

What Does it Mean to be Deaf? Changing Meanings of Deafness, Communication
Technology, and Beliefs about Normality in the US

by

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Abstract

How deafness is perceived as a problem by society dictates what types of technologies are leveraged to address the problem, and, conversely, available technologies shape how deafness is perceived. In this dissertation, I draw on multiple methods to explore the meanings of deafness in the US since the early 18th century to the present, examine how the meanings of deafness in those eras shaped deaf technology, and assess how available technologies shaped how deafness was understood. Using primary and secondary historical sources, I identify that every era identifies a different “problem of being deaf” and it is that problem that technologies are crafted to address. These technologies aim to “make normal” the deaf person, but by doing so, medicalize the condition of deafness, which both increases and decreases stigma surrounding the condition. Content analysis of advertisements for hearing aids from approximately 1910- to the present day, and present-day cochlear implant websites highlight these “problems of being deaf” and demonstrate how the particular technology advertised can achieve normality for the buyer. Through interviews with 33 parents, I find that goals of making their deaf children “normal” and improving communication are at the forefront of parents’ decision-making process for cochlear implants.

Dedication

Dedicated to all the pioneers in hearing technology science- from those who helped bring ASL-education to the United States in the 1700's to the cochlear implant visionaries of the present.

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Chapter 1. Introduction

Some deaf Americans consider deafness to be a “normal” state— many of these are members of the Deaf community, a cultural and linguistic group that views deafness as a difference, not a disability. Members of the Deaf community, that is to say, deaf people who use sign language to communicate, do not view deafness as a medical problem. Instead, it is seen as a difference to be celebrated (Lane 1999), and not an abnormality. Members of the Deaf community consider deafness to be akin to an ethnic minority (Lane 1999), complete with its own language, which like other languages is a constantly evolving technology, traditions, art, and humor (Lane 1999).

Others view deafness as an “abnormal disability” that should be ameliorated with medical technology such as hearing aids, cochlear implants, and specialized schooling and therapy. By the late 1800s, there were several technologies, including surgeries, to address deafness. These include the ear trumpet, early hearing aids, and surgeries to release pressure on the small bones in the ear. Until the mid-1980s, the dominant hearing technology available to deaf children and adults was hearing aids, but cochlear implants soon became a viable option, both for very young children, as well as for adults who had lost their hearing post-lingually. Cochlear implants are a small device implanted into the cochlea of a deaf person, that, when combined with intensive speech therapy, can allow

recipients to understand and produce speech. As of December 2019, approximately 736,900 cochlear implants have been implanted worldwide. In the United States, roughly 118,100 devices have been implanted in adults and 65,000 in children (National Institute on Deafness and other Communication Disorders 2021).

Nearly 4 out of every 1000 Americans over the age of 5 are functionally deaf, with more than half of these being over the age of 65 (National Center for Biotechnology Information 2011). Hearing loss affects two to three infants out of every 1000, and 90% of these children are born to hearing parents (National Institute of Deafness and Other Communication Disorders 2011). Deafness has many different etiologies, including genetic defects, such as the most common cause of congenital hearing loss, mutations on the gene Connexin 26 (National Center for Biotechnology Information 2011), and cytomegalovirus (National Institute on Deafness and Other Communication Disorders 2002). There are multiple ways families deal with congenital deafness in their child, including hearing aids, American Sign Language (ASL), and cochlear implants.

The concepts of normality, medicalization, and stigma will be defined, explored, and serve as anchors for this dissertation. Although there are several ways to approach the definition of normality, it is generally considered to be the statistical norm within a society, or as behaving in the way that “nature intended” (Horwitz 2016). Horwitz and

Wakefield (1999; 2009; 2008), conceive of normality as consisting of both biological aspects and social aspects. Indeed, deafness is a biological fact and these two theorists depart from traditional medicalization thought by highlighting the biological nature of social facts (Cotter 2013). Medicalization is when a biological process, behavior, or state falls under the purview of the medical establishment and becomes considered a medical problem to be treated by medical professionals and medical technology (Horwitz and Wakefield 2007). Medicalization occurs when normal human variation is transformed into treatable disorders (Conrad 2007; Mayes 2019; Warren 1981). Stigma theory describes the social processes of how people create “in-groups” and “out-groups” and how people with culturally undesirable characteristics are marked as having a “spoiled identity” (Goffman 1963). It is through these lenses that I will look at the history of deafness and deaf technologies, including providing some insight into how these technologies have been marketed and advertised, in the past, and into today.

The idea of what is normal informs what technologies are developed to address deafness, as well as guides marketing and advertisement strategies. I will explore the concept of normality, and how feelings of what is normal or abnormal play into the experience of parents and their decision to implant their child with cochlear implants. I will also look at how medicalization has given rise to a generation of deaf children with

cochlear implants— medicalization is the soil in which technologies for the deaf are nurtured and grown. Lastly, I will consider stigma as a reason why hearing parents get cochlear implants for their children. Stigma is also very impactful when analyzing the history of deaf technology, as well as advertisements for it.

I argue that how deafness is perceived by society dictates what types of technologies are leveraged to address the problem, and, conversely, available technologies shape how deafness is perceived. In this dissertation, I am going to explore the meanings of deafness in the US since the early 18th century to the current era, and examine how the meanings of deafness in those eras shaped deaf technology, and how available technologies shaped how deafness is understood. Every era identifies a different “problem of being deaf” and it is that problem that technologies are crafted to address. These technologies aim to “make normal” the deaf person. Advertisements for hearing aids and cochlear implants highlight these “problems of being deaf” and demonstrate how the particular technology advertised can achieve normality for the buyer. Goals of making their deaf children “normal” are at the forefront of parents’ decision making process for cochlear implants. Parents want their children to have “normal” childhoods and adult lives and think that cochlear implants and oral educations are the way to achieve that.

It is important to note that the scholarship in this dissertation apply to “little” d deaf groups only. I do not explore Deaf communities, or ASL in this dissertation. There is an ongoing debate among the Deaf and deaf communities, that as more and more deaf children, born mostly to hearing parents, will get cochlear implants, and therefore not join the culturally Deaf community, that community and language will eventually die out. This is essentially a demographic challenge to the Deaf community, and an existential threat, because their ranks will dwindle if there is not a constant influx of new members. This debate is better explored elsewhere, where it can be scrutinized and evaluated on its own.

The overall research question for the dissertation is “How have the social meanings of deafness, deaf technology, and beliefs about normality shifted over time?” Or, in short, “What does it mean to be deaf?” To answer this question, I will explore implications of deaf technologies from the viewpoints of normality, medicalization, and stigma. I contribute to the literature in each of these areas by incorporating the “meanings of deafness” across time, and how these meanings of deafness have influenced deaf technology, and, conversely, how technology has influenced the perceptions and meanings of deafness throughout the years.

For this multi-method dissertation, in which I use content analysis of newspaper and magazine articles on deafness and hearing technology from the 1700's-1800's, contemporary hearing aid and cochlear implant advertisements and websites, as well as interviews with 33 parents of deaf children implanted with cochlear implants, I draw on a rich history of sociological thought about normality, medicalization, and stigma. The first major sociologist I draw on is Allan Horwitz, who studies normality. Horwitz (2016; 2017), and Horwitz and his colleague Jerome Wakefield (1999; 2009; 2008), conceive of normality as consisting of both biological aspects and social aspects. Indeed, deafness is a biological fact and these two theorists depart from traditional medicalization thought by highlighting the biological nature of social facts (Cotter 2013)

I also draw on the work of Peter Conrad, and his work on medicalization (2007; 2014; 2010; 2008). Conrad uses examples of adult ADHD and Andropause as examples of medicalization (2007). Deafness has been medicalized since medical professionals, including doctors, surgeons, and audiologists became involved in the "treatment" of deafness, including surgeries, hearing aids, and cochlear implants. In fact, the first known modern surgery for deafness was developed in 1791, before ASL residential schools were commonplace (Lane 1999). This single failed attempt at medicalizing deafness notwithstanding, before medical professionals became involved in the treatment of

deafness, deaf children attended residential deaf schools that were run by clergy.

Treatment was not the goal at these schools— education, including religious and secular, were. Scholars influenced by Conrad have studied topics as diverse as social deviance and “badness” (Warren 1981) and others have drawn explicitly on Conrad’s own work on ADHD (Mayes 2019). In this dissertation, I aim to combine theories of medicalization with an example of sociotechnical change—cochlear implants and other hearing technology—, and how these technologies have contributed to, and influenced, medicalization of deafness.

The work of Erving Goffman (1963; 1959) informs my understanding of stigma, “passing,” and coping with a “spoiled identity” (Barmaki 2021; Takeshita 2020; O’Connell 2016; Stein 2009;) Deaf people have a “spoiled identity” because they are different from the rest of society, and as a result sometimes try to “pass” (Goffman 1963). Passing is easiest if one has a cochlear implant that allows easier access to hearing and speech. Some children implanted prelingually have such perfect speech, tonality, and accent, that nobody but close family know they are deaf. Scholars have drawn on Goffman’s work to explore topics ranging from ethnic identity (Takeshita 2020), to the Holocaust (Stein 2009). O’Connell expressly uses a Goffmanian framework to explore the concepts of normality and deafness (2016).

RESEARCH QUESTIONS

The overarching research question will be supplemented by a single research question for each findings chapter. To be explicit, these research questions are listed below:

RQ1: Drawing on historical accounts of deafness from the early 1800s to contemporary times, how have the social meanings of deafness, deaf technologies, and social beliefs about normality changed? (Chapter 4)

RQ2: How do advertising and marketing strategies for deaf technologies from the 1900s to the present reflect the changing social meanings of deafness and social beliefs about normality? (Chapter 5)

RQ3: How do contemporary parents' decisions to get a cochlear implant for their children reflect the relationships between social meanings of deafness, deaf technology, and social beliefs about normality? (Chapter 6)

OVERVIEW OF THE DISSERTATION

The upcoming chapters will explore different aspects of hearing technologies and the concepts of normality, medicalization, and stigma, as they relate to deafness. Chapter two is a literature review and explores scholarship on the topics of normality, medicalization, and stigma. It also examines the scholarship about advertisements for

medical devices, including hearing devices, and also explores the research regarding parents' medical decision-making processes. Chapter three presents the methods, where I describe my approach to data collection and analysis. Chapter four is the first of three findings chapters, and, using an historical method, examines the meanings of deafness in the US since the eighteenth century, and how those meanings of deafness have influenced hearing technology through the years. This is not a one-way street, however— as much as the meanings of deafness have influenced technology, available technology influences how deafness is understood. This chapter also presents a historical overview of the technological development of hearing technology, including ear trumpets, signed languages, hearing aids, and cochlear implants. The intention of this chapter is to demonstrate the recursive nature of hearing technology— social meanings are developed, technology is shaped to respond to the social meaning, which, in turn shapes the social meaning, and goes back to technology, etc. In this chapter, I rely on a variety of primary and secondary historical documents, including newspaper articles from the 1800s. Chapter five explores themes present in hearing aid advertisements since the early 1900's to the present, and also examines contemporary hearing aid and cochlear implant websites. The themes in these advertisements tend to map over the “meanings of deafness” explored in the history presented in chapter four. Chapter six is the last

findings chapter and presents the findings of my interviews with 33 parents who chose to implant their deaf children with cochlear implants. Seeking “normal lives” is an important theme in this chapter. Finally, in chapter seven, I’ll conclude the dissertation with a discussion of major themes and future directions.

Chapter 2. Literature Review

In this literature review, I will first explore the three theoretical concepts that frame this dissertation on the meanings of deafness and deaf technology: normality, medicalization, and stigma. These three concepts frame all discussion about deafness—whether or not it is “normal” to be deaf or have a cochlear implant, to what degree do we wish to have the medical profession influence decisions about deaf peoples’ communication methods, and lastly, how does stigma influence medical decision making and the day-to-day life of being deaf. I will then very briefly explore the Science and Technology (STS) method of understanding the recursiveness of the meanings of social problems and technology. This section will set up the discussion in chapter four about the history of the meanings of deafness and the history of deaf technology. I will then examine some of the literature regarding medical advertisements and marketing materials. Advertisements are one way in which the norms of society are disseminated, including medicalization of conditions, and in this way, normality can be communicated. This section of the literature review will examine advertisements broadly, then will focus in on medical and pharmaceutical advertisements. This scholarship provides the groundwork for my findings about advertising and marketing of hearing technology in chapter five. The last part of this chapter will focus on the parental medical decision—

making process broadly and about cochlear implants for their deaf children specifically. Cochlear implants are an interesting, although not singular, space in which to examine medical decision making. First, the medical decision in this case is almost always done by the parent, not by the recipient, or child. Secondly, because of the normative pressures of the hearing community, a decision to give one's child a cochlear implant is a normative decision as well as a medical decision. This scholarship provides context for my findings based on interviews with parents who choose cochlear implants in chapter six.

NORMALITY

Different social groups construct the meanings of physical difference to fit competing ideologies and interests (Zerubavel 1999). When a condition or state is identified as abnormal or disabling, corrective procedures and technologies are often offered to the afflicted individual(s) to restore or gain normality. Identifying normality is so important to us because of the outcomes for those labeled abnormal. People categorized as abnormal are, on the one hand, given special accommodations and treatment (such as preferred parking spots), and on the other hand, are stigmatized and outcast. As a society, we vacillate between accommodations and outcasting, and these outcomes seem to depend on the perception of the labeler- and it is the labeler who

stigmatizes, or accommodates, so it is a vicious cycle. Because of the biological nature of physical abilities such as hearing, specialists and laypeople alike forget the purely conventional and social nature of disability classifications, and instead attribute a profound natural power to these categories (Harkin 1994, Lane 1999). Bodies themselves are a highly contested space, in which competing cultures vie for the right to define and sculpt that body (Harkin 1994). The concepts of normal/abnormal and disabled/abled exist as social constructs— *people* have to define things as normal/abnormal— they are not “natural” states of being (Horwitz 2016; Zerubavel 2020). Defining a body as disabled or abled does not occur in a vacuum, nor is it an automatic classification; instead, it is always in contrast to the *normal* (or abled) that the abnormal (or disabled) is understood.

Social scientists and humanities scholars have identified three general ways to understand the competing categories of abnormal and normal. At one end is a pure social constructionist approach that argues that abnormal and normal are only real in their consequences because they have been socially defined as such (Berger and Luckmann 1967). At its most basic level, social construction theories contend that all systems of knowledge and ways of understanding are reflections of culturally specific processes (Foucault 1994; Foucault 2009). Our world is inseparable from the social processes that

allow us to comprehend and organize that world. Social constructionist scholars do not assume that taken-for-granted categories represent any natural reality, but instead they reflect and respond to shifting social forces (Berger & Luckmann 1967). Normality, therefore, is culturally created and there exists no universal normality in the same way as there exists no universal morality (Benedict 1934; Hacking 1986). This dissertation relies on this definition of normality and is social constructivist in its approach.

