While the explicit commentary on the distinction between *Deafhood* and *deafness* may not have played a significant role, the concepts themselves as defined by Ladd (2003) did, one of an ongoing, developing understanding of one's own Deaf experience and the individuality of that experience:

Deafhood is not seen as a finite state but as a process by which Deaf individuals come to actualize their Deaf identity, positing that those individuals construct that identity around several differently ordered sets of priorities and principles, which are affected by various factors such as nation, era, and class (xviii).

Metalinguistic Commentary on Cited Language Forms

A number of specific cited language forms occurred frequently in metalinguistic discussion of the language used to talk about Deaf people: *deaf*, *Deaf*, *Deafness*, *Deafhood*, *Hearing Impaired*, *Hard of Hearing*, *deaf and dumb*, and *deaf-mute*. Every discussion of cited language forms included direct references to respect.

I want them to view Deaf people more positively, to have respect and appreciation for them, and to understand they're not disabled. (R52)

Respect. That's the first thing that popped in my head. (R21)

Just say "Deaf people" (R56)

Preference of Signification, Pejoration, and Forms of Interaction

A number of themes emerged regarding the preference of signification and pejoration associated with cited language forms; however the most prominent theme was not concerned with language forms themselves, but with the pragmatic features associated with interactions with Hearing people such as hesitation, choice of discourse topic, avoidance and awkwardness in interactions. Of the participants that cited a preferred language form, *Deaf* was the most prominent.

When asked about how they felt about the language used to talk about Deaf people, a number of participants indicated that faculty and staff do not talk about Deafness or Deaf people, and those participants felt that they should not be:

I think if it is not related to the materials presented, they should not be talking about it. I have never had teachers talk about blindness or any other disability in the classroom. One time, I had a student mention she is blind. I never seen anyone else in class talk about blindness. (R12)

It's not up to them to talk about Deaf people and they don't really talk for us, that I know of. (R52)

However, this can be contrasted to the multiple participants who felt that it was by not talking about Deaf people and Deafhood that higher education was doing itself the greatest disservice and that only by talking openly about Deafhood allowed for a more free flowing dialogue which, in turn, raises awareness and education:

One of the best things that an institution can do is to speak freely about my hearing impairment. The more educated that faculty, staff, and administration are about how I function in the institution, the less awkwardness that there may be. Faculty, staff, and administration should feel completely free to discuss my disability with me without concern or fear of me being offended, this allows for the best communication and the easiest overall experience for all involved. (R43)

Prestige was attached to openness and *bluntness* was valued. The theme of nervousness played a strong role with Hearing people's reactions ranging from comic to offensive. One participant recounted their professor's tendency to write everything down in order to

communicate with her, acting with uncertainty, even after being told that such measures were not necessary and that she could speechread sufficiently to understand his spoken words:

I don't really talk about Deafness with my hearing professors; they speak English normally to me, but some do act a bit differently, with more uncertainty. A few teachers write down everything they say to me, even if I nod my head to show that I understand their spoken words. I didn't tell them to stop though... (R19)

Respondents noted that what they perceived as hesitation and timidity, even *fear*, on the part of the Hearing person made interactions awkward even when the Hearing people were in a setting specifically to learn about Deaf culture and ASL:

When I teach/discuss ASL or Deaf culture to hearing students at my ASL club and other Deaf events, some appear trepidatious and too timid to ask me more personal questions about Deafness. They just nod eagerly in agreement with everything I say. However, a few, especially those who are my close friends and thus are not "afraid" of me, seem genuinely interested and ask a lot of good questions about Deafness. I like that – sometimes their language to me is a bit "blunt", but I like that. I want them to fully understand and appreciate Deafness. Unfortunately, many hearing people still feel intimidated by Deaf people and avoid all personal or intimate aspects of Deafness. (R19)

Often professors were portrayed as unwilling to even attempt to communicate with Deaf students because of perceived insurmountable barriers to communication:

Some of the professors, especially during my undergrad studies at [Midwest State], are nervous or unsure how to work with a deaf person. They seem to struggle or approach me as regular/normal person but they feel a barrier that I may not understand the language they use even though they can't or won't try. (R20)

Students highly valued professors and administrators with previous experience with Deaf students, even knowledge of a signed language and Deaf culture, or institutions with a strong Deaf presence or sensitivity, although hesitation and *fear* still played a prominent role:

They've been wonderful. The institution in which I did my masters classes was surprisingly Deaf-friendly. The librarian knew LSQ², and most of the staff/professors tried to understand my Deaf identity and the language I use the most, LSQ. However, the "fear" of chatting with me, or to have small talks were pretty persistent during the full 2 years I've been there. Now that I moved out to the US and work at the UofM, I'm not in touch with them anymore except for my supervisors, through email exchanges. (R52)

The presence of academic departments dedicated to the study of Deaf culture and signed languages were viewed as a positive contributing factor to a Deaf friendly environment:

At my institution there are TWO departments dedicated to sign language(s) and Deaf Studies. One focuses on BSL and national Deaf culture, the other on sign languages and cultures internationally. So there is a great deal of awareness on campus. (R56)

² *Langue des signes quebecoise* 'French Canadian Sign Language'

While some students lamented a lack of a Deaf community on campus, they did feel that the accommodations provided by their institution and the flexibility of faculty, staff, and administrators when interacting with a Deaf student contributed to an affirming experience at the institution:

Actually, I don't see an issue with the faculty, staff, and administrators at my institution. I am impressed with how they all deal with people like me. When I need to communicate with them, they are more than willing to cooperate with me by passing notes or gesturing. They are often flexible with interpreters too. If I need to set up an appointment, I would get an interpreter right away in less than 72 hours. Even better, there is an interpreter available on campus from 8am to 8pm daily, even weekends too. This means I could set up an appointment right away if I need it. (R21)

On the other end of the spectrum, some students were hesitant to discuss their Deafness with Hearing people at all, skirting the topic to avoid inadvertently rude comments:

I try to avoid discussing my inability to hear with [hearing people] because it provokes rude responses sometimes. Most [hearing people] are unaware that they are rude responses because it doesn't sound that way when they are talking about it. (R8)

One student noted that their deafness posed less of a barrier than their ADHD: *I have to say that my ADHD was more of a problem than my Deafness - especially for 3-4 hour classes.*

The education of Hearing people and the responsibility of Deaf people to inform Hearing people, not only of their offenses, inadvertent or otherwise, but also the methods

of correcting of such behavior appeared multiple times: *If I get offended, I'd educate them.* The use of certain offensive language forms by Hearing people coupled with education of Hearing people also played a prominent role: *They often would use disabled or hearing impaired and this of course annoys me, but it's my job to educate them.*

Educating the Hearing community as a path to greater access, acceptance, and inclusion was viewed as a primary responsibility of Deaf people and the Deaf community, which mirrors the experiences of other linguistic minority communities. A variety of approaches were employed by students in an attempt to educate Hearing people about Deaf students, Deafness/Deafhood, and Deaf identity. One student experienced a great deal of difficulty in getting a teacher to talk to her rather than to the interpreter:

For instance, I had to explain to a math teacher to stop using phrases like "tell her that she has to turn in the project tonight" by signing to her the exact same words in ASL, "tell her I will complete my project tonight." Other times, I didn't explain to the teachers. Instead, I signed, "Tell her/him" to the teachers over and over again until they realized what was going on. Another example, the teachers in my high school talked directly to the interpreters when I was around. The approach I used to [address] this issue was talking directly to the interpreters in front of the teachers. Therefore, the teachers would feel uncomfortable and frustrated. This way, I could tell him/her that it is the way I feel too. (R21)

Another student used academic journals and a more research based approach to educate their Hearing faculty on what Deaf identity and Deaf culture entails:

I briefly explained what it is, being Deaf to my supervisors. To support my statements, I gave them few academic papers and videos (movies, clips, etc.) that explains what Deaf identity and Deaf culture means. (R52)

Another student relied on direct education of faculty, staff, and administrators about ASL, Deaf culture and communication with Deaf people to help convey information on the diversity of the Deaf community:

Yes, some of these days, I had to explained professors about deaf relates with communication and English structure where we rely on American Sign Language where it considered to be my first language. But at the same time I always believed in English as my first language. It was difficult position for me to tell professor where is my weakness and strength so they can aware that all deaf people are different based on from their background such as growing up different cultures or environment exposing differently. (R53)

Perceptions and Discussion of *disability* and Deafness/Deafhood

The term *disability* and the acceptance of its application to the Deaf community was a particularly salient discussion. Responses represented a variety of positions on the application and applicability of *disability* to the Deaf community. Many students indicated offense or annoyance at the term *disability*. One student preferred *identity* to *disability*: *Often I replace the term, disability, to the term as identity... I know many of my deaf friends are having a hard time to accept their identity as a deaf person. That part bothers me more than just the term of disability.*

For some participants, the term *disability* always has a pejorative meaning attached to it: *I consider those words as a proof of obvious ignorance among those who*

use that one. For others the rejection of *disability* was coupled with a sense of Deaf pride, Deafhood being constructed in direct opposition to *disability*³:

Deafness is not a disability. Period. I have never viewed myself or other Deaf people as disabled. I am proud of us -- fiercely proud. We have a beautiful language, which is severely under-appreciated by many, an amazing, lively culture, and a powerful sense of identity and community. Whenever hearing people say "disability" or "hearing loss" or "hearing impaired," I feel offended and annoyed. I want to shout at them that Deafness is not any of those terms; it is simply "Deaf." The term "disability" always bothers me.

