ABSTRACT

Hearing Humanities: A Holistic Approach to Audiology Education

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This thesis explores the intersection of Deaf/disability identity and the practice of audiology, and has three aims: first, to establish broad background information about the common cultures, identities, and models that relate to disability; second, to connect this background information to the personal and social domains of the lives of people with hearing loss; and finally, to establish current problems and provide direction in training future audiologists in order to ensure clinicians provide care that is above and beyond minimum ethical standards. The first aim will be accomplished by outlining the history and development of Deaf culture and its key features, framing the parallel history and development of disability culture and identity, and comparing and contrasting Deaf culture and identity with disability culture and identity. The second aim of this work will be accomplished by revisiting the definition of disability models, introducing the models that might have bearing on the lives of people with disabilities, and applying these models to the social experience of a person with hearing loss. The final aim of this work will be accomplished by establishing a brief history of the field of audiology, examining the ethics that guide audiology practice, defining and describing audiological counseling, and introducing a new approach to training clinicians that incorporates the humanities.

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HEARING HUMANITIES:

A HOLISTIC APPROACH TO AUDIOLOGY EDUCATION

A Thesis Submitted to the Faculty of

Baylor University

In Partial Fulfillment of the Requirements for the

Honors Program

By

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Waco, Texas

April 2021

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*Dedicated to Camille,*

*who awakened me to the notion that human beings,*

*even and perhaps especially at our most vulnerable,*

*are by our creator deemed worthy of unconditional love;*

*this love becomes an infinite source from which we can give,*

*and Camille gave abundantly.*

INTRODUCTION

*Audiology's Scope of Practice*

The American Academy of Audiology (AAA) defines an audiologist as a person who is academically and clinically trained and certified "to provide a comprehensive array of professional services related to the prevention of hearing loss and the audiologic identification, assessment, diagnosis, and treatment of persons with impairment of auditory and vestibular function, and to the prevention of impairments associated with them."[1] AAA also outlines the scope of practice which broadly, though non-exhaustively, describes the roles an audiologist is expected to fill. This scope of practice categorizes the practice of audiology into identification, assessment and diagnosis, treatment, hearing conservation, intraoperative neurophysiologic monitoring, research, and additional expertise.[2] While any one of these categories is worthy of closer examination, it is the realm of treatment to which this work will attend.

Audiological treatment as described by AAA involves evaluation, fitting, and verification of amplification and assistive listening devices, as well as counseling and training regarding the use of these devices. Audiologists are also expected to serve as team members for cochlear implants, bone anchored hearing aids, and other implantable devices; the audiologist's roles on an implant team include determining candidacy, implant programming, auditory training, and counseling throughout the process.

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[1] "Scope of Practice," American Academy of Audiology, January 2004, https://www.audiology.org/publications-resources/document-library/scope-practice, "Definition of an Audiologist."

[2] AAA Scope of Practice.

Additional roles of an audiologist in general include being "a source of information for family members, other professionals, and the general public" and offering expertise in "counseling regarding hearing loss, the use of amplification systems and strategies for improving speech recognition."[3] Finally, audiologists are expected to provide "counseling regarding the effects of hearing loss on communication and psycho-social status in personal, social, and vocational arenas."[4] All of the domains of counseling for which an audiologist is responsible fall into the category of "audiological counseling," which serves as the central focus of this work.

The diagnosis and treatment of hearing loss do not occur in a vacuum, and as such, people who are diagnosed with hearing loss, as well as their loved ones, often face a challenge of incorporating the experience of disability into their lives and worldviews. For people who have no prior experience with disability, the diagnosis of hearing loss opens the door to a new process of identity formation. For people who have prior exposure to disability and perhaps even to Deaf culture and identity, the diagnosis of hearing loss might lead to an entirely different but still novel pathway of identity formation. In any case, the experience of hearing loss in "personal, social, and vocational arenas" is the product of far more than a mere diagnosis and treatment plan, and it is outlined in the scope of practice of audiologists to understand and provide counseling in these domains.

This work aims to provide some broad background information about a few of the most common personal and social impacts of disability, with specific attention to hearing

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[3] AAA Scope of Practice, "Treatment."

[4] AAA Scope of Practice, "Treatment."

loss, and to reveal the extent, often greater than healthcare professionals presume, of

these impacts on the lives of patients.

*Nomenclature*

The technical terms in this work are used with an understanding that

nomenclature in disability studies is ever-changing, due largely to the tendency of these

terms to eventually become "charged with negative connotations."[5] Nevertheless,

because "definitions of [disability's] meaning are dependent on particular semantic

communities,"[6] some commonly used terms and their definitions for the purposes of this

work are provided below.

> *Culture* - "the customary beliefs, social forms, and material traits of a racial,
>
> religious, or social group; also: the characteristic features of everyday existence
>
> (such as diversions or a way of life) shared by people in a place or time."[7]

> *Deaf culture/Deafhood* - the "language, values, traditions, norms and identity"[8]
>
> passed down through generations of Deaf people. "Deaf," when capitalized, refers

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[5] Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids, MI: William B. Eerdmans, 2008), 46. Reinders argues that "what induces us to look for new words again and again is not inherent in language but in the attitudes of people who use the language." In other words, the negative connotations attached to many terms from disability nomenclature exist because of the way people think about disability. Thus, changing the nomenclature will never be a permanent solution until the attitudes of people are changed as well.

[6] See note 5 above.

[7] *Merriam-Webster.com Dictionary*, s.v. "culture," accessed March 24, 2021, https://www.merriam-webster.com/dictionary/culture.

[8] Joanne Cripps, "What is Deaf Culture?" *Deaf Culture Centre*, Canadian Cultural Society of the Deaf, Accessed March 24, 2021, https://deafculturecentre.ca/what-is-deaf-culture/.

to the culture or community, while "deaf" refers to the physiological condition of hearing loss. The terms "Deaf culture" and "Deafhood" are used interchangeably in this work.

*Disability* - "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being."[9] This is distinct from "handicap" or "impairment," which are defined below.

*Handicap* - "a disadvantage for a given individual that limits or prevents the fulfillment of a role that is normal"[10] particularly in social settings. A handicap is the social implication of a disability. The word has recently become controversial due to the development of negative connotations[11] and "handicapped" as an adjective is commonly replaced by "accessible" per the *People First Respectful Language Modernization Act of 2006*.[12]

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[9] Sheena L. Carter, "Impairment, Disability, and Handicap," Developmental Progress Clinic, Emory University School of Medicine, 2018, https://med.emory.edu/departments/pediatrics/divisions/neonatology/dpc/impairment-mx.html

[10] Carter, "Impairment, Disability, and Handicap."

[11] See note 5 above.

[12] "People First Language." Office of Disability Rights. Accessed March 24, 2021. https://odr.dc.gov/page/people-first-language

*Identity* - "who a person is, or the qualities of a person or group that make them different from others."[13] Identity is an aspect of an individual that, when shared, forms culture.

*Impairment* - "any loss or abnormality of psychological, physiological or anatomical structure or function."[14] Impairment refers exclusively to the physical description of atypical or absent anatomical functioning. A physiological impairment leads to the experience of disability.

*People with Disabilities* - refers to anyone who has been or might be classified as having a disability. Because this categorization is thought to be socially constructed rather than self-evident, the term is used in this work most often to refer to the population of people who embrace disability identity and/or belong to disability culture. The term is an example of "people first language," a common practice in disability literature which "puts the person before the disability, and describes what a person has, not who a person is."[15]

<div align="center"><em>Looking Ahead</em></div>

The aim of this work is threefold: first, to establish broad background information about the common cultures, identities, and models that relate to disability; second, to

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[13] *Cambridge Advanced Learner's Dictionary & Thesaurus,* s.v. "identity," accessed March 24, 2021, https://dictionary.cambridge.org/us/dictionary/english/identity.

[14] Carter, "Impairment, Disability, and Handicap."

[15] "People First Language."

connect this background information to the personal and social domains of the lives of people with hearing loss; and finally, to establish the current state audiological counseling and provide direction for the training of future audiologists in order to ensure clinicians provide care that is above and beyond the minimum ethical standards for the field.

The first aim will be accomplished by chapters one and two. Chapter one will define models of disability and introduce two of these models which have significant bearing on the lives of people with disabilities. Additionally, this chapter will outline the history and development of Deaf culture and describe its current key features, such as the use of American Sign Language and the mentality of collectivism. In the past, most individuals who pursue audiologic intervention did not identify as culturally Deaf and thus audiologists did not have as much responsibility to understand cultural Deafness. However, changing perspectives and improved technology have served to bridge this gap enough so that counseling in the psycho-social impacts of hearing loss might often involve at least a general knowledge of Deaf identity and culture.

Chapter two will parallel chapter one in framing a broad history and development of disability culture and identity. This chapter will also detail the disability rights movement, which is important for audiologists to understand in order to convey the rights and accommodations available to their patients. Additionally, this chapter will compare and contrast Deaf culture and identity with disability culture and identity in order to show that the cultural model of disability is distinct from the social model. Knowing these distinctions is a vital part of understanding and communicating the social impacts of

hearing loss, which falls within the responsibility of audiologists per AAA's Scope of Practice.

The second aim of this work— to connect the background information from the previous chapters to the personal, social, and vocational domains of the lives of people with hearing loss— will be accomplished in chapter three. This chapter will revisit the disability models outlined in chapters one and two before introducing more models that might have bearing on the lives of people with disabilities. This chapter will then turn its attention to the process one undergoes to adopt a personal model of disability. Understanding this process is another crucial part of audiological counseling as the process is often something audiologists and patients must work through together. Moreover, this process is not exclusively experienced by people with disabilities; therefore, audiologists have, knowingly or unknowingly, adopted personal disability models that have significant bearing on patient care. This chapter will also define and discuss invisible disability. All of these definitions and their implications will be applied hypothetically to the life of Jane Doe, a young woman who has adopted Deaf identity, in order to illustrate the extent of the consequences, for oneself and for others, of knowingly or unknowingly adopting a disability model.

The final aim of this work will be accomplished in chapter four. This chapter will establish a brief history of the field of audiology in order to contextualize audiological counseling as a relatively new discipline in a relatively new field. This historical account will include development of the relationship between the Deaf community to the field of audiology, how the relationship has changed, and how the relationship fits into a broader understanding of current ethical standards for clinical audiology practice. The American

Speech-Language-Hearing Association's (ASHA) Code of Ethics will be examined and AAA's Scope of Practice will be revisited with specific attention to their implications for audiological counseling. Finally, a new approach to training clinicians in audiological counseling will be proposed. This new approach will combine central ideas from medical ethics and from disability culture in a way that has not heretofore been attempted, but that will ultimately lead to better, more patient-centered care for people with hearing loss.

CHAPTER ONE

Deaf Culture and Identity

*Introduction*

An individual's perceptions are significantly shaped by his identity, culture, and prior experiences. The manner in which these factors shape views of disability are called models of disability, and they inform how people with disabilities are perceived and how they perceive others. Thus, models of disability have significant bearing on the lived experience of people with disabilities, including people who are deaf or hard of hearing.

Pertaining to the specific disability of hearing loss, one possible category of identity is cultural Deafness, or Deafhood.[1] This identity, tied closely to a particular cultural experience and formed in the midst of diverging understandings of disability and society's relationship to it, empowers individuals to embrace their hearing loss as a central component of their identity. Deafhood asserts that differing from the norm in this way is not merely acceptable, but is actually advantageous and enriching.

The first section of this chapter will consider two models of disability which have significant bearing on the experience of hearing loss. The next four sections will examine the history and development of cultural Deafness, with particular attention to Deaf history in the United States. The final section will introduce modern Deaf culture, which is central to Deaf identity and, as will be discussed in a later chapter, profoundly shapes Deaf individuals' perceptions of audiology.

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[1] Paddy Ladd, *Understanding Deaf culture: In search of Deafhood* (Clevedon, UK: Cromwell Press, 2003), xviii.

*Models of Disability*

Understanding the differing identities and experiences of those with hearing loss begins with examination of two common models of disability. A disability model is a particular view of people with disabilities accepted by an individual or group. This view includes a definition of disability as well as a relation of that disability to the individual and a relation of the individual to society.[2] There are as many models of disability as there are nuanced definitions, but some models have a greater influence on modern thought than others. Two such models which have significant bearing on the view and experience of deafness are the medical model and the social model.

The medical model of disability is the most long standing of the disability models.[3] In this model, disability is considered the direct result of an impairment, which is a physical condition that changes or prevents some function in the human body.[4] As medical knowledge of anatomy and physiology have increased, an understanding has developed of what does and does not constitute human functioning. These are the kinds of qualifiers that might first come to mind when the question, "What are human beings like?" is posed; for example, one might say that humans have the ability to walk because they have two legs, or that they have the power of rational thought due to a well-developed prefrontal cortex. Impairment is defined as the physiological breakdown of any such function: for example, a missing or partially missing leg or an under-developed

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[2] Alycia Reppel and Segun Dawodu, "Conceptual Models of Disability," last modified September 20, 2014, now.aapmr.org/conceptual-models-of-disability/.

[3] Alana Officer and Nora Ellen Groce, "Key concepts in disability," *The Lancet (British Edition)*, *374* no. 9704 (2009): 1795, https://doi.org/10.1016/S0140-6736(09)61527-0

[4] Reppel and Dawodu.

prefrontal cortex would be considered impairments. Disability, then, is the extension of that impairment to a person's interaction with the world; for instance, a person with the impairment of an underdeveloped prefrontal cortex has reduced (or perhaps altogether absent) cognitive abilities. This reduced ability, considered reduced relative to what is "normal" and given a name that helps categorize appropriate symptoms and treatments, is called a disability.

Because disability in this model is biologically rooted, attention can be given to biomedical means of curing the disability. Cure is an implicit and foundational element of this model, because the underlying claim is that in disability some intrinsic element of an individual's health is obstructed or destroyed. Healthy humans, by the medical model's definition, are those who are fully functional to the extent medicine and biotechnology allow. Medicine aims to restore health where it is lost or damaged, and the medical model of disability defines an impairment as the loss or damage of healthy function. Thus, medicine often targets impairments. Consider the impairment of a breakdown in function of the peripheral or central auditory system, which constitutes the disability of hearing loss: for those with hearing loss, the simple solution offered by the medical model is a hearing aid or a cochlear implant. However, not everyone with hearing loss sees this solution as simple or ethical; furthermore, there are disabilities for which science offers no cure, raising the question of society's most appropriate response.

Society often celebrates medicine when it targets impairments of function that are easily restored, but some impairments are not so easily addressed. When an impairment is incurable by any other means, eradication of that impairment might become eradication of a person or even a whole group of people with that impairment, i.e. genocide. This

startling implication of the medical model fueled the eugenics movement at its height of popularity in the United States and was used as justification for the mass sterilization, experimentation, and "Operation T4," the mass killing of people with disabilities in Nazi Germany.[5] The same rationale is often employed by pro-abortion arguments, such as the eradication of Down Syndrome by means of prenatal screening.[6] On the other hand, the medical model of disability has also inspired research that has saved and improved countless lives, such as the biomedical engineering of tools ranging from corrective lenses to artificial organs and the Human Genome Project, which advanced diagnosis and treatment of gene-related illnesses and disorders beyond any previous collaborative research effort.[7]

The medical model by itself is neutral, capable of being used for innovation and for destruction. While innovations inspired by the medical model have largely been embraced by culture, its problematic interpretations have often barred people with disabilities from full access to workplaces, schools, churches, healthcare, and relationships with others. For instance, people with profound hearing loss who elect not to receive treatment must hope, at best, for closed captioning or a competent sign language interpreter. One frustration often expressed by Deaf individuals is the high frequency of awkward, embarrassing, or frustrating situations in which these accommodations are not provided. The buildup of these experiences sends an implicit

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[5] Horst Biesold, *Crying hands: Eugenics and Deaf people in Nazi Germany*, trans. William Sayers (Washington, DC: Gallaudet University Press, 1999), 7.

[6] Henrik Friberg-Fernros, "Clashes of consensus: On the problem of both justifying abortion of fetuses with Down syndrome and rejecting infanticide," *Theoretical Medicine and Bioethics, 38* no. 3 (2017): 196. https://doi.org/10.1007/s11017-017-9398-8

[7] Human Genome Program, *Genomics and Its Impact on Science and Society: A 2008 Primer* (Washington, DC: U.S. Department of Energy, 2008), 2.

message to Deaf people that they are not as welcome as hearing people, and it seems to be a consequence of their choice not to be "fixed" or "cured" by medicine. Similar examples pervade the experience of people with disabilities. This chronic exclusion has led a number of people to believe a different model of disability might be more appropriate, and so a new model began to form. Elimination of exclusion and increased access are emphasized in this model, which has come to be known as the social model of disability.

The social model simultaneously stems from and challenges the medical model. Proponents of the social model accept the medical model's claim that an impairment is a physiological condition which impairs or modifies some function in a person. However, the social model rejects the conclusion that a disability is the mere physically experienced consequence of an impairment; rather, a disability is a social consequence of a broader societal lack of consideration for various impairments.[8] An individual with hearing loss unarguably has an impairment of auditory function; however, in the social model this individual's disability is not deafness itself, but rather an environment without even the simplest of accommodations which might make hearing loss not at all disabling, such as captioning, light-based alarms, and other visual cues. This environment, designed and controlled predominantly by individuals with normal hearing, creates a disadvantage for people with the physiological impairment of hearing loss, and thus the disability of deafness is socially constructed.