Moving away from a pure constructionist perspective, an interactive approach understands normality and abnormality to be a dialectic between the social and the biological (Fleck 1979; Hacking 1986; Hacking 1999) in such a way that the social understanding of bodies informs the construction of physical bodies, and vice versa. This perspective explicitly brackets the question of what is “real” and instead focuses on the dynamic between social and physical bodies.

Lastly, on the opposite end of the continuum from social constructionism is a naturalist approach that understands bodies to be a real, “hard” physical reality outside of the realm of the social. This approach argues that the body has natural functions based in evolutionary processes, and that the abnormal can be understood as harmful dysfunction (Horwitz and Wakefield 2007; Wakefield 2007). Table 1 highlights the key points of each of the three conceptions of the medical model of disability.

Table 1. Conceptions of Normality by Theorist

Normality Concept	Main Theorists	Key Points
Pure Constructionism	Canguilhem, Foucault, Goffman, Conrad	<ul style="list-style-type: none"> —Normality is context—specific —Normality is centered on a being's ability to adapt to the environment
Interactive	Hacking	<ul style="list-style-type: none"> —Humans create normality, physiology creates bodies —Social value placed on physical bodies is cultural —Interaction between the labeler and those labeled
Harmful Dysfunction	Wakefield, Horwitz	<ul style="list-style-type: none"> —Every body part has an evolutionary function —A body part can be dysfunctional, e.g.: not work the way it is supposed to, but not be harmful e.g. albinism —The harmful component is normative and socially constructed

MEDICALIZATION

Social constructivist/medicalization perspectives vary across time and space. As will be seen in chapter four, deafness as a medical disability can definitively be understood as a social construction, because it has not always been conceived of as a medical problem, and even today, not all social groups consider it a problem to be solved by advanced medicine. As I discuss in chapter four, prior to the 1850's, deafness was conceived of as a spiritual disability, but it was not medicalized as a medical problem, so,

by and large, it was not treated with medical interventions. The problem of deafness was understood as a religious problem, and the treatment, therefore, was a spiritual and educational treatment. However, by the end of the 19th century, and the beginning of the 20th century, the problem of deafness became more of a “medical” problem, and this will be examined in fine detail in chapter four. As time has gone on, deafness has become more and more medicalized, as the technology to treat it has become more and more “medical.” In this way, not only does the understanding of deafness influence the technology available to treat it, but the technology available influences the understanding of deafness. The increasing medicalization of deafness is important because, as it becomes more medicalized, more and more deaf, and hard-of-hearing people will be considered “disabled” and in need of medical/surgical correction. To the ASL-using Deaf community, this medicalization can represent an existential threat—as more and more deaf children are implanted with cochlear implants and speak and hear instead of using ASL, the ASL-using community will become smaller and smaller and may face cultural and linguistic extinction. It is important to note, that although the two concepts are closely related, normality and medicalization are separate ideas. Ideas about normality almost always coincide with medicalization, however, many things are normalized that are not also medicalized.

The idea of “problems of deafness” is related to Peter Conrad’s concept of “Risk Scares” (2007). Risk scares come about when medical professionals tell patients that something very bad will happen if they do not do “x” (Conrad 2007). In this context, surgeons, and other medical professionals such as audiologists imply that their child will not be normal, and may live an isolated, inferior life without cochlear implants

Sociologists have long been concerned with how diagnostic criteria of illness and disability are created and transformed, and how determinations are made as to what is considered to be illness or disability (Horwitz, 2002; Horwitz and Wakefield, 2006; Horwitz 2007). In particular, social constructionist perspectives describe the process by which certain symptoms come to be seen as problematic, while others do not, and how human conditions are intimately connected to concepts of deviance and abnormality (c.f. Szasz, 1960; Horwitz, 2002).

In one account of medicalization, Richie (2019) writes, “Medicalization occurs when an aspect of embodied humanity is scrutinized by the medical industry, claimed as pathological, and subsumed under medical intervention.” Medicalization of deafness first appears in history in the 1790s, when Luigi Galvani experimented with Galvanism to correct deafness (Lane 1999). In this attempt, Galvani used a medical treatment to

address deafness, rather than a social or cultural intervention, and so is considered among the first attempts to medicalize deafness. However, his surgery failed, and so the event is considered an “attempt” at medicalization, but not a successful one. Attempts such as this to medicalize deafness can be seen by those adopting a cultural understanding of deafness as parallel to eugenics or genocide (Cherney 1999, Baynton 1996, Lane 2005).

Mauldin (2016), in her book about the medicalization of deafness writes, “We can now engage in attempts to treat, find relief, look or feel more ‘ideal,’ or pass on traits of normalcy— which have social value— to our children.” In contrast to Mauldin’s findings, Pfister (2018), in an article about deaf children of hearing parents in Mexico, comments that the parents in her study eventually came to realize the goal is not to “fix” their children, but rather to adopt communication technologies such as signed language to facilitate communication. In this manner, Pfister’s (2018) subjects rejected the medicalization of deafness, and instead adopted a cultural technology. Ethnic Chinese deaf minorities in Tibet and Mongolia have been subject to a “civilizing project” (Hofer and Sagli 2016) and, as such, have been compelled to use Chinese Sign Language (CSL) instead of local signed languages. This “civilizing project” recalls the problem of deafness as connection to the Nation and to humankind, which will be explored in detail in chapter four— that language adoption of the dominating country or culture is a form of

normalization and cultural domination. Although the use of CSL (or ASL) is not medicalizing, this example shows how structures of power and dominance can influence how deafness is perceived and the kinds of technology that will be used to address the problem as it is conceived. Hayes and Hanold (2007) argue that medical and allied medical professions contribute to the medicalization of people with disabilities. In the case of deaf children, this would include the audiologist who conducts the first Auditory Brainstem Response (ABR), a definitive test for deafness. In essence, it is this test, and these medical professionals, who first medicalize the deaf child.

Medical technology is used to ameliorate abnormality. Ideas of what is normal- such as the idea that hearing is normal- inform what problems of living are medicalized, and once a problem has been medicalized, medical technology can arise that addresses the newly medicalized problem. Medical technology cannot be used unless a problem has already been made abnormal and medicalized. An example of this is found in the development of the erectile dysfunction medication Viagra. In clinical studies the medication was found to improve older male's sexual performance, but, at that time, "erectile dysfunction" was not medicalized, sexual performance degradation was regarded as a standard process of aging, and so the medical establishment had to "create"

the medical problem of “erectile dysfunction” in order to sell medication for it, thereby medicalizing a previously-understood “normal” bodily process (Carpiano 2010).

When a condition is medicalized, some people adopt the medicalized model of the condition, and other people resist the medicalized label. Deaf culture is one such group that largely rejects the medicalized model of deafness. This culture is notated by a capital “D,” (Lane 1999) whereas deaf people who are verbal and listen using cochlear implants or hearing aids are classified with a lowercase “d.” Most of the people who are Deaf use sign language (Lane 1999). As 90% of deaf children are born to hearing parents, if even 80% of those children are given cochlear implants, and not taught ASL and welcomed into the Deaf community, the Deaf community fears the death of their community because of the dearth of new members. What Deaf community members are fighting against is the “infirmity” understanding of deafness— the understanding that deafness is a medical and social problem that needs to be fixed through technology.

Although the term “deaf eugenics” implies the reduction or elimination of deafness through compulsory exogamous marriage and sterilization or through gene therapy (Lane 1999, Lane 2005), the term “genocide” evokes a more active attempt to eliminate a group of people or a culture. The word genocide recalls vast pogroms and systematic killing, however, the slow elimination of a minority group can occur by the

destruction of the distinct elements that bind the collectivity, such as language, customs, and art forms (Lane 2005). Because the medicalized model of deafness aims to, in the words of one speaker at a National Academy of Sciences meeting, “clear out the schools for the deaf” (qtd. in Erickson 1990), and eliminate the need for ASL, the loss of this language by either outright elimination or dialectizing it (Lane 1999), could result in the loss of the culture itself. In this way, language death, or glottocide, can lead to the loss of cultural identity (Nicholls 2005), and may represent the denial of the basic human and civil rights of children to speak their native language (Lane 2005, Nicholls 2005). Technology can be a medicalizing force, contributing to the demographic issues in the Deaf community.

The affirmation of the infirmity understanding of deafness leads to the search for new and better technologies to address deafness, including stem cell research (National Institute on Deafness and other Communication Disorders 2009) and gene transfer therapies that aim to ultimately eliminate the birth of deaf infants (Lane 2005). These techniques are never neutral and raise important moral and ethical questions (Bosteels et al., 2017). These advanced techniques, if “successful,” will have the effect of regulating and, according to some deaf advocates, eventually eliminating Deaf culture, language, and Deaf people (Lane 2005).

While the social meanings of deafness (or the medicalization of deafness), influences the technology that arises to correct it; the opposite is also true, available technologies shape the perception of deafness. Technology as a means to achieve medicalization is prevalent throughout the literature on medicalization. Sperm freezing as a technology to preserve men's reproductive capacity as they aged was, in one study (Law 2020), rejected by men as an affront to hegemonic masculinity. In this example, medical technology was rejected by potential consumers because it conflicted with other values and beliefs about the self. Women who highly medicalized their infertility by utilizing infertility technologies (Greil et al. 2019), were found to also use non-medicalized technologies such as herbs. In this example, medicalizing technologies were not the only recourse for a medicalized problem. Other studies (Santos 2020; Santos & Gottschang 2020) explore how medical technologies are used for a moralizing project and found that the technological medicalization of childbirth arose alongside a moral discourse about childbirth and motherhood. Lastly, research on the medicalization of "smart textiles" (Kelly 2019), found that these devices blurred the boundaries between the medical clinic and the home, and that technology that, in the past, would have been seen as intrusive has been normalized and is even seen as "comfortable." The three approaches I use to study normalization/medicalization/stigma, are historical analysis of

primary and secondary sources, content analysis of hearing aid advertisements from the early 1900s-current, and interviews with parents who chose to implant their deaf children with cochlear implants. These approaches to studying the meaning of deafness have merit because they each have the potential to reveal a normative pressure to be hearing, or at least appear hearing. STIGMA

The concept of structural stigma relates directly to issues regarding Deaf/deaf culture. Structural stigma refers to how stigma is embedded in the social structure (Sukhera et al., 2021), so that anyone who occupies that social space, will be stigmatized. An example here would be ASL-using Deaf people in a hearing environment. By the very fact that they are deaf and using a signed language, they are stigmatized, even if the rest of their social behavior is normative. Structural stigma and discrimination are weaved together with the social fabric, and policy and practice towards those stigmatized individuals are enacted. Stigma cannot be separated from power structures, inequality, and resistance (Thomas 2020). For example, medical stigma has been found in the association between a cancer diagnosis and job loss (Shim et al., 2021) Stigma as defined by Goffman is a relational and dynamic concept (Ruusuvuori et al., 2021). There have been studies that demonstrate stigma against adults using hearing aids (Ruusuvuori et al., 2021); no literature was found on stigma among children using cochlear implants.

Goffman's theory of stigma includes deviance, and he identified several forms of deviance, one of which, "deviance in presentation of the self in social interactions," (Barmaki 2021) is most aligned with the concept of deafness as deviance, or something to be stigmatized.

There exists a rich literature on stigma and deafness. Scharp and Barker (2021) explore the meaning of deafness for adults who use hearing aids. Stigma relating to the aids was prominent in their interviews, however, they also discovered a theme of, "this is just my life." (Scharp & Barker 2021). Other studies have found that deafness impedes social exchange and relationships (Oleszkiewicz 2021). Self-efficacy can be impacted by stigma, and those deaf people who experience the most stigma also have lower self-efficacy scores (Crowe, 2021). Deaf people, like others with disabled bodies, must manage stigma (Lash & Helme 2020). In one study, parents of disabled children dismantle stigma by rewriting the narrative of being the parent of a disabled child (Thomas 2020).

In the remaining sections of this chapter, I will draw on the theoretical concepts described above as I examine the literatures relevant to each findings chapter: STS approaches to studying technological history (chapter four), medical and pharmaceutical

advertisements (chapter five), and then will provide a survey of the literature on parental medical decision making (chapter six).

STS (SCIENCE & TECHNOLOGY STUDIES) SCHOLARSHIP OVERVIEW

Technology can be a space for resistance and empowerment (Scholtz 2016, Woodcock 2017, Cant 2019), and cochlear implants are no different. As a technology, cochlear implants can bring people “back” or “to” the land of the hearing, and so can engender normality in that way. Science and Technology Studies (STS) is a specific multi-disciplinary academic field that studies how science and technology recursively inform each other (Bijker 1997). STS includes areas such as the history of science, philosophy of science, sociology of scientific knowledge, politics of technology and economics of innovation (Martin 2020). Thomas Kuhn’s “Structure of Scientific Revolutions” (1962, Fu 2012, Zhang 2012) birthed the field of STS by stating that technological change was revolutionary in nature; later theorists have disputed this and have shown that technological change tends to be recursive, political, and glacial. Bijker demonstrates in his book, “Of Bicycles, Bakelite, and Bulbs” (1997) this recursiveness in the development of the bicycle. He emphasizes the development of the bicycle was a series of “detours.” It was not a straight path from the hobby horse to today’s \$21,000 carbon fiber bikes. We’ll see the same sort of detours in chapter four, which is an STS-

informed analysis of the development of hearing technology. In his book, Bijker (1997) shows how the development of the bicycle was recursive— early prototypes were developed, problems were found with them, sent back to the developers who made changes, sent the bike back to the public, who found more problems, who sent it back, and etc. (Bijker 1997). The same process can be seen in the development of the audiphones and dentaphones, detailed in chapter four.

Bijker (1997) also asks, “how do artifacts become instruments of power, and how do power relations materialize in artifacts?” (p.12) I explore this question as it relates to cochlear implants in chapter six, but Bijker maintains the role of power in the mutual shaping of technology and culture (1997). Technological decisions, including medical diagnoses such as a deafness diagnosis, are socially shaped under the broader social context (Kuiper et al., 2021). STS frameworks have been utilized in disability studies (Blume et al., 2014), and these studies have found that in industrialized societies, the medical profession has authority over the determination of who should count as disabled while “assistive technologies” enable “specific kinds of subject positions” (Blume et al., 2014). STS frameworks have been used specifically to study cochlear implants and other hearing technologies. Laura Mauldin (2019), whose research on parents of deaf children is described above, used an STS informed approach that placed the CI within a complex

sociotechnical system and examined cochlear implant “failure.” Singleton et al. (2019) explored deaf technologies utilized by older deaf adults and concluded that this population should be included in the recursive process to refine and adapt technologies.