(R21)

Other participants readily accepted the label of *disability*: *Doesn't bother me. It's a factual information; I believe it to be an accurate description of a deaf or hearing impaired individual and with support most deaf and hearing impaired individuals can overcome this disability.*

However, the majority of responses contained more nuanced discussions of the interaction of *disability* and a Deaf identity. In some cases, participants noted varying degrees of the medicalization of deafness and the insufficiency of *disability* to accurately describe the complexity of a Deaf experience:

I don't think it should be called disability because I am deaf and they are hearing so we are human. If I am deaf then I would [be] called profound deaf instead of disability. More formal word than that... If they want called

³ This language example was used previously in the analysis but has been included here to further illustrate the complexity of the Deaf relationship to *disability*

disability then they have to more explain what is disability about or what is it for? (R36)

Others drew more complex distinctions, assigning different meanings to different discursive contexts, providing a *correct* and *incorrect* context where *disability* might appropriately be applied to a Deaf person:

I come to conclusion that if hearing people use 'disability' correctly, I am fine. I do not have the ability to hear very well. If they use disability as the reason why I cannot function well, then I am upset. (R12)

For some of these participants, the application of *disability* to the Deaf community was only appropriate insofar as it allows for the civil rights protections available to persons with disabilities under the law; however, it is interesting to note that in the same response as cited above, it was also argued that the basis for protection should be not only disability but minority language status as well:

While there are overlaps of the Deaf and disability experience, I don't think it really applies. However, it is thanks to the ADA and other disability-related legislation that the Deaf community has gained access to larger society. We are a minority language group, but unlike other minority language groups, we cannot learn to use the language of the majority community (e.g. spoken English in the U.S. or UK). So in that way, the physical difference (not hearing as hearing people do) can be considered a disability within hearing society. (R56)

A culturo-linguistic model of disability was prevalent in the discourse surrounding *disability*, acknowledging that deafness as a disability and Deafhood as a

cultural identity are not necessarily incompatible: *It's both a disability AND a culture. I don't think the terms are mutually exclusive.* This distinction was extended to assign *disability* in a primarily Hearing context but not in a Deaf context, dismissing the medicalization of Deafness often associated with being deaf in a hearing world and classifying Hearing people as *disabled* in a Deaf context:

Well, I would be idiotic if I refuse to admit that deafness is a disability where the society is dominated by hearing people. However, if the society is dominated by deaf people, then deafness is not a disability. The term, disability, relating to Deaf people in an enriched deaf community does not make sense. The term should apply to hearing people, if they are a part of a deaf community. Honestly, I don't like the term, disability, because I don't consider myself disabled and have to be fixed. (R21)

Finally, one participant accepted *disability* in a Hearing context but viewed the failure to accept one's own Deafness as a greater problem than their lack of access in a Hearing world:

I do accept I do have some kind of a disability for many things such as movie theater, musical plays, talking on the phone, or any other things that I cannot do my own independently. Fortunately, movie theaters do have closed captions now but not enough movie theaters have this option. I know many deaf people do not like the term of disability because it barriers them from doing everything they are capable to do so such as request interpreters at physician's office, or anything but it is more of relying on something else that can be available as you or one day only of interpreters at a musical play

rather than more than one day musical plays. I know many of my deaf friends are having a hard time to accept their identity as a deaf person. That part bothers me more than just the term of disability. (R20)

Findings: Interviews

Introduction.

While the structural themes presented above represent the experiences of a group of Deaf students presented in aggregate, these data give context to the experiences of the individual Deaf students whose experiences are represented in the case studies presented below. As with any cultural group, the individual Deaf experience is the experience of a single individual. The diversity of the Deaf experience extends to their preference for language and communication. Many use pure ASL and do not speak, some use a signed equivalent of English, others use a combination of ASL and spoken English, while some only speak.

Demographics.

A total of seven interviews were conducted through a variety of online media including video chat, text chat, and email. The participants were representative of the geographic and institutional diversity of higher education. The only geographic region not represented was the Southwest. Each of the interviews lasted approximately an hour and a half. All of the interviews presented below were conducted using written English through an Internet chat service or email; none of the interviews were conducted in ASL.

Case Study: Kim S., 30s, Architecture

Kim pursued an education in a field that was considered by many to be impossible for a Deaf woman, Architecture. However, through perseverance and will, she was able

to succeed and establish herself in the field, contrary to what her professors and doctors thought possible. Her story was dominated by themes of educating Hearing people in efforts to increase their awareness and acceptance of her not only as a Deaf woman, but as an architect. She expressed themes of sameness in difference, the idea that we are the same simply because we are all so different.

Her experience exemplified common themes among participants: misunderstandings and underestimation of a d/Deaf person's abilities due to the ignorance of a primarily Hearing world, barriers to access primarily because of communication, and what a Deaf person can add because of their living in the visual world instead of the verbal.

Kim faced great challenges when she entered the field of architecture, due in large part to what she perceived as the audist tendencies of the academy. Professors *think it was impossible because it required a lot of communication... professors did not think a deaf woman who can do this*. However, Kim felt that her professors were assuming that communication must involve verbal communication. She was provided access to an interpreter; however, this was awkward, as she recalls,

It was not easy for me to communicate with interpreters as well, because they do not study architecture. I am. It was not easy to explain to them what I want to say or demonstration. It was a lot of loads on my shoulders. It was very stressful experience I ever had.

In the end, the responsibility fell on Kim to teach her professors that the visual world, the Deaf world she inhabits, is not only *not* a disability, but also an asset in a highly visual field like architecture. The successful completion of her degree which her

visual orientation made possible is coupled with a sense of pride in proving her doubters wrong:

But, end of the graduation, I proved them all wrong... But I have to keep myself as reminder to educating them because they thinks communication is number one. But at the point, it were never point of communication because I used different communication by pointing things or gesture a lot relates with buildings, etc. It puts a lot of visual and it actually helps architecture environment because it rely on visual than verbal.

This pride even extended to her doctor who believed that she would not be able to successfully complete the requirements for her architecture degree:

Many doctors out there thinks deaf people can't be succeed in anything. When I graduated in architecture, well, actually I have been in schooling for long time because I fought what I believed in. I went to see my same doctor that always been knowing me for years. I showed him my college degree. He was blindsided about it and he could not believe it.

While she had a complex relationship with the word *disability* and its connotations, Kim credited being labeled as a *person with a disability* as one of the driving factors in her success, constructing her identity as a Deaf person in contrast to *disability*:

I told [my doctor] what it makes me get through [graduating] is hearing the word "disability" actually bothers me a lot. So, I fought to prove people wrong every time... I finally realized that disability actually put me a lot of great advantage to

put myself to get through where I want to be at but at the same time when the situation is the final.

She felt that the education of Hearing people was one of her main responsibilities as a Deaf person, not only in the academy, but also in the world. *I realized there are many people are not educating about how to deal with many people who has disability like me. I have to teach them what is my weakness and strength to make things works.*

After she graduated, she faced similar challenges of educating her employers on her abilities not only as an architect, but as a member of an office community and culture:

When I started working few months ago, my boss never understand how much skills I dominated that actually help his business to keep going. I told yes, it always will be difficult using communicate because nobody learns all the language where we supposed to learn.

Her construction of her Deaf identity was also a linguistic one. She constructed Deaf identity not only in contrast to a disabled one, but also to an English speaking one:

Universe considered English is the first language. I disagreed with that and I believed that everyone should use all languages as possible it can so we can become more succeed and efficiently. It will exposed people to change their mind about being "disability".

She considered herself to be bilingual having first acquired English and acquired ASL in her late twenties, although she admitted that her ASL at that point it *becomes more likely a pidgin sign language*. She grew up most of her life speaking and in speech therapy. *It is not one hundred accurate for me to speak but it helps me to get through.* Currently, she uses a combination of speech and ASL, which she feels puts Hearing

people more at ease and helps to more effectively facilitate communication. She was pragmatic when it came to communication and worked hard to meet the other person where they were at, helping them to understand communication in new and different ways when necessary:

Other language is visual which it is new for other people. Some people do not understand what it means, I had to use my body language, my hands, arms, legs to show the buildings relationship. I had to make hand modelings and it explains everything in visual. That is my language. I do not have to use verbal or anything. It shows professors to learn how to read my projects themselves. That is where they realized it did not required to communication to presenting my projects.

In many of her interactions with faculty, she preferred to interact directly with her professors rather than through interpreters to assert her independence, even though interpreters were available:

If they want to ask me few questions, they will ask me why, what, how by through interpreters but at the same time I told interpreters to back off and let professors to talk to me directive. I want to be able to show them they do not need interpreter because in the real world we will never use interpreters at workforce 24/7 where it becomes too expensive. So I educated them and they realized that we can do it in writing or anything that displays in visual.

Kim was particularly enthusiastic about the advantages offered by technologies which allow Deaf people to communicate directly with Hearing people without the need for an intermediary or interpreter:

I actually happy that iPad was invented and I was able to use notepad and when professor uses speak. It types for me and I understood. But it did not automatically perfect to speak and type it out perfect because of their accents that iPad do not recognize. It helps me.

Kim had a complex understanding of the concept, construction, and signification of *disability*. Although she did not like the term *disability*, she acknowledged, that higher education's understanding of disability should be expanded, recognizing that disability as 'barrier to full participation' affects everyone:

Well, there are an advantage and disadvantage about this terminology. I never really like the terminology since I grew up because there were never provided evaluate to determine you are labeling a "disability"... I always think that we need to expand on evaluate more on everybody because nowadays more people gets different kind of disability and realized that almost everyone had one minor disability that always will considered to be disability.

She also acknowledged that the system of disability support and social welfare is complex and that finding work for people with disabilities poses its own unique set of challenges:

Disadvantage of being labeled disability will makes other people works too hard to pay their tax to support other disability to keep survive. They feel it was too much responsible but really, it was not. They should have hire people who has disability in every career or anything that would succeed them to do it. If one person is great in crocheting and sell them. So be it! Anyone can work even

though one just can't do it. It is ok. Always find a way that makes work for them.