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[8] Dimitris Anastasiou and James M. Kauffman, "The social model of disability: Dichotomy between impairment and disability," *The Journal of Medicine and Philosophy 38* no. 4 (2013): 442. https://doi.org/10.1093/jmp/jht026

An important distinction between this model and the aforementioned medical model is the placement of responsibility and obligation. In the medical model, disability is an individual issue, and though it might not be explicitly stated that an individual with a disability is to blame for the disability, he or she is obligated either to obtain the necessary accommodations and modifications to participate in a pre-established culture, or to voluntarily exclude him or herself from that culture. Essentially, the medical model of disability says that if an individual brings less than full functionality and normalcy to the table, he must either find the means necessary to compensate for his lacking, or he must find a different table. The social model, however, shifts the responsibility and obligation to the people who created a table at which not all are welcome. In this model, socially constructed ideas about what gives a person full access to personhood are criticized and deconstructed in order to build a new table which is accessible to people with disabilities. While there are some harmful implications in this approach (as we will see in a later chapter), many people with disabilities have used this model as fuel to create advocacy groups and bring about positive social and political change, culminating in the Americans with Disabilities Act in 1990.[9] Those at the forefront of this wave of change today would say the work is far from over, but people with disabilities are finally on their way to finding a place at the table.

In the ever-growing rift between the medical and social models of disability, people with hearing loss have long since found and fostered a unique position known widely as Deaf identity. Deaf culture was born of groups of people, otherwise isolated due to their hearing loss, who found each other and created community. This community

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[9] James Concannon, "Mind matters: Mental disability and the history and future of the Americans with Disabilities Act," *Law & Psychology Review 36* (2012): 90.

was formed in the face of growing popularity for an early version of the medical model, in which it became clear that those with hearing loss would not have a seat at the table unless they adapted, learning to speak and read lips in order to interact with a predominantly hearing world. At this time the social model had not yet insisted on modifications to the table, so the earliest Deaf communities came together to create a table of their own.

<p style="text-align:center"><em>Deaf History in Western Europe</em></p>

The earliest recorded development of Deaf culture occurred in France in the mid-eighteenth century. This development is inseparable from the history and development of deaf education, not necessarily because the education of deaf people formed Deaf community, but because deaf history was not well observed or recorded prior to the normalization of deaf education. Prior to the mid-eighteenth century, deaf education was private and left to the family, if it existed at all. At this time, the Christian Church sought to bring basic needs, including education, to the marginalized. However, Church leaders generally interpreted scriptural passages such as Romans 10:13-17 literally, and therefore believed that since "faith comes from hearing," deaf people could not have faith.[10] In looking to other passages in scripture for ways around this barrier, Biblical scholars often stumbled upon the passage in Mark 7 in which Jesus restored the hearing of a deaf man.[11] Normate interpretation of this passage suggested that the deaf man was ill-equipped for salvation until his hearing was restored. As a result, the Church often neglected deaf

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[10] Rom. 10:17 ESV. "So faith comes from hearing, and hearing through the word of Christ."

[11] Mark 7:31-37 ESV.

people unless they had been educated to speak and read. Meanwhile, the secular world continued to marginalize deaf people, particularly in terms of education.

In 1760, a French abbot named Charles-Michel de l'Epee was fueled by a desire to minister to those whom others perceived as impossible to teach or disciple, and it was with this mission in mind that he first encountered Deaf individuals. De l'Epee's work was contrary to that of his contemporaries in education or ministry because he believed that understanding of foundational truth could be achieved in any language, as long as that truth was communicable.[12] This belief, along with his sense of urgency to teach Christian truths as quickly and efficiently as possible, informed a teaching method that involved learning the system of signs Deaf people in France were already using. Where this system lacked vocabulary that aligned with Christian teaching, de l'Epee expanded it. He taught this revised sign language and its translation into written word at a school he funded privately and ran himself until his death in 1789. In 1791, the French legislature approved funding for de l'Epee's school and renamed it the Royal Institution for the Deaf. It is still running today under the name *Institut National de Jeunes Sourds de Paris*, or "National Institute for Deaf Children of Paris," and offers free, public, and personalized education to Deaf children aged 3-20 in Paris.[13]

Abbot de l'Epee's story is critical to the foundation of contemporary Deaf culture firstly because it demonstrates the beginning of mainstream validation of sign language. De l'Epee's endeavor to teach signs and their associations to written language paved the

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[12] Luzerne Ray, "The Abbe' de L'Epee," *American Annals of the Deaf and Dumb, 1* no. 2 (1848): 71-72. http://www.jstor.org/stable/44401099

[13] "Presentation of the INJS of Paris," Institut National de Jeunes Sourds de Paris, accessed September 17, 2020, http://www.injs-paris.fr/.

way to understanding a sign system as a language of its own. For hearing people, the recognition of sign language as a legitimate language is a foundational element in comprehending Deaf culture because it demonstrates respect and validation. In doing so, hearing people grant Deaf people the freedom to be exactly as they are, rather than forcing them to assimilate themselves to the hearing language and culture. Deaf people consider this freedom a basic right which has historically been infringed. Since the eighteenth century, massive strides have been made to validate sign language, and the majority of this progress has been brought about in the field of deaf education, for which Abbot de l'Epee's early work was foundational.

De l'Epee's school also represents the first recorded instance of organized manual deaf education. Only about a century earlier, John Locke's emphasis of *tabula rasa*, or the "blank slate," which represents the mind of all humans prior to experiential learning, introduced the possibility that any person could be educated, regardless of that person's physical traits.[14] Specifically, Locke argued in *Some Thoughts Concerning Education* that an individual's nature only accounts for about ten percent of his traits and behaviors, and the other ninety percent could be taught.[15] In 1670, William Holder and John Wallis claimed to be the first to apply this concept to deaf students in Great Britain, teaching them to speak and lipread. This method disregarded the work of John Bulwer, who in 1648 published a study of manual sign systems. This trend of favoring oralism (i.e., the education of deaf students by means of speech and lipreading) over manualism (i.e., the

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[14] Encyclopædia Britannica, s.v. "Tabula rasa," last modified May 21, 2020, https://academic-eb-com.ezproxy.baylor.edu/ levels/collegiate/article/tabula-rasa/70856

[15] John Locke, *Some Thoughts Concerning Education By John Locke, Esq*. (London: printed for A. Bettesworth and C. Hitch, J. Pemberton, and E. Symon, 1732), 2.

education of deaf students by means of sign language) continued in Great Britain with the opening of the Braidwood school in 1760. Meanwhile in France, de l'Epee approached deaf education by offering a curriculum taught primarily by means of signing.[16] This method might not have left the confines of de l'Epee's school if he had not been motivated to serve the poor and underserved in his community. At the time, deaf education was private and expensive; de l'Epee believed Christian teaching was necessary for all, and was particularly important for the poor. Thus his school was the first free public school for the deaf, which increased its renown and drew the attention of deaf education pioneers in other countries.

Perhaps most importantly of all, de l'Epee's efforts introduced to those with a normate (or early medical model) perspective the idea that Deaf people might be capable of doing anything hearing people can do. This idea is central to contemporary Deaf identity: as former Gallaudet University president I. King Jordan famously put it, "Deaf people can do anything hearing people can do, except hear."[17] The idea that deaf students could move beyond the learning of functional communication and be taught complex theology and doctrine was revolutionary in eighteenth century France. The success of Abbot de l'Epee's school sparked the fire that fueled Deaf people's efforts to define the Deaf experience as something equal in quality to the hearing experience, if not more enriched.

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[16] Harry Lang, "Perspectives on the History of Deaf Education," in *The Oxford Handbook of Deaf Studies, Language, and Education*, *1* no. 2 (2011): 6, https://doi.org/10.1093/oxfordhb/9780199750986.013.0002

[17] "About I. King Jordan: In his own words," Gallaudet University, accessed September 17, 2020, https://www.gallaudet.edu/about/history-and-traditions/deaf-president-now/profiles-and-viewpoints/i-king-jordan.

*Deaf History in the United States: from Origins to Cultural Distinction*

While educators in Europe grappled with the most effective methods for instructing the deaf, the United States were preoccupied with the establishment of other systems: namely, a government. Nevertheless, American Deaf history from this time period is well recorded thanks to a few already well-formed Deaf communities. The existence of these communities demonstrates formation of Deaf culture that was not caused primarily by inclusion in mainstream culture (i.e., education), but by exclusion from it.

In seventeenth and eighteenth century America, there are numerous mentions of deaf individuals who achieved various degrees of education, married, had children, and participated in society. However, there is no evidence of organized attempts to educate these individuals, and it is thus assumed they were privately tutored at varying levels of quality depending on the family's means; after all, disabilities at this time were considered a private problem for families to handle individually as they saw fit. In this sense, deaf individuals were not entirely barred from social participation; however, they were also not entirely included. American colonists "imagined free and full participation as citizens of a community," and "so, apparently, did their deaf neighbors."[18] Deaf people from this era seemed to recognize that they would only ever partially belong in the world as it existed, so they sought to create their own and began to colonize within the colonies.

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[18] Harry Lang, "Genesis of a community: The American Deaf experience in the seventeenth and eighteenth centuries," in *The Deaf History Reader*, ed. John Vickrey Van Cleve (Washington, DC: Gallaudet University Press), 19.

Two of the earliest deaf colonies were established in Martha's Vineyard, Massachusetts and Henniker, New Hampshire.[19] The Henniker community emphasized the formation of culture that was exclusively Deaf, and records of hearing people living in the Henniker community are few and far between. Meanwhile, the Martha's Vineyard community attempted to flip the script by including hearing people in the community, but using a sign system (known by sign language historians as Vineyard Dialect) as a primary means of communication and encouraging Deaf people to fill roles traditionally reserved for hearing people only. In doing so, the historical communities of Martha's Vineyard and Henniker serve as a microcosm of the factions of Deaf cultural perspectives that exist today. Essentially, "it takes a 'them' for an 'us' to develop."[20] Thus, for the Deaf people in Henniker, "the boundary with the surrounding hearing community was relatively sharply demarcated," while the inclusion of hearing people in Martha's Vineyard encouraged Deaf and hearing individuals alike to regard each other with respect.[21] Moreover, hearing people in Martha's Vineyard recognized the practical truth that they were not physiologically limited in their capacity to learn signed language, while their Deaf neighbors faced a physiological barrier to learning spoken language. In this way Martha's Vineyard demonstrated an early instance of the social model of disability at work, long before the model was explicitly introduced or defined.

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[19] Harlan Lane, Richard C. Pillard, and Mary French, "Origins of the American Deaf-world: Assimilating and differentiating societies and their relation to genetic patterning," in *The Deaf History Reader* ed. John Vickrey Van Cleve (Washington, DC: Gallaudet University Press, 2007), 47-48.

[20] Lane, Pillard, and French, 66.

[21] Lane, Pillard, and French, 67.

For American deaf people who lived in the communities established during colonization, it is likely that education was the responsibility of the individual's family. However, there is evidence of a number of deaf individuals in other parts of the United States, and the questions of whether and, if so, how to educate them were not seriously addressed until the early nineteenth century. At this time, two approaches emerged, with the first approach developing in Virginia in 1815.

William Bolling, a wealthy hearing Virginian, had grown up separated from his deaf brothers and sister, who were sent to Scotland to learn at the Braidwood School, which took the approach of oralism. While impressed by his siblings' ability to learn spoken English at a competent level, he also recognized the strained relationships between his family members as they lived apart. When two of Bolling's children were born deaf, he began to seek a solution that would allow them to be educated close to home. In 1812 John Braidwood, the grandson of Braidwood School's founder Thomas Braidwood, relocated to the United States seeking an opportunity to start a school for the deaf. Braidwood took his ideas and Bolling's funds (and two children) and started the Cobbs School, which was private, geared towards the wealthy, and like the Braidwood School in the United Kingdom, took the approach of oralism. Word of the school's opening traveled quickly, but due in part to Braidwood's ambiguous moral character and in part to Bolling's underestimation of the cost of running the school, it closed only a year after opening.[22]

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[22] Barry A. Crouch and Brian H. Greenwald, "Hearing with the eye: The rise of Deaf education in the United States," in *The Deaf History Reader*, ed. John Vickrey Van Cleve (Washington, DC: Gallaudet University Press, 2007), 37-38.

One individual who was particularly impacted by news of the Cobbs School's opening and closing was Connecticut resident Mason Fitch Cogswell. Cogswell had a deaf daughter, and like Bolling he believed his daughter would be more successful if she could be educated without being sent abroad. Unlike Bolling, however, Cogswell did not believe private funding was the best means to opening a school for the deaf. He was well-connected in New England, and after hearing about the Cobbs School's opening, he quickly conducted a regional census to determine the number of deaf children in the area. He found eighty-four, which warranted the establishment of a school in the area. Cogswell networked and raised funds in order to send a representative overseas to learn about deaf education in Europe, where it was relatively well-developed. The representative chosen for the task was Thomas Gallaudet, a personal friend of Cogswell's who had worked with his daughter, though he had no formal training in deaf education at the time.[23]

In 1816 Gallaudet returned to the United States, having visited the Braidwood School in Scotland and the Royal Institution for the Deaf in Paris, with an instructor from the Royal Institution named Laurent Clerc. Together Cogswell, Clerc, and Gallaudet opened the Connecticut Asylum for the Education and Instruction of Deaf and Dumb Persons in Hartford, Connecticut in 1817. The school, later renamed the American School for the Deaf (ASD), operated on public funding and used the manualistic methods first employed by Abbot de l'Epee. Unlike the Cobbs School, ASD flourished and is still in operation today. Scholars disagree on whether the vastly different fates of these schools was mainly due to their opposing methods, their difference in funding strategies,

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[23] Crouch and Greenwald, 38.

or merely the character and dedication of the individuals who ran them.[24] Regardless of the cause, the success of ASD shaped the development Deaf culture significantly.

In the years immediately following the opening of ASD, it was the only U.S. school of its kind and thus students came from many states. As the Henniker and Martha's Vineyard communities largely consisted of the same core families, the ASD students in Hartford represented the first time and place in American history that Deaf people gathered and formed a community around the central identity of being Deaf and communicating with sign language. By this time Clerc's *Langue des Signes Française* (LSF) had blended with Vineyard Dialect to form an early version of what would become known American Sign Language (ASL).[25] Metaphorically, American Deaf culture "is the flowering plant that has grown from the seeds and roots" of ASL and the group identity formed by sharing a language and history.[26] By this understanding, it can be said that ASD begot modern American Deaf culture.

ASD's reputation for turning out well-educated, socially active Deaf people encouraged the opening of more manualist schools for the deaf in other states, and manualism remained the preferred method of educating the deaf in the United States for decades thereafter. This movement culminated in April 1864 when President Abraham Lincoln signed federal legislation authorizing the Columbia Institution for the Instruction of the Deaf and Dumb and the Blind, later to be renamed Gallaudet University, the first

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[24] Crouch and Greenwald, 40-42.

[25] Crouch and Greenwald, 42.

[26] Lang, 2.

institution for higher education made entirely accessible through ASL.[27] Manual deaf

education and ASL thrived in the mid-nineteenth century, and the effect was an increase

in cultural distinction and self-awareness for Deaf people in the United States.[28]

*Deaf History in the United States: the Dark Age*

The era of Deaf cultural expansion and thriving was short-lived, due largely to the

intervention of Alexander Graham Bell in the 1870s.[29] While the oralism movement was

supported by numerous reputable individuals, it is said that no one "popularized and

legitimized the oral philosophy" more.[30] Bell became a teacher of the deaf in 1870 and

used oralist techniques. It was the combination of his interest in deaf education and his

work in telegraphy that led to both his eventual marriage to a deaf woman (Mabel

Hubbard, the daughter of Bell's partner in the telegraphy business) and his eventual

invention of the telephone.

While Bell's interest in telegraphy waned, his interest in the deaf and their

education remained throughout his life and led him on a number of ventures, including

the opening of a day school, which closed only two years later, and advocacy for oralism

and day schools across the United States.[31] In 1880 at the Milan Conference, in which

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[27] David F. Armstrong, *The history of Gallaudet University: 150 years of a deaf American institution* (Washington, DC: Gallaudet University Press, 2014), ix.

[28] Susan Burch, *Signs of Resistance American Deaf Cultural History, 1900 to World War II* (New York: NYU Press, 2002), 2-4.

[29] Crouch and Greenwald, 42.

[30] Richard Winefield, *Never the twain shall meet: The communications debate* (Washington, DC: Gallaudet University Press, 1987), 11.

[31] Winefield, 17-20.

deaf educators from around the world met in Italy to deliberate on whether oralism or manualism should be globally accepted as best practice, the majority ruled that oralism was superior.[32] This ruling, combined with Bell's efforts, effectively eliminated the use of manualism to educate the deaf in the United States. Suddenly a culture that had formed around a shared language had its language revoked, and almost a century of victories in the Deaf community's quest for a place at the table were swept away.

From the 1880s to the 1960s, oralism remained the perceived best practice in deaf education, and as a result this period is often considered the "Dark Age" of Deaf culture. However, while the use of ASL in education was restricted and the Deaf community appeared to be silenced, there is still evidence of an "active, self-aware, and tenacious community."[33] If anything, the experience of forced assimilation and oppression brought about by the enforced use of spoken English and lip reading as opposed to sign language in school settings led to a stronger sense of community. The intervention of hearing people on deaf education and life led deaf people to look for leaders who were "deaf community insiders, users of sign language, and familiar with the values and experiences of deaf life."[34] Essentially, the Deaf community was lying in wait for the tide to turn again in favor of the hearing world's recognition and respect of Deaf identity and culture.