STS is a valuable framework from which to examine deafness and cochlear implants. Technological change is not the “revolution” that Kuhn described (1962), but, rather, it is a circular process by which users use the device and find problems with it, the device goes back to the developers, who address the specific problem, users find different problems that garner different solutions, etc. My contribution to the STS literature on cochlear implants and deafness is that I consider issues of normality and medicalization and go beyond examining how specific technologies are iteratively co-constructed by developers and users. Instead, I show that this iterative process is driven by pressures to be normal and to medicalize previously non-medicalized conditions.

HEARING AID AND COCHLEAR IMPLANT ADVERTISING

In contemporary consumer society, marketing and advertising communicate the society’s values and morals (May et al., 2021; Bayefsky 2020; Mohapatra & Fox 2021; Simmank & Avram et al., 2020) Advertising slogans usually represent catchy and memorable phrases, or in the case of the hearing technology advertisements and websites that I evaluated, memorable or poignant images. These phrases and images are built on

aesthetic and normative elements to create a clear intention: They are meant to induce positive appraisal (Simmanck & Avram et al., 2020; Dimofte & Yalch, 2007) and expectations regarding the experienced utility or satisfaction of a product or service (Plassmann, O'Doherty, Shiv, & Rangel, 2008). Product advertisements have been shown to trigger the decision-making part of the prefrontal cortex (Simmanck & Avram et al. 2020) and appear similar to moral decision making in fMRI studies (Simmanck & Avram et al. 2020). In the case of the medicalization of deafness, advertisements and the marketing of products intended to ameliorate deafness are expressly *value* statements— if you don't purchase this particular product for your deaf child, you are a bad parent (Taylor 2020; Popa 2018), or at the very least, a neglectful one. Popa (2018) found, in a survey of women's magazines, that children's products advertised were presented in terms of 'buying this product makes you a good parent'. The marketing of deaf-related technologies reaffirms the medicalization of deafness, by presenting *medical* treatment of the problem— such as cochlear implants.

Imagery in print advertisements has been shown to influence consumer's perceptions about health information (Banovic & Otterbring 2020). Advertisements, simply put, influence behavior (Sciglimpaglia et al., 2021; Lawrence et al., 2021; Yen & Chiang 2021; Fernandez-Escobar & Parada et al., 2021). In Fernandez-Escobar & Parada

et al., (2021) they showed television advertisements to teens featuring unhealthy food. One group was shown the unhealthy food advertisements without any additional content, and the other group was shown the same advertisements with health warnings attached to the ads. The researchers found no significant difference in the two groups about which foods (healthy or unhealthy) the subjects ate after the study was presumedly “over.” These results suggest that images are more powerful than words in advertising, and so this supports my approach of mostly analyzing the pictorial content of the advertisement or web content. In this dissertation, I analyze the pictorial content of advertisements.

Bodies themselves serve as powerful advertisements, as can be seen in research regarding body image (Camerino & Camerino et al, 2020). Advertisements on the body itself (such as a young deaf child seeing another child with a cochlear implant and wanting one for themselves), or as branded images on clothing, shoes, and hats, are a kind of advertising that you “can’t turn off”—it’s always there, as opposed to magazine or internet ads that you can “turn off or turn over.” Te Eni-Harari & Eyal, (2020) found that adolescents internalize advertisements messages of a thin ideal, and that in order to be beautiful, one must also be thin and famous. These body-image studies shed light on the cochlear implant case, as well. Parents internalize the messages of cochlear implant and hearing aid advertisements as the only way to raise a healthy successful child.

Although there appears to be no sociological analysis of hearing aid or cochlear implant advertisements, there is a substantive literature on medication advertisements. Although on the surface, pharmaceutical advertisements and cochlear implant/hearing aid advertisements appear to be fundamentally different from each other, there are some similarities. First, medication and cochlear implant advertisements both tend to focus on improving the quality of life of the person who consumes/uses the medication or device. Secondly, there can tend to be a normalizing component to the advert— many medication advertisements imply that one can achieve normality by taking/using the product, Babineau and colleagues (2017) found that, after viewing advertisements for antidepressants, women redefined the meanings of “normal” and “depression.” In this way, advertisements can actually shape what is considered normal. Scalvini (2010), in his study of the images in HIV medication advertisements, found that advances in HIV medications have now changed the image of an HIV patient— ads in his study portrayed people who had healthy, “ideal,” “normal” bodies.

I am not aware of any prior research on advertisements or marketing of either hearing aids or cochlear implants, nor did I find any research into advertisements for products aimed at Deaf people, such as VideoPhones or FaceTime. There are, however, websites that carry products aimed at D/deaf people, including bed shakers, modified fire,

and door alarms, and the Videophone (Maxiads.com). I will fill this gap with an evaluation of advertisements and marketing schemes for hearing aids and cochlear implants in the 20th and 21st centuries in chapter five.

PARENTS' MEDICAL DECISION-MAKING PROCESS

I will broadly discuss parental medical decision-making scholarship, then will address parental decision making in the case of cochlear implants which in part is influenced by hearing aid and cochlear implant technology advertisements and websites.

Madrigal et al. (2012), in a study about parental decision making in a Pediatric Intensive Care unit found that parents prefer to make medical decisions in combination with the doctor, or alternatively, prefer significant independence in the decision (Madrigal et al., 2012). Although this data comes from studies in which children are significantly more ill than deafness, there is no evidence that suggests that the medical decision-making processes are different between life-threatening and “lifestyle threatening” conditions. In researching “voluntariness” in a study about parental decision making for seriously ill children, male gender, non-white status, and lower SES all contributed to a lower perceived voluntariness of the medical decision (Miller and Nelson 2012). Voluntariness is perceived to be key in parental decision-making. If one feels forced to decide, they may make the decision with less deliberation and less feeling of choice.

In a study of the parental decision-making process in circumcision, it was found that parental education had no bearing on the decision-making process (Binner et al, 2002). For the parental decision about giving their pre-teen daughters the HPV vaccine, trust in the medical system was key (Allen et al. 2010). In a comprehensive review of parental medical decision making, Carlton et.al. (2013) identified several factors that parents considered when making medical decisions for their minor children. Overall, their findings were that recommendations from others were most often identified as influencing decisions, and that pragmatic issues, effectiveness, and research evidence, were also very important in the decision-making process (Carlton et al. 2013).

Other studies (Jackson et al, 2008, Lipstein et al., 2011) had similar conclusions as Carlton et al (2013). Social factors, such as embarrassment, were also identified by parents as influencing their decision-making, along with past experience and the outcomes of previous decisions. The child's preferences for treatment and the parent's expectations or goals for their child, and parents' emotions, beliefs, and values, have also been identified as factors influencing decision-making (Lipstein et al., 2011). Parents need direct support and handholding in order to make decisions regarding their newborn's deafness.

Kluwin and Stewart (2000), in their study of parental motivations for seeking a cochlear implant for their child, found that parents relied heavily on information from

medical professionals. If they sought help from medical professionals, they were much less likely to seek information from other sources (Kluwin and Stewart 2000). However, other research has found that parents do research on the Internet to make the cochlear implant decision, and that this information was an important adjunct to information from doctors and professionals (Porter and Edirippulige 2007). Most parents found the decision process difficult and stressful, but some found it easy because they perceived there was no other option for their child (Hyde et al. 2010). Parents are often influenced in their decision-making process by their personal beliefs, attitudes, and values, at least as much as they are influenced by the data available to them (Li et al. 2004). Kluwin and Stewart (2000; Christiansen and Leigh 2002) also found that the most important deciding factor in giving their child an implant was allowing their child to hear and speak like a hearing person. This speaks to parents' desire for their child to be normal. Normal speech was especially important for these parents (Hyde et al. 2010; Kluwin and Stewart 2000). Most of the parents in their study did not consider any other alternatives to the cochlear implants (Kluwin and Stewart 2000). Not all parents see the cochlear implant as positive, though. Solomon, in his book about children who are profoundly different from their parents, writes about one parent who said, "[we] decided to respect Emma for who she was rather than to fix her." (Solomon 2012).

Laura Mauldin, in her study about parents and cochlear implants (2016), quotes a parent whose daughter is implanted with cochlear implants:

Nobody's talking about Deaf culture. With the technology we're being faced with, it will never have the chance to evolve because it's not big enough. It's such a teeny tiny little culture we don't talk about it, and the reason we don't is because the majority of parents want their kids to talk.

With this excerpt, it is apparent that even the parents of cochlear implanted children predict the upcoming death of Deaf culture, in part due to the increasing prevalence of cochlear implants and the smaller number of people who use ASL. Mauldin (2016) concludes that parents are simply anxious about their children's future and want their children to have as much access to the English language as possible.

In a study analyzing the factors that led to parents deciding that their children should have cochlear implants, it was found that personal biases and opinions were the main factor leading to oral-language based solutions, such as a cochlear implant (Li et al., 2004). In particular, a parent who values hearing and speaking over sign language is more likely to select a cochlear implant (Li et al, 2003). Kluwin and Stewart (2000) found that there were two types of decision-making processes for parents choosing cochlear implants for their young children. The first type got all of their information from a doctor or surgeon, and the other type first learned about cochlear implants from a family member or a parent with a deaf child and supplemented this information from research gained on the internet

and from books (Kluwin and Stewart 2000). Speech and language development have been found to be important decision-making factors (Incesulu et al., 2003) in other studies that examine the parental decision for cochlear implants.

Current literature has explored why parents decide to get a cochlear implant for their deaf child and has examined some of the factors parents consider when making this decision. What is lacking, however, is a discussion about normality and how thoughts about normality inform this decision. What is also lacking is a historical perspective on how cochlear implant technology came to be, and how social perception of deafness influences deaf technology, including cochlear implants. In this dissertation, I am going to address these gaps and explore specifically how thoughts of normality affect the parental decision. I will also examine how conceptions of the meaning of deafness and hearing aid and cochlear implant marketing are informed by understandings of what is “normal.”

Before presenting the findings on the history of the meanings of deafness and technological history, advertising and marketing of hearing aids and cochlear implants, and interviews with parents, I will next engage in a discussion about the multiple qualitative methods that inform each of the three findings chapters.

Chapter 3. Method

This multi-method dissertation uses two main methods to answer all three of the research questions: first, content analysis of newspapers, magazines, and print and online advertisements and marketing materials from the mid-19th century to the present; second, semi-structured interviews with 33 parents of deaf children with cochlear implants. Researchers from different disciplines are increasingly finding that using multiple methods can help to analyze complexity and obtain more comprehensive explanations (Gil-Garcia and Pardo 2006), triangulate results between different parts of the overall study (Harden and Thomas 2005), and expand the inquiry into areas not easily examined by only one method (Tashakkori and Teddlie 1998). While the term “multi-method research” typically refers to combining qualitative and quantitative methods (Creswell 2003), this study uses multiple qualitative methods. This approach allows me to examine the subject from multiple angles and perspectives. I chose these approaches because there are several different ways at getting at the construct of “what is normal.” Historical documents and articles document the origins of understanding deafness and hearing in terms of “normal” and “abnormal,” as discussed in chapter four. Advertisements, as will be seen in chapter five, can be used to communicate what is “normal” or “expected.”

Lastly, chapter six draws on semi-structured interviews with parents of children with cochlear implants, which I chose because previous research (Burrows 2013; Mauldin 2016; Mauldin 2019) suggested that deaf and hearing people framed hearing technologies such as the Videophone or cochlear implants in terms of “normality.” These interviews aimed to understand how understanding of the concept of “normality” influenced parental decision making around the cochlear implant.

ARCHIVAL AND CONTENT ANALYSIS

Chapter four relies on the analysis of historical newspaper and magazine content, as well as utilizing primary sources that I initially located in secondary source material. To gather this material, I visited the Rutgers University library website, and accessed the database “Lexis Nexis” (now known as “Lexis Uni”). I chose this database for my search because it houses full-text newspaper and magazine articles, both historical and present-day. Using the search engine, I searched for “news + deaf” and “news + hearing aid.” Because I wanted to document the meaning of deafness historically and the history of hearing loss technologies, I selected the date range for each search to be January 1, 1700 (which was the earliest available data), to December 31, 1910. I chose 1910 as the end date because battery-powered hearing aids were beginning to be made available by this time, and thus, the modern era of hearing aid technology was ushered in. The search

“news + deaf” returned 28 articles from this timeframe, and the search “news + hearing aid” returned 34 articles, from sources such as the *New York Times* and *The Youth’s Companion*. In addition to this search, I also used the data included in the secondary source, Douglas Baynton’s 1996 book, *Forbidden Signs: American Culture and the Campaign Against Sign Language*. I included for analysis the primary sources that he quoted in chapter one of his book, which detailed the meanings of deafness across different eras. In this book, Baynton traces some of the anti-ASL sentiment throughout the years, and links different time periods with different forms of stigma. I took his history and my source data and reworked it as the “meanings of deafness.” The historical background is Baynton’s, but the analysis is mine. Baynton’s book covers the time period of the early 1800s up to the early years of cochlear implants in the 1990s. Also helpful was Richard Winefield’s 1987 book *Never the Twain Shall Meet: The Communications Debate*, which chronicles the conflict between Alexander Graham Bell and Edward Miner Gallaudet (Thomas Hopkins Gallaudet’s son) about whether oral language or signed language was more beneficial for deaf people.

I specifically searched for popular articles, rather than peer-reviewed articles from sources such as JAMA (*Journal of the American Medical Association*), which first started publishing in 1883, or the *New England Journal of Medicine*, which first started

publishing in 1811, because I wanted to capture the rise of the public perception of deafness and deaf technology. Although the influence of powerful organs of medicine such as JAMA and NEJM are important to include, in this analysis I focused on popular conceptions of deafness and deaf technology only. Future research should include an analysis of the messages coming from these powerful institutions and how they framed and shaped the narrative and public discourse around deafness and deaf technology in these eras. Once I had the data compiled from the Lexis Nexis search and from the Baynton and Winefield books, I began the two-sort open coding process. I used an open coding approach (Strauss and Corbin 1998) that evolved into a more focused coding approach once codes emerged. Open coding allows the data to speak for itself (Strauss and Corbin 1998) and invites codes to emerge from the dataset. The two-sort approach first sorted the materials into broad categories, and then a more focused approach took those broad categories and made them more specific and narrower, and as these categories became more distinct, answers to the research questions came into view. These categorical and coding choices were enlivened by my knowledge of the literature, but, as the open-coding method demands, were primarily driven by the data itself.