Be happy about it than be worry about it too much.

In the story she told about confronting her doctor after graduation, she explained *disability* to him by contextualizing her Deafness and relating it to spoken language:

I told him, if he never learned English or never spoken but able to hear, is it considered label as disability? No, it is not. It is just that how we connect to people where we were taught from our background such as bad parenting, or bad schooling, or anything behind that would causes it.

The education of Hearing people as her responsibility appeared frequently and was a highly developed theme. In many instances, education was necessary to prove her abilities in order to be given a chance; in others, it was in exasperation at always having to serve as the token member of the Deaf community, always having to educate Hearing people about the Deaf world. The experience of living in two worlds, Deaf and Hearing, was also prominent:

I had to explained [to] professors about deaf relates with communication and English structure where we rely on American Sign Language where it considered to be my first language. But at the same time I always believed in English as my first language. It was difficult position for me to tell professor where is my weakness and strength so they can aware that all deaf people are different based on from their background such as growing up different cultures or environment exposing differently.

Frustrations with interpreters as well as praise for their tact and abilities also featured in the discussion of educating Hearing people, including educating the interpreters themselves:

Well, some interpreters as staff, I did not get along with them because of their philosophy difference. It caused a lot of conflicted between them and me, the reason that they do not understand my background. They thinks deaf people are all the same. The facts it is not. I am sorry to say this but that is fact that I m seeing other people who had different lifestyle, different culture, different world, etc. Other situation that some interpreters actually strong supporting deaf community which it is nice of them to do that. Also, some staff shows me no respect for example, my accommodation was not meet my needs. They required me to expand the reason and their heads blocked because they do not understand how to be in my shoes. That is where it leads a lot of issues for me to deal with.

Kim believed that Deaf history should be taught as a full constituent member of American history and hold its proper place in the canon:

How do I tell them? I do encourage them to talk about deaf people because our history never been taught. We already learned about Native American, and black as African American through their history. But, where is ours??? It should have been included in world history so it can exposed their philosophy about deaf people. I am somewhat tiresome to educating them over and over because so many people out there did not realized about deafness means in many different way.

Case Study: Thomas S., 24, Mechanical Engineering

Much like Kim, Thomas entered a highly technical field at a primarily hearing institution. Much of Thomas's experience focused around his integrity as a Deaf person and acknowledgement of that integrity by others. Thomas was a mechanical engineering student and one of the few Deaf students on campus. He considered ASL to be his primary language.

His story exemplified and was dominated by themes of respect for Deaf people, Deaf culture, and Deaf identity; open communication and education as the key to breaking down barriers; and barriers to access primarily due to issues in communication. His experience with engineering faculty was overwhelmingly affirming: *I think they would be unbiased in the deaf situations because all of my professors are engineers and focusing on the subject is number one for them.* However, Thomas described his overall experience in higher education as *quite difficult to deal with:*

Being deaf isn't easy in hearing institutions. Esp. its hard to make friends around here. I have put in more efforts than anyone here on campus to make friends and attended more office hours to get help. Its quite tiresome for me because I rather do sign language wherever I go and its relaxing for me.

He would *rather deal with my educations first then deal with the staffs and others.*

However, at his current institution, due to the low enrollment and a lack of presence of other Deaf students, *the quality and supports are very low and difficult to strive for more learning.*

One of the primary issues that he identified with a lack of qualified interpreters with the specialized knowledge he needed access to in order to effectively learn mechanical engineering:

I believe more availability of interpreters around campus will help out more.

Instead of volunteer note takers, they can supply such payments for their time.

Having an interpreters with more knowledge on the subjects I am taking will be a huge plus.

He takes the initiative when interacting with his faculty members and approaches them either before the beginning of the semester or during the first class session to explain that he is Deaf and will be using an interpreter. Interactions with and through the interpreter as well as the qualifications of the interpreter played a major role in his recounting of his experience:

It is difficult to talk with the professors about my deafness. When I have Student Service Disability accommodation, like an interpreter to help me, I have to explain to the professors why I need them.

He felt professors often didn't know what to think at first because of their preconceptions of Deaf people: [My professors], *at first, were offset because they think deaf people don't talk, and I was talking to them. They took an approach either in pitiness or compassion.* Most professors were receptive to having the interpreter in the classroom and offered their help. However, continually bearing the responsibility for educating Hearing people about how to work with Deaf people was beginning to take it toll: *Its starting to annoy me that I have to explain every semester to new professors and get the same results. My interpreter once a while had to jump in to help me out to explain to my professors.* The

experience, as one that had been repeated countless times over the years, began as an awkward one, but as time went on, Thomas refined his explanation for maximum clarity and effectiveness:

In order to start explaining to the professor about deaf kid in class, I have to tell him who I am and what are my abilities. This took awhile for me to get it right without confusing the professors hahaha.

Now, he has it down to a set pattern:

I let them proceed to ask questions about what they can do to help. I offer my plan to them such as sitting in front, allowing time for me to write down all the notes which the professors have written on the board, and have the professors stop moving away from me or turning their backs as they talk.

His experience had been that since Hearing people expect Deaf people to sign and use an interpreter to help facilitate communication, the presence of interpreters added to the validity of his Deafness from their perception and increased access to other support services: *The interpreters I have right now helped me a lot because its give me more evidence to make the professors believe in me more and allowing me to get more help.* The process became more efficient and effective with practice: *At first, its take awhile to take used to it but it works out at the end.*

He believed that open and frank communication between Deaf and Hearing people is important and he was interested in a more honest conversation. He wanted to hear about the experiences of Hearing faculty, staff, and administrators and what they honestly thought about Deaf people while maintaining primary control of the flow of

information. He also noted that he had been taught to have such conversations while remaining objective, that open communication is key to effective interactions:

Quite frankly, If they begin to talk about the deafness, they would begin as experiences they had and how they would interact. They would not talk anymore than that due to limited experiences... if they begin talking about deafness and begins to talk more, I will be open to listen to entire thing and ask them questions. I want to understand what they think of us as we are to them. There might be pros and cons but I am taught to handle the situation without getting emotional in any sorts. If they take it too far, then I will step in.

In spite of the success of streamlining his introductory interactions with faculty and staff, Thomas still found the behavior of his professors to be a bit hesitant and unsure. They tended to focus more intently, their actions and words more deliberate, in interactions with him than they were with other, Hearing students:

They behave as they were thinking to find an answer and response. First thing they would do is to look at me directly. If another students interfere, they will tell them to be quiet. If I ask them to repeat what they said that I don't understand, they hesitate to figure out what to say in different way for me to understand. They are more focus on me than other hearing students in order to help me.

Many professors and other Hearing people held a number of preconceptions about Deaf people which colored their interactions with him:

From personal experiences, they automatically assumed we are always non talkative people. there are some deaf who can talk. Some of the people would act

slowly when they find out that we are deaf. Some people become dramatic to communicate with us. Most of them think we are not intelligence as they are.

Thomas felt that many of the issues that he described could be greatly improved through education, that Deaf history should be taught as a part of history: *I think [hearing people] should be given an opportunity to learn about who we are and how we can help the world. Like add deaf culture into civil rights history class.* However, he believed that it was important for the most authentic and productive experience that either a Deaf person or a person with a great deal of experience with Deaf culture be responsible for teaching such courses:

I believe that a person who have high quality time with deaf culture should be able to teach the class or a person who have an education in deaf culture. I would simply forbid a person who have no experiences or educations in deaf culture to teach because they need to know why and who we are.

Thomas was raised in a hearing family, but considered his first language to be ASL. He learned spoken English to help facilitate mainstreaming for education and agreed with the classification of Deaf people as members of a linguistic minority: *minority, that's it...nothing more or less.* He felt strongly about the term *disability* and especially its application to Deaf people: *I am against the term that given to us. Disability to me feels like a crime charges against the deaf people.* The term carried significant pejorative meaning: *Often times, my friends and I thinks that the word disability say We are forbidden and shall not be listened to.* He constructed his Deaf identity in opposition to *disability*: *After awhile, I ignored the word and keep striving to the best of my ability.* In fact, his pejorative associations with *disability* were strong

enough to color his interactions with the disability services office on campus: *On campus, I have to go to "disability" office and I don't want to go there anymore. If they change the name to something different, I wouldn't mind go there.*

He felt that *person with a disability* was an *easy way for people to label us*, but insists *I want them to say that I am deaf and that's all*. He asserted that Deaf people are the same as Hearing people save for differences in language and communication reinforcing the culturo-linguistic model:

I am same as hearing people but used different way to learn and communicate. Its like communication with foreign people. They just find a different way to communicate, but many people degrade us more [than foreigners.]

Thomas felt that he not only models what Deaf people can accomplish for Hearing people, but also for other Deaf students who are reluctant to study at a majority hearing school and for students in general who might be doubting their abilities. His experience was not only that of a student but that of a Deaf student:

I attended to [East Coast State] where there are the fewest deaf people and help other deaf students learn that they can do it. I am sick of my deaf friends saying that they are very appreciative of me attending to a tough institutions that they couldn't attend. They do have a chance but its the people that degrades us preventing us from moving ahead. I gone through a lot but I'm not ready to turn in my time card once I graduate. I hope a lot of people out there can hear about this. Not just deaf people, but people who are having are time getting higher education.

Case Study: Miranda T. , 20s, Business/Marketing, minor in Non-Profit

Administration

Miranda felt a strong sense of belonging and pride in the Deaf community but did not want her experience to be medicalized or essentialized to *that deaf girl*. Her story explored interacting and overlapping themes of Deaf identity. Miranda was raised in a mainstream school and wished that she would have attended a residential Deaf school:

I wish I would've gone to a Deaf school because I feel, in my Deaf/H.o.H

Community, I am accepted for how I am and understood better around those who have the same struggles as I do, and trouble with classes that I have.