*Deaf History in the United States: DASL and Deaf President Now*

[32] Pasquale Fornari, "Report of the International Convention for the Amelioration of the Lot of Deaf-Mutes, held at Milan from the 6th to the 11th of September, 1880," *American Annals of the Deaf and Dumb 27* no. 2 (1882): 120-121.

[33] Susan Burch, "Biding the Time: American Deaf Cultural History, 1900 to World War II" (dissertation, Georgetown University, 1999), iii-iv.

[34] Kent Olney, "The Chicago Mission for the Deaf," in *The Deaf History Reader* ed. John Vickrey Van Cleve (Washington, DC: Gallaudet University Press, 2007), 201.

This long-awaited turning tide came in 1965 when William Stokoe, an English professor at Gallaudet University, published the Dictionary of American Sign Language (DASL), demonstrating ASL's properties as all those necessary to constitute an official language.[35] At last the academic world so long monopolized by hearing people again recognized the merits of the language of the Deaf. American Sign Language was reintroduced into the academic world, and programs based on manualism began to re-emerge around the U.S. While this was a major victory for the Deaf community, it remained true that education for the deaf was left in the hands of the hearing. During this time, "dependence and autonomy co-existed in an uneasy struggle" for Deaf people, and they struggled to claim power over their own access to society at large.[36] The next step towards progress was education for Deaf people by Deaf people, the fight for which drew national attention like the Deaf community had not previously seen.

Prior to the 1980s, the largest tidal waves in the Deaf experience at best created ripples in the hearing world. Deaf culture sought recognition and respect from hearing culture, but hearing people largely did not know Deaf culture existed. After the previous century, which was marked by hearing people's undermining of Deaf people's desire for manual education as well as a blatant disregard for ASL, the American Deaf community had cultivated a strong "us vs. them" mentality. In 1988, this mentality came to the forefront when Gallaudet University announced its new president. Out of the pool of

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[35] Julie A. Hochgesang and Marvin T. Miller, "A Celebration of the Dictionary of American Sign Language on Linguistic Principles: Fifty Years Later," *Sign Language Studies, 16* no. 4 (2016): 563.

[36] Reginald Boyd and John Vickrey Van Cleve, "Deaf autonomy and Deaf dependence: The early years of the Pennsylvania Society for the Advancement of the Deaf," in *The Deaf History Reader*, ed. John Vickrey Van Cleve (Washington, DC: Gallaudet University Press, 2007), 170.

candidates, chosen finalists included Dr. Elisabeth Zinser, a hearing woman, and two

Deaf men. On March 6, a representative from the Board of Trustees, Jane Spilman,

announced that Gallaudet would inaugurate its first female president, Dr. Zinser.

Immediately, speculation began among the Deaf students and faculty as to why the

hearing candidate was chosen over the Deaf candidates, though their questions on the

subject were not clearly answered at the gathering where Spilman made her

announcement due to the fact that Spilman did not know sign language.[37]

Arguments for the selection of hearing presidents over deaf ones in the past had

included the idea that a deaf person could not easily communicate with the outside world

(e.g., with donors or government officials), and that deaf people generally lack

management and organizational skills.[38] Naturally, these arguments were not well-

received by the Deaf students and faculty at Gallaudet, and their frustration was further

compounded by the announcement of the Board's 10-4 vote, particularly when it was

revealed that the only three Deaf board members who voted accounted for three of the

four votes against Zinser. This made students and faculty aware of the unequal

representation of the Deaf voice in Gallaudet's administration. Irate Deaf community

members hastily organized protests against the announcement of the new president and

the hearing majority of board members. These protests grew rapidly in size and quickly

garnered media attention. Speculation on the reasons for the sudden onslaught of national

media attention include the idea that large campus protests had died down significantly

since the end of the Vietnam War, the perception of the subject of the protests as a

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[37] Armstrong, 105.

[38] Armstrong, 106.

fundamental civil rights issue, and the fact that the majority of proceedings were communicated in ASL, which fascinated the previously unexposed mass of hearing media consumers.[39]

On March 7, 1988, protestors came together and organized a list of four demands: 1) immediate appointment of a deaf president, 2) removal of Spilman as a chair of the board, 3) 51 percent majority of deaf board members, and 4) guarantee of no reprisals against protestors.[40] On March 10, Dr. Zinser declined the offer of the presidency. On March 11, protestors marched to the Capitol in order to convey to the board that the meeting of any less than all four demands would not be enough. On Sunday, March 13, the board reconvened, agreed to all four of the protestors' demands, and named Dr. I. King Jordan the first Deaf president of Gallaudet University.[41] This protest and surrounding events are referred to as "Deaf President Now," which is said to have "confirmed the benefits of American Sign Language" and the "reemergence of the American Deaf community as a force."[42] Deaf President Now can be considered the birth of modern Deaf culture; however, it is better understood as a revealing of the Deaf culture and identity that had existed for more than a century but simply had not been recognized.

*Modern Deaf Culture*

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[39] Armstrong, 114.

[40] Armstrong, 112.

[41] Armstrong, 120.

[42] Crouch and Greenwald, 42.

Modern Deaf culture is largely shaped by its own choice of self-referential term. While "culture" is often understood as having "distinctive religion, clothing, diet" or "particular geographical space," Deaf culture does not share any of these traits.[43] Nevertheless, the cultural identity Deaf people assume is based upon a shared experience of "the schools they attended, the communities they joined after leaving school, the jobs they had, the poetry and theater they created," and "the vocabulary they gave themselves for describing what they know."[44] In a world that is still fairly limited in its accessibility to those with hearing loss, there are so many places and experiences available to those who choose cultural Deafness.

When one Deaf person meets another, it is common practice to begin with an exchange of fingerspelled names and sign names. Sign names are an important element of cultural Deafness in which a person's identity is represented with either an arbitrary or descriptive sign, typically both simple and distinct. Sign names cannot be self-assigned, but are given by other members of the Deaf community. In order to receive a sign name, an individual must have a meaningful relationship with at least one other Deaf person, and must be able to communicate with ASL. Thus, in having a sign name, he shows that he belongs to Deaf culture.

After names are exchanged, a first meeting of Deaf people includes the swapping of schools attended and cities lived in before any other topic is discussed. Sharing the schools which one attended is common because many Deaf people attended their state's school for the Deaf. As people relocate for college and careers, networking occurs, and

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[43] Carol Padden and Tom Humphries, *Inside deaf culture* (Cambridge, MA: Harvard University Press, 2006), 1.

[44] Padden and Humphries, 2.

connections to mutual friends are easily made. Cities lived in are also an important detail to share because major cities often have large Deaf communities, and again, connections to mutual friends are easily made. Whether these connections are made or not, friendship forms quickly between Deaf people when they meet, because even if they have not lived in the same place or known the same people, they share the experience of being Deaf.

The Deaf experience is one that, in the absence of sound, is centered around "seeing," not in a heightened sense per se, but in a sense developed from "interacting with the world in certain ways—in cultural ways."[45] Because of this shared experience, anyone who is physically deaf or hard of hearing can be culturally Deaf regardless of age, ethnicity, gender, sexuality, religion, or any other category in which people might otherwise be sorted. This is not a transcendence over socially constructed categories, but a choice to assume the category which, for Deaf people, has most significantly shaped their experience.

It is here that cultural Deafness simultaneously embraces and diverges from the social model of disability: the social model holds normative culture responsible for creating the experience of disability, and Deaf culture agrees. In this sense, Deaf culture can be understood as a part of the social model. However, the social model concludes that normative culture should reshape itself to include people with disabilities in the "normal" experience, while Deaf culture shrugs off the normal experience in favor of what is seen as a more fulfilling way of life. Because this way of life is so grounded in ASL, the understanding of disability it has created is called the "culturo-linguistic" model.[46]

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[45] Padden and Humphries, 2.

[46] David J. Thomas, "Not a hearing loss, a deaf gain: Power, self-naming, and the Deaf community" (dissertation, Old Dominion University, 2013), 35.

The culturo-linguistic model posits an idea that the physical impairment of hearing loss is irrelevant to the Deaf experience; rather, the majority's suppression of ASL in history followed by the majority's ignorance of and unwillingness to learn ASL in modern times has forced Deaf people to move between two languages and cultures in order to participate in the world.[47] While this forced adaptation resembles the forced assimilation experienced by deaf people prior to the 1960s, it is different in that it leaves room for Deaf people to fully embrace their shared language and community amongst each other. The resulting position Deaf people often take is that Deaf culture is not a poor imitation of or lesser option than normative (i.e., hearing) culture; rather, it is an enrichment of the "normal experience." As Deaf culture commonly puts it, "hearing loss" gives way to "Deaf gain."

*Conclusion*

For many culturally Deaf people, audiological intervention is not wanted or needed, and hearing people who want to extend kindness to Deaf people should do so by learning ASL and familiarizing themselves with Deaf culture. If the culturo-linguistic model of disability was the only model accepted by individuals with hearing loss, it might be possible that an understanding between the Deaf and hearing cultures could be somewhat easily reached, and there would be no need to further explore the experience of deafness.

However, not everyone who experiences hearing loss identifies as culturally Deaf, and there exists an entirely different pathway to understanding disability for people who

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[47] Thomas, 36.

have sufficient hearing loss to be classified as "deaf" but who either reject cultural

Deafness or are simply unaware of it. This pathway and its implications for the lives of

those who take it will be discussed in the next chapter.

CHAPTER TWO

Disability Culture and Identity

*Introduction*

The previous chapter outlined the medical and social models of disability, two

models which have a particularly significant bearing on the experience of people with

hearing loss. Additionally, the culturo-linguistic model that underpins Deafhood was

introduced. The culturo-linguistic model of disability satisfactorily addressed ethical and

social problems the medical and social models posed for Deaf people by reframing the

experience of deafness as a cultural one. However, the same quandaries revealed in the

previous chapter's discussion of the medical and social models remain salient for any

person with a disability that is not culturally Deaf. This includes people with disabilities

other than deafness as well as some people with hearing loss who do not identify as Deaf.

Together these categories represent a much larger population than the population of Deaf

people, and thus it is critical that perceptions of disability be examined from this

population's perspective.

This chapter will introduce the history and culture of people with disabilities and

explore how people with hearing loss fit into this narrative of disability. The first four

sections will examine a broad history of disability in order to show how disability has

been treated and perceived throughout antiquity, the Middle Ages, and the early modern

era. The next section will consider key events in the disability rights movement and the

legal and social changes brought about by it. The final section will compare and contrast

modern disability identity with Deaf identity in order to form a better understanding of

how the two identities inform individual perceptions of audiology.

*A Brief History of Disability*

A historical account of disability could in theory be as extensive as a historical account of humanity in general. Most worldviews, whether naturally or supernaturally oriented, hold that as long as humans have existed they have encountered imperfections and obstacles. Thus, examination of disability across the span of its existence is beyond the scope of this work. Instead, this account of the history of disability will consider the subject through the ages, including evidence of its existence and perception in antiquity, the Middle Ages, and the early modern era. It is also beyond the scope of this work to closely examine perceptions of disability in every culture throughout history, so attention will be given to global patterns in perceptions rather than specific culture-by-culture analysis.

*Disability in Antiquity*

It is widely accepted that the experience of disability is as old as human culture itself; however, the views and experiences of people with disabilities vary widely even across modern cultures. As much as human culture has changed over time, disability and the experience of it have changed. For this reason, "archaeologists and anthropologists should be inherently interested in this issue."[1] However, this interest is met with two major challenges. First, it is not until the modern era that people with disabilities began to record their own history and culture. This history of disability is most often conveyed

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[1] Charlotte A. Roberts, "Did they take sugar? The use of skeletal evidence in the study of disability in past populations," in *Madness, disability and social exclusion: the archaeology and anthropology of "difference"* ed. Jane Hubert (London, UK: Routledge, 2000), 46.

from a normate, outside-looking-in perspective. Second, as much as the experience of disability has changed over time, so has the definition. If the social model is the best fit, disability can be defined as any condition "that leads to a person being perceived as 'different' by others in their social group."[2] Thus, a condition is only a disability if it differs from what is normal in any given group—and normal varies widely between social groups. Moreover, some conditions which might have been considered disabilities throughout history are not disabling anymore due to advances in medicine and biotechnology. So, the endeavors of archaeologists and anthropologists to understand disability in past cultures are limited to some extent by what is understood about those cultures.

Earliest evidence of people with disabilities is limited to what can be ascertained from skeletal remains, which rules out conditions that affect soft tissue and conditions that cannot be identified from fragmented remains. Nevertheless, skeletal remains show evidence of cancers, non-specific infections, injuries, skeletal and muscular deformities, and some metabolic and cardiovascular diseases.[3] Archaeologists and anthropologists must be careful to present this evidence without making ethnocentric claims about what these conditions and diseases meant in terms of what is disabling. It is here that researchers look to "historical, iconographic, and ethnographic material" to explain what the skeletal record cannot.[4]

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[2] Roberts, 46

[3] Roberts, 48-51.

[4] Roberts, 54.

Ancient Greece contains an abundance of writing about the human experience, including physiological impairments and symptoms. Ancient Greek storytellers particularly emphasize descriptions of the eyes. Analysis from a modern ophthalmological perspective demonstrates that the ancient Greeks were quite knowledgeable about diseases of the eye and causes of blindness, and yet, instances of blindness in Greek myths and stories often had metaphysical implications as well. For instance, Achilles's transient blindness in the *Iliad* seems to have been understood as non-organic, "hysterical" blindness which would still lead to literal visual impairment.[5] At the same time, Achilles's metaphysical blindness with regards to his strengths and weaknesses ultimately leads to his downfall. Similar associations between impairment of the body and impairment of character were common during this era.

Another source from early antiquity with frequent references to disability is the Hebrew Bible. Blindness is frequently mentioned, first as a natural consequence of age[6] and later as a punishment for sin[7] and a stumbling block on the path to righteousness.[8] Nevertheless, laws in the Torah offered protection for blind people,[9] as well as other vulnerable people. Other general comments about disability in the Old Testament suggest that physical impairments such as blindness and deafness are indications of intellectual

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[5] Constantinos Trompoukis and Dimitrios Kourkoutas, "Greek mythology: The eye, ophthalmology, eye disease, and blindness," *Canadian Journal of Ophthalmology 42*, no. 3 (June 2007): 458.

[6] Gen. 27:1, Gen. 48:10.

[7] Lev. 26:16.

[8] Lev. 21:18-19.

[9] Lev. 19:14, Deut. 27:18.

and/or moral capacity. Rather than saying that people fail to understand, prophets often

claim people are blind or deaf. Psalm 115 illustrates that this blindness and deafness is

not literal; the people "have eyes, but do not see" and "ears, but do not hear."[10]

Conversely, the Old Testament includes claims that God restores the sight of the blind[11]

and the hearing of the deaf,[12] and that these restorations may be literal or figurative.

One specific instance of disability worth noting in the Old Testament is David's

encounter with Jonathan's son Mephibosheth. David seeks out remaining members of the

house of Saul in order to show kindness to them, and through a servant he learns of

Mephibosheth (2 Sam. 9:1-4 ESV). The servant describes Mephibosheth as "a son of

Jonathan" who is "crippled in his feet," (2 Sam. 9:3 ESV) whereas David addresses

Mephibosheth by his name (2 Sam. 9:6 ESV).[13] The narrator ends the story of the

encounter by emphasizing Mephibosheth's disability (2 Sam. 9:13), reminding the

audience of a fact which David appears to overlook.[14] The ignoring of Mephibosheth's

disability stands in direct contrast to David's treatment of the blind and the lame among

the Jebusites a few chapters earlier, at which point he claims the blind and the lame will

not be welcome in the City of David.[15] This contrast may suggest a radical change of

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[10] Ps. 115:5-6.

[11] Ps. 146:8.

[12] Is. 29:18.

[13] 2 Sam. 9:1-13.

[14] Rod Thompson, "Mephibosheth at the table: A high point in Davidic kingship - 2 Samuel 9:1-13," in *Theology and the experience of disability: Interdisciplinary perspectives from voices down under* ed. Andrew Picard and Myk Habets (London, UK: Routledge, 2017), 148.

[15] 2 Sam. 5:8.

David's heart regarding disability, or it may suggest different circumstances warrant

different responses to disability. Either way, the narrative of David and Mephibosheth

suggests that David's kingdom, and moreover God's kingdom, is a kingdom of

hospitality and friendship towards people with disabilities. This sort of kingdom stands in

diametric opposition to the worldly kingdom, which at the time of this encounter was

harsh and exclusive towards people with disabilities.

The New Testament provides a glimpse of disability as it was perceived in the

Roman Empire at its height. The culture of Rome prioritized strength of body, mind, and

character as instruments of civic and moral responsibility. Additionally, philosophers,

astrologers, and physicians in late antiquity often associated physical characteristics with

internal qualities. This association between physical characteristics and morality, called

"physiognomics," was a popular field of study in late antiquity.[16] During this era, culture

was saturated with "physiognomic consciousness;" thus, people with physical disabilities

were generally thought to be depraved and were often marginalized.[17] Still, a thread of

the hospitality and friendship of the divine kingdom can be seen in Jesus's treatment of

people with disabilities, especially when one reads the New Testament gospels with

physiognomy in mind.