For the primary sources found in newspapers, magazines, and the Baynton book, I first sorted the data into broad categories, such as “deaf-sinner,” “deaf-lonely,” and

“deaf- bad attitude.” From these categories, the “meanings of deafness” that are so central to chapter four and inform the analysis in the remainder of the findings chapters, began to emerge. From 41 broad categories such as these, the second sort refined these categories into only three categories— “Connection to God,” “Connection to humankind,” and “Connection to the nation.” These categories became the “meanings of deafness” that I use as an analytical tool throughout the dissertation. These categories are supported by the secondary literature, including Baynton (1996) and Winefield (1987), which are the two secondary sources that I utilized the most for this analysis.

Chapter five relies on data from two main sources— archival data of print hearing aid advertisements from the turn of the 20th century to the mid-1970s, and website images and language from contemporary hearing aid and cochlear implant manufacturers. These data sources were combined into one chapter because they both are essentially the same thing— advertisements for hearing technology.

On May 10, 2010, I visited the Kenneth Berger Hearing Aid Museum in Kent, Ohio. The museum has in its collection a vast array of hearing aids, ear trumpets, and other hearing devices. The collection also includes an extensive archive consisting of patent applications and print hearing aid advertisements from the turn of the 20th century to the mid-1970s. There are no patents or advertisements for cochlear implants in the

archive. At the museum, I took a picture of each advertisement in the archive, of which there were 75.

To identify the content of contemporary hearing aid and CI websites, I used a Consumer Reports (2019) article on the best and worst hearing aids in order to create the universe of potential hearing aids and manufacturers. I visited the websites of the 16 hearing aid manufacturers included in the Consumer Reports survey. For the cochlear implant websites, I relied on the web presence of the three cochlear implant companies in the US— Cochlear Americas¹, Med-El², and Advanced Bionics³. I only analyzed the images on the websites, except in the rare cases where text was blown up and put in large text boxes. Future research should delve more deeply into the text content of these websites to see if the messages about hearing aids and cochlear implants is consistent between images and textual content. I took screen-prints of each image on the websites (and text-blocks where appropriate).

To analyze the archival and website data, I used the same two-sort process

¹ www.cochlear.com.

² www.medel.com.

³ www.advancedbionics.com.

described above. I sorted the advertisements by theme/content, such as “hearing aids connect people to God and church,” “hearing aids allow one to lead a full life,” and “hearing aids are discreet”). I developed 19 broad categories using this process. The second sort refined these 19 categories into, like the second sort of the newspaper and magazine articles, three categories, again led by the data. These three categories were “Inconspicuousness,” “Modernity/space age/supra modernity,” and “Connection with family and community.” These three categories are the backbone of chapter five, with the addition of one other category that was developed during the analysis of the hearing aid and cochlear implant websites.

For the website content, the first sort yielded 9 categories, including “hearing improves community and family connection,” and “cochlear implants bring success.” The second sort developed four focused codes, the first three being the same as I identified in the historical print advertisement analysis— “Inconspicuousness,” “Modernity/advanced science,” and “Connection with family and community.” In addition to these three, the website analysis generated one more category that was not found in the historical print advertisements— “success.”

INTERVIEWS

In 2014 I conducted 33 semi-structured interviews with the hearing parents or parent of children with cochlear implants. In all but two families I interviewed the primary caretaker which in all cases was a mother. In the remaining two interviews, I interviewed both parents together. Because of the relative scarcity of families with children with cochlear implants, and the difficulty in connecting with these families, I used a convenience sample and I did not stratify it in any way. The only requirement for parents to be interviewed is that they had at least one deaf child who had been implanted with at least one cochlear implant. Although this is a small sample, the findings are transferable to other families with the same sociodemographic characteristics as those in my study. By the time I had interviewed 33 families, I had reached the saturation point, that is, I was not learning much new information from the later interviews. This tells me that, at least for white Americans, which comprised my entire sample, that their voices and stories are representative of other people in the same sociodemographic categories.

I used several different methods to recruit these families. First, I contacted the Alexander Graham Bell association, which is the leading oral and cochlear implant non-profit group in the country and asked if they would be willing to post my study ad in their national newsletter, which they agreed to do. Secondly, I contacted all the oral deaf

schools in the country and asked them to publicize my study. This was done by sending letters to all the schools and then following up with a phone call about two weeks later. Lastly, I posted my ad in open Facebook groups aimed at parents of children with cochlear implants. Due to the nature of the sample being spread out all over the US, all interviews, except for the two families located in Portland, Oregon, were conducted, and recorded, over the phone. For the two parents I interviewed in Portland, both interviews took place in outdoor cafes of the participants' choosing. Each interview, whether in-person or over the phone, lasted between 45-90 minutes. Each interview was audiotaped and transcribed by a professional transcriptionist. The interview guide is provided in the Appendix.

Originally when I began my research, I planned to not only interview parents who had chosen cochlear implants for their child, but to also interview parents who had chosen ASL or another signed or manual language (such as Signed Exact English— SEE, or Cued Speech) for their children. I wanted to understand how Deaf and hearing parents who chose ASL for their children understood normality and the meaning of deaf technology. Although this study does not include ASL-using people, I can still address RQ3 (“How do contemporary parents’ decisions to get a cochlear implant for their children reflect the relationships between social meanings of deafness, deaf technology,

and social beliefs about normality”), because the research question focuses explicitly on those parents who decided on a cochlear implant. Without the ASL-using sample, the research had the capacity to be very one-sided and not tell the whole story. To recruit subjects whose children used ASL, I posted a recruitment ad on Facebook groups for parents of Deaf children. Concurrently, I sent letters, and made follow up phone calls, to all 34 of the US ASL schools, using the same process I used when contacting the cochlear implant/oral schools. However, the response I received from the ASL schools and Facebook groups was profoundly different than the response received by oral schools. By and large, the oral schools were happy to participate, and went out of their way to advertise the study to parents. However, in the ASL group, not a single school responded to my request. It was the same situation with the Facebook ads— not a single parent responded to the ads. This one-sided sample was discouraging, and I think it limits the generalizability of the findings to only families of deaf children, and not Deaf families. Understanding how Deaf families understand the concepts of normality, medicalization, and stigma would shed light on how a distinctly “abnormal” group (by a statistical conception of normal)- ASL-using Deaf people- explain normality in the face of using a non-typical communication method. One can learn a lot by studying the *absence* of a phenomena, in this case, not implanting children with cochlear implants. It

is possible that the existential threat felt by some Deaf people, specifically the demographic problem presented by cochlear implants, led Deaf educators or parents to resist being the subject of research. Research conducted by people already imbedded in Deaf culture— either by virtue of identifying as Deaf, or close friends, family members, or interpreters (Mauldin 2016) of Deaf people will probably have a greater chance of conducting research with Deaf families. However, even with the lack of ASL-using families, my interviews with hearing parents of children who use cochlear implants provide insight into how some people understand normality, medicalization, and stigma as it relates to deafness and technology.

Overwhelmingly the sample was female, and white. Only two participants were male, and none of the participants were non-white. The lack of diversity in the sample does not necessarily reflect a lack of diversity of children receiving cochlear implants. Medicaid, which disproportionately covers families of color, covers cochlear implants in most cases, so low SES/racial intersectionality should not have affected the lack of diversity in the sample. However, the oral schools are all private-pay, with few scholarships available, so low SES/racial intersectionality in the sampling universe (all children who attend oral schools), may have played a part in the lack of racial diversity within the sample. Increasing racial diversity, by targeting children who use cochlear

implants and attend public schools should be a focus of future research. When asked to report their social class, 24 participants responded, “middle class,” three defined themselves as “lower middle class,” and six defined themselves as “upper middle class.” I used the respondents’ own language to define their social class and did not probe any further about their characterization. All names are pseudonyms.

Transcribed interview data were loaded into the qualitative data analysis software NVivo and the data were open coded (Strauss and Corbin 1998). As described previously, open coding allows the data to “speak for itself,” and the method follows the trails left by the data. Open coding (Strauss and Corbin 1998) led to the formation of 412 preliminary codes, and subsequent coding focused those codes into eight themes. Themes that emerged from the data using this method were: decision easy; decision difficult; rational decision; emotional decision; how to achieve normality; other parents influence decision; other deaf children influence decision; powerful group influence decision.

At the time of data collection and analysis, I was a white middle-class cis woman in her 30’s and 40’s in graduate school. All the parents in my study were white, and so it is possible that my personal characteristics helped ease the conversation. However, all but two conversations occurred over the phone, so the respondents didn’t know my race, however, I knew their race. What is more salient were my opinions of cochlear implants

and ASL before I started this project. I came to this project by way of several Deaf friends telling me how awful cochlear implants were, and how they were tantamount to genocide of Deaf culture. It was important for me to find ways to mitigate these initial impressions and biases, so I asked open-ended questions and sought to understand participants rather than evaluating their decisions. Throughout the process of doing the interviews, my preconceived notions softened and became far more nuanced, and I no longer hold those rigid positions.

Chapter 4. The Social Meanings of Deafness and how Technology Addresses Them

Sociologists have long been concerned with how normality criteria are created and transformed, and how determinations are made as to what is considered to be disability (Horwitz 2002; Horwitz and Wakefield 2007; Conrad 2007), which is related to the social process known as medicalization. Shifrer (2021) writes, “Medicalization is the process whereby a condition formerly considered to represent normal human variation comes to be considered a disability, illness, or disorder.” Making a claim for a disability is not entirely negative— benefits are often given to people in certain disability classifications (Conrad 2007). For example, children who are diagnosed deaf in infancy are eligible for in-home speech and sign language services for the whole family. Without the disability label, these children wouldn’t be eligible for these benefits. Social constructionist perspectives describe the process by which certain conditions come to be seen as problematic, while others do not, and how illness is intimately connected to concepts of deviance and abnormality (c.f. Szasz 1960; Horwitz 2002; Conrad 2007; Goffman 1963). The social construction of deafness as a medicalized problem is illustrated in the upcoming discussion in this chapter about the changing meanings of deafness— deafness was (and is) considered a problem in so long as certain conditions are met. This chapter addresses the first research question developed in chapter one:

Drawing on historical accounts of deafness from the early 1800s to contemporary times, how have the social meanings of deafness, deaf technologies, and social beliefs about normality changed?

In this chapter, I explore the changing meanings of deafness in the US across time, which is one way of saying I explore how deafness is socially constructed and medicalized across time periods. The demonstration that deafness means different things in different eras emphasizes its social constructivist origins. Deafness also means different things in different places. Deafness is understood very differently at Gallaudet University— the world’s premier ASL university— than at Clarke School for the deaf, which is a leading primary school chain for children with cochlear implants. The existence of these counter narratives demonstrate the social origins of the meaning of deafness— meanings change from person to person, from time to time, and from place to place. Exploring this history through the lens of social constructionism will also shed light on how normality and stigma are understood in the context of deafness in different eras. For each time period, I will explore the technology that arose out of these meanings of deafness. The way deafness is perceived influences the technology that arises to treat it, and, in its turn, technology influences how deafness is perceived.

I explore three different eras; I examine how deafness was/is understood in each of those eras and how technology provides an answer to each of those conceptions. I've chosen these time periods because these are time periods in which a major technological shift occurred. The first era, starting in the 1810's, began with Thomas Hopkins Gallaudet founding the first ASL school for the deaf in the US. In the second era, starting in the 1870's, early hearing assistance devices and surgeries were developed, later followed by in-ear hearing aids. The third era, beginning in the 1980's, represents the increasing use of cochlear implants. These technologies influenced the meanings of deafness in the particular era, but also, the meanings of deafness influenced the technology that was necessary to arise to meet the "problem" of deafness as it was conceived in that particular era.

The data for this chapter comes from primary sources such as newspaper articles of the period, as well as secondary sources, as described in chapter three. My information about the development of hearing aids and cochlear implants comes largely from peer-reviewed journal articles, as well as a personal interview I conducted with William House near the end of his life, who is widely considered one of the fathers of cochlear implants. Themes of normality are not always explicitly present in the "problems of deafness," but

where they are, I will highlight them. As it is used in this chapter, the concept of “problem” means “that which is not normal.”

I take an STS-informed approach to this chapter, of which the foundations are laid out in chapter two. Mauldin (2019) establishes the benefits of this approach in her STS analysis of parents’ perceived success and failure of cochlear implants in their children. The analysis of the historical data that inform my understanding of the “meanings of deafness,” as well as the exacting and exhaustive attention to detail with respect to the development of deaf technologies is both an STS academic tradition as well as a requirement to frame the remaining discussion in this dissertation. My intent with using the STS framework and the level of detail it requires is to show the iterative process between society and technology.

Figure 1: A Deaf Technology Timeline of Invention and Adoption from 1750s to Present (2020)

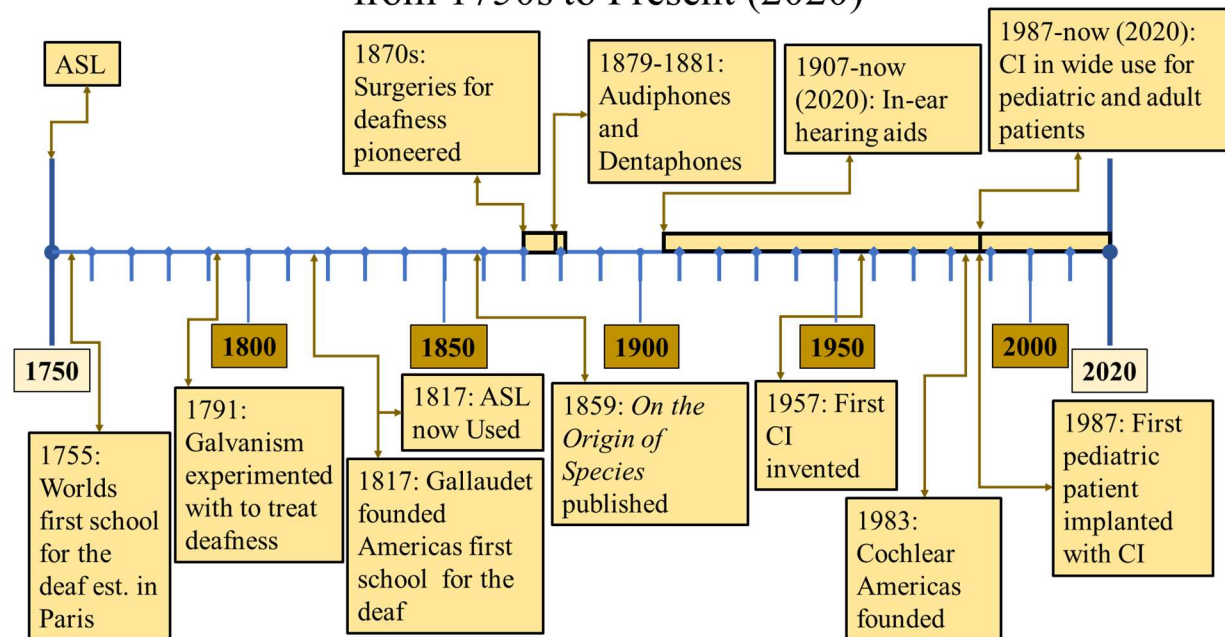


Figure 1 shows the history of major events in hearing correction technology. The items on top of the timeline bar show things that span several years and may overlap with other technologies. This can be seen with the in-ear hearing aids, first developed in the early 20th century, but spans over a century and they are still used today, even though cochlear implants are now in wide use.