Her descriptions of what it was like to interact with Hearing people, or to have to live in the Hearing world, centered around the amount of effort required of Deaf participants:

Being around hearing people is hard because they don't fully understand me. They don't understand what its like to have to make a constant effort on my behalf to understand the conversation, when I'm only getting 30% and missing the "joke" or the "point" in the midst of it.

She considered the Deaf world to be her world, something of which she was intensely proud: *I talk about being Deaf as something I'm proud of. Its part of who I am, its my culture, and its what I know.* When she talked to Hearing people, especially her professors, she attempted to make the interaction a tangible experience that might help them empathize with Deaf people:

To me, being deaf is like floating through a miasma. You can't see anything in all directions, and when you do see something, you struggle to figure out just what the shape of the object is. So being deaf is a struggle of catching everything that

people say, even if you only catch bits and pieces, you try to fill them in with the words that make sense so you can get the gist of what the person is saying.

Her account of her experiences in higher education included images of *lab rats*, ignorant questions and remarks, and the essentialization of her experience down to *that deaf girl*:

In school, being deaf makes me, to some professors, a lab rat. They want to know how I function the way I do, how I live, how I "do what I do". Its the same with hearing people, they are all curious, yet they do not know where the sensitive boundary is and cross it multiple times... I feel that they ask stupid question, therefore, I feel inclined to give them stupid answers. For example, a common question I'm asked; "How do you talk on the phone?" My response is "With my butt." I try to remind myself that they are only curious and that I shouldn't be so rash but I feel as if they think people such as myself are unable to communicate with others outside of physical, face-to-face communication.

She felt that essentializing her experience to that of *that deaf girl* was oppressive, reminding her of what they believed she could or could not do:

I feel that the boundary of sensitivity, for me, is when they start to touch the subjects of labeling me as "that deaf girl" or touching the subject of all the things I cannot do. (I know what I can and cannot do, I don't like being reminded all the time.)

She felt that education is the key to dealing with some of these issues, especially those surrounding language and inappropriate questions and comments:

I do feel that hearing people should be educated about Deaf/H.o.H identity, culture, and history because it would give them more common sense to NOT say some of the

things that they say to people... Otherwise, how will hearing people learn unless we show them?

Miranda felt that many hearing people believed *we are useless to society, that we can't drive, we shouldn't "waste our money" going to the movies because, hello!, we can't hear* and that hearing people minimized Deaf people's understanding of communication because it differed from their own. She felt that because of their difference in communication Hearing people *believe that we should stay in our "own" groups with people who can understand us and communicate with us* and that *think all deaf/h.o.h people have to "look" a certain way.*

She supported a culturo-linguistic model of Deafhood and an understanding of Deaf people as a linguistic minority. She felt that the majority of the effort put forth in communication with Hearing people is on the part of the Deaf participant, a common theme among minority language users, and that Hearing people should be learning signed languages or at least making an effort as well:

Its aggravating because we speak this beautiful language with our hands and when we interact with hearing people, the effort is more so on our behalf. Not the others. We're not being met half-way communication wise. The sooner people understand that they can speak to us using what they already have, the better it would be for all of us... I'm not saying every person should go out there and learn sign language and be expected to be perfect. I'm just saying, if they choose to interact with people or know they will come in contact with people like us, knowing the basics of sign language or fingerspelling wouldn't hurt.

Miranda had strong feelings about the concept of *disability* but was less bothered by the label of *disability* than the essentializing label of *deaf*. She viewed *disability* as a term of fact, although she acknowledged that for many in the Deaf community *disability* is not viewed as such a benign term:

The term "disability" doesn't bother me nearly half as much as the term "deaf" does. It doesn't bother me because, it is true. I have a disability that hinders me from being able to hear the birds, trains, and ice cream trucks. I feel that when the term disability is applied to deaf/h.o.h people, it can strike a nerve with some people, but it all depends on how it is used. I don't get upset when I'm described as a person with a disability or a hearing impairment because its not intrusive and rude...If someone stood in front of me and said "That deaf girl" it would upset me.

Her experience with faculty had been professional and straightforward for the most part with most bad experiences being attributed to general ignorance about the Deaf community:

The professors just want to accommodate me and we move on with our lives. My overall experience with some of the faculty here at [West Coast State] has been okay. I've had some bad experiences with some of my professors due to the general misconceptions that they have about deaf/h.o.h people.

Her overall experience in higher education had been positive: *The staff here at Upstate are amazing. The administrators are nice. Disability services has been nothing short of understanding and helpful.*

She had discussed Deaf culture and identity with some of her faculty to great success:

I've discussed culture and identity with some of my teachers to give them a better understanding of my life and how it is. And they are genuine about it and want to learn more...I explain how most of the misconceptions are wrong. I discuss with them how people identify me as that "deaf" girl and how I don't appreciate that... I would prefer they avoid anything direct and blatantly rude.

She explained not only the abstract aspects of Deaf culture but the more logistical aspects as well, such as etiquette for interacting with a Deaf person:

I explain to them that no matter how loud they yell or enunciate to/for a deaf person, it doesn't help them hear. It makes communication difficult. And its basically overcompensating for the senses we lack by making the communication awkward...Don't ever talk about a deaf person in third person if they are in front of you. Don't ever describe them as deaf. That is the rudest thing ever. I would prefer they say things like "That girl with the brown hair, she's very smart, and she has two cochlear implants that help her hear" etc. Things like that.

She wanted Hearing people, especially faculty, staff, and administrators to know that it is possible to have Deaf pride and still abhor essentializing the experience of a whole person down to one defining characteristic and that the language we use does have a real world effect on people:

My words to those who will be reading this are to be mindful of what you say. Don't judge a book by its cover and don't go by a piece of paper that showcases a deaf/h.o.h disabilities rather than their capabilities. We can do so much more than what we're deemed limited to. We just need the chance to show you what we can do and hope for a fair assessment from you after that.

Case Study: Dale Mc., 20s, Automotive Technology, Light Duty Diesel

A friendly, outgoing person, Dale attributed his success in higher education partially to his personality which made people more willing to work with him, especially as regards communication with professors and administrators: *I was able to get along with almost every one of them.* His story had one main theme, that Deaf people are people first and that their experience is richer because of their Deafhood not in spite of it: *they don't understand that only thing we can't do is hear.* He pointed out that his Deaf friends lived the same sorts of lives that his Hearing friends lived, that the Deaf experience is a human experience: *most deaf friends I have are doing the same thing as a hearing person is doing working/school.*

His experience as a student was overwhelmingly positive. Although faculty were initially hesitant, they quickly adjusted to a classroom with a Deaf student:

I usually just tell them I'm deaf. Usually the first reaction is how they will work with me how they will interact with me...some of them are very interactive with the way they teach to make sure I understand some teachers teach normally like they would have teached a class without me there.

His faculty were very accommodating and would work with him and adjust their teaching to make the information more accessible even though they had no prior experience with Deaf students; due to the more hands on nature of the work, automotive technology, lends itself to a more visual approach:

I have had awesome instructors in my tech school training. They were awesome with helping me through out my time as a student there and now that is amazing

because the school was in a very rural area they have not come across with a deaf person before.

He did not accept the term *disability*. He viewed himself as *a perfectly normal person*. While he did not personally accept *disability*, he understood the classification of deafness as a disability. He contrasted being Deaf with his sister who has Downs Syndrome:

I don't like it how it is applied to deaf people but I understand why it is considered as a disability but the same time I don't like it and also I have a younger sister with Downs Syndrome that I can understand why the word disabled is being used...I am not against it but it is a hurtful word but I don't know what word to use to substitute it.

Case Study: Joshua P., 22, College Student Personnel

Deaf Identity as evidenced through discussion of Deaf culture and the legitimacy of Deaf culture as a fully developed and valued culture were the primary themes in Joshua's story. From his perspective, familiarity with the culture as well as the proximity of a thriving Deaf community were the most important factors necessary for sensitivity to the needs of Deaf students. Before entering graduate school, Joshua attended a private, liberal arts college that was close to a residential Deaf school, and the university offered a Deaf Education major. The effect of the proximity to a Deaf school and a large Deaf community as well as engagement with the Deaf community and Deaf culture was strong enough to influence the acceptance and behavior of community members with no direct involvement in either the school or the major: *Due to this culture, and due to this*

institution being a private and liberal arts college, the conversations were reflective, open, and frequent.

He contrasted his experience during his undergraduate years with his graduate work at a larger, state university: *The lack of Deaf culture presence means fewer, less insightful conversations. How do I talk about being Deaf? With more cultural presence: In a way to feel a shared experience. With less: In a way to educate those with less cultural competency.*

He was purposeful with his interactions with Hearing people, structuring each of his interactions as a teachable moment to educate about Deaf culture. Joshua was intentional in his interactions with his faculty members and *coordinate[s] [his] presence by remembering the need to put my experiences in context, since others can only assume.* His experience with higher education professionals was inconsistent, spanning the spectrum of involvement of faculty, staff, and administrators in providing support services: *Some professionals want to help, and know how. Some want to help, and do not know how. And others do not appear to care to help, for various reasons both known and unknown.* He classifies his experience as *a continuous need to assess who does and does not have the mindset of assistance and accommodation, and evaluate the capabilities of both of those mindsets, in terms of cultural competency.*

He asserted that good intentions when coupled with a lack of cultural knowledge and competency could still lead to insensitivity. He contrasted the culturo-linguistic model that he advocated with the medical model of hearing loss:

Currently, due to the lack of cultural competency combined with a mindset of "wanting to help," their sentences are hesitant yet insensitive. Perhaps it is due to

their personalities and backgrounds, but they are unfamiliar with Deafness as a culture, and assume the existence of simply the hearing loss.