Kindness toward the marginalized was a hallmark of Jesus's life; for example, in

Jericho Jesus sought out and was a guest of Zacchaeus, a man who was despised for

being a tax collector and was likely additionally marginalized for being "small in

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[16] Mikeal C. Parsons, "'Short in Stature': Luke's Physical Description of Zacchaeus," *New Testament studies 47*, no. 1 (2001): 51.

[17] Parsons, 52.

stature," a trait which in a physiognomic understanding indicated smallness of character.[18] Jesus reminded grumbling bystanders that even despite Zacchaeus's moral and physical shortcomings, he was still "a son of Abraham" and therefore just as eligible for inheritance of the divine kingdom as anyone else present.[19] This encounter stands out in Jesus's ministry because there is evidence of spiritual healing, but no physical healing or change. Zacchaeus is offered a chance to repent and rectify his past wrongdoings, and he does so without growing taller. This event challenged the physiognomic consciousness that existed at the time it was recorded, and it still serves as a challenge to the idea that "one's place in the body politic" is predetermined "by the shape of one's body."[20]

Jesus's ministry included many other encounters with the marginalized and disabled, and many of these encounters were met with healing. In Capernaum, Jesus forgave the sins and healed the body of a paralyzed man.[21] Between Samaria and Galilee, Jesus healed ten men with leprosy, restoring their access to community.[22] In Bethsaida, Jesus healed a man born blind and rebuked the idea that the man's blindness was a punishment for sin.[23] In the region of the Decapolis, Jesus healed a deaf man, restoring his hearing and speech.[24] These instances of healing further emphasize the hospitality of

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[18] Parsons, 53.

[19] Lk. 19:1-10.

[20] Parsons, 57.

[21] Mk. 2:1-12.

[22] Lk. 17:11-19.

[23] Mk. 8:22-26, Jn. 9:1-12.

[24] Mk. 7:31-37.

the divine kingdom, in which the marginalization is reversed and "the last will be first."[25] Following the example of Jesus, early Christianity challenged the cultural tendency to marginalize people with disabilities. This movement brought about some positive changes for people with disabilities. Nevertheless, portrayals of disability as a punishment or as an impairment of character continued to pervade culture throughout antiquity and into the Middle Ages.

### *Disability in the Middle Ages*

Understanding disability in the Middle Ages is met with a similar challenge to that of antiquity in that the texts available today are mostly from a normate perspective and therefore only describe "how non-disabled people thought about the disabled."[26] While this perspective is informative to an extent, it is also limited, particularly within the context of the modern social model of disability. With this in mind, disability historians aim to "reconstruct the social and cultural history of groups previously deemed historically invisible."[27] Thus, study of disability in the Middle Ages is "a cultural history, a study of mentalities, focusing on social attitudes rather than on personal testimonies and identities."[28]

One means of examining attitudes toward disability in the Middle Ages is through laws pertaining to people with disabilities. Such laws varied, and some offered

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[25] Mt. 20:16

[26] Irina Metzler, *A Social History of Disability in the Middle Ages: Cultural Considerations of Physical Impairment* (London, UK: Routledge, 2013), 1.

[27] Metzler, 3.

[28] Metzler, 3.

restrictions while others offered protection and compensation.[29] Compensation was

particularly common for injuries which led to permanent disabilities. Conversely, some

laws were also met with punishment by mutilation, which in some cases led to permanent

disability. For instance, in Anglo-Saxon England from 1020 to 1023, the laws of Cnut

were compiled in an apparent attempt to prevent executions. These laws increased the

severity of consequences as the  number of offenses increased: a first offense could be

paid for with a fine, while second offenses would be punished with the cutting off of

hands or feet and third offenses would be punished with eye-gouging or the cutting off of

the nose or ears or upper lip.[30] Interestingly, these laws reconstruct a hierarchy of

disability in which orthopedic impairments are considered less severe than sensory

impairments. All impairments, however, are seen as less severe than death since living,

even with impairments, preserves the soul.[31]

Preservation of the soul would have been prioritized throughout the Middle Ages

due to the strong influence of religion. This prioritization of holiness, or at least the

perception of it, pervaded social and vocational expectations of people, including people

with disabilities. Disabilities that prevented people from working, both in secular and

religious contexts, were viewed particularly negatively. People who could not work to

maintain a living were compelled to beg, which only further stratified them as lower-

class, lower-valued, and problematic.[32] At the same time, compassion for the poor and

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[29] Metzler, 12.

[30] Metzler, 12.

[31] Metzler, 13.

[32] Metzler, 43.

marginalized increased in popularity as organized religion did, and thus healing miracles

and charity were integral to the experience of people with disabilities in the Middle

Ages.[33]

Healing miracles, particularly those performed on people with disabilities, were

considered a victory for all parties during this time. Religious leaders and miracle

workers garnered more followers and stronger support by demonstrating channeled

power of the divine; recipients of healing miracles were able to rejoin society and live by

their own means. However, these miracles also perpetuated an early medical model of

disability; the only way for a person with a disability to belong fully in society was to

thoroughly mask his disability or to rid himself of it entirely.[34] Charity, on the other hand,

allowed people with disabilities to maintain their status, but simultaneously prevented

them from fully belonging. Almsgiving was encouraged, and Christian teaching

emphasized the poor and needy as important members of God's kingdom; nevertheless,

hospitality was almost exclusively defined by monetary handouts, and the poor and

marginalized, including those with disabilities, tended to remain poor and marginalized

throughout their lives.[35]

Based on available evidence, it is easy to assume that most people with

disabilities suffered through the Middle Ages as poor, marginalized people marked by

suffering and sin. This conceptualization of a whole group of people, however, is "rather

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[33] Metzler, 154.

[34] Metzler, 44.

[35] Metzler, 156.

simplified and stereotyped."[36] It is more likely that the experience of disability was as diverse as cultural contexts of that time, and that a number of people made good lives for themselves not in spite of their disabilities, but including them. Still, there is not evidence to support the idea of people with disabilities forming social groups or setting themselves apart as leaders during the Middle Ages. These conditions persisted from late antiquity well into the modern era.

*Disability in the Early Modern Era*

While people with disabilities are largely invisible in recorded history of antiquity and the Middle Ages, alternative sources typically suggest that disabilities were privately handled in families and communities. Thus, with the exception of social exclusion and workplace limitations, people with disabilities were able to live with minimal infringements. Additionally, many ancient and medieval laws existed to protect people with disabilities. In established European nations, this approach to disability remained prevalent until the Industrial Revolution. However, with the early modern period came the colonial era for the New World, in which small community histories were recorded in detail and fewer individuals were overlooked. As a result, the thread of disability can be more easily traced through this period.

When colonial Europeans encountered indigenous people in North America, they were met with new languages and new conceptions of normalcy. Indigenous North Americans, including the deaf and hard of hearing, frequently communicated using signs. Europeans described these systems in accounts as unsophisticated gestures, while modern

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[36] Metzler, 204.

scholars argue that these signs belonged to elaborate sign systems that existed long before Europe became a frontrunner in deaf education and Deaf culture in the seventeenth century.[37] Other colonial European accounts include the rapid spread of various diseases, a number of which caused blindness, deafness, disfigurement.[38] These disabilities were "routine and unremarked upon" among European colonists, but had dramatic consequences for indigenous nations.[39]

By the early eighteenth century, colonial North America largely resembled contemporary Europe in the handling of disabilities. Families were left to deal with disability privately as it affected their members, and in cases where families could not provide, it became the responsibility of the local community.[40] On the one hand, this societal structure allowed for people with disabilities to be cared for by family and friends, which increased prioritization of these people's well-being. On the other hand, when families and communities ran out of options, there were no systems in place to relieve them; thus, the institutionalizing of people with disabilities grew in popularity during this time.[41]

The prevalence of institutionalization, along with other social and emotional challenges for people with disabilities, dramatically increased as a result of the Industrial Revolution. At the turn of the 19th century when the economy became based on

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[37] Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2012), 19-20.

[38] Nielsen, 26.

[39] Nielsen, 27.

[40] Nielsen, 45.

[41] Nielsen, 53.

industrial production, a person's ability to work became central to his social value. Thus, people with disabilities "were less tolerated and more laws were passed to restrict their lives" insofar as they were unable to work.[42] It should be noted, however, that at this time disabilities were also categorized by the extent of their handicapping in the industrial workplace, and that many people who would be considered disabled today would not have been during the Industrial Revolution.[43] Thus, while some disability historians consider the Industrial Revolution an "unmitigated disaster" for people with disabilities, there is evidence that many people with disabilities persisted quietly and privately through this time with few social, emotional, or economical challenges.[44] Still, others suffered or were marginalized, and any advocacy for people with disabilities was made *for* them rather than *by* them. As a result, tension and unrest continued to grow throughout the nineteenth century and into the twentieth.

*The Disability Rights Movement*

While consequences of the Industrial Revolution clouded the turn of the nineteenth century, the next few decades were filled with dramatic changes in the lives of people with disabilities. The first school for the Deaf was established in the United States in 1817. In 1829 Louis Braille invented a dot system that allowed blind people to read, and in 1841 Dorthea Dix began a campaign to reform jails and poorhouses, which prior to

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[42] Roberts, 56.

[43] Daniel Blackie, "Disability and work during the industrial revolution in Britain," in *The Oxford Handbook of Disability* ed. Michael Rembis, Catherine Kudlick, and Kim E. Nielsen (New York: Oxford University Press, 2018), 14.

[44] Blackie, 15.

that time were places of abuse and injustice towards people with disabilities.[45] Dix's

efforts brought more attention to struggles of people with disabilities, but it remained a

charitable effort on their behalf. Meanwhile, the development of the Deaf community

discussed in the previous chapter was unfolding rapidly and garnering additional

attention.

From 1817 to 1880 deaf education *for* deaf people *by* deaf people grew

exponentially in popularity, culminating with the 1864 chartering of the National Deaf-

Mute College (later renamed Gallaudet University). While 1880 stands out in Deaf

history as a challenging year due to the Milan Conference, at which sign language in

schools for the deaf was banned, the year also held the founding of the National

Association for the Deaf (NAD).[46] The NAD is responsible for "safeguarding and

protecting the civil rights" of deaf and hard of hearing Americans, and it was the first

nonprofit organization founded to protect the rights and accessibility of people with

disabilities.[47] Most importantly, the NAD was founded by deaf people, making it the first

advocacy group formed *by* people with disabilities *for* people with disabilities. The

National Mental Health Association followed in 1909, along with the American

Foundation for the Blind and the Department of Veterans Affairs in 1921.[48] At last,

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[45] Doris Zames Fleischer and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia: Temple University Press, 2011), xxv.

[46] Fleischer and Zames, xxv.

[47] "National Association of the Deaf," *American annals of the deaf, 164* no. 2 (2019): 337, accessed January 15, 2021, https://www.jstor.org/stable/26898352.

[48] Fleischer and Zames, xxv.

access and rights of people with disabilities began to be seen as something they could demand for themselves.

A central purpose of disability advocacy groups has been to change and create laws in order to protect fundamental rights and increase access for people with disabilities. In 1936 the Social Security Act was passed, providing benefits and assistance to the elderly, the blind, and children with disabilities. In 1956, and again in 1960, the Social Security Act was amended to allow adults eligibility for disability insurance. In 1964, the Civil Rights Act was passed, and while its central focus was not people with disabilities, it set a precedent for laws that followed.[49] The Rehabilitation Act of 1973, particularly sections 501-504, played a critical role in increasing access to several areas for people with disabilities: sections 501 and 503 provide access in the workplace, section 502 provides access in architecture and transportation, and section 504 protects civil rights in programs receiving federal financial assistance.[50]

The most significant legal change brought about by the disability rights movement was the passage of the Americans with Disabilities Act (ADA) in 1990. The ADA was slow to be enacted because although it was well-supported by multiple disability advocacy groups, there was some fear that a "watered-down" version of the ADA would encourage discrimination rather than eliminating it.[51] This fear, along with the recognition that the previously existing laws were not maximally effective, transcended political divisiveness and led to the creation of an act that has holistically

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[49] Fleischer and Zames, xxvi.

[50] Fleischer and Zames, 49.

[51] Fleischer and Zames, 89.

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increased access and protected the rights of people with disabilities for over thirty years.

Beyond the legal protections it provides, the ADA can also be considered "an insurance

policy against discrimination" that all Americans, typically-abled or not, "should cherish

and protect as a matter of enlightened self-interest."[52]

Outcomes suggest that the disability rights movement's central focus has been

creating legislation that helps people with disabilities. More specifically, the movement is

the converging of two aims: first, to secure "equal access to transportation, education,

employment, housing, and health care," and second, to help people with more severe

disabilities maintain independence.[53] These two aims allowed people with disabilities to

form a group identity based on what they have in common: disability. Disability would

otherwise be a difficult concept around which to form a group identity because

disabilities are not typically desirable.[54] Additionally, disabilities are socially imposed

labels on impairments. Counteracting this imposition offers the catalyst for forming

group identity: "mutual affirmation."[55] If an impairment does not in some way bar a

person from participating in an activity considered typical, it is not a disability. The

experience of impairment is rarely similar enough between two individuals to form group

identity. However, the experience of being placed in a socially constructed category,

particularly one that is lower on the social hierarchy than that of the typically-abled,

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[52] Fleischer and Zames, 109.

[53] Fleischer and Zames, 200.

[54] Fleischer and Zames, 201.

[55] Fleischer and Zames, 201.

creates common ground for people with a wide variety of impairments. Thus, group

identity is formed by the experience of having a disability.


*Disability Identity vs. Deafhood*

In many ways, the development of Deafhood and disability identity are deeply

intertwined. The Deaf community often led the pack in the disability rights movement;

for instance, the first school for people with disabilities was a school for the deaf, and the

first disability advocacy group was the NAD. In these cases, Deaf people demonstrated to

the typically abled that people with disabilities could fully participate in society when

given access. Furthermore, Deaf people demonstrated to other people with disabilities

that self-advocacy was a worthy goal for which to strive. The group identity modeled by

the Deaf community is in many ways mirrored by the group identity other people with

disabilities have formed.

Disability identity and Deafhood are also similar in their starting point. Both

identities are rooted in the experience of being marginalized by broader society due to an

impairment that the individual did not choose. Both Deafhood and disability identity

reject the medical model of disability, wherein individuals must "cure themselves to fit

existing nondisabled standards."[56] Both identities also reject charity and condescension

on the part of typically abled people. Up to this point, the two identities are largely

inseparable. In fact, the disability rights movement has been described as "a coalition of

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[56] Eve Hill and Daniel Goldstein, "The ADA, Disability, and Identity," *Journal of the American Medical Association 313,* no. 22 (2015): 2227, accessed January 16, 2021, 10.1001/jama.2015.4936.

disparate groups run by and for disabled people," which suggests the Deaf community might merely be a faction of the larger body of people with disabilities.[57]

On the other hand, disability identity and Deafhood differ slightly in their aims. Disability identity focuses on accessibility.[58] Beyond law reform via the disability rights movement, people with disabilities have argued for inclusion, often in the name of diversity.[59] Put simply, this identity is rooted in being as much like "everyone else" as possible. This is not the same pursuit of normalcy proposed in the medical model, such that people with disabilities should be "fixed" or "cured" in order to belong in society; rather, this pursuit of normalcy presupposes that a person's impairments should not truly be disabling as long as society is structured properly. Individuals who assume disability identity seek a place of acceptance and belonging in broader society.

The previous chapter describes the experience of Deafhood and how, contrary to disability identity, Deafhood does not seek belonging in the whole society. The Deaf community seeks acknowledgement from the hearing world, but belongingness comes from having a place in the Deaf community. If a Deaf person so chose, he could live in an entirely Deaf world; he could attend a school for the deaf, have a Deaf family, attend a Deaf church, and build an exclusively Deaf network of friends. Many members of the Deaf community elect to do so. Both identities seek inclusion and acceptance in a culture whose majority is typically-abled, but this sets Deafhood apart from disability identity:

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[57] Ravi Malhotra and Morgan Rowe, *Exploring Disability Identity and Disability Rights through Narratives: Finding a Voice of Their Own* (New York: Routledge, 2014), 3.

[58] Malhotra and Rowe, 182.

[59] Bonnielin Swenor and Lisa M. Meeks, "Disability Inclusion — Moving Beyond Mission Statements." *New England Journal of Medicine 380*, no. 22 (2019): 2089, accessed January 16, 2021, 10.1056/NEJMp1900348.

disability identity seeks inclusion *in spite* of disability, while Deafhood seeks inclusion *because* of disability.

## *Conclusion*

For people who are deaf but elect not to participate in cultural Deafness, audiological intervention may be necessary insofar as it provides more access to a world that is predominantly hearing. However, modern disability identity is rooted in the social model; therefore, the primary mode of assistance for deaf and hard of hearing individuals in this category is accommodation. Closed captions and hearing assistive technology (e.g., fm systems, induction loop systems, amplifiers) have been developed for this purpose and have significantly increased accessibility. A key component of disability identity is self-advocacy, which has increased the prevalence of accessibility technology as schools, business, and other public settings have risen to meet demands.

For deaf and hard of hearing individuals who embrace disability identity, audiological counseling mostly entails awareness of hearing assistive technology and increased confidence in self-advocacy. It is therefore important to distinguish this category of identity from Deafhood in order to provide more effective interventions and counseling. Still, there are other models of disability, and these models have their own best practices for audiological intervention. These models and their application for people with hearing loss will be discussed in the next chapter.