CHANGING MEANINGS OF THE PROBLEM OF DEAFNESS

The social meaning of hearing and of deafness changes in concert with the broader social and political environment. Among the congenitally deaf, there exists a

deficiency of both hearing and speaking, and in different eras, these deficits are differentially valued. In some eras, the loss of hearing was highlighted as the most serious disability, and in others, the inability to speak was considered the most pressing issue. Whether hearing, speaking, or both were theorized to be the main “problem of being deaf” dictated to a degree what type of technologies were devised and were considered sufficient. The way deaf people are perceived by the wider society, says as much about the society as it does about deaf people. The “social problem” of deafness reflects on society broadly, especially shedding light on what that society values and undervalues. Deafness, in this manner, can serve as a microcosm of the broader society. There can be resistance to the dominant meanings, and this resistance usually takes the form of using technology that is out of the mainstream. For example, in the modern era, resistance to the medicalized view of deafness may take the form of using ASL and eschewing cochlear implant technology.

CONNECTING TO GOD AND ASL AS TECHNOLOGY

Prior to the 1860s, deafness in the US was defined as primarily a problem of being isolated from God (Baynton 1996; *The Youth's Companion* 1831). In *The Youth Companion's* 1831 article “History of David Dorlan,” they write, “As David Dorlan increased in years, he began to manifest the usual characteristics of the deaf-mute:

irritability of disposition, Godlessness.” Baynton (1996) quotes the reverend and teacher Collins Stone from 1869 as saying:

In this Christian land there are still deaf people living in utter seclusion from the direct influences of the gospel. These deaf people might as well have been born in benighted Asia, as in this land of light, and were little short of a community of heathens at our doors.

If one could not speak to God, or hear the gospels, then one would not be saved.

Signed languages, then, were seen by the original ministers who instituted the first residential schools for deaf children in the United States, as a crucial means to connect these children to God and to a Christian community (Baynton 1996). Quoting Collins Stone, Baynton (1996) reports he said, “scarcely a ray of moral or intellectual light ever shines in his solitude, if he dies unblessed by education he dies in utter moral darkness, even in the midst of Christian society, he must grope his way in darkness and gloom.” The use of ASL as a communications technology in the early 1800s arose as a direct result of the understanding of deafness as being a spiritual or religious crisis. When deafness was defined as primarily a problem of spiritual salvation, therefore, morality was associated with ASL. There were very few options for resistance to this morality grounded in ASL, as technological assistance for speaking and hearing was invasive, dangerous, and largely ineffective (Lane 1999). The only form of resistance that could exist was a resistance to learning ASL, which would have been understood as a rejection

of God and religion. An interesting corollary of this was that deaf people who used ASL were considered by many to be more spiritually pure than most hearing people, because they were not sullied by the temptations and influences of a corrupt world, from which they were perceived to be isolated. Signed languages were understood to be purer, and closer to God's original language, than spoken languages, and were therefore a natural extension of God's will for deaf people (Baynton 1996).

The use of ASL as a communications technology in the early 1800s arose as a direct result of the understanding of deafness as being a spiritual or religious crisis. In 1755, the world's first school for the deaf was established in Paris, France by Abbe' De l'Epee in an attempt to connect deaf children to God (Winefield 1987)⁴. De l'Epee utilized the manual⁵ language already used by French deaf people, and by 1790, the school, run by De l'Epee's successor Abbe' Sicard, was entirely a manual school (Winefield 1987). Manual teaching methods are poised as an alternative to oral methods

⁴ However, the ancient Greeks and Romans used a fingerspelling system that was not reserved for the deaf (Friend's Weekly Intelligencer, 1851).

⁵ There are two broad methods of teaching the deaf: oral methods which rely entirely on speech training and residual hearing, and manual methods which rely entirely on signed languages. Mixed methods also exist which combine some elements of each method.

of education, which teach speech to deaf children. In 1815, an American minister, Thomas Hopkins Gallaudet, visited a British school for the deaf and Sicard's French school in order to learn methods for teaching the deaf. The British school utilized oral methods of teaching the deaf, but the school refused to divulge the secrets of teaching the oral method to Gallaudet (Winefield, 1987). The manual French school was more welcoming, so Gallaudet learned the manual method of teaching deaf children (Baynton 1996; Winefield 1987). He returned to the states with a French teacher, Laurent Clerc, who became the first teacher of the deaf in the US at the American Asylum for the Deaf and Dumb in Hartford, Connecticut in 1817 (Winefield 1987). The school utilized the signed language already being used in the US and did not use the French Sign Language in use at Sicard's school⁶. Edward Miner Gallaudet formed Gallaudet University in 1864. I mark the 1810s, when ASL was first taught in the US at residential schools, as the

⁶ Signed languages, like spoken languages, are not universal, and all countries have regional or local signed languages that distinct and incompatible with each other. ASL, for example, is fundamentally different from BSL (British Sign Language) and Auslan (Australian Sign Language), and Deaf individuals from these three countries would need interpreters to communicate with each other. Signed languages, including ASL, are organic, natural languages with their own grammar, syntax, and vocabulary. Signed languages are not a translation of the national spoken language in which it resides.

beginning of the first era of the meaning of deafness, in which the problem of deafness was a lack of connection to God and the technological solution was ASL.

As a testament to the perception that ASL was the accepted normal and natural way for deaf people to communicate, deaf residential schools, in which ASL was taught and used exclusively, were commonplace prior to the 1880s (Baynton 1996; Winefield 1987). These schools, while founded by ministers for religious purposes, served to nurture what later became a robust and unique Deaf culture. Within the residential schools, children learned not only how to communicate with each other, but also about Deaf culture, norms, and expectations. The earliest residential schools gave birth to Deaf art, Deaf theater, and a tradition of manual storytelling (Baynton 1996). Within the residential schools, children often met their spouses and lifetime friends (Lane 1999). The residential schools served as an important anchor for the nascent American Deaf culture, fomenting resistance to oral methods of deaf education, especially as medical options for deafness such as hearing aids and cochlear implants became widely available. Each era has a series of distinct concepts associated with deafness. In this era, being deaf was primarily seen as a problem of speech and not being able to speak to God. Pierre Desloges wrote in 1779 that deaf people were (quoted in Baynton 1996) “were isolated and resigned to the world of things and bodily needs.” Dee-Price (2020) explores the role

of isolation in people with disabilities during COVID-19 and determines that deaf people, like those with other disabilities, are isolated and lonely during the COVID-19 pandemic. She fails to explore in this article the isolation and loneliness experienced by people with disabilities when there is no pandemic.

Collins Stone (1869 quoted in Baynton 1996) said, “Scarcely a ray of moral or intellectual light ever dawns upon his solitude. If he dies unblessed by education, he dies in utter moral darkness. Even in the midst of Christian society, he must grope his way through darkness and gloom.” Baynton (1996) summarizes the situation as that “The darkness, the emptiness, the solitude were all of a particular kind: deaf people were cut off from the Christian community and its message.”

When the problem is speaking to God, key concepts associated with deafness are lost, pathetic, pitiful, damned, and doomed. These themes show up in the source documents that Baynton relies on, as well as in the primary sources I located. The technological goal in this case would be to achieve speaking, or communication, which could be achieved through education via ASL. Ministers and educators became the mediators between God and the deaf, and ASL became the medium of communication. ASL came to be seen by Protestant evangelists (who ran the Deaf schools) as a means to connect otherwise heathen people to God, and indeed, saw ASL as a special gift from

God to deaf people (Baynton 1996). Most important for Gallaudet was connecting deaf children to God. As he puts it, “They knew nothing of God and the promise of salvation, nor had they a firm basis for the development of a moral sense” (Baynton 1996).

As a technology, ASL accomplished the goal of connecting the deaf to God and to a Christian community. The use of ASL in the early 19th century did not offer a medicalized view of the deaf, instead it offered a solution to a spiritual problem. ASL was perceived by many as a beautiful, pure, emotional, and, above all, *natural* language provided by God for the deaf (Baynton 1996). Until the middle of the 19th century, ASL and the manual method of teaching children remained the preferred pedagogical and communication method for the profoundly deaf.

CONNECTING TO HUMANKIND AND TO THE NATION THROUGH MEDICALIZED HEARING TECHNOLOGY

In 1859, Charles Darwin published *On the Origin of Species*, which led, in part, to technologies that focused on oral education and speech and hearing as opposed to manual education and ASL. Darwinian evolution, as it was understood in the late 19th century, was seen as a call to morality; “positive” evolution would only continue if active and purposeful steps were made to ensure this outcome (Baynton 1996). Without this purposeful crafting of the nation and the human race, humans ran the risk of “reverting”

to an ignoble, impure, and immoral species. This line of thinking led to categorizing groups of people, and individuals, as either “good” or “bad” (Baynton 2001, Carey 2009, Samuels 2014). Evolutionary theory viewed modern societies as being more advanced, and therefore as more evolved, than prior societies and technologies. As a result, ASL was considered closer to the apes, and inferior to the “newer” oral education and speech and hearing technologies that became more prevalent in the 1860s (Baynton 1996). Signed languages were also associated with “savages” and the uncivilized (Jastrow 1886). Social Darwinism led to eugenicist measures such as calls for the prohibition of deaf intermarriage (Baynton 1996; Winefield 1987) and even forced sterilization (Lane 1999). People such as deaf people, who were perceived to lack self-sufficiency, were “othered” (Erevelles & Minear 2010), and the concept of “deviance” emerged as opposite of “normality” (Davis 2013).

ASL was no longer seen as the “normal” method of communication for deaf people, as ASL was considered primitive and obsolete. Speech was seen as one of the primary attributes that delineated humans from animals (Baynton 1996), and sociologist Charles Cooley (1911) said, “the achievement of speech is commonly and properly regarded as the distinctive trait of man, as the gate by which he emerged from his pre-human state.” From this perspective then, any technology that did not encourage speech,

and secondarily, hearing, separated deaf persons from the preferred, evolved, and evolving species of human.

During this, the second era I discuss, the problem of being deaf was primarily a problem of being separated from the species of homo sapiens. In this era, being deaf was primarily seen as a problem of speech, and secondarily, hearing and of being separate from, and inferior to, the rest of humankind. Key concepts associated with deafness in this era are less evolved and primitive. The technological goals in this era were to achieve, at the very least, speaking because it was speech that separates humans from animals, and more highly evolved species from less evolved species. Educators who used only the oral method became the mediators between humankind and the deaf, enabling them to rejoin the human race.

I suggest that the ‘impairment’ cannot be separated from the socially constructed disability (Collinson 2020). Disability is a socially constructed concept. The word, “Disability,” or rather, Dis-ability, means the opposite of something (Miriam Webster Dictionary 2020), and in this case, the opposite of ability. But who defines ability? As an example, it wasn’t until 2001 that dyslexia was considered a disability (Collinson 2020). Who did this defining? A female academic without any lexicographical challenges (Collinson 2020). People with dyslexia did not define themselves as disabled (Collinson

2020). It is the same with deafness. In the 1750's, there is no evidence that deaf people considered themselves disabled. The teachers of the deaf defined them as backwards, savages, and immoral (Baynton 1996), but notably, not disabled. Additionally, as deafness was beginning to be seen as a disability — a disability that isolated and alienated the Deaf from humankind and the nation— it was in the best interest of the nation and the species to eliminate, as much as was possible, the condition of deafness (Baynton 1996; Winefield 1987).

People who were considered disabled in the 1800s included the mentally and physically disabled, alcoholics, widows or orphans, and they were put into “almshouses” or “poorhouses,” where they received minimal medical and physical care (Minnesota Department of Administration 2020). Luckily for deaf Americans, there was an alternate institution to the almshouse for deaf people— the Deaf School. Conditions were generally better in the Deaf Schools than in the poorhouses and almshouses. One potential cause for this better treatment is that the Deaf Schools were founded and run by ministers who wanted to “save” the deaf child.

This shift parallels a similar shift in attitude toward many conditions. As our medical and scientific knowledge increased, differences in groups and individuals became increasingly medicalized. Life's problems are often distressing, debilitating,

confusing, and difficult to understand. This complexity leads to an urge to seek a medical diagnosis— changing undefined clusters of symptoms into organized syndromes (Conrad 2007). With deafness, and this will become clear in chapter six in which I discuss interviews with parents of deaf children, there are at least two ways of dealing with the medicalization. First, among the Deaf community, deafness is not considered a disability. People in the Deaf community widely consider deafness to be a difference, not a disability (Baynton 1996; Lane 1999). Alternatively, the parents in my interview study widely considered deafness a disability that should be medically treated with cochlear implants. They use language such as having a “responsibility” (Burrows 2013) to medically treat their children.

This second era of the meaning of deafness has many of the same themes from the 1880s that were carried forward into the early 20th century, but by the early 20th century a new concern arose around deaf people— not only were they not seen as part of highly evolved mankind, but now connecting with the nation became a concern as well. As the cultural impacts of the first and second wave of European immigration began to be felt in the US, assimilation into mainstream American culture was the subject of an ongoing national conversation. Just as Italian, German, or Irish immigrants were feared, ridiculed, and isolated for speaking a language other than English, the Deaf were also seen as

threatening foreigners. Deaf people were known to use “the foreign language of signs,” according to JD Kirkhuff in 1892 [quoted in Baynton (1996)], an oralist educator at the Pennsylvania Institution for the Deaf and Dumb, the first state institution to offer an entirely oralist education (Baynton 1996). In the same speech, Kirkhuff said the deaf are “foreigners in tongue” (qtd. in Baynton 1996) The term “threatening” was often used to refer to immigrants, and that language was made to explicitly refer to deaf people by Alexander Graham Bell in 1884 at the National Academy of Sciences annual convention (quoted in Baynton 1996). He said, “a great calamity for the nation was imminent due to the intermarriage of the deaf” (Baynton 1996). No longer was deafness considered a problem defined as isolation from God, nor as merely isolation from humankind, but deafness instead was constructed as being a problem of nationhood and national identity, with Deaf people framed as isolated from the nation.