He was aware of different models of disability and also asserted that there is a lack of language that suggests a familiarity with disability support culture, such as "person-first" language. He reasserted the theme of open, honest communication as the key to intercultural contact and communication that has appeared frequently throughout the data:

The feelings I carry following conversations of this nature, due to their infrequency and my understanding of the culture I have entered, are of understanding and confidence. I understand why the professors are uneducated, and I feel confident enough to share and educate and correct. I believe these feelings to be the markers of success of educators in creating a reflective, open, uncritical dialogue and atmosphere.

Joshua embraced *disability*, again, in part, constructing his Deaf identity in contrast to his *disabled* identity. He pointed to the struggles and triumphs of the Deaf community as a reason to recognize that in the Hearing world, Deaf people are denied access, making their achievements even more monumental:

I believe the term "disability" should not garner any negativity. I believe Deaf people DO have a disability. Personally, I believe I AM a person with a disability and/or hearing impairment. To say otherwise to any of these statements, in my opinion, is to negate the triumphs and social disadvantages that persons with disabilities have experienced.

He talked about the perceptions of *disability* in the Deaf community in terms of cultural artifacts and culturally bound values:

The majority of Deaf people, due to various reasons, have cultural values that dictate these terms to be unnecessary and even insulting, but this belief is specific to this culture. That specificity does not negate its validity, but the specificity does not also mean the cultural value needs to spread to other cultures.

He advocated for an intercultural approach to language of reference that is agreed upon through mutual discussion and *developing cultural reflection*:

Whether or not other cultures manipulate their languages to match Deaf culture should depend on developing cultural reflection, not simply because Deaf people believe so.

Joshua's holistic description of Deaf culture extended to his understanding of Deaf culture as a linguistic minority: *If a way to describe Deaf culture existed, "linguistic minority" would be it. Deaf people are a minority due to their methods of communication.*

He believed that intercultural education is the key to success in intercultural communication and interaction:

All cultures should strive to be educated by all other cultures. The "Pocahontas Paradigm" (Ettinger, 1992) suggests that the colored savages will always save the white man, out of love. The falsity of this paradigm held by uneducated majority cultures should suggest that hearing people should educate themselves. The education of oppressive cultures is not the role of the oppressed, nor does the oppressed culture possess the influence to do so. In fact, it would be better phrased to say "all cultures should strive to educate themselves on all other cultures."... I

am unfamiliar with how other students of my age and profession feel, but I am confident in the future of building a multicultural society, including Deaf culture integration and reflection.

Case Study: Kathy W., Food Science and Technology, Microbiology and Foodborne Diseases

Kathy's story was primarily concerned with the interactions of Hearing and Deaf people in the classroom and the benefits and effects that a willingness to adapt on the part of both parties could have on the discourse event. When first meeting with a professor she explained that she is completely deaf in both ears and that she relies on hearing aids and lip-reading to understand what people are saying. She uses a combination of signing and speaking, also known as Sim-Com: *this makes it better to communicate with both those that are hearing and those that are deaf/hard of hearing.*

She was a strong self advocate and took the necessary steps to ensure that she was communicating her needs and how she needed to be accommodated as clearly as possible to her faculty:

I make an appointment via e-mail prior to first day of class. This way it is in a quiet environment instead of right after class where there is a lot of background noise and impatient students waiting for their questions to be answered. I explain that I am completely deaf in both ears and wear hearing aids. Although they are somewhat helpful, I fully depend on lip-reading for communication. I ask that I sit in the front row so lip-reading is at its best and to face me/the class when lecturing. Also, to repeat student's questions and to provide PowerPoint or lecture notes in advance (it is the expectation that I have review the materials prior to class). I

actually have a person that “c-captions” my class notes (type everything that is discussed by professors word to word) and I read it off the computer screen. It is best describe like c-captioning on TV. I will explain that to the professor and professor will be e-mail a copy of the lecture notes.

She found that professors who are older or more experienced seemed to be more adaptive and worked with her more to make sure that her needs were being met. She had one professor who even went so far as to change his physical appearance to help her succeed:

I had one professor who had a full facial beard. Lip-reading was difficult and exhausting; my grades were suffering. He knew I was a hard worker, because we met 3 times a week to review lecture notes and it was evident how much material I was missing out. About 3 weeks into the course, he shaved his beard. My grades improved tremendously and I was extremely appreciative. I actually took 3 more of his courses because he was accommodating to my needs... He explained at the end of the course he found “c-captioning” notes to be valuable as he saw why students did poorly on certain test questions because he will review the notes and saw he did a poor job explaining the materials. He also made notes available to international students and they found it to be valuable as well.

She contrasted this experience with her experiences with younger, less experienced professors who she felt weren't as willing or able to accommodate her in their courses:

However, inexperienced or younger professors I find to be most frustrating. They explain “Oh sure, sure I get it”. But, often are unprepared for class by uploading

lecture notes right before class, making difficult office hours, and extremely impatient when explaining lecture notes. Often times, I am advised to see a tutor. In fact, I have been told at two separate times by two different professors that my accommodations would not be made available. I took it to the Student of Disability Services at school to explain the situation and the professors were very hostile for the remainder of the semester. Rude and discriminatory comments were made in class towards people deaf when it was irrelevant on course materials.

She expressed frustration at the language used by many of her professors when discussing deafness including *hearing impairment, deaf and mute* and *deaf and dumb*. Due to her speaking abilities she also experienced problems because Hearing faculty members assumed that she could hear them: *because I speak clearly, professors refer me as hearing impairment regardless of the fact that I cannot hear airplanes flying above my head.*

She noted that professors noticeably altered their behavior when they were conscious of the presence of a Deaf student:

I noticed that if professors are unaware that there is a deaf student in the class, they speak confidently. However, if they are aware there is a deaf student, I find they hesitate, look nervously at me, and often tend to walk around the class room as opposed to standing still.

She did not accept the term *disability*, actively rejecting it: *The term disability does not sit easily with me. I was raised that I can do anything except “hear” and to not expect any special privileges. It is the expectation that I have to work just as hard to be*

successful in life. She made a distinction between Deaf people and other *people with a disability*, assigning *disability* to people who are physically disabled:

I often associated people with disability as those who are physically disabled such as those using a walker and wheelchairs for transportation... I do not accept that term. We are perfectly capable of obtaining a job, buying a house, driving a motorized vehicle, and raising children. Yes, I agree deaf people have daily challenges but we overcompensate by adapting to survive.

She regarded *person first language*, *person with a disability*, as highly offensive, even discriminatory: *I do not like it. I feel it is offensive and discrediting my character when a person says I am disabled therefore I feel I am denied of an opportunity.*

She was a strong advocate for educating Hearing people about Deaf identity and views this as the key to improving communication and reducing barriers:

simple hand-finger spelling can be valuable, or communicating on a notepad instead of simply taking the easy way out by saying no. A qualified person such as those who have received special training or a recognized degree is qualified regardless if they are hearing or deaf. It is simply promoting awareness about deaf culture and how to make communication much simpler.

Kathy viewed herself as a pioneer and a model for other Deaf students and believed that if higher education were to change the way it talks about Deaf people, it could make a great deal of progress toward intercultural understanding: *I believe deafness is not a [hearing] loss but a 'deaf gain'.*

Case Study: Mark S., 20s, College Student Development and Counseling

Mark's story was dominated by themes of community and intercultural inclusion. His experience in higher education was positive overall: *My experience with them are excellent. There are bumps though. It is easy to overlook little things like for instance closed captions for movies or videos.* His experience with faculty was mostly positive; however, he did point out that they had a tendency to forget *those little things* often making the class difficult for Deaf students:

Some professors just act same like for instance talking fast as they usually does.

That can be tough to keep up. And another example, group discussion, it is hard to keep up especially with overlapping conversations...Some professor may act unsure but that is usually with one-to-one meetings or a small classroom.

He also encountered affronts to Deaf etiquette such as professors talking to or looking at the interpreter rather than at him as the discourse participant:

They usually look at the interpreters when I am actually talking so that shows.

Sometimes hesitation when discussing about something or not sure who's turn to be talking. That usually happens. Body language- not a lot of change but usually it's when they are talking- it shows.

He qualified administrators and staff as willing but that they don't always understand the significance of providing interpreters for events: *Inclusion aspect is crucial feature to have.* A lack of knowledge and experience with Deaf students also played a role in interactions with university staff.

He did not have a preferred set of terms of reference; however, he did express a negative association with *hearing impaired* and its *negative implications*. He rejected

disability; he felt that it has a *negative connotation*: *I feel like that word has a negative implication when people hear it when it has nothing to do with that*. He felt similarly about person first language: *it is like saying we are not capable of doing anything*. He did, however, accept disability insofar as it provided him with the resources he needed to succeed: *In a way it is hard because I don't see myself disabled but I do need those resources that are provided to me under ADA laws. Those are like the tools for me to use*. He had to negotiate multiple identities, that of his Deaf identity constructed in opposition to *disability* and a disabled identity as a person who is entitled to certain protections under the law.

He viewed Deaf culture as a linguistic minority and viewed language as the central and defining feature of a culture: *I would agree to that aspect because of our language and our common denominator- is what becomes a culture*. If pressed for a preference of terms, he preferred *Deaf, Hard of Hearing, culture, and minority*. He supported the use of education to help spread awareness of Deaf culture and help tear down barriers, reinforcing notions of sameness and capability: *Realize that we are not so different and that we are capable like them when given right tools/resources to use*.