CHAPTER THREE

Other Disability Models

*Introduction*

The last two chapters have discussed the medical, culturo-linguistic, and social models of disability. This discussion has focused on the physiological precursor (i.e., impairment) and the social impact (i.e., handicap) of disabilities for individuals who have them. The disability of deafness presupposes impairment of the auditory system, but this disability's social impact varies based on a combination of an individual's identity and culture. A person's identity in terms of disability is a function of that person's adherence to a particular model of disability; for example, a person who embraces the culturo-linguistic model of disability would claim Deafhood as central to his identity, while a person who adheres to the medical model of disability might reject Deafhood and make hearing loss a more peripheral part of his identity. Yet disability models affect more than just people with disabilities; they also inform the culture in which people with disabilities exist. This aspect of disability models is largely out of the control of people with disabilities, and yet it significantly impacts their lives.

This chapter will delve into disability models and explore what life looks like for people with disabilities as a result of them. First, the social and medical models of disability will be revisited. Second, models of disability related to the medical and social models will be introduced and defined. Third, the process of forming an individual model of disability will be examined from the lens of people without disabilities and people with disabilities. Fourth, the experiences of people with disabilities that are not externally apparent will be considered in the context of various disability models. Finally, various

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disability models will be observed and applied to real-world experience, particularly for a person with hearing loss.

*Medical and Social Models Revisited*

Knowledge of the medical model of disability is central to understanding the experience of people with disabilities because it has defined the history of disability and because it is often implicit in healthcare for those with disabilities. Medicine often categorizes symptoms and behaviors as either "normal" or "abnormal." As a result of these categorizations throughout the history of medicine, "illness and disability became separated from everyday life and were constructed as forms of individual pathology."[1] As a previous chapter established, this view of disability as a form of pathology has led to groundbreaking interventions and accommodations for people with disabilities, but it has also historically led to their exclusion and, in extreme situations, their persecution. Out of opposition to this exclusion and persecution, the social model of disability was formed.

The social model of disability brought about a distinction between impairment, disability, and handicap. An impairment fits the medical understanding of disability in that it is "a state of the body that is non-standard."[2] Thus, impairment is defined only by physiological description. Disability is defined as a "restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered

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[1] Pamela Fisher and Dan Goodley, "The Linear Medical Model of Disability: Mothers of Disabled Babies Resist with Counter-narratives," *Sociology of health & illness 29*, no. 1 (2007): 67.

[2] Sara Goering, "Rethinking Disability: The Social Model of Disability and Chronic Disease" *Current reviews in musculoskeletal medicine 8*, no. 2 (2015): 135.

normal."[3] Handicap combines the physiological and experiential with the social, and is defined as "a disadvantage for a given individual that limits or prevents the fulfillment of a role that is normal."[4] By these definitions, a disability does not necessitate a handicap, nor is it wholly in the power of a person with a disability to determine whether a disability will result in a handicap. Rather, the power to create or prevent handicaps lies in the hands of the majority culture. The social model of disability focuses on both "institutional norms" (e.g., stairs instead of ramps, videos without closed captioning, alerts presented with audio but no visual cues, etc.) and "attitudinal obstacles" (e.g., assumptions about quality of life, intelligence, ability to work, etc.) that render people with disabilities "incapable of work and social relationships."[5]

In targeting institutional and attitudinal obstacles rather than individual impairments, the social model of disability suggests that given proper access, people with disabilities ought to be able to accomplish anything people without disabilities can accomplish. This stands in sharp contrast to the medical model, which suggests that disability must be "cured" in order for a person to achieve "normal" functioning. Because these models are well defined and easily distinguishable from one another, they are often presented as an over-simplified dichotomy of disability. However, as Chapter 1 established, there are actually many models of disability. Many of these models might be

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[3] Sheena L. Carter, "Impairment, Disability, and Handicap," Developmental Progress Clinic, Emory University School of Medicine, 2018, https://med.emory.edu/departments/pediatrics/divisions/neonatology/dpc/impairment-mx.html

[4] See note 3 above.

[5] Goering, 135.

considered derivative of the social or medical models, but they are nuanced enough in their definitions and applications to warrant further discussion.

*Models Related to the Medical Model*

The medical model is one of the oldest models of disability, but the concept of disability predates the modern concept of medicine, as is established in Chapter 2. The moral model of disability, sometimes known as the religious model, appears to have pervaded premodern times.[6] The central claim of the moral model is that "some disabilities are the result of lack of adherence to social morality" or "proclamations that warn against engaging in certain behavior."[7] The moral model becomes the religious model when disability is "regarded as a punishment from God" or some other divine entity.[8] As a result, interpretations of scripture have historically associated and sometimes even equated disabilities such as blindness, deafness, and chronic illness with sin. This association is in some ways related to physiognomy, a philosophy discussed in Chapter 2 that relates physical traits to internal character qualities. As people without disabilities avoid those whom they perceive to be of lesser character, disability leads to exclusion from community. Additionally, the thought of disability as punishment leads to a rift in the relationship to the divine, and perception of sinfulness within the community leads to

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[6] Marno Retief and Rantoa Letšosa, "Models of disability: A brief overview," *HTS Teologiese Studies/Theological Studies, 74* no. 1 (2018): 2.

[7] George Henderson and Willie V. Bryan, *Psychosocial aspects of disability* (Springfield, IL: Charles C. Thomas, 2011), 7.

[8] Retief and Letšosa, 2.

further isolation in the church and in the community. Thus, people with disabilities who live within this model often live in physical, emotional, and spiritual exile.

There is also another form of the religious model in which people with disabilities are "specifically selected by God to receive a disability."[9] In this variation of the model, disabilities are not punishments, but are "essentially a test of faith or even salvific in nature."[10] One application of this model is that if an individual receives "physical healing" or in some other way is freed from his or her disability, it is a testament to that individual's faith.[11] Another application of this model is that beyond testing faith, disability is an opportunity for character development.[12] This application is in many ways the opposite of the other variation of the religious model because in the former disability might be considered a curse, while in the latter people with disabilities are "regarded as blessed" because of their "opportunity to learn some important life lessons that able-bodied people do not necessarily have the opportunity to learn."[13]

In either case, people with disabilities are categorized as separate from the typically-abled by divine design. Neither of these forms of the moral/religious model are particularly prevalent in the modern era. Reverend William C. Gaventa, Chair of the National Collaborative on Faith and Disability, sums up the transformation:

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[9] Susan Niemann, "Persons with disabilities" in *Religious and spiritual issues in counseling: Applications across diverse populations*, ed. Mary Burke, Jane Chauvin, and Judith Miranti (New York, NY: Brunner-Routledge, 2005), 106.

[10] Retief and Letšosa, 2.

[11] Kathy Black, *A Healing Homiletic* (Nashville, TN: Abingdon Press, 1996), 26.

[12] Black, 27.

[13] Retief and Letšosa, 2.

As the focus has shifted away from "special" toward inclusion in the past thirty years, there has been a rapid growth in theological interpretations of disability, new historical explorations and discovering of the multiple ways disability has been interpreted in scriptures and histories of major faith traditions, and increasingly creative, diverse forms of inclusive spiritual support and ministries by clergy and faith communities.[14]

Gaventa suggests that the gap between spirituality and disability is closing as faith communities move from rejection to acceptance to advocacy, and finally to a place of "shared contributions, belonging, and community membership."[15] Still, older forms of the religious/moral model regularly impact the lives of people with disabilities in their faith communities and sometimes even in their self-perception. For instance, "the basic philosophy underlying the model is still frequently encountered in the way people reason when confronted with illness or disability."[16] This philosophy might be presented in the form of questions such as "Why me?" or "What does this mean?" and may be directed towards a divine entity, or they might be posed to the self. Either way, there is a lingering association between disability and an individual's greater purpose that was born out of the moral/religious model of disability.

The moral model of disability has a close relative, the charity model. The charity model claims that for people with disabilities, "their situation is tragic, and they are suffering."[17] This perspective is similar to the variation of the religious model of disability: the religious model views disability as a punishment, and the charity model

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[14] William C. Gaventa, *Disability and Spirituality* (Waco, TX: Baylor University Press, 2018), 3.

[15] Gaventa, 28.

[16] Retief and Letšosa, 2.

[17] Vali Duyan,"The community effects of disabled sports" in *Amputee sports for victims of terrorism* (Amsterdam, NL: IOS Press, 2007), 71.

views people with disabilities as "victims of circumstance who should be pitied."[18] In either case, the experience of disability is thought to be exclusively negative. As such, the charity model encourages "humane treatment of persons with disabilities" and calls typically-abled people to take special care to act in the best interest of those with disabilities.[19] The charity model also draws from the variation of the religious model in which people with disabilities are seen as having special importance or something unique to offer. One problem faced broadly when it comes to charity is that motives are often self-centered, such as the motivation to "accomplish something worthwhile," to "be a person of significance," or to "pursue a noble cause."[20] As a result, economically advantaged people "sometimes unintentionally reduce poor people to objects" used to strengthen character, provide a sense of nobility, or cultivate a better public image.[21] The same phenomenon can occur when people without disabilities behave charitably towards those with disabilities: people with disabilities can easily be demoted from human beings to character-strengthening or ego-boosting service centers. This model is somewhat common among typically-abled people, and is regarded with contempt by many people with disabilities as it portrays them as "helpless, depressed, and dependent, on other people for care and protection, contributing to the preservation of harmful stereotypes and misconceptions."[22]

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[18] Retief and Letšosa, 6.

[19] Henderson and Bryan, 7-8.

[20] Steve Corbett and Brian Fikkert, *When Helping Hurts: How to Alleviate Poverty Without Hurting the Poor… And Yourself* (Chicago, IL: Moody, 2009), 61.

[21] Corbett and Fikkert, 62.

[22] Retief and Letšosa, 6.

Both the moral/religious and charity models of disability are related to the medical model in their perception of the experience of disability as something that is largely negative. In each of these three models, people with disabilities are at a disadvantage and have something to overcome. These models encourage people to minimize their disabilities as much as possible and thereby improve their quality of life. The religious/moral model suggests this can be achieved through faith healing or through strengthening of character. The charity model suggests this can be achieved by accepting help from the typically-abled. The medical model suggests this can be achieved through biotechnological or pharmaceutical intervention that cures or at least curbs disability. In any of these models, the experience of disability is thought to be inherently negative; however, this experience can be transformed into a positive one with the right kind of intervention.

These three models stand in contrast to those related to the social model. Whereas the medical, religious/moral, and charity models imply that people who opt out of intervention (such as Deaf people who elect not to receive cochlear implants) are acting contrary to reason, the social model and models like it claim that the experience of disability is inherently positive and enriching. In these models, the experience of disability only becomes negative when culture makes it so; thus, interventions should be targeted towards culture at large rather than specifically people with disabilities. Models of this nature will be discussed in the following section.

*Models Related to the Social Model*

One model of disability to which Chapter 1 attended is the cultural or culturo-

linguistic model. This model "assumes that impairments and disabilities are structuring

culture(s)" that are distinct from majority culture.[23] At the same time, the cultural model

"focuses on how different notions of disability and non-disability operate in the context

of a specific culture"[24] In other words, the cultural model posits that disability exists in

culture and creates culture simultaneously. It considers the culture-creating effect of

exclusion and discrimination described by the social model, but it also "questions the

other side of the coin, the commonly unchallenged 'normality,' and investigates how

practices of (de-) normalization result in the social category we have come to call

'disability.'"[25] Deafhood is an example of this model applied in that it is defined by the

experience of not hearing in a world where the majority of people hear. Thus, Deaf

culture is something distinct from hearing culture in more ways than just its exclusion

from hearing culture.

Another model of disability that is closely related to both the social and cultural

model is the identity model. This model, like the social model, claims that "the

experience of disability is socially constructed."[26] However, it differs from the social

model in that it is "less interested in the ways environments, policies, and institutions

disable people, and more interested in forging a positive definition of disability identity

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[23] Anne Waldschmidt, "Disability Goes Cultural: The Cultural Model of Disability as an Analytical Tool," in *Culture – Theory – Disability: Encounters between Disability Studies and Cultural Studies* ed. Anne Waldschmidt, Hanjo Berressem, and Moritz Ingwersen (Bielefeld, DE: Transcript Verlag, 2017), 20.

[24] Retief and  Letšosa, 6.

[25] Waldschmidt, 24.

[26] Retief and Letšosa, 5.

based on experiences and circumstances."[27] The identity model also connects with the cultural model insofar as shared identity creates "a recognizable minority group" as is the case broadly for people with disabilities and specifically for the culturally Deaf.[28] The identity model differs from the cultural model in that it centrally focuses on self-image and affirmation, rather than exploring culture at large. The output of the identity model is an increase in "disability pride," but with increased disability pride comes an increased risk of undermining the social and economic inequality that is often faced by people with disabilities.[29]

One response to the undermining of inequality for people with disabilities is to bring the matter of equality to the forefront, as is done in the human rights model of disability. The human rights model, like the social model, considers disability from a social perspective and thus emphasizes social rights. In addition, the human rights model considers civil, political, economic, social, and cultural rights.[30] A key distinction between the social and human rights models of disability is that the social model is largely focused on understanding "the underlying social factors that shape [the majority culture's] understanding of disability," while the human rights model "moves beyond explanation, offering a theoretical framework for disability policy."[31] The social and

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[27] Elizabeth Brewer, Brenda J. Brueggemann, Nicholas Hetrick, and Melanie Yergeau, "Introduction, background, and history," in *Arts and Humanities*, ed. by Brenda J Brueggemann (Thousand Oaks, CA: Sage, 2012), 5.

[28] Brewer et al., 5.

[29] Retief and Letšosa, 5.

[30] Theresia Degener, "A new human rights model of disability" in *The United Nations convention on the rights of persons with disabilities: A commentary,* ed. Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (Cham, CH: Springer, 2017), 44.

[31] Retief and Letšosa, 5.

human rights models are often viewed synonymously, but they are better described as complementary: the human rights model has a close connection with political and legal changes in the best interest of people with disabilities, but understanding the best interest of people with disabilities in society comes from the social model.

<div align="center"><em>Adopting a Personal Model of Disability</em></div>

For people without disabilities, adopting a disability model often depends on individual experiences with others who have disabilities. Parents, siblings, and children of people with disabilities often form models of disability based on the experiences of their family members with disabilities. Some of these groups even have a place in subcultures of disability. For example, "Children of Deaf Adult (CODA) is an acronym that refers to a hearing child born to one or two Deaf parents."[32] CODAs typically learn ASL as their first language, and they learn English around the same time but slightly later. CODAs, like other bilingual children, have been shown to use their ASL skills to become more proficient English word learners.[33] CODAs often serve as interpreters between their Deaf parents and hearing teachers, friends, and relatives. Because they typically have involved lives in the Deaf community as well as activities and friends in the hearing world, CODAs offer a unique perspective that has helped to bridge the gap between Deaf and hearing culture.

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[32] Jane Harrison and Brian Watermeyer,"Views from the Borderline: Extracts from My Life as a Coloured Child of Deaf Adults, Growing up in Apartheid South Africa" *African journal of disability 8* (2019): 2.

[33] Tim Brackenbury, Tiffany Ryan, and Trinka Messenheimer, "Incidental Word Learning in a Hearing Child of Deaf Adults." J*ournal of deaf studies and deaf education 11*, no. 1 (2006): 87.

For people without disabilities who do not have close relationships with people with

disabilities, models of disability are often formed unintentionally. In these cases, people

learn to understand disability and decide how to treat people with disabilities based on

whatever or whoever is of highest priority to them. For people who place highest value

on religion, whichever variation of the religious/moral model their pastors, priests,

teachers, or other authority figures promote are likely to take root.[34] For those who place

highest value on the dignity of human life, variations of the charity or human rights

model develop naturally. For students who pursue medical education, the medical model

is implicit in the training.[35]

These developments are almost always implicit, and people without disabilities

are often unaware of the models that impact their interactions with people with

disabilities. When people without disabilities operate in the framework of models that are

perceived negatively by people with disabilities and have no awareness of or justification

for operating in this manner, it can present as ableism, which is "stereotyping, prejudice,

discrimination, and social oppression toward people with disabilities."[36] Ableism is based

on the founding principle that people with disabilities are outsiders, and it "creates an

environment in which outsiders are privileged and insiders are disadvantaged."[37] People

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[34] Retief and Letšosa, 2.

[35] Jeff Nisker, "Social Model of Disability Must Be a Core Competency in Medical Education," *Canadian Medical Association journal (CMAJ) 191*, no. 16 (2019): E454. The relationship between disability models and healthcare education has become increasingly nuanced as the disability rights movement has progressed. Developments in the field of disability studies have enhanced the academic merit of understanding disability culture, identity, and models. Nisker argues that there is still a great deal of progress left to be made. Arguments for and against this stance will be discussed in the next chapter.

[36] Kathleen R. Bogart and Dana S. Dunn, "Ableism Special Issue Introduction," *Journal of social issues 75*, no. 3 (2019): 651.

[37] Bogart and Dunn, 659.

without disabilities can avoid unintentional ableism by intentionally analyzing disability models and applying them appropriately in their interactions with people with disabilities.