By the beginning of the 20th century, immigration into the US was a main concern among Americans. Immigrants were seen as inferior to native-born citizens, and immigrants were the object of prejudice and stereotyping. Deaf people, especially those who used ASL, were seen as foreigners in their land. With deaf people perceived as suspect, other, threatening to the nation, or as indicators of a fractured nation, ASL was no longer a sufficient technology to address these problems. Instead, the primary goals of

the new correctional devices were to achieve speaking and hearing and eliminate difference. There was a wealth of hearing technologies used during this time frame—from audiphones, dentaphones, and, slightly later with the invention of the micro-battery, the in-ear hearing aid. Technological managers such as research scientists, inventors, and surgeons mediated between the alienated deaf and the rest of the nation. Next, I will explore the surgical and medical technologies that tried to address the problems of being deaf as they were understood in the late 19th century through the early part of the 21st century. An interesting shift occurred around this time, in which deaf people were no longer considered isolated individuals, but instead began to be viewed as a “people.” In 1847 in the inaugural issue of the “Annals of the Deaf and Dumb,” the authors write, “the Deaf and Dumb constitute a distinct and in some respects a strongly marked class of human beings.” This quote shows that by the mid-1880s, deaf people were no longer considered alienated individuals, but rather a group of people with a shared history and shared values.

In 1900 Katherine Bingham wrote in *Science Magazine* that sign language in the schools led to students being “foreigners in their own land” (quoted in Baynton 1996). Technologies that sought to provide speech, including oral teaching methods with their focus on teaching English, was a way to rectify the problem of deafness as it was

conceived; eliminate the “clannishness” and alien nature of Deaf people by eliminating their language of choice (Baynton 1996; Lane 2005). Proponents of oralism during this time said,

if deaf people are to intelligently exercise the rights of citizenship, then they must be made people of our language. The English language must be made the vernacular of the deaf if are not to become a class into themselves – foreigners among their own countrymen (quoted in Baynton 1996).

One teacher of the deaf, quoted in Baynton (1996) said, “a deaf person who does not use English as a primary language can never acquire the command of that that would make him an American.” The same teacher (Baynton 1996) went on to say, “no gesturer can become an American. The gesturer is, and always will remain, a foreigner.”

Some of the earliest external aids began their life in the early 19th century, when ASL was still the dominant technology and the problem of deafness was considered to be a spiritual problem. ASL was more commonly used for children with little or no prior language development (Baynton, 1996), whereas the earliest precursor to today’s external aids, the ear trumpet, was used to assist those adults with prior language acquisition. The ear trumpet only helped people with minimal hearing loss and was generally used to cut out ambient noise during conversation (Kenneth Berger Hearing Aid Museum 2010). In 1812, the metronome inventor Johann Maelzel made four different ear trumpets for Beethoven (Ealy 1994). However, it soon became apparent that holding an ear trumpet is

incompatible with playing the piano, so Maelzel invented a special hands-free headband for his ear trumpet (Ealy 1994). And voila'— the first no-hands hearing aid!

At approximately the same time as ear trumpets reached their peak usage, other types of hearing technologies were being experimented with. Like with the ear trumpet, most of these technologies were developed for post-lingual deaf adults, as no external amplification aid can help a congenitally deaf infant with no residual hearing. Small private experiments in 1815 and 1817 demonstrated that objects held between the teeth could send vibrations into the head and thus create a sense of “hearing” (Ealy 1994; New York Medical Magazine 1815). These discoveries were the precursors to a type of hearing aid that swept the US for about one very intense year in the 1880's, even though they may have been completely useless in supporting hearing (Smith 1880). These devices, the audiphone and dentaphone, and their close cousins eventually led to the behind-the-ear aids as we have today and were also consistent with oral methods of education which become predominant in this time period (Baynton 1996). I mark the beginning of the second era as the turning point (starting in the 1870s), in which early hearing assistance devices and surgeries were developed and widely adopted.

The first audiphone was invented in early 1879, by a man named Richard Rhodes (New York Times 1879). Rhodes was a deaf man in Chicago who had discovered the

property of “hearing” through ones teeth accidentally when he placed his teeth next to his pocket watch and learned he could hear the tick of the watch through his teeth (*The American Socialist* 1879). The Rhodes audiphone consisted of a collector plate shaped like a large vulcanized rubber fan that was curved to collect sound waves. The fan was attached to a handle that was placed against the teeth of the user (*Scribner’s Monthly* 1880). Soon after its release to the public, however, the first complaint about the Rhodes audiphones came in: it was difficult to be used by those with false teeth (*Medical and Surgical Reporter* 1880); Rhodes immediately responded and provided a modified mouth plate for false teeth. At the same time as Rhodes was making this adjustment however, denture makers had discovered that well-fitted vulcanite dentures were the best sound conductors and encouraged clients to purchase new dentures (*Medical and Surgical Reporter* 1880). Also, for patients with no teeth at all, false vulcanite teeth were fitted directly into the roots in such a way as to be conducive to using the Rhodes audiphone (*Medical and Surgical Reporter* 1880). In this way, the audiphone became connected to the denture industry, which was expected because in many cases the customers for both products were the same.

As quickly as audiphones flooded the hearing aid market, they were gone, and as early as February 1880 a new product, the dentaphone, came onto the market (Western

Christian Advocate 1880b) and largely supplanted the audiphone. What explains the audiphone's rapid rise and fall? In addition to the denture issues mentioned above, there were other critical issues that ultimately led to its demise. First, with an audiphone in one's mouth, one cannot speak⁷. Recall that by the early 1880's, the problem of deafness had become a problem of both hearing and speaking, so a technology that did not allow for speech did not sufficiently address the problem as it was conceptualized in that era. Also, the audiphones only worked, if at all, with patients who did not have a damaged auditory nerve (*Philadelphia Medical Times* 1880b; *Scientific American* 1879), severely limiting its consumer base. Also, like ear trumpets, audiphones were physically cumbersome and conspicuous (*Medical and Surgical Reporter* 1880). A year after their advent, medical opinion was suspicious that vibrations to the small bones in the head jarred the brain, causing brain damage (*Philadelphia Medical Times* 1880b). Additionally, audiphones were seen to be too expensive (about \$10) (*New York Times* 1880; *Western Christian Advocate* 1880), and the hardened rubber used in the devices

⁷ Although the Rhodes audiphones specifically advertised the audiphone's ability to help the deaf learn speech (*American Socialist*, 1879; *Medical and Surgical Reporter*, 1880), pre—lingually deaf children were generally not helped by the audiphones to learn speech or speech recognition when spoken to (*Scientific American*, 1879).

was so fragile that they cracked in the winter (*New York Times* 1880). These concerns led to the invention of a device that was 1/10th of the price as the standard audiphone and that used pasteboard instead of rubber as the collection device (*New York Times* 1880).

However, this last device, invented in Geneva, did not stop the decline of the audiphone, and by the middle of 1880 most hearing aid innovation focused on a different, but related product known as the dentaphone. The dentaphone suffered the same problems as the audiphone and disappeared from the hearing technology market almost as soon as it entered it. The same fate befell the Otocoustic fan, a device similar to the audiphones and dentaphones, and by the end of one frenzied year, audiphones, dentaphones, and Otocoustic fans were a thing of the distant past.



Figure 2. Drawing of Ear trumpets being used. Notice the Dentaphone at the far left of the main dining table (Hearing Systems 2020).

Surgical interventions

The most preferable methods to intervene in deafness during the late 19th century and early 20th century were interventions directly in the ear to enable hearing, and, by extension, speech. Successful technologies could actually eliminate deafness at its source. The surgical intervention of deafness has been recorded at least as early as the 1790's. In 1791, a deaf Versailles man experimented in surgery by blowing air and liquid into the tympanum through the Eustachian tubes; he claimed to cure his own deafness through

this method (Lane 1999). Also, in 1791, Luigi Galvani experimented with Galvanism⁸ for the treatment of deafness, and at least one child was claimed cured with the use of an electrostatic generator (Ealy 1994). Both of these techniques were done with no anesthesia, no antibiotics, and no electric lights, and both had lots of complications (Ealy 1994; Lane 1999). By the 1870's, early versions of surgeries still performed today, including stapes and fenestration⁹ surgeries began to be performed (Lempert 1951). The first stapes surgery had the benefit of both anesthesia and electric lights, and eventually evolved into the modern fenestration surgery in the 1920's (Lempert 1951). Fenestration was expensive, invasive, and required at least 3 weeks recovery, however, for adult-onset deafness, it had an 80% success rate. However, the risks of fenestration meant that very old patients were not qualified for the surgery, and so by 1952, the first modern stapes surgery was performed by Dr. Samuel Rosen (Fowler 1981) although it was modified substantially in 1956 by Dr. John Shea (Shea Ear Clinic 2009). These newer, more

⁸ The contraction of a muscle with electric current.

⁹ Stapes surgery refers to the loosening of the small stapes bone in the inner ear; fenestration surgeries create a “window” in a small bone, with the aim to make the bones in the inner ear move more freely.

relaxed stapes surgeries involved gentle, pulsing pressure to release the stapes bone, but they, like fenestration, only work for patients with hardening of the bones in the inner ear, or osteosclerosis. There are multiple factors that influence the changing techniques of the ear. First, as the causes of deafness change so does the technology. For example, only older adults with hardening of the stapes bone are candidates for either the stapes or fenestration surgeries, as childhood illness or inherited conditions tend to be less amendable to surgical interventions. Secondly, as the meaning of deafness changes so does technology. Although there were some attempts to surgically correct hearing in the 18th and early 19th centuries, these attempts became more concentrated during the time periods when deafness was seen as a threat to humankind and to the nation. Although when the meaning of deafness changes, the technology changes, it is also true that as technology changes, the meaning of deafness changes. For example, during the earliest attempts at hearing surgeries, there were no electric lights, antibiotics, or an understanding of germ theory and hygiene (Ealy 1994; Lane 1999; McCoy 2015). Once these scientific advances occurred, it became possible for more advanced surgeries to be developed. When stapes surgeries, and micro-battery behind-the-ear hearing aids became common place, the meaning of deafness changed from “connection with God,” to “connection with the nation,” This is because, as a language technology, ASL was able to

address a perceived isolation from God, and since ASL presumedly allowed communication with God, ASL was sufficient technology for the problem at hand. However, as the meanings of deafness expanded to include isolation from humankind and isolation from the nation, ASL was no longer a sufficient technology, and thus new technologies were invented to address these new problems of deafness. These changes happened in dialectic with each other— one did not lead the other. Lastly, as medical, and scientific knowledge of the ear and acoustics change, so does technology. For example, in 1863, the German physician Helmholtz “discovered” the middle ear bones required for hearing (Rosen 1958), of which knowledge led to both the stapes and fenestration surgeries.

Battery Powered Hearing Aids

In 1886, a full seven years after the release of the first audiphones, the Blodgett Microaudiphone was invented (*Scientific American* 1886). The microaudiphone looks like a modern in-ear hearing aid and was made of hard xylonite with a vibrating diaphragm (*Scientific American* 1886). By 1907, similar devices were being powered by small electric batteries (*New York Times* 1907); the age of the in-ear/behind the ear hearing aid had finally arrived. The first battery operated hearing aid was invented in 1898 by Miller Reese Hutchinson (Hearing Systems 2020), although an argument could

be made that Alexander Graham Bell's invention of the telephone was actually the world's first hearing aid, as it included features such as controlling the loudness of the receiver (Winefield 1987). In 1913 the first mass marketed hearing aids were available; however, they were not very portable (Hearing Systems 2020). Vacuum tube hearing aids were produced in the '20s, and this was the main kind of hearing aid available until after WWII and the invention of the transistor. Transistors quickly replaced vacuum tubes as they were smaller, needed less battery power and had less distortion (Hearing Systems 2020; Healthy Hearing 2020). In the 1970s the transistor gave way to microprocessors and ushered in the use of digital technology (Hearing Systems 2020; Healthy Hearing 2020). At this point, hearing aids started evolving rapidly with the creation of high-speed processors in the 1980s, and the appearance of the first all-digital hearing aid in the 1990s. Today, hearing aids are paired with Bluetooth devices for even more flexibility.

ACHIEVING SUCCESS: THE MEANING OF DEAFNESS AND TECHNOLOGIES IN THE AGE OF COCHLEAR IMPLANTS

So far, this discussion has focused on how deafness has been problematized in the past— isolation from god, from humankind, and from the nation. I argue that today the “problem of being deaf” is the problem of success. Americans tend to be obsessed with appearances and success and are afraid their deaf children can't succeed with “broken

bodies.” (Del Sotto et al., 2020; Banerjee et al., 2020; Garg et al., 2021) Success is seen to be threatened by deafness such as success in friendships and childhood sports, college, in marriage, in career, in childrearing. Since the problems of deafness, as they are conceived of in a particular era, are informed by available technologies, and likewise, technological invention informs the meanings of deafness, the cochlear implant and the definition of the meaning of deafness as success are co-constructed. In my interview with her, Marty, the mother of a 12-year old bilaterally implanted son, said “I want him to have a normal life, normal college, normal marriage. I guess you could say I just want him to be as successful as his hearing brother. Yes, I compare them.” While our society still focuses on a connection with God, a connection with humankind, and a connection with the nation, the focus on personal success is a pressing one.

As noted earlier, the meanings of deafness help shape the technologies that evolve to address it, and technologies, in turn, shape the meaning of deafness. As cochlear implants were in their infancy in the 1950s and 60s, so were the social ideals of white middle-class success (Ciciolla et al., 2017; Jamal 2020; Schaus 2018). These two artifacts from that era- middle-class success and cochlear implants, shaped each other into existence. When technology became available to provide near-normal hearing, the goal of having “normal” success became possible. I mark the 1980s and the founding of the first

CI manufacturer in the US as a turning point where the problem of deafness shifted to success and the technological solution became CIs.

The question arises, why now? Why is success the “problem” of deafness (Yigider et al.,2020; Delgado et al., 2020) in the modern era, and not connection to God, humankind, or the nation? Deaf people who use ASL may come in conflict with hearing norms (Delgado 2020; Luft 2016), such as a norm to not mention people’s weight (which, while a norm in English-speaking culture, is not a norm in ASL-using culture), or a norm against speaking loudly in public. These breaches of hearing norms make it difficult to blend into hearing culture, and so the problem of “success” can be complicated by these norm transgressions. Normality is a common theme across eras, but in the modern era, education has become part of the pursuit of normality (Lamont 2019; Snyder-Hall 2018). However, there appears to be a decline, especially among working class Republicans, in the respect given to institutions of higher education (Snyder-Hall 2018). With the rise of homeownership after WW II, and the availability of the GI Bill (for white Americans), becoming middle-class, replete with a refrigerator and range, became the new American Dream. Rising to the middle class meant your children could go to college, and, for boys, have successful careers, and buy their own homes. This drive toward white middle-class success has not waned since the 50s — the desire to raise a family in middle—class

America and see your children off to college, with promising career prospects and pleasurable marriage prospects – is still a driving force for many parents. Many middle-class parents wish this success for all their children— deaf or not.