Mark believed that the presence of Deaf students, as well as an understanding of ASL and Deaf culture, improved the experience on campus for all students as well as helping to prevent Deaf students from feeling alone and isolated. Having other Deaf students on campus was important especially for schools which may be located far away from any established Deaf community:

Having Deaf students on campus are certainly a bonus or someone who speaks in ASL. Because Deaf students can and will get lonely if there is no connection to the

campus community. They do feel rejection or not respected if there is no inclusion of the campus to all different types of learner. Deaf just happen to learn, see things and communicate differently which doesn't make us any different from others.

His own experience was influenced by the supporting presence of a Deaf community that used ASL as a primary mode of communication. He assigned this need for community as one of the primary reasons that many Deaf students attend Deaf schools:

I know this from a personal experience so it is relevant to have a open welcoming community that includes everyone and that ones speak in a same language. ASL is English but in a different form...It is like that's why many go to Gallaudet or NTID or CSUN.

Case Study: Roberta F., 20s, Social Work

Roberta spoke frequently about Deaf culture as an authentic culture in terms of a culturo-linguistic model contrasted to a medical model of disability: *I talk about being Deaf as not just being a medical term for "unable to hear" but rather being a part of the Deaf community, Deaf culture, the use of ASL and about the shared experiences of Deaf people everywhere.* She acknowledged that the defining characteristic of a member of the Deaf community was not a loss of hearing, but acceptance of the cultural artifacts of the society:

I myself am medically hard-of-hearing, but I identify as Deaf so there are generally a lot of questions about that. Essentially that the medical diagnosis is different from a persons involvement in the community, and identification with the language and culture. I'm very direct and open about it.

She had an overall positive experience in higher education and actively advocated for herself, introducing herself and her interpreters to her professors at the beginning of each semester, especially if she had never taken a class with them before:

If it's a professor I haven't had I will go up and introduce myself and my interpreters before the first class starts. Then I will explain how to use interpreters, and also ask that we have captions for movies, transcripts for radio clips etc.

She accepted *disability* and used it as a means to expand her social sphere and further develop community even working to form a Coalition for Students with Disabilities: *Right now I'm working with a 3 other students to create a Coalition for Students with Disabilities, which will be the first disability club/org on campus.* She felt that this would help to raise awareness on campus and fill a void that the Disability Services program could not. The office was overworked and understaffed and generally only had the resources available to provide accommodations and had little time to devote to education and outreach to faculty, staff, administrators, and students.

She felt that education and outreach was one of the most important aspects of changing campus climate: *I don't believe that people are unaccepting or create a campus of inaccessibility out of malice or malintent, they are just ignorant. Which, they can't really help.*

Roberta cited a number of language forms when talking about her interactions with her professors: *hearing impaired, hearing issues, hearing difficulties, hearing problems, and then deaf and hard-of-hearing.:*

Usually I try to explain the language that the community prefers to use. I talk about how some people do identify as hearing impaired but not many that many prefer to be identified as a person who is Deaf or Hard-of-Hearing.

She felt that communication was more open and free flowing with her social work professors than in some of her other courses but that they were still members of Hearing society, so they made the same mistakes as other Hearing people: *I think that they ask more questions and are more curious and want to learn but they often make the same mistakes that other professors make from other departments.* Her experiences with professors show that the longer professors worked with a Deaf student, the more experience they had, the more comfortable their interactions became. Like Dale, she also credited much of her positive experience to her outgoing personality and aptitude for school:

Often when people first meet me they will talk extra loud and/or slow and they will seem hesitant but then once they get to know me even for a day that behavior usually changes for most of them its just the first time they've ever met a D/HH student. I've also had a professor obviously think that I needed extra help like double checking that I knew where we were in the syllabus stuff like that but then they realize that I'm one of the more outspoken students in class and that I get really good grades.

Roberta accepted and felt that she was reclaiming *disability* and that it connected her to a larger community of people with shared experiences. However, while she extended her sense of Deaf identity to include a disabled identity, she was still constructing the disabled identity in opposition to *disability* as it is applied to a person in an essentializing

way. She preferred person first language and had mixed feelings about other forms of more recently adopted forms such as *differently abled*:

I actually don't mind the word disability. I personally like that it connects us with a bigger community of people who have shared similar experiences. And in my work in doing some disability organizing on campus, I think its been really powerful to meet students with other DA and learn about their experiences. I'm more of the reclaiming camp but I don't like people being called disabled I prefer person w/ a DA and I guess it really depends on how people use it I have mixed feelings about the differently abled thing while I appreciate the gesture I also think "different from what?" that term feels condescending to me

She felt that a Deaf identity as a member of a linguistic minority did not have to be constructed separately from that as a member of a disabled minority. However, she acknowledged that her understanding and incorporation of a disabled identity into her Deaf identity was dependent upon her situation as a minority member of the community. She felt that she would have a different relationship with *disability* if she were in a majority Deaf environment rather than one of three Deaf students at her institution:

I don't think they're mutually exclusive and I understand the sentiment. And I think I would feel differently if I were at an institution where I was surrounded by other Deaf people, but I'm one of 3 students at my school of 7,000 so not only am I a linguistic minority but I do also have trouble hearing and understanding the things that are happening around me. I don't define myself by that piece and I don't believe that makes me inferior or superior to anyone else, but it is a part of my experience.

She expressed a preference for *Deaf or Hard-of-Hearing* or speaking in terms of the *Deaf/Hard of Hearing/Deaf-Blind community* and *not talking in the lack perspective but rather recognizing all of the amazing gifts that Deaf or Hard of Hearing people have not in spite of being Deaf or Hard of Hearing but because of it*. She wanted to express that the Deaf community is a community of diverse individuals and that their experiences as individuals have value:

I think that people think we're not as smart that the community is really homogenous and that the experiences are not as individual as they really are ie. some people use speech, some people speech read, some people use ASL, some people use only ASL etc. I think that a lot of hearing people are generally oblivious to the fact that the Deaf community is a cultural and linguistic minority and also that when Deaf people communicate with hearing people its the hearing people who have to do the "work". This is just not true.

Roberta felt that education is an important tool in breaking down barriers and ending discrimination. She believed that ASL and Deaf Studies should be given equal status in the academy with courses being housed in linguistics, languages, and sociology departments instead of special education departments:

There should be more ASL classes and Deaf studies classes available across the country and Deaf individuals should teach them... I think they should be housed in either a Deaf studies program or in a sociology or language/linguistics department.

She felt strongly that the language that we use has power and that it is important to pay attention to the language we use when talking about people and especially the language we use when talking to and about people who come from a different culture:

I think that I believe that the language we use to identify and/or describe people is extremely important. And that I wish that people would take more responsibility for learning about the experiences and needs of many different students. I think one of the hallmark experiences of being part of a minority is the daily task of education and that gets exhausting. Academic is all about curiosity so I wish that more administrators, faculty and students applied that to their interactions with students with all kinds of disabilities including the Deaf community.

CHAPTER 5 - DISCUSSION

Introduction

Language forms a core part of identity and, as such, any investigation which has as its focus the understanding and use of language will necessarily address more than simply the language under investigation. The present study is no exception. The discussion of the findings of the study and their implications are organized by the research questions which guided the study; however, due to the inextricable nature of language from all aspects of culture and identity, many of the responses could be coded into multiple categories, and while clear structural themes are present, codes often intersect.

Summary

There were three major themes present in the narrative experience of Deaf students in this study: the consistent need to educate Hearing people on Deaf culture and how to interact with Deaf people, a complex relationship between a Deaf identity and the term and concept of *disability* and what constitutes *disability*, and the construction of sameness in difference, that Deaf people are a part of human diversity and that their difference should be respected in the same way that other cultures are respected.

Research Questions

The present study was guided by four research questions which will be discussed in relation to the multiple phases of data collection:

- (1) What language is being used by Deaf students when discussing deafness with their professors, university staff, and administrators?

- (2) How do Deaf students feel about the language used by university faculty, staff, and administrators when discussing deafness?
- (3) What are Deaf students' perceptions of the term *disability* as it is used by faculty, staff, and administrators in higher education?
- (4) What major themes are present in the narrative experiences of Deaf students as they relate to language?

**Research Question 1: Language Used by Deaf Students When Discussing Deafness
Deaf Identity and Its Construction**

Deaf identity was constructed through a complex intersection of cultural factors. A culturo-lingual model of disability was prevalent in most of the participant's narratives. *Deaf* was constructed in opposition to *deaf*, although a certain amount of overlap with the intersecting identities of *Deaf*, *deaf* and *disability* did occur. The primary defining cultural artifact identified by participants was the centrality of ASL, and signing more generally, to the Deaf experience as well as the respect and status of ASL as a language in the world-at-large. Intertwined with the primacy of ASL was the distinction between the visual world inhabited by Deaf people and the verbal world inhabited by Hearing people. The salience of ASL extended to the designation by participants of Deaf culture as a linguistic minority, one defined primarily by linguistic rather than sensory differences.

Discourse surrounding the cultural aspects of Deafhood included the benefits of a visual orientation in a verbal world as well as the benefits of living in multiple cultures. Participants constructed Deaf pride as a strong primary identity. They simultaneously advocated sameness as well as a unique cultural identity: *Deaf and Hearing are the same*

human period. The construction of Deaf pride was pride in Deaf culture and specifically ASL. This pride was not only constructed in relation to the members of the Deaf community, but the Deaf community and its place in the world as a distinct culture with its own cultural heritage and value.

Finally, reinforcing the culturo-lingual model of disability, which considers the Deaf community to be a primarily social, cultural, and linguistic minority rather than a disabled one, the discussion of *Deafhood* and *deafness* played a central role. While most participants did not express a preference for one term or the other, those that did indicated a clear preference for *Deafhood* over *deafness* citing *deafness* as being clinical contrasted with the *culturally appropriate Deafhood*, which will be discussed in more detail below.