For people with disabilities, individual models form as experiences are compiled and relationships are formed. Regardless of whether disability is central to a person's identity, identity is central to a disability model. Often, people with disabilities seek identity formation by observing and consulting with people who represent them, sometimes in families or local communities, and sometimes in pop culture at large. As a result, disability often becomes central to identity as "a positive sense of self" and "feelings of connection to, or solidarity with, the disability community" are formed.[38] This process leads to the formation of individual disability models that resemble the social, cultural, or identity models. Formation of models like these is thought to be beneficial for people with disabilities because such models can "help an individual adapt to disability" and "navigate the social stresses" of being in a minority group and of living with disability in a world that is often built with the typically-abled in mind.[39]

For some people with disabilities, group identity is not easily formed. This can occur for a number of reasons. For people with profound intellectual disabilities, the cognitive process of forming identity might not be possible. Moreover, communication might be limited to an extent that makes relating to others difficult. This of course does not mean that people with intellectual disabilities live in absence of community; rather, "the desire to be loved as a person" is vital to all people and is "at the source of all self-

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[38] Dana S. Dunn and Shane Burcaw, "Disability Identity: Exploring Narrative Accounts of Disability," *Rehabilitation psychology 58*, no. 2 (2013): 148.

[39] Dunn and Burcaw, 155.

esteem."[40] Nevertheless, group identity formed in the midst of profound intellectual disability is more easily observed among caregivers.

In other cases, group identity does not form because the disability is not as immediately evident. General disability identity can be formed around the shared experience of being marginalized, but this identity is strengthened by a depth of shared experience specific to particular disabilities. These shared experiences can be mundane, such as having to enter through the back of a building where the wheelchair-accessible ramp is or having to wear closed captioning display devices in a movie theater. Experiences can also be more significant, such as being barred admission from a school or losing a job due to direct or indirect effects of a disability. These kinds of experiences might be salient for conversations when one person with Down syndrome meets another or when one person who uses a wheelchair meets another, but some disabilities are not externally evident. Compounded with the rarity of some illnesses and disabilities, some individuals find opportunities to connect with others who understand and relate to their experiences to be few and far between.

*Invisible Disabilities*

Disabilities that are not externally apparent, often called "invisible disabilities" in disability literature, present even more complexity in context of the social model and other related models. People with invisible disabilities "have the widest possible range of options open to them for managing stigma, as they may choose to fully disclose, partially

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[40] Jean Vanier, "What have people with learning disabilities taught me?" in *The Paradox of Disability,* ed. Hans S. Reinders, (Grand Rapids, MI: William B. Eerdmans, 2010), 20.

disclose, or hide their impairment."[41] For example, a person with mild or moderate

hearing loss might go through the process of filing for accommodations at work. This

would be an example of full disclosure. Alternatively, the individual could elect not to

file for accommodations and instead inform coworkers and employers as needed, a partial

disclosure. The individual could also choose not to disclose the hearing loss at all.

People with invisible disabilities often elect to use partial disclosure, or

"covering,"[42] to "reduce the visibility of their stigmatized condition."[43] Some

accommodations are helpful in certain settings, but such accommodations often come at

the cost of stigma.[44] People with invisible disabilities are not always compelled to face

stigma with the same disability pride often demonstrated by people with more externally

apparent disabilities. In cases where disabilities are recently acquired, this hesitancy may

stem from unfamiliarity with disability identity. In other cases, the invisible nature of the

disability might make people feel as though they are "not disabled enough."[45] Some

individuals, out of these feelings of unfamiliarity or lack of belonging, deny disability

altogether and attempt to "pass as nondisabled."[46]

Disability activists oppose the choice to hide impairments based on the claim that

it promotes ableism. By this reasoning, the attempt to pass as typically abled is rooted in

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[41] Heather Dawn Evans, "Un/covering: Making Disability Identity Legible," *Disability studies quarterly 37*, no. 1 (2017). "An intersectional approach to stigma, passing and covering."

[42] Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (New York, NY: Simon & Schuster, Inc., 1963), 102.

[43] Evans, "An intersectional approach."

[44] Goffman, 3.

[45] Evans, "Molly: *I am not disabled enough…"*

[46] Evans, "Conclusion."

the idea that typical ability is a goal for which to strive; by the same reasoning, disability

is something which should be cured or removed when possible. As such, this approach

resembles the medical model, and in fact, many people who take this approach pursue

biotechnological and pharmaceutical interventions to mask or accommodate for their

disabilities. This approach is justified for proponents of the medical model and others like

it, and it presents an option for people with disabilities to live comfortable and

unassuming lives. On the other hand, opposition to this approach is justified in the

context of the social model and other models like it, and such opposition is often found

among disability activists. However, this perspective pushes to the fringes those who

already do not believe they are "disabled enough" to belong to the community of people

with disabilities. Perhaps it would be most just to allow people with invisible disabilities

a welcome place in both the community of people with disabilities and the community of

the typically-abled, but there is not a place for this perspective in any existing disability

models. Thus, people with invisible disabilities are typically forced to choose whether to

strongly display disability pride at the risk of appearing to exaggerate their disabilities, or

to hide their disabilities as much as possible.

*Disability Models Applied*

The previous chapters and sections have outlined seven disability models. Each of

these models is vastly complex and nuanced in different individuals and cultures, and

these models only represent a small fraction of the disability models that have existed and

continue to evolve and develop. It might in fact be said that there are as many different

disability models at any given time as there are individuals in the world. Understanding

the ubiquitousness of disability models is critical when considering that the lived experience of people with disabilities is a product not only of their individual models, but also of every model they encounter in their interactions with others. In theory, disability models are distinct from each other and easily identifiable; in practice, disability models collide in a way that can be chaotic and disorienting for people with disabilities and for their typically-abled friends, families, and caregivers.

Consider, for example, a high school student, Jane Doe, who is Deaf. Most immediately, by participating in cultural Deafhood, Jane has adopted the cultural model of disability for herself. Now, imagine Jane's family: her mother is Deaf, but her father is hearing, and she has a hearing sister. Because there are Deaf people in the family, the cultural model of disability is central to the family dynamic. The hearing family members participate in Deaf culture as well, so they understand the cultural model, but because Jane's sister often fills the role of ASL interpreter, she sees merit in the social model. From her perspective, her sister is only limited by her access to communication in a predominantly hearing world.

Now, consider Jane and her sister's life at school. They both attend a public high school that has a deaf education program. Jane attends a mix of regular classes and classes tailored to her specific needs as a deaf student. In her regular classes, Jane has an interpreter seated near her, along with a few friends from the deaf education program who also use an interpreter. During free period, Jane attends sessions with a speech-language pathologist to help her with literacy and with speech-reading. All of these interventions and procedures are based on the human rights model and its implications for public school accommodations. At lunch time, Jane sits with her sister and a few of

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their friends, who are a mix of Deaf, hard of hearing, and hearing. Some of the hard of hearing students use cochlear implants and hearing aids in application of the medical model. The hearing students are comfortable around Jane, and some of them have even learned to sign, either out of friendship to Jane or inspired by the charity model.

After school, Jane goes to her church's youth group meeting with her sister and some of their friends. Most members of the youth group have known Jane for a long time and do not acknowledge her deafness. A few of them regularly offer to pray for her and remind her that God may yet heal her of her deafness. One of the adult volunteers frequently asks Jane to speak about her experience with deafness and what God is teaching her through the process. All of these interactions demonstrate variations of the moral/religious model at work. Jane shrugs off the missteps because for her, the benefits of being Deaf outweigh the frustrations of interacting with people who do not understand. This response is possible due to the influence of the identity model on Jane's perspective. By the time Jane gets home at the end of the day, she is exhausted. As the family shares a meal and easy banter in Jane's first language, ASL, Jane is thankful that her sister and father are not like many of her hearing friends, behaving as though Jane's deafness is something they must go out of their way to accommodate.

Stories like Jane's are common for people with disabilities. Individual models of disability dictate people's attitudes as they go about their days, but internal feelings are typically where the sense of agency stops. Experiences at school, work, church, and even home are informed by the choices of others; for instance, confident Deafhood does not deter schools from offering speech and language therapy or fellow church-goers from offering to pray deafness away. These experiences can be shrugged off as well-intended,

but they can also compound frustration and shame. The social model and models like it

use the experience of compounded frustration, shame, and marginalization to fuel group

identity and advocacy for rights and access. The medical model and models like it

suggest that frustration, shame, and marginalization can be eliminated by the same means

that eliminate illness. And so it can be said that most models of disability, though they

vary widely in approach, have the same end: to free people with disabilities from

frustration, shame, and marginalization.[47]

*Conclusion*

The models, definitions, and applications discussed in this chapter are of

immediate importance to people with disabilities, those with hearing loss being no

exception, as they seek to form a sense of self and a sense of belonging. However, all the

work a person with a disability can do to create a system of understanding his disability

in terms of himself and his community is for naught if his community understands

disability in a fundamentally different way. As demonstrated in this chapter, disability

models affect more than merely the abstract philosophies and internal attitudes of the

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[47] Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids, MI: William B. Eerdmans, 2008), 68, and Tobin Siebers, "Disability Studies and the Future of Identity Politics," in *Identity Politics Reconsidered,* ed. Linda Martin Alcoff, Michael Hames-Garcia, Saty P. Mohanty, and Paula M. L. Moya (New York, NY: Palgrave Macmillan, 2006), 16.

Reinders describes the disability rights movement as "self-conscious" people who come "together with other like-minded people, equipped with political imagination and the will to bring about social change." This approach empowers many people with disabilities, but it excludes certain types of disabilities such as profound intellectual disabilities. Thus, this approach runs the risk of creating what Siebers calls "a caste system that ranks people with physical disabilities as superior to those with mental ones." Proponents of Deaf and disability identity and pride must be wary of this caste system as it insidiously corrodes the foundations of models like the social model, which claim that all people have value that does not depend on their ability to think, speak, act, or contribute any particular thing to the world beyond their very existence.

people who think about them; disability models affect every interaction between people with disabilities and the rest of the world, including other people with disabilities, people without disabilities, architecture, political structure, healthcare, and more.

The widespread impact of disability models demands that all people, regardless of ability, should increase their understanding of those models and their applications to everyday life. This action is essential for those who frequently interact with people with disabilities, such as family, friends, and caregivers. Providers of healthcare hold a special responsibility to this task as their training is typically rooted in the medical model, and the ways in which these roots affect medical practice can be difficult to see for those who have the luxury of not seeing. In terms of people with hearing loss, this responsibility falls to audiologists, who are responsible not only for the restoration, preservation, and maintenance of hearing, but also for audiological counseling that ensures patient-centered care. The current state of audiological counseling and its connection to the topics discussed so far will be examined in the next chapter.

CHAPTER FOUR

The Audiologist's Role

*Introduction*

The discussion of the previous chapters has aimed to broadly define the experience of people with disabilities and has only turned towards the specific population of people with hearing loss in examples and illustrations. The aim in this was to understand the lives and experiences of people with disabilities and increase the respect and dignity with which typically-abled people treat those with disabilities. It is also an important step because people with hearing loss, whether by physiological description or by social construction, belong to the broader category of people with disabilities; thus, the narrative, identity, and culture of people with disabilities is worthy of special consideration by those who frequently interact with the Deaf and hard of hearing. This group consists of family, friends, and coworkers of people with hearing loss, and it also includes healthcare providers. As part of the broader healthcare industry, audiologists have a responsibility to construct at least a general understanding of Deafhood and disability history, culture, and identity.

This final chapter now turns attention towards the population of people with hearing loss, and more specifically, audiologists' interactions with this population. First, a history of audiology will be given, including the motives for establishing the field and key medical discoveries and technological development since its establishment. Second, the current code of ethics for audiology practice will be discussed, with specific attention to the American Speech-Language-Hearing Association (ASHA) and its impact on audiology training and clinical practice. Third, the development of audiological

counseling as a critical component of audiological practice will be explored. Finally, a new approach to clinical education for audiology, based on the precedent of other medical professions, will be defined and discussed. Altogether, this analysis aims to define audiologists' role in the lives of people with hearing loss beyond mere diagnosis and treatment, both in terms of what is minimally required and in terms of what might be possible if the training of clinicians in the field of audiology is systematically transformed.

*History of Audiology: Origins in Otology to World War II*

The history of the field of audiology illuminates the motives that have fueled its development from mere observations about hearing loss into a diverse field of clinical practice and research. This history is useful for conceptualizing the foundation of current technical standards for practice, and it also reveals something of the motives for establishing the ethical standards that currently guide speech-language pathology and audiology.

While evidence of hearing loss extends at least as far back as the Deaf history discussed in chapter one, the field of audiology was not formally established until the 1940s, following the dramatic increase in prevalence of noise-induced hearing loss in World War II veterans.[1] Prior to the introduction of audiology as a field, the history of hearing loss can be traced through the history of otorhinolaryngology, or more specifically, otology. Otology, study of the ear, dates back at least as far as Hippocrates

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[1] "A Brief History of Audiology," University of North Carolina Health Sciences Library, January 22, 2021. https://hsl.lib.unc.edu/speechandhearing/professionshistory

and Galen, who in the fifth and second centuries BC, respectively, described anatomical components of the ear.[2] Expansion of these ideas is not evident in medical literature until the sixteenth century AD, during which Italian anatomist Bartolomeo Eustachi wrote a book on the anatomy of the ear[3] and French surgeon Ambroise Paré described "acoustic trauma" in his work on military medicine.[4] In the late seventeenth and early eighteenth centuries, Antonio Valsalva continued the endeavor of describing the anatomy of the ear by dissecting over a thousand human heads.[5] Valsalva was the first to divide the ear into outer, middle, and inner portions, and he gave names to the *scala vestibuli* and *scala tympani* of the cochlea. He also introduced what is now called the Valsalva maneuver, the covering of one's mouth and nose while blowing out in order to equalize pressure on either side of the tympanic membrane.[6]

The field of otology expanded rapidly in the nineteenth century. Prosper Meniere's discovery of the association between vertigo and disorder of the inner ear introduced vestibular science as an integral part of otology and later audiology.[7] Additionally, anatomists continued to investigate the structure and function of the middle and inner ear by studying cadavers.[8] Meanwhile, military medicine dramatically

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[2] Ashraf Yakoot, "The Remarkable History of Otology," *The Egyptian journal of otolaryngology 29*, no. 1 (2013): 59.

[3] Yakoot, 59.

[4] D. Scott McIlwain, Kathy Gates, and Donald Ciliax, "Heritage of Army Audiology and the Road Ahead: The Army Hearing Program," *American journal of public health (1971) 98*, no. 12 (2008): 2167.

[5] Yakoot, 60.

[6] See note 5 above.

[7] Yakoot, 60.

[8] Yakoot, 61.

increased awareness of hearing as veterans of the American Civil War presented with high rates of noise-induced hearing loss.[9] With the increased prevalence of noise-induced hearing loss came the popularization of "the first artificial hearing aid," the ear trumpet, which allowed for only a slight (i.e., 15-25 dB) amplification of sound.[10] Despite the increasing demand for hearing loss treatment and prevention, investigations of the ear's structure and function continued to dominate research in otology well into the twentieth century. It was not until the 1940s that research interests turned towards understanding noise-induced hearing loss and finding ways to prevent it.[11]

*History of Audiology: World War II and Beyond*

The movement to fill the gap in research regarding noise-induced hearing loss was largely perpetuated by the significant amount of World War II soldiers who came home with hearing loss and attempted to reintegrate themselves into their former workplaces and social settings. For many veterans, lack of prior exposure to Deaf or disability identity led to the experience of hearing loss as an invisible disability. As such, demand was high for hearing aids, aural rehabilitation, and accommodations that could minimize the disabling effects of hearing loss. Thus, the first hearing rehabilitation programs were established in military hospitals around the United States, and rapidly standardized treatments introduced a need for training programs at universities.[12] These

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[9] McIlwain, Gates, and Ciliax, 2167.

[10] Ioannis Mylonakis and Alessandro Martina, "The First Artificial Hearing Aid: Re-Evaluating the Role of Paolo Aproino," *Hearing, balance and communication 15*, no. 2 (2017): 57-58.

[11] McIlwain, Gates, and Ciliax, 2167.

[12] "A Brief History of Audiology."

programs were the first to use the term "audiology" to encompass the intersecting fields of otology and speech-language pathology, with the earliest evidence of the term being used around 1946.[13]

Raymond Carhart was instrumental in bridging the gap between military medicine and academic training in audiology. Carhart studied speech pathology and psychology before joining the U.S. Army Medical Administrative Corps, where he served for seven years, including several as the director of the acoustic clinic at one of the hearing rehabilitation centers established for veterans during World War II. Carhart would ultimately come to be known as the "father of audiology," both for his pioneering work in speech audiometry[14] and for his role in training many of the leaders in the field of audiology for the next several decades.[15] Carhart's clinical work and research focused mostly on people who at one time had normal hearing and who experienced hearing loss. At the height of Carhart's success, the Deaf community was still in what many have called "the Dark Age" discussed in chapter one, and it is worth noting that the founding of audiology has no apparent relation to the Deaf community and identity. The conflict between audiology and Deafhood did not arise until audiology turned its attention to pediatrics and cochlear implants.

Prior to the development of cochlear implants, hearing rehabilitation was limited to sound amplification. This ruled out the possibility of hearing interventions for those

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[13] K. W. Berger, "Genealogy of the words 'audiology' and 'audiologist,'" *Journal of the American Audiology Society*, *2* no. 2 (1976): 38.