I argue that deafness is a problem of success in the early 21st century. Cochlear implants arose in part to answer this problem— Cochlear implants provide both speech and language, and therefore are poised to offer the implanted person academic, personal, and professional success. In an earlier study, (Burrows 2013) Deaf adults who use the Videophone talked about how the Videophone gave them independence and diminished their reliance on others. In an interview with him, James said, “I can order a pizza and my neighbor doesn’t need to know!” Betty, also a Deaf adult who uses the Videophone said in her interview, “When I was growing up, my deaf mother and all of us deaf kids we had to have the neighbor make calls for us and help us with things that I can now do myself!” (Burrows 2013). In this context, deaf people are seen as limited, and reliant upon others. By offering a chance at hearing and speech, cochlear implants seem suited to resolve the problem of success and provide a chance at “normality.”

The John Tracy Clinic is a hearing and listening based clinic in California that is named after John Tracy, the actor Spencer Tracy’s deaf son. They are a speech and listening, pro-cochlear implant organization (John Tracy Clinic 2018) which states its

goal is to support parents of deaf children. Their website states, “John Tracy Clinic provides parent-centered services locally and globally to young children with hearing loss, offering families hope, guidance, and encouragement. (John Tracy Clinic 2018). A parent is quoted as saying, “Our experience with JTC was life changing. It was the first time that we saw the whole picture of how we can support our child with hearing loss. Now we have hope for our son.” (John Tracy Clinic 2018). While John Tracy is based in Los Angeles, they offer distance learning for families with new cochlear implants (John Tracy Clinic 2018). The John Tracy Clinic is one example of an organization that medicalizes deafness by promoting the medical intervention of cochlear implants.

The conceptualized problem of hearing loss in the modern era is a problem of success and of meeting white, middle-class ideals of what a “good life” looks like. The definition of a “good life” vary across time, space, and culture (Van der Boor et al., 2020). Hegemonic white values and ideas of a “good life” may differ from those of other socioeconomic and racial groups (Banerjee 2020). The white parents of deaf children in my interview study are focused on their child’s achievements in life- achievement in school, achievement in career, and achievements in married life. These goals are grounded in parents’ social, political, economic, and social contexts. Most of the parents in my interview study were white, middle class professionals, and so aimed for the same

lifestyle for their children. Parents from a lower socioeconomic stratum were less concerned with economic success and more concerned with overall happiness and life satisfaction. Joan said, “I just want her to be happy, and have a good academic and career life. I don’t want her to be limited.” Unlike in earlier eras where signed languages could address the conceptualized problems of being deaf, speech and hearing is critical to meeting these success goals.

Cochlear implants arose during this era in order to meet these needs. A cochlear implant is a small electronic device that provides a sense of sound to the wearer— it does not increase volume like a hearing aid does. The implant consists of an external portion that sits behind the ear and a device that is surgically placed under the skin. As shown in Figure 3, an implant has the following parts:

- A microphone, which picks up sound from the environment.
- A speech processor, which selects and arranges sounds picked up by the microphone.
- A transmitter and receiver/stimulator, which receive signals from the speech processor and convert them into electric impulses.

- An electrode array, which is a group of electrodes that collects the impulses from the stimulator and sends them to different regions of the auditory nerve (National Institute of Health 2017).

An implant does not restore normal hearing. Instead, it can give a deaf person a useful representation of sounds in the environment and help him or her to understand speech (National Institute of Health 2017).

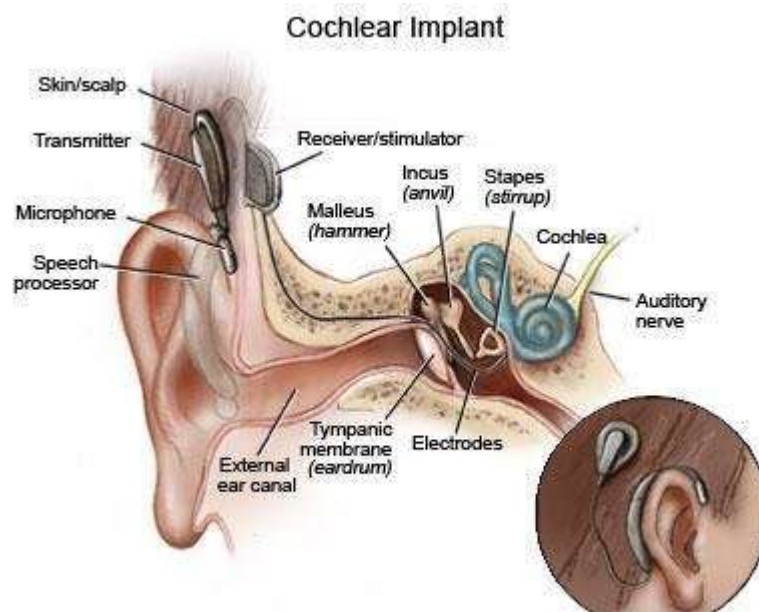


Figure 3. Diagram of a Cochlear Implant from the National Institute of Health (2017)

The National Institute of Health (2017) explains hearing with a cochlear implant in this way:

A cochlear implant is very different from a hearing aid. Hearing aids amplify sounds so they may be detected by damaged ears. Cochlear implants bypass damaged portions of the ear and directly stimulate the auditory nerve. Signals generated by the implant are sent by way of the auditory nerve to the brain, which recognizes the signals as sound. Hearing through a cochlear implant is different from normal hearing and takes time to learn or relearn. However, it allows many people to recognize warning signals, understand other sounds in the environment, and understand speech in person or over the telephone.

French physicians André Djourno and Charles Eyriès are credited with inventing the original cochlear implant in 1957. Their original design was a single-channel device, starkly different from the modern 22-channel device (Svirsky 2017). Djourno, a physician working within an academic research environment, was interested in applications of electricity in medicine. He experimented by placing little coils in small animals such as frogs and rabbits (Seitz 2002). The earliest of these coils were implanted in the animals' diaphragm with the intention of implanting the coils into humans to aid in breathing after surgery (Seitz 2002). While doing these experiments, Djourno contemplated using his implants to stimulate the cochlear nerve in deaf people. Eyriès first met Djourno four years after Djourno considered using the implant to stimulate the cochlea. Eyriès was an Otologist working within the medical establishment and had recently done surgery on a deaf man using electricity, and the man reported that he could hear during the surgery (Seitz 2002). The two physicians collaborated on an implantable device for the cochlea and implanted it into Eyriès' patient. On March 9th, 1957, the two

physicians, along with 2 colleagues, published their first article about Eyries' patient. The patient was a 50-year-old man who had profound loss of hearing in both ears caused by infection. Five months after the surgery, he was able to identify a short list of words like "mum," and "allo" (French for "hello") (Seitz 2002). Unfortunately, a few months later, the implant broke, so the patient was re-implanted, which, like the first, worked for several months and then broke. The two then implanted a deaf woman, but six months after surgery she left the country, so they were not able to follow her progress. Djourno and Eyries argued about the commercial value of their implant. Djourno was adamant that an invention of this potential deserved to be in the public domain, so refused to patent it, however, Eyries wanted to patent it for financial gain (Seitz 2002). By 1959 Djourno's team had 12 publications, two patients, and mountains of experimental data. Key among these data was a prototype of a multichannel cochlear implant, the true forebear of today's cochlear implant (Seitz 2002).

It is widely cited that Dr. William House invented the cochlear implant (Martin 2002), and, to his credit, he was the first to implant a child in 1980 (Eisenberg & House 1982), but as more researchers read the work of Djourno and Eyriès, it is becoming evident that they, in fact, should be recognized as the first scientists to invent the cochlear

implant. House read their publications and relied on their experiences to make his inventions. House's four channel implant was invented in 1961 (Martin 2002).

House was originally a dentist and experimented with fenestration surgery, a surgery that opens a new hole in the bony labyrinth in the ear to correct certain types of hearing loss in older people (House, 2011). His interest in fenestration and hearing loss made a natural transition to cochlear implants. A colleague showed him the Djourno and Eyriès article and he "became excited" about it. He writes in his memoir (2011),

I became very excited about this. I had seen that deaf children with some residual hearing who could hear a degraded signal with a hearing aid could learn lip reading. It seemed possible that if an implant could give totally deaf children some hearing, they could learn lip reading, be successful in an oral school, understand the English language and learn to read.

House's first implants were of two adults in 1961. Things proceeded as expected, with the adults hearing ambient noise, but then they both developed infections and House ex-implanted both patients. House's influence on the development of cochlear implants can't be underestimated. He followed in the footsteps of his predecessors, Djourno and Eyriès, and made steps forward by implanting additional patients and advancing the technology. In 1964, Blair Simmons and Robert J. White implanted a six-channel electrode in a patient's cochlea at Stanford University (Mudry and Mills 2013). That

implant had limited success in terms of hearing and speech results but was one of the first implants that didn't have complications requiring re-implantation.

Another crucial step in this period involved the independent evaluation of cochlear implants. The first such evaluation was published in 1977 by the audiologist and neurophysiologist Robert Bilger (Bilger & Black 1977) from Pittsburgh. Over the course of 5 days, Bilger's group evaluated 13 patients with implants (11 who had undergone implantation by William House with a single-channel electrode, and 2 by Michelson) and remarked that “[t]he implant surgical procedures were well-tolerated by the subjects and did not disrupt middle ear function” (Bilger and Black 1977) The patients “did score significantly higher on tests of lipreading and recognition of environmental sounds with their prostheses activated than without them” (Bilger and Black 1977). They concluded as follows: “To the extent that the effectiveness of single-channel auditory prostheses has been demonstrated here, the next step lies in the exploration of a multichannel prosthesis” (Bilger and Black 1977).

The modern multichannel cochlear implant was independently developed and commercialized by Graeme Clark, an independent inventor from Australia, and, independently from Clark, Ingeborg Hochmair and her future husband, Erwin Hochmair. The Hochmairs first implanted a person in December 1977 and Clark's was first

implanted in August 1978. (Lasker Foundation 2013). Clark hypothesized that hearing might be reproduced in people with deafness if the damaged or underdeveloped ear were bypassed, and the auditory nerve were electrically stimulated to reproduce sound. Clark's first multi-channel cochlear implant operation was done at the Royal Victorian Eye and Ear Hospital in 1978 by Clark and Dr. Brian Pyman. (Lasker Foundation 2013) The first person to receive the implant was Rod Saunders who had lost his hearing at age 46 (Roche and Hansen 2015). Less than one year later, a second patient was implanted. In 1982 Clark supervised the initial clinical studies mandated by the Food and Drug Administration (Clark 2006). After a world trial in 1985 the FDA granted approval for his multi-channel cochlear implant for adults 18 and over who had hearing before going deaf (Clark 2006). It thus became the first multi-channel cochlear system to be approved as safe and effective by the FDA (Clark-2006). In 1990 after a detailed analysis of results the FDA announced that the 22-channel cochlear implant was safe and effective for congenitally deaf children from two to 17 years of age (Yawn, et al., 2015).

After Clark and the Hochmair's first implantations the challenge came to manufacture the implant en-mass and convince surgeons the devices were safe and effective. This was accomplished by the rise of three companies: Cochlear America in

1983 (Cochlear America 2018b), Advanced Bionics in 1993 (Advanced Bionics 2018), and Med-El, based in Europe, in 1990 (Med-El 2018).

In 1987 Holly McDonnell, at the age of four, was the first pediatric recipient of the commercial Nucleus (a Cochlear America product) cochlear implant. She still has her original implant and has had five sound processor upgrades since then. "With my cochlear implant, I was able to happily attend mainstream schools and successfully achieve my own personal and career goals" said Holly at age 26 (Cochlear America 2018b).

The global cochlear implants market size was valued at USD 1.1 billion in 2015 and is projected to grow at a compound annual growth rate (CAGR) of 10.5% (Grand View Research 2018). This high growth can be attributed to the advancements in cochlear implants, growing penetration of implants due to expanded geographical reach of market players, and government support, such as the fact that Medicaid covers cochlear implants (Grand View Research 2018). Technological advancements, strategic initiatives by the industry players, and favorable insurance reimbursements for cochlear implantation surgery are the other key drivers of the market.

Deaf resistance to cochlear implants

While there is a historic trend towards increasing hearing technology, there is also resistance against this technology. Some members of Deaf culture resist a disability definition of deafness, and so use assistive technology only to the extent that they are compatible with a cultural, and not medical view of deafness. On the back of the book cover for the pro-ASL book, *Deaf Like Me*, (Spradley & Spradley 1985) the *Norwich Connecticut Bulletin* is quoted as saying,

[In *Deaf Like Me*,] the heartbreak, love, and anxieties of all parents of a handicapped child are simply and movingly expressed in this story of a family's desperate fight to teach their deaf daughter to speak so she will be considered normal. The result is a moving story of how a small deaf girl breaks the chains of ignorance and prejudice that have held her mute for five years— to discover the world she cannot hear [through communication via ASL] and to teach her family what love and being normal really mean [by teaching them about ASL and Deaf culture].

This excerpt demonstrates that “normality” is only achieved when the protagonist adopts ASL. It suggests that for a deaf child, in the era before cochlear implants were readily available, normality is achieved by communication by *any means possible*— ASL is just as preferred, if not more so, than English. The book was published by Gallaudet University Press, the first and largest Deaf university in the world, which is a hint towards the book's position on oralism vs. ASL. This book was published in 1985, before cochlear implants were common among children, but this quote could very easily have been taken from a book written today. The emphasis on “normal”— both in terms of

speaking and in terms of ASL shows how both sides of this issue utilize the language of normal.

As has been noted elsewhere in this dissertation, culturally Deaf people have been known to mount resistance towards the oralist movement and hearing and speaking. It is notable that there is no Deaf resistance to other hearing technologies— Deaf people regularly avail themselves of hearing aids, VideoPhones, Closed Captioning, etc. But the cochlear implant is unique because it threatens to redefine what it means to be deaf. Prior to cochlear implants reaching the mainstream, deafness was a lifestyle, a community, a set of values— now it has been degraded (or upgraded?) as a medical problem that can be fixed. Since 90% of deaf children are born to hearing parents, and most of those parents will chose cochlear implants for their kids, there will be no pipeline of new people into the community, and eventually the language, and therefore, the culture, will die (Lane 1999). Some Deaf people who believe cochlear implants predict genocide, use ASL actively to resist and deny cochlear implants' place in the deaf world. For example, at the national Alexander Graham Bell Association Annual cochlear implant conference, a conference aimed at parents of children who use cochlear implants, Deaf people annually gather and protest. An interview respondent for my study who saw these protests described it as, “There was a sign that said, ‘Deaf Beautiful Baby!’ It was eerie— quiet

and angry at the same time. I was scared and we moved our hotel room, so we didn't have to walk past them." It is notable that the Deaf community's resistance against CIs is singular—there are not protests against hearing aids, for example. As a matter of fact, many Deaf adults use hearing aids to supplement residual hearing. This demonstrates the cochlear implant's perceived power to dominate the culture—the cochlear implant, and apparently, only the cochlear implant, can “take over” Deaf culture.