Research Question 2: Perceptions of the Language Used by Higher Education

Metalinguistic Commentary on Cited Language Forms

A number of specific language forms were cited in the data: *deaf*, *Deaf*, *deafness*, *Deafhood*, *Hearing Impaired*, *Hard of Hearing*, *deaf and dumb*, *deaf-mute*, *identity* and *differently abled*. While many participants did not cite preferred specific language forms, those that did overwhelmingly preferred *Deaf* as a premodifier, as in *a Deaf person*. Perceptions of person first language, *person who is deaf*, were mixed. While some participants indicated a preference for person first language, others actively rejected it, although it should be noted that the cited person first language forms were all *person with a disability* so the pejoration may be attached more to *disability* than to person first language. One participant did prefer *person who is deaf*, while another made direct reference to person first language as a marker of familiarity with *disability support*

culture without necessarily indicating a preference for such language, but person first language as a grammatical construction did not feature prominently in responses.

Deafness, when cited, was viewed negatively and constructed in contrast to *Deafhood*. *Deafness* was considered to be an outmoded term focusing on the medical model with *Deafhood* being considered more *culturally appropriate* as it reflects the lived experience of Deaf people aside from or because of their experience of *impairment*. While *Deafhood* as a cited linguistic form did not play a major role in the narrative experiences of students and only appeared in three participant responses, the concept of *Deafhood* as defined by Ladd (2003) as the individual experience of being Deaf in the world did play a major role in all participant responses.

Hearing Impaired, although considered a viable and less offensive alternative to *deaf* by the majority of the Hearing world, *hearing impaired* was viewed by participants as an *awkward* term used by Hearing people because it is *easy*. One participant wanted to *shout at them that Deafness is not any of those terms; it is simply "Deaf"*.

Interestingly, even when citing *hearing impaired* as a pejorative and offensive term of reference, one participant ascribed parallels to *Deaf* and *Hard of Hearing* as accepted terms of reference by drawing a visual distinction, capitalizing *Hearing Impaired*.

Differently abled, a term which also came about as a more recently adopted alternative to *deaf*, was viewed as confusing and awkward. *Hard of Hearing* appeared as a preferred term of reference to *Hearing Impaired* and was used in conjunction with *Deaf* to indicate the cohesiveness of the Deaf community: *Deaf/H.o.H. community*. Other participants used the distinction between *Deaf* and *Hard of Hearing* to draw a clinical distinction between Deaf or *profoundly deaf* and *Hard of Hearing*, and their preferred identification

with the Deaf community. *Deaf and dumb* and *deaf-mute* are generally considered offensive, even in the Hearing community and as such they appeared as loaded pejorative terms in the narratives of participants.

Language Being Used in Deaf/Hearing Interactions

In addition to the cited language forms discussed previously, the pragmatic aspects, or the use of language in social contexts, characteristic of the interactions between Deaf and Hearing people featured prominently in the data. The primary pragmatic features were hesitation, choice of discourse topic, and avoidance and awkwardness on the part of Hearing people in interactions with Deaf students. While most participants viewed open and honest dialogue as the key to overcoming differences in communication and culture, others felt that Hearing people could not possess the cultural capital necessary to discuss deafness because they could not understand what it might be like to be Deaf.

A majority of participants recalled that *hesitation*, *timidity*, and *fear* were common aspects of their interactions with professors. All of the participants noted that the more experience a professor had with Deaf students and Deaf culture, the more comfortable their interactions. Among other factors, the proximity of an established Deaf community, the presence of a Deaf Studies or ASL program of study at the institution, the quality of the outreach performed by student disability services offices, and the presence of other Deaf people on campus all contributed significantly to the overall experience of the participants. One participant noted that older or more experienced professors were more accommodating and more interested in working with her to provide her with everything she needed, while younger, less experienced professors seemed to be

dismissive and less prepared and therefore less accommodating than their more experienced colleagues.

Research Question 3: *Disability, the Deaf Community, and Its Use in Higher Education*

Categories of Identity and Association with *Disability*

The discussion of *disability* and its interaction with Deaf identity revealed four major categories of identity and association: participants outright rejected the classification of *disability* as pejorative; participants rejected *disability* as inaccurate and constructed *disability* as a trait of the Other, that is people with disabilities other than Deaf or Hard of Hearing people; participants accepted *disability* but still constructed their Deaf identity in opposition to the social construct of *disability*; and participants accepted *disability* only insofar as it provided for rights and protections under the law.

Many participants rejected *disability* outright and perceived its pejorative meaning to be inseparable from any other meaning that *disability* might convey, for example as a reclaimed term in the Disability Rights Movement. One participant suggested *identity* as an alternate term for *disability*. Some participants not only attached a pejorative meaning to *disability*, but also perceived those Hearing people that assigned *disability* to the Deaf community as demonstrating *obvious ignorance*, some going so far as to call *person with a disability a crime charges against the deaf people*.

Other participants readily accepted *disability* as a term of reference. However, these participants, using a social model of disability, actually accepted the reality of the impairment of a loss of hearing, while still acknowledging that the barriers created are social in nature and can be *overcome*. These participants, while accepting *disability* in its

colloquial meaning, which includes *impairment*, constructed their Deaf identity in terms of overcoming adversity and in direct contrast to *disability*.

Often participants perceived *disability* to be a pejorative term that inaccurately described Deaf people and applied it more readily to other groups, constructing *disability* in terms of a deficit, directly in opposition to how they construct their own Deaf identity. *Disability* is constructed as parallel to *needs help* and *unintelligent*, citing other recognized disabilities as being *more disabled* than Deaf people: *ADHD, Downs Syndrome, and those who are physically disabled such as those using a walker and wheelchairs for transportation*.

Disability was accepted as a term of reference and classification for a number of participants only in the capacity that accepting *disability* allowed participants access to the legal protections available to persons with disabilities: *It is thanks to the ADA and other disability-related legislation that the Deaf community has gained access to larger society*. However, even when participants accepted *disability* as a means to access, they classified the Deaf community as a linguistic minority and the barriers to access identified by participants as those of a linguistic rather than a disabled minority. Participants did acknowledge that unlike most linguistic minorities, the Deaf community has the added barrier of *we cannot learn to use the language of the majority community ... So in that way, the physical difference (not hearing as hearing people do) can be considered a disability within a hearing society*.

The relationship of the Deaf community and, in particular, the Deaf students in this study to *disability* is complex and fluid. However, as evidenced in the majority of participant responses, even when participants accepted *disability* as a term of reference,

they still constructed their Deaf identity in opposition to *disability* as a construct, not viewing themselves as disabled while still acknowledging that Deaf people can be considered disabled in a Hearing context.

Research Question 4: Other Themes Present in Respondent and Participant

Narratives

While the survey instrument and interview protocol were designed to elicit responses from participants related to their understanding and perceptions of the language used to talk about Deaf people, participant responses included information about their overall experience in higher education. Language, understandably, is at the root of the discussion of their experience and the cause of many of their frustrations. To address the issue of the Deaf experience in higher education, it is necessary to use a holistic approach including education, inclusion, and validation with attention to academic affairs as well as student affairs and activities.

Deaf students are representative of the diversity that is higher education, and this extends to diversity in their Deafhood. Some Deaf students speak and sign, while some only speak and others only sign. Within the Deaf community, the varieties of signing vary greatly and include ASL, Pidgin Signed English, Signed Exact English, and Cueing among others. Additionally, while some students are raised in Deaf schools where ASL or another signed variety is the primary language of instruction, most Deaf students in higher education have attended mainstream programs where they might have been the only Deaf student.

Education as a key to increasing access and inclusion of the Deaf community played a significant role in participant narratives. Participants talked about the need to

educate Hearing people about how to talk to Deaf people and about working with Deaf people. Participants indicated that it was *somewhat tiresome* to constantly be responsible for educating Hearing people about Deafness in order to have any type of interaction. If institutions of higher education took responsibility for this education through Deaf studies and ASL courses, or including Deaf history *as history* or as part of *civil rights courses*, great advances toward full inclusion could be achieved.

The participants felt that the majority of the work done in a Deaf-Hearing interaction was done by the Deaf discourse participant, having to try many different modalities to make themselves understood, while Hearing people tend to only repeat themselves or make communication more difficult by overcompensating. While the mediation of interpreters in explaining how interactions with Deaf students is usually necessary, interpreters are there to facilitate communication and are, by the very nature of their job, not discourse participants. However, frequently Hearing discourse participants feel awkward and include the interpreter as an active discourse participant. A lack of direct interaction with the faculty, coupled with a poor understanding of Deaf etiquette by faculty can make interactions with the aid of an interpreter awkward. Participants reported that professors often spoke to interpreters instead of to students. Some students noted that once they reached a certain level of specialization in technical fields, a lack of interpreters with the specific disciplinary knowledge necessary to effectively interpret courses and interactions with students and faculty also posed a major barrier to access.

Perceptions of Language Being Used to Talk About Deafness/Deafhood

Respect was the primary theme in the discussion of perceptions of the language being used to talk about Deafhood. The most prominent recurring theme was that of the

Deaf student wanting to be respected as an individual by the university community, and to have their experience viewed as unique as that of every other student. Higher education needs to acknowledge that the Deaf experience is a human experience, unique, yet the same. One Deaf experience is simply that -- one Deaf experience -- and experiences can vary greatly from person to person, community to community:

Hearing people tend to group Deaf people together. Often they compare me to other Deaf people they've met (e.g. their grandmother who needs you to yell at her, or who doesn't wear hearing aids). I have an older sibling who is hard of hearing and people do not believe her or me when she reveals she is hard of hearing - hearing people cannot seem to fathom that there is a wide spectrum of hearing loss and it's not just black and white or clear cut.