[14] Robert Traynor, "Paternity Suits: Who Is the Real Father of Audiology?" *The Hearing review 20*, no. 4 (2013): 12.

[15] Brad A. Stach and Virginia Ramachandran, *Clinical Audiology: An Introduction, Third Edition* (San Diego, CA: Plural Publishing, 2021), 23.

with a degree of hearing loss so high that maximum amplification was still below the threshold of audibility. Research on typical child development established a critical period during which hearing thresholds correlated with expressive language development, so children who were born with or acquired severe to profound[16] hearing loss before this critical period were expected to require significant speech and language therapy in order to catch up with their typically developing peers. Meanwhile, otologist William House and neurosurgeon John Doyle began administering cochlear implants in 1961, and their limited success led to an explosion of research and development of implantable hearing devices. Reception of these devices by audiologists and otologists was skeptical and critical at first.[17] Nevertheless, by the end of the 1980s, cochlear implants had become "routine care for adults with profound hearing loss" and had begun to be used with some success in children.[18]

The use of cochlear implantation in children presented an ethical dilemma for audiologists and parents of deaf children alike: should a child have the ability to hear at the expense of Deaf community and culture, or should he have a sense of belonging in the Deaf community at the expense of the ability to hear? By this point, American Sign Language had been recognized as an official language and the Deaf President Now

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[16] Standard diagnosis of hearing loss is defined by type, degree, and configuration. Degree of hearing loss is categorized into ranges including "normal," "slight" (used only in pediatrics), "mild," "moderate," "moderately severe," "severe," and "profound." The standard range of severe to profound hearing loss describes audibility thresholds of greater than 70 dB. More information on degrees of hearing loss can be found at https://www.asha.org/public/hearing/degree-of-hearing-loss/.

[17] Adrien A. Eshraghi, Ronen Nazarian, Fred F. Telischi, Suhrud M. Rajguru, Eric Truy, and Chhavi Gupta, "The cochlear implant: historical aspects and future prospects." *Anatomical Record 295,* no. 11 (2012): 1971. doi:10.1002/ar.22580

[18] Stach and Ramachandran, 24.

movement at Gallaudet had garnered national attention for the competence and confidence of the Deaf community. For hearing parents with no exposure to Deaf culture, cochlear implants were seen as an access point to the world of sound. For many Deaf parents with deaf children, cochlear implants were seen as a threat to Deaf culture and identity that might leave their children excluded and isolated. Yet other Deaf parents, often those with friends and family in the hearing world, perceived certain opportunities they missed due to hearing loss. These parents saw cochlear implants as a means to give their children the choice to live and thrive in the Deaf world or the hearing world, a choice which had not been available to them.

The ethical debate regarding cochlear implantation in children intensified in the 1990s with the introduction of a means of measuring otoacoustic emissions (OAE), which allowed for screening the hearing of infants.[19] OAE testing could only describe hearing in terms of pass/fail, but it allowed parents and healthcare providers of infants with substantial hearing loss the opportunity to pursue intervention earlier than ever before. OAE testing allowed audiologists to "screen for hearing loss in the newborn nursery, to diagnose hearing loss in early infancy, and to provide hearing aid fitting within weeks of birth."[20] While OAE was initially only used when certain risk factors were present, it became standardized to all newborns by the end of the decade. Currently, thirty-six U.S. states, Guam, Puerto Rico, and Washington, D.C. have laws requiring

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[19] Stach and Ramachandran, 24.

[20] "A Brief History of Audiology."

newborn hearing screening; Guam, Puerto Rico, Washington, D.C., and seventeen states require some or all health insurers to cover newborn hearing screening.[21]

Resistance from the Deaf community was initially strong to the increased prevalence of newborn hearing screenings and cochlear implantation in children. One common argument was that implanting children who would otherwise be a part of Deaf culture was a form of ethnocide. However, influence from the medical model on medical training and clinical practice suggested the idea that cochlear implantation was in the best interest of children with hearing loss; thus, many medical professionals attempted to refute the ethnocide argument with the medical ethics standard that "the best interests of the child should certainly supersede those of a special interest group."[22] This argument reveals the heart of the conflict between the Deaf community and the medical community: a special interest group and a culture are two fundamentally different ways of identifying a group of people.

A culture is a group sharing "characteristic features of everyday existence" including "customary beliefs, social forms, and material traits,"[23] whereas a special interest group seeks "to influence legislative or government policy to further often narrowly defined interests."[24] A special interest group need not even consist of the same people for whom interests are being furthered. Defining the Deaf community as a special

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[21] "Newborn Hearing Screening Laws," National Conference of State Legislatures, May 2011, https://www.ncsl.org/research/health/newborn-hearing-screening-state-laws.aspx

[22] Eshraghi et al., 1972.

[23] *Merriam-Webster.com Dictionary*, s.v. "culture," accessed March 24, 2021, https://www.merriam-webster.com/dictionary/culture.

[24] *Merriam-Webster.com Dictionary*, s.v. "special interest," accessed March 24, 2021, https://www.merriam-webster.com/dictionary/special%20interest.

interest group undermines the communal identity and shared cultural experience that has so often historically been ignored or even suppressed. Overcoming this ignorance and suppression through mutual affirmation and self-advocacy gave Deaf culture the momentum to demand acknowledgement and equality, pointing to a shared language, customs, and practices as evidence of a distinct culture, not unlike other minority cultural groups. Referring to a cultural group as a special interest group significantly reduces the weight of that group's claims and dismisses their needs as requests for special treatment, rather than demands for fundamental human rights.

Without the recognition of Deaf culture and based on the assumption that the Deaf community was a glorified group of lobbyists, medical professionals saw opposition to cochlear implantation as an obstacle to children's typical language development, and by extension, their educational and vocational success. Thus, when the Deaf and disability communities offered a second argument against implantation in children— that they could not provide informed consent— it was met with a rebuttal that "parents have the right and the responsibility to determine their children's best interests"[25] when children are unable to do so. Again, this best interest was perceived by the medical community to be cochlear implantation.

The fundamental difference in understanding of culture and identity between the Deaf community and the medical community created a large rift between the two, and to date some Deaf people remain antagonistic towards audiologic intervention in children and even adults. However, as cochlear implant technology has improved and been shown to be safer and more effective than ever before, "most parents of deaf children now opt to

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[25] Eshraghi et al., 1972.

have their children implanted," including parents who belong to the Deaf community.[26] Today, many people who fully participate in Deaf culture and assume Deaf identity use cochlear implants, hearing aids, and other available technology to participate in the hearing world while still fully embracing Deaf culture and identity.

Conflicts aside, the idea of optimizing the benefit of cochlear implants, as well as hearing aids, is still central to audiology research. While cochlear implants, hearing aids, and vestibular science are long-standing areas of research in audiology, there is still much that is not understood about the mechanisms of hearing, and new technologies and methodologies for diagnosis, treatment, and prevention are being developed every day. Current audiology research covers a wide array of these diagnoses, treatments, and preventions, and has also turned its focus towards new areas which are expanding rapidly, especially since the entire field of audiology is less than a century old. Some broad topics of current interest include hearing conservation, etiologies of hearing loss, disorders related to hearing loss, hearing assistive technology, psychoacoustics, and telepractice.[27] Telepractice, or remotely administered medicine, is relatively well-established in the medical field at large, but has only recently been considered an option for audiologists. Teleaudiology has sought to provide "remote solutions for [cochlear implant] programming, auditory training, and other audiological provisions" for patients in the absence of the testing booth and equipment typically available at audiology

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[26] Eshraghi et al., 1972.

[27] A more complete list of topics in audiology research can be found at https://www.asha.org/aud/focused-topics/.

clinics.[28] Telepractice for audiology may soon present a need for the refining of the

current ethics of clinical practice, but so far research has mostly focused on the feasibility

of teleaudiology and not on ethical considerations[29] beyond the claim that "quality of the

service should be equivalent to in-person service."[30]

*Ethics in Audiology*

Since speech pathology and audiology are closely related, the entities that create

ethical standards for speech pathology also create standards for audiology. This has been

the case since the first professional organization for speech-language pathologists and

audiologists was formed. This organization, currently called the American Speech-

Language-Hearing Association (ASHA), was established in 1925, before the field of

audiology existed, and was originally called the American Academy of Speech

Correction.[31] In 1947, the name was changed to the American Speech and Hearing

Association in order to incorporate audiology. ASHA's first Code of Ethics was

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[28] Yang-Soo Yoon, Callie M. Boren, and Brianna Diaz, "Effect of Realistic Test Conditions on Spectral and Temporal Processing in Normal-Hearing Listeners," *American Journal of Audiology 30,* no. 1 (2021): 166.

[29] Ethical considerations for teleaudiology are mostly similar to those of in-person audiology, and thus mostly focus on patient privacy and quality of care. The use of technology that is relatively new means new standards might need to be introduced, especially regarding patient privacy as information is exchanged via the internet. Quality of care might also need to be redefined in terms is what is feasible over long distances. For instance, there is the question of how valid audiometrics can be when tests are self-administered. These considerations may begin to be explored in the literature when the overall feasibility of teleaudiology is better supported.

[30] "Code of Ethics," American Speech-Language-Hearing Association, March 1, 2016, https://www.asha.org/code-of-ethics/, "Terminology."

[31] "History of ASHA." American Speech-Language-Hearing Association. Accessed March 22, 2021. https://www.asha.org/about/history/

published only a few years later in 1952, and a Board of Ethics was established to meet regularly and update the Code as needed.[32]

The current ASHA Code of Ethics, in effect since March 1, 2016, consists of fifty-five rules, or "specific statements of minimally acceptable professional conduct or of prohibitions" subsumed under four guiding principles.[33] The four principles categorize rules into areas regarding "(I) responsibility to persons served professionally and to research participants, both human and animal; (II) responsibility for one's professional competence; (III) responsibility to the public; and (IV) responsibility for professional relationships."[34] These principles and rules apply to "licensed clinicians, researchers, interns, and students" in the fields of speech-language pathology and audiology.[35]

The purpose of applying a code of ethics to all the members of the aforementioned group is to present "a unique context for decision-making and one that may be different from public opinion, legal doctrines, or personal views."[36] For people in general, action in response to the information given in the previous chapters of this work might be governed by any combination of public and personal opinions, morals, or laws. ASHA's Code of Ethics, like any code of ethics in a healthcare setting, is intended to assist with the "explication and examination of certain ideals" for audiologists in order to

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[32] Robin L. Edge, Bess Sirmon-Taylor, and Raul F. Prezas, "A Comprehensive Review of the 2016 ASHA Code of Ethics," *Journal of human services: training, research, and practice 1*, no. 2 (2016): 3-4.

[33] Edge, Sirmon-Taylor, and Prezas, 4.

[34] ASHA Code of Ethics,"Preamble."

[35] Edge, Sirmon-Taylor, and Prezas, 4.

[36] Shelly S. Chabon and Sandra R. Ulrich, "Uses and Abuses of the ASHA Code of Ethics." *ASHA leader 11*, no. 2 (2006): 23.

protect their patients, their colleagues, and themselves.[37] As such, the Code of Ethics can

be used as a guideline for this work's goal of framing the role of audiologists in patient

counseling with respect to disability culture and identity. However, it is important to

remember that "the Code of Ethics itself does not make a person ethical" and that "ethical

decision-making involves a commitment to applying the ethics code to construct rather

than simply to discover solutions" to the ethical questions and dilemmas faced by

audiologists.[38] In other words, ASHA's Code of Ethics cannot serve as a complete

response to the issues and conflicts raised between people with disabilities and the

medical community as a whole or the audiology community specifically.


*Audiological Counseling*

The attention of this chapter will return to ethics in audiology practice shortly, but

first the origin of audiological counseling[39] must be established. Much like the field of

audiology itself, the concept of audiological counseling existed before the term came to

be used. From the beginning, audiology practice "has focused on both the measurement

of hearing and the impact of hearing loss on communication and social function."[40] The

focus on communication and social function ultimately led to the establishment of

audiological counseling. In the infancy of audiology, communication and social function

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[37] Chabon and Ulrich, 23.

[38] Chabon and Ulrich, 30.

[39] Details of the definition and constitution of audiological counseling are provided in the overall
introduction to this work. As a reminder, the term "audiological counseling" describes counseling in both
the technical and psycho-social domains of hearing loss. According to the American Academy of
Audiology's Scope of Practice, audiologists are responsible for patient counseling in both domains.

[40] "A Brief History of Audiology."

were regarded mostly as products of the ability to perceive and produce speech. After all, this was the central need of veterans who had already developed communication skills and merely needed amplification of sound in order to continue to use those skills. The use of speech audiometry as the primary mode of assessment used by audiologists in the early years reveals the prioritization of speech perception. However, as time went on and research continued, it became apparent that social function and communication involve several components outside of speech perception, including self-confidence and self-advocacy when needed. The discovery of these components of social success revealed a new role for audiologists.

Audiological counseling originated from a practical need to help patients understand their hearing loss and "the role and value" of various audiologic interventions such as hearing aids and cochlear implants.[41] These needs were particularly evident in children, and their families, who had questions about the causes and prognoses of their hearing loss. The implementation of an audiological counseling program at a school for the deaf in New York offered audiologists the opportunity to correct misinformation, such as the idea that a parent had caused the child's hearing loss or that the child would regain his hearing as he grew.[42] Children who still had difficulty coping with their hearing loss could continue with more regular counseling as needed.

As counseling became a more standardized aspect of audiology practice, studies turned attention towards measuring its effectiveness in terms of quality of life. One

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[41] Henna Grunblatt and Lisa Daar, "A Support Program: Audiological Counseling," *Language, speech & hearing services in schools 25*, no. 2 (1994): 112.

[42] Grunblatt and Daar, 114.

observation that increased the use of audiological counseling in clinical practice was that individuals who underwent audiological counseling reported more frequent and more effective use of hearing aids.[43] These individuals also reported "a more relaxed relationship with their hearing impairment"[44] and "increased support and self-confidence."[45] The success of audiological counseling in increasing support and confidence in people with hearing loss shifted the focus of audiological counseling away from mere practical tips for hearing loss management and towards "empowerment, empathy, and confidence."[46] Attempts have been made to standardize counseling in order to achieve these goals, but studies have shown that counseling is optimal when it can be diversified as needed.[47] Approaches that increase the sense of empowerment and confidence in individuals with hearing loss vary significantly based on personal identity and culture. Some sources of empowerment and confidence are already familiar to some patients, and audiological counseling is most successful when clinicians listen and recognize these sources.

Some of the counseling approaches supported by research, such as providing clear technical instructions about how to use devices and addressing both patient and family concerns, are currently being taught in courses for clinical doctoral students in

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[43] Gunnel A. M. Backenroth and Bo H. Ahlner, "Quality of Life of Hearing-Impaired Persons Who Have Participated in Audiological Rehabilitation Counselling," *International journal for the advancement of counselling 22*, no. 3 (2000): 237.

[44] Backenroth and Ahlner, 228.

[45] Backenroth and Ahlner, 237.

[46] Erik Borg and Birgitta Borg, "New Perspectives on Counselling in Audiological Habilitation/rehabilitation," *International journal of audiology 54*, no. 1 (2015): 11.

[47] Borg and Borg, 18.

audiology.[48] Concerns have been raised that not enough programs offer thorough courses in audiological counseling,[49] and while these concerns have been addressed to some extent, courses in the subject are still often offered as electives, near the end of clinical training, and with "insufficient resources, coursework, materials, or time."[50]

## ASHA Ethics, Disability Identity, and Audiological Counseling

ASHA's current Code of Ethics does not address explicitly audiological counseling or patient counseling of any kind in any rules. As such, it could be argued that the ethics of patient counseling are left up to some level of interpretation. However, the goals of audiological counseling outlined in the American Academy of Audiology's (AAA) Scope of Practice[51] fall under the first principle of ASHA's Code pertaining to "responsibility to persons served professionally."[52] This principle includes a rule that requires keeping patients informed "about the nature and possible risks and effects of services provided, technology employed, and products dispensed," as well as "possible effects of not engaging in treatment or not following clinical recommendations."[53] This

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[48] Nicole Pearson, Karen Muñoz, Trenton J. Landon, and Kim Corbin-Lewis, "Counseling Skills in Audiology," The Hearing Journal 72, no. 3 (2019): 50.

[49] Crandell, Carl C. "Counseling Instruction Within Audiology Programs: A Major Deficit in Training?" *Audiology Online*, April 24, 2000.

[50] Pearson et al., 51.

[51] "Scope of Practice," American Academy of Audiology, January 2004, https://www.audiology.org/publications-resources/document-library/scope-practice, "Definition of an Audiologist." Additional explication of AAA's Scope of Practice can be found in the overall introduction to this work.

[52] ASHA Code of Ethics, "Preamble."

[53] ASHA Code of Ethics, Principle I Rule H. "Individuals shall obtain informed consent from the persons they serve about the nature and possible risks and effects of services provided, technology employed, and products dispensed. This obligation also includes informing persons served about possible

principle also includes a rule prohibiting discrimination on any basis, including

"disability" and "culture."[54] Other rules under Principle I include offering the highest

possible standard of care to patients, disclosing important information about treatment to

them, and providing alternatives for obtaining care when the best possible care can no

longer be provided by the current practitioner.

Overall, the theme of the first principle of ASHA's Code of Ethics is providing

the best possible care to patients. One way to "help practitioners better match their

techniques to client needs at appropriate points in time" is to listen "for the presence and

influence of disability identities during the therapeutic process."[55] The previous chapters

of this work have established the numerous ways in which various disability identities

influence a person's experience with healthcare and with the world at large. Disability

scholars have argued that for healthcare practitioners who work with people who have

disabilities, understanding of these disability identities offers an opportunity "to highlight

a particular disability identity theme potentially connected to the client's own disability

experience."[56] This approach is likely to increase the empowerment and confidence

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effects of not engaging in treatment or not following clinical recommendations. If diminished decision-making ability of persons served is suspected, individuals should seek appropriate authorization for services, such as authorization from a spouse, other family member, or legally authorized/appointed representative."

[54] ASHA Code of Ethics, Principle I Rule C. "Individuals shall not discriminate in the delivery of professional services or in the conduct of research and scholarly activities on the basis of race, ethnicity, sex, gender identity/gender expression, sexual orientation, age, religion, national origin, disability, culture, language, or dialect."

[55] Dana S. Dunn and Shane Burcaw, "Disability Identity: Exploring Narrative Accounts of Disability," *Rehabilitation psychology 58*, no. 2 (2013): 155.

[56] Dunn and Burcaw, 154.

obtained through audiological counseling and thereby improve the overall experience of people with hearing loss who pursue audiologic intervention.

Understanding disability culture and identity also ensures the non-discrimination policy outlined in ASHA's Code of Ethics. Antipathy towards people with disabilities can be expressed behaviorally, but it is more often implicit in the attitudes of people without disabilities who "lack meaningful personal relationships with people with disabilities or have not had sensitization training."[57] As a result, typically-abled people might assume things about the experience of people with disabilities that are not necessarily true. For example, many people without disabilities do not separate the negative experience of disability from impairment, whereas most accounts from people with disabilities "explicitly point out that the main and sometimes the only disadvantage of the impairment is not physiological, but social; the ugly and unwelcoming attitudes of others, the strict insistence on the standard modes and levels of functioning, and the physical impediments to access all make people suffer."[58] For healthcare professionals, including audiologists, who frequently encounter people with disabilities, "becoming familiar with disability narratives and their identity components is likely to be a convenient and compelling way to combat the aforementioned antipathy (often unknowingly) harbored" by people without disabilities.[59]

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[57] Dunn and Burcaw, 150.

[58] Sara Goering, "Rethinking Disability: The Social Model of Disability and Chronic Disease," *Current reviews in musculoskeletal medicine 8*, no. 2 (2015): 137.

[59] Dunn and Burcaw, 154.

Developing familiarity with disability identity and narratives can prove to be a difficult task for healthcare professionals for a number of reasons. There is, first of all, the influence of the medical model of disability on medical training. Medical professionals are not alone in recognizing that there are negative effects of impairments and that there are advantages to using biotechnology, pharmacology, and other resources to reduce these effects. It seems that acknowledging these disadvantages and advantages is an act of rebellion against the social model of disability, but there is a grey area in which "medical professionals [can] talk candidly about negative impairment effects while maintaining full respect for individuals with disabilities and fighting for disability justice, for full inclusion of people with disabilities in society."[60] In fact, this grey area may be the optimal approach for healthcare practitioners, including, and perhaps especially, audiologists.

Models of disability "can cause prejudice and discrimination," "provide responsibility attributions," and "guide the formulation and implementation of policy."[61] Because of these aspects, disability models can easily become entangled with care for people with disabilities in ways that create complex ethical issues. ASHA's Code of Ethics exists to help disentangle these matters, but it is not specific or exhaustive enough to avoid all the ethical quandaries healthcare professionals, including audiologists, might encounter. The preamble to the Code accounts for these quandaries by encouraging

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[60] Goering, 135.

[61] Marno Retief and Rantoa Letšosa, "Models of disability: A brief overview," *HTS Teologiese Studies/Theological Studies, 74* no. 1 (2018): 1. https://doi.org/ 10.4102/hts.v74i1.4738

professionals to "uphold the spirit and purpose of the Code,"[62] which overall promotes

"duty, accountability, fairness, and responsibility"[63] to the public, to fellow professionals,

and perhaps most centrally, to patients.

In cases that the Code of Ethics does not address, other aspects of personal value

systems might guide decision-making. In these instances, caregivers must remember that

"models of disability are not value neutral,"[64] and as such, presumptions and prejudices

towards people with disabilities might implicitly affect the quality of care being provided.

Therefore, audiologists who aim to offer the best possible care to their patients do not

have the option to passively adopt whichever disability model is most salient to them.

Rather, excellent patient care requires thoughtful and intentional analysis of as many

disability models as possible *before* individual patients are considered. This work extends

to case-by-case care as audiological counseling reveals the aspects of disability culture

and identity adopted by each patient and by his network of family, friends, coworkers,

and caregivers.

Since counseling competence requires a certain level of cultural and identity

competence, there currently exists a minimum level of this work to be done by all

professionals in the field of audiology. But then, the ideal healthcare practitioner should

not be satisfied by the minimum level of care in any area, so perhaps a higher bar should

be set. In more well-established areas of the fields of speech pathology and audiology,

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[62] ASHA Code of Ethics, "Preamble." "Because the Code is not intended to address specific situations and is not inclusive of all possible ethical dilemmas, professionals are expected to follow the written provisions and to uphold the spirit and purpose of the Code."

[63] ASHA Code of Ethics, "Preamble."

[64] Retief and Letšosa, 1.

ASHA's Code of Ethics demands lifelong learning for all professionals to whom the Code applies. A similar level of diligence applied to audiological counseling would warrant lifelong learning about disability culture, identity, and models. In doing so, audiologists would "uphold the spirit of the code"[65] by serving the best interests of patients, fellow practitioners, and the public as a whole.

Understanding disability as patients might and committing to grow this understanding through the span of one's time in clinical practice is systemically under-observed. A survey of Department of Veterans Affairs (VA) audiologists regarding common audiological counseling practices showed that while almost all clinicians cover the domain of audiological counseling regarding use of hearing devices, realistic expectations for them, and communication strategies, far fewer clinicians usually discuss the psychosocial impacts of hearing loss.[66] Another study reported a highly unequal distribution of time devoted to technical components of an appointment versus time devoted to counseling.[67] The study also reported a majority of "audiologist dominated interactions," indicating that in a typical appointment, audiologists spend much more time talking than listening to patients and families.[68] Neither the lack of time spent on counseling in general nor the lack of time spent listening to the patient's questions,

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[65] See note 60 above.

[66] M. Samantha Lewis, Michelle Hungerford, and Garnett McMillan, "Audiological Counseling Practices," *Audiology Today*, *31* no. 4 (2019): 22.

[67] Vinaya Manchaiah, Monica L. Bellon-Harn, Ashley L. Dockens, Jamie H. Azios, and William E. Harn, "Communication between Audiologist, Patient, and Patient's Family Members during Initial Audiology Consultation and Rehabilitation Planning Sessions: A Descriptive Review," *Journal of the American Academy of Audiology*, *30* no. 9 (2019): 810.

[68] Manchaiah et al. (2019), 813.

concerns, and comments appear to be due to time constraints, as most "respondents reported a willingness to add clinical time for counseling if it improved outcomes."[69]

Current literature on audiological counseling supports the idea that "empathetic listening and good clinician–patient communication helps in better understanding the problems experienced by the patient and understanding their stage in the journey through hearing loss," which "is critical in developing personalized management plans."[70] Research also links patient-centered care to "improved quality and outcomes in healthcare."[71] Yet, surveys and reviews suggest that audiologists do not always practice patient-centered care. The reasons for this are unclear. Some have argued that the apparent lack of patient-centered care is actually a "noncongruence in preferences for patient-centeredness among audiologists and patients with hearing loss."[72] Others have argued that underrepresentation of the psychosocial domain of audiological counseling in practice may be "because audiologists feel less prepared to have these types of conversations."[73] In one survey of clinicians, almost half reported that they "did not have adequate training to provide counseling" to patients with hearing loss.[74]

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[69] Lewis, Hungerford, and McMillan, 24.

[70] Manchaiah et al. (2019), 818.

[71] Vinaya Manchaiah, Ashley L. Dockens, Monica Bellon-Harn, and Erin S. Burns, "Noncongruence between Audiologist and Patient Preferences for Patient-Centeredness," *Journal of the American Academy of Audiology*, *28* no. 7 (2017): 636.

[72] Manchaiah et al. (2017), 642.

[73] Lewis, Hungerford, and McMillan, 23.

[74] Manchaiah et al. (2019), 818.

*A Different Approach*

A simple way to incorporate more of this domain into practice is to incorporate it into the training required to become a clinician. This would not require the modifying of any clinical or ethical standards. Clinician training programs could easily maintain ASHA's Code of Ethics and ensure adequate training in AAA's Scope of Practice by adding and requiring a course or courses in audiological counseling to the already existing curriculum. There are certainly enough studies and reviews on the topic to frame an evidence-based approach that could be standardized across all programs, and within the next decade a new generation of audiologists would enter the field with greater competence and confidence in audiological counseling than ever before.

The above approach would be relatively easy to implement and would achieve results quickly, but it operates on the assumption that maintaining ASHA's Code of Ethics and AAA's Scope of Practice in education is sufficient training for ideal, patient-centered care. This assumption is dangerous because clinical practice and research in audiology are often industry-driven, and as a result ethical quandaries not specifically presented any ethical code often present themselves.[75] In the field of audiology, it is impossible to cleanly separate patient care from industry, and it is equally impossible to create an exhaustive ethical code. Thus, standardized education on patient-centered care would still leave many decisions up to individual interpretation of vague ethical guidelines. Audiological counseling practices might improve, but overall training for clinicians would still be missing something.

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[75] Stella L. Ng, Jeffery Crukley, Emilia Kangasjarvi, Laya Poost-Foroosh, Steve Aiken, and Shanon K. Phelan, "Clinician, student and faculty perspectives on the audiology-industry interface: implications for ethics education," *International Journal of Audiology*, *58* no. 9 (2019): 577.

Other health professions have faced similar difficulties in crafting an education that prepares clinicians to make ethical decisions. These professions have set a precedent that "beyond codes, guides and regulation, another form of education is useful, one that focuses on virtue ."[76] This form of education "would not ignore ethical codes, principles and guides," but rather "would position things like codes of ethics as akin to clinical practice guidelines – a starting point but not the end point."[77] This approach assumes that "the ability to make practically wise choices is dependent on the possession of good moral character,"[78] and thus focuses on "organizing a community in such a way that the moral and intellectual excellences are provided the proper conditions to flourish."[79] The aim to flourish, or "to grow luxuriantly,"[80] suggests that while a code of ethics can serve as a starting point, no ending point can clearly be defined. Patient-centered healthcare practice requires from its practitioners the determination and diligence of constant pursuit as well as the humility to recognize continued need for transformation and growth.

This sort of approach has already begun to be formed in general medical education, and it is being applied in programs at more than fifty institutions[81] in the

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[76] Ng et al., 583.

[77] Ng et al., 583.

[78] Warren A. Kinghorn, "Medical Education as Moral Formation: An Aristotelian Account of Medical Professionalism," *Perspectives in biology and medicine 53*, no. 1 (2010): 102.

[79] Kinghorn, 103.

[80] *Merriam-Webster.com Dictionary*, s.v. "flourish," accessed March 24, 2021, https://www.merriam-webster.com/dictionary/flourish.

[81] Beth Howard, "More Pre-Med Students Opting for Health Humanities Programs," Association of American Medical Colleges, December 11, 2016, https://www.aamc.org/news-insights/more-pre-med-students-opting-health-humanities-programs

United States at either the undergraduate or graduate level, depending on the institution.[82]

One such program, the Medical Humanities program at Baylor University, defines the

discipline of medical humanities:

> Medical humanities is an exciting interdisciplinary field emerging at the
> intersection of the biomedical sciences and the humanities. Disciplines from the
> realm of the humanities (philosophy, history, literature, religion, ethics, social
> sciences, behavioral health and the arts, among others) are seen as complementary
> and not incompatible with the basic sciences that have traditionally dominated
> premedical and pre-health education… Studies in the medical humanities are
> meant to enhance medical education and clinical practice by restoring more
> holistic values into the healing arts and healthcare settings and reminding us that
> our explicit focus in healthcare should include the experience of patients as
> human beings, not just as particular body parts or pathological processes.[83]

The premise of education in medical humanities is that human beings "are not

simply physical beings with a merely *additional* psychological, personal, or spiritual

aspect," but rather, "our bodily tissues inform our personal identities, appearances,

motives, desires, appetites, abilities, hopes, and fears."[84] Physicians lessen the quality of

their patients' care when they attempt to cleanly separate the experience of an illness or

an impairment from the experience of being human. This attempt at separation is

traditionally made during training, in which undergraduate education allows students to

explore the humanities as long as they also acquire a sufficient foundation in the natural

sciences. Once students reach medical school, the humanities are attenuated and replaced

by purely clinical training. This traditional approach suggests that the humanities are

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[82] "Other Health Humanities Programs," Stanford Center for Biomedical Ethics, accessed March 25, 2021, https://med.stanford.edu/medicineandthemuse/ProgramLinks/OtherPrograms.html.

[83] "Medical Humanities at Baylor University." Baylor University. Accessed March 25, 2021. https://www.baylor.edu/medical_humanities/index.php?id=874014

[84] Martyn Evans and Ilora G. Finlay, "Introduction," in *Medical Humanities*, ed. Martyn Evans and Ilora G. Finlay (London: BMJ, 2001), 1.

optional and perhaps unnecessary; on the other hand, the medical humanities approach

argues that "humanities are not an (optional) addition to scientific medical knowledge but

hold an *integral* place with the natural sciences at the core of clinical medicine."[85]

The implementation of humanities-based approaches to medical education has

been met with a mix of enthusiasm and concern that curricula are "already tightly-

packed."[86] Despite initial concerns, demand for the humanities-based approach has

increased astronomically in the last twenty years. Medical humanities programs "have

quadrupled since 2000," and now include 16 undergraduate majors and 41 minors offered

by schools as of 2016.[87] Programs have also begun to be integrated at the doctoral level,

even in some of the nation's most reputable medical schools. Programs such as Stanford

University School of Medicine's "Medicine and the Muse" program,[88] Harvard Medical

School's "Department of Global Health and Social Medicine,"[89] and Yale School of

Medicine's "History of Science and Medicine" program[90] integrate art, history, culture,

and other domains of the humanities with the traditional natural science disciplines. So

these programs, and others like them, have demonstrated that expansion into the

humanities does not diminish technical excellence in the sciences. Instead, integration of

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[85] Evans and Finlay, 2.

[86] Evans and Finlay, 3.

[87] Howard, "Curriculum Variations."

[88] More information about Stanford's medical humanities program can be found at https://med.stanford.edu/medicineandthemuse/about.html.

[89] More information about Harvard's medical humanities program can be found at https://ghsm.hms.harvard.edu/.

[90] More information about Yale's medical humanities program can be found at https://hshm.yale.edu/graduate-studies.

the sciences and the humanities produces clinicians with a deeper understanding of the inseparability of physical health and mental, emotional, and spiritual well-being. These clinicians are better equipped than ever before to provide top-quality, patient-centered care.

*Conclusion*

The field of audiology is less than a century old. In the context of the history of medicine as a whole, audiology is in its infancy. As a result, the field of audiology has a unique opportunity to imitate other disciplines in medicine and proverbially stand on the shoulders of giants. Advances in research and clinical practice in the medical field at large have allowed research and clinical practice in audiology to expand quickly in breadth and depth, and these expansions are not limited to the natural sciences. Recently, medical education has turned its attention from enforcing ethical guidelines towards forming moral character that allows practitioners to make ethical decisions that the writers of ethical codes might not be able to foresee.

Clinical doctoral (AuD) programs in audiology, much like traditional doctor of medicine (MD) programs, are densely packed with technical training. As MD programs are modified to include elements of the humanities and of moral formation, AuD programs should not be idle. There is no reason to expect that the same kind of formation that makes holistically excellent doctors in other medical disciplines will not be effective for the training of doctors in audiology. Thus, the humanities-based education approaches being implemented in general medical education should be implemented in audiological education. The lack of preparation in audiological counseling would be directly addressed

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in this implementation, as expansion into the humanities would better equip clinicians to understand and discuss culture and identity with patients.

For medical professionals, special consideration should be given to disability models as a branch of humanities in education. Understanding models of disability and their bearing on the lives of people with disabilities is central to holistic, patient-centered care. A well-rounded understanding of Deaf identity and culture (chapter one), disability identity and culture (chapter two), and the experience of invisible disability (chapter three) is especially important for audiologists, as they will encounter patients who are grappling with these cultures and identities every day. Moreover, comprehending the significance of the impact of disability models on the lives of people with and without disabilities (discussed in chapter three) enables audiologists to engage in more constructive conversations about the psychosocial domain of hearing loss.

Current standards for audiological practice are clear: audiologists are responsible to patients and to the whole public regarding communication of the causes, treatments, and impacts of hearing loss. Current educational standards ensure that clinicians are competent in the domains of understanding and communicating causes and treatments, but these standards are lacking in the domain of understanding and communicating the psychosocial impacts of hearing loss. Fortunately, this gap in preparation can be filled with more well-rounded training at the entry level. Current and future audiologists can play a key role in the filling of this gap by demanding transformation of existing clinical training programs. The precedent is established and the path is well-paved. The only work left to be done is to follow the path and see where it might lead.

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