Avoiding the essentialization and medicalization of deafness, as exemplified by Miranda and her experience with *that deaf girl*, was a salient theme. The flattening of diversity and homogenization of the group to one salient characteristic, deafness, ignores the many other factors which feature in the construction of a complex personal identity. Such a holistic approach supports the culturo-linguistic model advocating for the recognition not only of the status of ASL, Deaf culture, Deaf identity, and Deaf pride which were also major themes, but also inclusion as individuals in the culture of higher education and recognition that their communities are as varied as any other.

Implications for Future Research

The data in the present study focus on the interaction of language and a Deaf identity, and participant responses provided a wealth of information on the Deaf experience in higher education. Further research could include a survey of how Deaf

students approach self-advocacy and how effective they view their efforts to be; how Deaf students feel they are perceived by Hearing faculty, staff, and administrators at institutions of higher education; and their experiences with faculty, staff, administrators and interpreters. While this study examines the relationship of *disability* to the Deaf community, a more focused study investigating the construction of a Deaf identity in relationship to intersection with *disability* and exploring the themes and categories identified by this study.

Examining the relationship of other groups to the term *disability* and its impact on self-advocacy, association and relationships with student support services, and self-image would provide invaluable insight into the experience of students with disabilities and especially those who belong to a group whose identity could parallel or intersect with a disabled one. While the Deaf community might be the only community bound primarily by language that might meet these criteria, with the increasing use of the Internet and social media, other groups are forming communities of their own, including those on the Autism spectrum, the blind community, and increasing numbers of veterans with varying degrees of paralysis and Post Traumatic Stress Disorder.

In addition to the communities that might be classified as disabled minorities, other culturally bound groups or groups that feel a strong cultural connection to their identity would also benefit from research investigating their understanding not only of the language used to talk about them, but also in helping to shape the conversation about themselves and their community. Feagin (1984) identifies five major characteristics of a minority cultural group: suffering discrimination and subordination, physical or cultural traits which are distinguishable from those of the dominant group and are generally

regarded negatively by the dominant group, a shared sense of collective identity and a shared lived experience, socially agreed upon rules for determining in-group status, and a tendency to marry within the group. While ethnic and racial minorities have long been understood as cultural minority groups, other minority groups that might benefit from further research might include the Lesbian, Gay, Bisexual, and Transgendered community, veterans, religious communities, and, while not generally considered a minority in the general population, non-traditional students, especially in an institution where enrollment is primarily traditional aged college students.

Implications for Higher Education Administrators

An inclusive linguistic and cultural policy toward Deaf students, including the official recognition of ASL and the specific needs of Deaf students is paramount to full inclusion in the higher education community. Deaf students should be afforded the same support and efforts at recognition and inclusion all other linguistic and cultural minorities that make up the diverse world of higher education are. Inclusion of training, cultural and communicative, in the ongoing education efforts aimed at higher education, and specifically student affairs administrators, will not only help to remove some of the burden of education from the individual Deaf student, but also increase their sense of belonging and institutional identification.

Conclusion

Any inclusive, affirming language policy must be not only a linguistic policy but a policy which gives value to the individual student as a whole and respects the student as an individual. In order for this to occur, it is necessary follow a model of power sharing and negotiation of meaning between the student as an individual, the student as a member

of a community, and the University. The traditional top-down model is effective in promoting language change; however, without an ongoing dialogue, a solely top-down approach will prolong a paternalistic system of naming and continue to contribute to ongoing oppression. On the other hand, a bottom-up approach places too much of the burden of education on the individual Deaf person and is reliant primarily on the skills of the individual in order to effectively communicate their wishes and ideas.

The development of an inclusive cultural, linguistic policy is accomplished by a blending of the two paradigms of linguistic analysis in the prescription of description. That is, that rather than prescribing specific language forms as prescriptive language policy up to this point has done, an adaptive, descriptive model, which embodies the negotiation of meaning, must be used. In the case of Deaf people, or of any cultural or linguistic minority, language policy must be considered in terms of intercultural contact and communication. Negotiation not only of linguistic form and function, but of social, cultural, political, and ethical power and capital is of utmost importance. Any such policy must also take a global approach which includes ongoing education and open and respectful dialogue, as well as an understanding of the cultural factors at play.

It is possible, and indeed necessary, to respect first and foremost personal preference, self-identification, and self-naming in order to adhere to the spirit of the principle of non handicapping language by “maintaining the integrity of individuals as whole human beings.”

Higher education and, more specifically, student affairs lauds itself as a welcoming and inclusive place where individuals can realize their potential. A diverse campus climate that encourages respect for students, faculty, staff and administrators has

become the norm. With this culture of diversity and inclusion comes a responsibility to understand that diversity, which by its very nature, is constantly morphing into something new, absorbing cultures as they appear, recognizing that humanity is not static. The ability to adapt is the ability to survive. By acknowledging the unique, rich, and full cultures of the members of the academic community, we not only open doors between cultures, we allow for effective communication which might revolutionize the world as we know it.

That being said, higher education needs to acknowledge that an inclusive, responsive language policy is only one aspect of the solution. Deaf culture and ASL need to be given equal status in the academy. Equal status includes respect for ASL and Deaf culture in terms of academic affairs, inclusion of Deaf organizations in student affairs, Deaf events in cultural programming and Town and Gown events, and the education of Hearing people on issues of Deaf etiquette and respect.

ASL occupies a unique disciplinary space in that it is a living language, a minority language, and a language which operates in a different modality than the other languages taught in most institutions of higher education. Regardless of the unique circumstances of ASL, in order to accord Deaf culture the same recognition as other cultural and linguistic minorities, ASL and Deaf studies courses should be located in the same department as other equivalent disciplines per the university. For instance, if all modern languages are taught through the department of foreign languages, it would be effectively marking ASL as Other to locate it in a linguistics program, or as it is in most institutions, in departments of communication disorders or special education. If languages are accorded their own departments and coupled with cultural studies, the

same should be true of ASL and Deaf studies. Deaf history should be incorporated into American history and politics courses in a manner consistent with other cultural and linguistic groups.

By increasing education and cultural programming and encouraging interaction between Deaf and Hearing students, institutions can help to expand the intercultural understanding on campus between Deaf and Hearing members of the community. Issues of interaction and etiquette for faculty, who are most likely to encounter Deaf students, should be included as a part of ongoing education which faculty members already regularly participate in. Education should include information such as how to interact effectively with a Deaf student with the aid of a bilingual, bicultural interpreter, issues of logistics, such as remembering to face the class when writing on the board and providing as much information in writing as possible.

The college student experience is not limited to the classroom. The extracurricular activities of a student are an integral part of the education that takes place at school. Social interaction and the support structure of student organizations and the sense of belonging that participation in campus activities engenders is currently an area where full access and inclusion of Deaf students is still lacking. There is a small, though robust Greek life system in the Deaf community with a combination of Deaf and Hearing fraternities and sororities. Many of the conventions of modern sports, including the huddle and signing in baseball, have their origins with Deaf teams or Deaf athletes. Deaf theatre and storytelling hold a significant place in Deaf culture and could provide a natural place to begin incorporating Deaf culture into the cultural programming of the institution.

A holistic approach is called for when educating faculty, staff, administrators, and students about Deaf culture and about interacting with Deaf people. While the disability student services office certainly should be involved in the development and implementation of a larger cultural education plan, to restrict outreach and education efforts to the disability student services office would perpetuate the second-class status following a medical model of disability. An inclusive cultural education approach which respects a culturo-lingual model of Deafness would include not only realignment of ASL and Deaf Studies courses, but the inclusion of Deaf students in student activities, student organizations, and student support services.

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APPENDIX B - ELECTRONIC SURVEY QUESTIONS

1. How do you talk about being Deaf with your professors? Examples?
 - a. What language do you use? Examples?
2. How do you feel about the language your professors use to describe Deaf people?
3. How do you feel about the term *disability* when it is applied to Deaf people?
4. Describe an experience with faculty, staff, and administrators at your institution.
5. What language would you prefer your professors, staff, and administrators use when talking about Deaf people?
6. What other issues concerning the language our institution uses to talk about deafness would you like to talk to us about?

APPENDIX C - SEMI-STRUCTURED INTERVIEW PROTOCOL

1. How do you talk about being Deaf with your professors or other hearing people?
2. How do you talk to your professors about the logistics of having a Deaf student in class?
3. How would you describe your overall experience with faculty, staff, and administrators at your institution? Examples?
4. How do professors word their sentences in their discussion about Deafness? How do you feel about this language?
5. How do they behave (body language, facial expressions, hesitation)?
6. Do they ask you about intimate aspects of Deafness as well, or simply avoid those aspects?
7. How do you feel about the term *disability*?
8. How do you feel about the term *disability* when it is applied to Deaf people?
9. How do you feel when you are described as *a person with a disability* or *a person with a hearing impairment*?
10. How do you feel about Deaf people as a *linguistic minority*?
11. What language would you prefer your professors, staff, and administrators use when talking about Deaf people?
12. What common misconceptions do Hearing people have about Deaf people?
13. Do you feel that Hearing people should be educated about Deaf identity, history, and culture? Who should do the education?
14. Is there anything else that you would like to discuss about your experience as a student?

VITA

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Education

Ph.D. in Higher Education. Dissertation: *Not a Hearing Loss, A Deaf Gain: Power, Self-Naming and the Deaf Community*. Old Dominion University, Darden College of Education, 2013.

Studies in Sociocultural Linguistics and Evolutionary Phonology. Linguistic Society of America Institute. Stanford University and the Linguistic Society of America, 2007.

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