Resistance in the Deaf community sometimes came in the form of a proxy, who has been recently deceased (Sandomir 2019): Harlan Lane, a hearing psychologist is probably the most well-known proponent of Deaf culture. Much of our understanding of Deaf culture as a culture comes from Lane (Sandomir 2019). Without Lane's voice, it is unknown who will emerge as the main proponents of Deaf culture.

CONCLUSION

Table 2. The Evolving Meaning of Deafness

How early 19 th century institutional power defines:
The “problem” regarding deaf persons: Disconnection from God
The “goal” for deaf persons: Connection to God
The “solution” to achieve the “goal” for deaf persons: American Sign Language

How late 19th century-early 20th century institutional power defines:

The “problem” regarding deaf persons: Disconnection from humankind/nation

The “goal” for deaf persons: Connection to Non-Deaf Society/nation

The “solution” to achieve the “goal” for deaf persons: Speaking and Listening with the aid of oral schools/hearing aids

How early 21st century institutional power defines:

The “problem” regarding deaf persons: Disconnection from Opportunities, Access, and Resources

The “goal” for deaf persons: Connection to Opportunities, Access, and Resources

The “solution” to achieve the “goal” for deaf persons: Cochlear Implants

This chapter started by exploring the meaning of deafness throughout the years. After I explored the meaning of deafness in each era, I explored the history of the deaf technology that evolved in that time frame. The chapter covered technological advancements in both hearing aids and cochlear implants. This technological analysis demonstrated that it takes an army to make a technological advancement— one person or

group makes the original attempt, and then other people take that attempt and make it better. There is a feedback loop from user groups (such as the feedback that audiphones did not work well for people with false teeth, which then transferred the technology back to the developers to address the problem). This kind of discovery was apparent with the audiphone and dentaphone— competing inventors came up with over four different audiphones and dentaphones in the scope of one year! Simultaneous attempts on different continents are also possible, such as the cochlear implant advancements made by Graeme Clark in Australia and the Hochmairs in Europe.

The meaning of deafness is a socially constructed viewpoint of what deafness means, both to those who are deaf as well as those who are hearing. In the early 1800s, the meaning of deafness was the fear of being isolated from God. Minister-run residential schools that taught ASL were the solution to this problem. Residential schools became the cultural center of Deaf culture, where friendships and marriages were often begun. In later eras, the meaning of deafness was related back to other social problems, such as a growing awareness of evolution and struggles with immigration, and in these time periods, deafness meant isolation from humankind and from the nation. The idea of deaf people as being threatening is salient in this second era— in the 1880s, deaf people were considered evolutionarily “behind,” and were seen as a threat to an advanced gene pool.

With regards to immigration, deaf people were seen, much as Irish, Italian, or Jewish immigrants, as threatening to an intact nation. In the modern, or third, era, I identified “success” as the meaning of deafness. Success as the meaning of deafness is tied back to white, middle-class American ideals that emerged in the post-war period in the 1950’s. Only cochlear implants, and not ASL or hearing aids, can offer hearing and speaking to congenitally deaf children in such a way that success, as it is typically defined, in terms of school, friendships, childhood sports, college, career, and marriage, can be achieved.

Normality as a theme runs throughout the entire chapter. As the meanings of deafness show, connection with, and blending in with, the larger community is paramount— and this “blending in” can be seen as a type of enforcing normality. “Normal” people are part of the Christian community, part of the nation, part of humankind and achieve personal and professional success. To a degree, this normalcy was enforced, such as the eugenic practices upon deaf people at the turn of the century. The social construction of disability is key to understanding how deaf people have been understood differently throughout the eras- distant from God, distant from humankind, distant from the country and incapable of achieving personal, academic, and professional success. The fact that deaf people are perceived differently in different eras is evidence in itself that deafness as a disability is a social construct. In the next chapter, I will explore

how images of hearing technology and deafness in advertising map onto the meanings of deafness as I explicate them in this chapter.

Chapter 5. The History and Present of Hearing Aid and Cochlear Implant Advertising

In this chapter of the dissertation, I am going to analyze the print marketing materials of hearing aid ads from around 1910, the advent of the micro-battery in hearing aids, to approximately the 1970's, as well as hearing aid and cochlear implant websites. This period spans the second era described in the previous chapter (when the goal of hearing technologies was to connect deaf people to humankind and the nation) and the third era (when the goal of hearing technology was to achieve success). In addition to being in line with the problems of deafness, I also suggest that these advertisements rely on concepts of normality, medicalization, and stigma to market their products, which is one of my primary contributions in this chapter. This is true in the historical hearing aid advertisements as well as the contemporary hearing aid and cochlear implant websites. This chapter addresses the second research question— how does advertising and marketing strategies for deaf technologies from the 1900s to the present reflect the changing social meanings of deafness and social beliefs about normality? I have identified four overarching central themes in the advertisements: connection, inconspicuousness, modernity/space age/supra modernity, and success. These themes largely, but not completely, map onto the problems of deafness as they were defined in the last chapter. The theme of connection relates back to the problems of deafness as it

was defined in the older eras- connection with God, humankind, and the nation. In these eras, *lack of* connection is the problem as it was understood, and so advertisements from these eras focus on how their products create connection and diminish isolation. The theme of inconspicuousness relates back to stigma, as deafness is often a stigmatizing condition, and anything that can diminish that stigma, such as discrete hearing aids, are desirable to people who are worried about the stigma of hearing loss. The theme of modernity/space age/supra modernity relates back to medicalization. Recall that medicalization occurs when a condition, behavior, or state of being becomes to be considered a medical problem to be addressed by medical science and technology. Advertisements that describe advanced science fiction or science fact demonstrate the medicalization of deafness- they are marketing advanced *medical* interventions to the problem.

Ultimately, the desire to be “normal” is what lies behind all these ads and websites. The advertising encourages people to want to be normal- and the ticket to normality lies in purchasing one of these products. Most of the advertisements featured people, who assumedly have hearing loss and are using an aid of some sort, in relationship with others— carrying on normal life activities such as talking to others, playing with children, or conducting business. These life activities were portrayed as

“normal,” and it was implied that people who buy the aid or implant can achieve normality as well. Of course, having a cochlear implant or hearing aid is not “normal,”—unless one is quite advanced in years, most people don’t need cochlear implants or hearing aids. So, these ads are negotiating the fine line between selling “normalcy” and recognizing that, by its very nature, it is not “normal” to need these products.

INCONSPICUOUSNESS



Figure 4. Hearing Aid advertisement that focuses on Inconspicuousness. Kenneth Berger Hearing Aid Museum.

The earliest advertisements focus on the inconspicuousness of the hearing aid product, although this theme appears in contemporary materials as well, so because it appears at the earliest timepoint and expands across all eras, I will discuss this theme first.

Hearing aid advertisements- both historical and contemporary- emphasize their small size and inconspicuousness. These ads emphasize that deafness is a private matter that no one else need know about (Goffman 1963). He explains:

Given these several possibilities that fall between the extremes of complete secrecy on one hand, and complete information on the other, it would seem that the problems people face who make a concerted and well organized effort to pass are problems that wide ranges of people face at some time or another. Because of the great rewards of being considered normal, almost all persons who are in a position to pass will do so by some occasion by intent.

Figure 4 shows a woman wearing an inconspicuous hearing aid. Persons with all forms of disability may attempt to hide their disability from others, and my findings document this in a different way, by showing how marketing to disabled persons rely on themes of hiding, privacy, and secrecy. For example, in one study, participants talked of hiding their disabled body parts with clothing (Taleporos and McCabe 2001), and deafness itself is one disability that people in the professions have tried to hide (Woodcock, Rohan, and Campbell 2007), although at much lesser rates than the non-deaf perceive hiding behavior (Cayton 1982).

People are more likely to try to “pass” as not having a disability based on the level of societal acceptance for the disability (Goffman, 1963, Taleporos and McCabe 2001). Some passers will be so successful that most acquaintances won’t know they live with chronic disability, and may even make an effort so that close friends and family “forget” about the disability (Maynard and Roller 1991), and that people who hide their disability may suffer the most psychic harm and be the least well-adjusted than others that do not hide their disability (Maynard and Roller 1991). Feelings of shame about one’s own body, as well as discomfort and the perceived lack of societal acceptance for one’s disability will lead people to hide (Taleporos and McCabe 2001). Women in particular may be more prone to hiding their disability (Lloyd, 1987; Stone 1995). This may be because women tend to be more judged on their appearance and judge their appearance more harshly than men than do (Stone 1995), which might be why many inconspicuous hearing aid products are aimed specifically at women (see Figure 5).



Figure 5. “Hear-Rings” marketed towards women. Kenneth Berger Hearing Aid Museum.

The decision to hide a chronic condition such as deafness may be the result of stigma or perceived stigma (Joachim and Acorn 2000; Goffman 1963). Some parents of children with a disability may instruct their children to not disclose their disability to others (Joachim and Acorn 2000), raising children who go to great lengths to pass as nondisabled. Hiding or denying a disability has been associated with “passing” to avoid stigma associated with the disability (Olney and Brockelman 2003; Goffman 1963).

This stigma can lead to a situation in which people are forced to hide both their

disability as well as their identity (Gibson et al. 2005; Goffman 1963) and may be done to maintain the pre-disability identity. This kind of hiding can lead to loss of social contact and social isolation (Gibson et al. 2005; Goffman 1963). This type of hiding is exemplified in hearing aid types that are disguised as something else, such as earrings, pens, tie clips, wrist watches, and, as is seen in Figure 6 below, eyeglasses.



Figure 6. Hearing aids disguised as glasses. Kenneth Berger Hearing Aid Museum.

Modern-day hearing aid websites also make a point of demonstrating how inconspicuous their products are, by explaining micro technology and showing how small their devices are. The products shown below in Figure 7, made by Miracle Ear (2021), are marketed with the language: “This hearing aid offers the ultimate in discreet hearing solutions.”

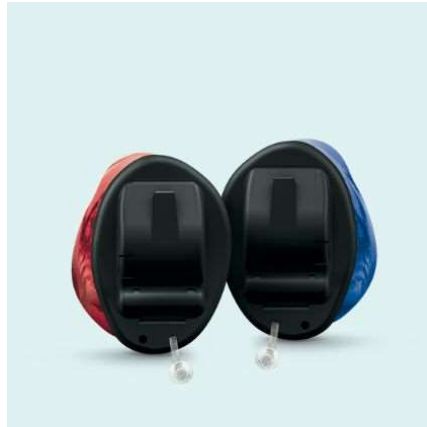


Figure 7. Miracle Ear “discrete hearing solution” 2021. Miracle Ear.



Figure 8. Playing music with a discrete cochlear implant. Cochlear Americas.

2020.

The picture shown above, taken off the Cochlear Americas website, in Figure 8 shows a couple enjoying music and together time. This is one of the only pictures on any of the cochlear implant sites that do not show an individual with an obvious cochlear implant, however, one is left to imagine that one, or both, of the two are wearing a cochlear implant that is not visible. This “hiding” of the implant, which is markedly different from other pictures on this site in which the cochlear implant is visible, reflects the theme of inconspicuousness. It may also suggest how “normal” these activities are—playing music without the help of technology showcases how normal a cochlear implant

wearer can be. The themes of this picture are inconspicuousness, togetherness, and relationships.

These examples of inconspicuousness relate very strongly to themes of normality. If one hides their deafness successfully by disguising their hearing aid in glasses or jewelry, or by having hair that hides a cochlear implant, then people, even close friends and family, may never know, or will “forget” that the person is deaf. If you don’t know someone is deaf, then that someone, barring other situations, will be considered “normal.” Saying your product is inconspicuous is the same as saying “you’ll be seen as normal if you use this product!” Products from earlier eras, such as audiphones and dentaphones, cannot claim normality for their users— their products are extremely conspicuous and by using them, everyone around the user will know they are deaf. Battery powered hearing aids led the way to these inconspicuous aids, allowing people to achieve “normality.” In this case, “normality” is directly related to medicalization— by medicalizing your hearing challenges, you have the possibility of “passing” as normal. These ads suggest that the only way you can be considered normal, or even close to normal, is if you invest in hearing aids or cochlear implants.

A curiosity of hearing aids (but not cochlear implants) is that, even though they are a medical product, that, in most states, must be prescribed by a medical doctor, they

are not sold by medical professionals. To buy a hearing aid, one goes to a hearing aid “center,” which is usually not connected to a medical facility. These centers exist in malls, on busy street corners, everywhere except in a medical facility. While the people who sell hearing aids in these centers are professionals, they are not *medical* professionals. This situation actually adds to the image that a hearing aid will make you normal—they are bought in a “regular” store, sold by “regular” people. In this way, buying a hearing aid is much the same as buying a cell phone—they are sold in specialty stores with salespeople who are experts in the merchandise, but no medical degree is required, destigmatizing the purchase as a “lifestyle” purchase and not a “medical” one.

MODERNITY/SPACE AGE/SUPRA MODERNITY

The second theme to emerge from the data was modernity/space age/supra modernity, although it is true that this theme was more prominent beginning in the 1950’s and into the present than in the earlier eras. These ads compared hearing aids to modern appliances, science fiction, or to the space program, or, in the contemporary hearing aid and cochlear implant websites, to science fact and advancements in scientific knowledge. These advertisements appeal to the allure of the modern. They emphasize high-technology and advanced science. These advertisements appeal to the “brain,” as opposed to the “heart,” and imply that the hearing device advertised is the most modern and

sophisticated device on the market. Space exploration iconography was present in ads from the mid-century. Even though the modern hearing aid and cochlear implant websites did not use “space” imaging or language, they did focus on the supra-modern hearing aids and cochlear implants of today that address modern problems such as communicating in crowded environments and communicating with people wearing face masks (Audibel 2021). These websites showed all the technical details of the hearing aid or cochlear implant, and in this way, have similarities with the “modernity/space age/supra modernity” advertisements that focus on hyper-modern technologies (Devezas 2016; Osborne 2015; Costa 2020; Erickson 2018). When discussing the space race in the 1950’s, Costa (2020) writes:

Science was conceived as a neutral power to be supported, but it required political guidance to harness it and turned it into social progress.” The “space race” that was most closely followed in the 1960’s is that between the USSR and the US.

Erickson further explains (2018):

In critical respects, Washington's lunar landing stemmed from an effective systems management program, while Moscow's moonshot succumbed to the Soviet system, which proved unequal to the task. In less than a decade, Soviet space efforts shifted from one-upping, to keeping up, to covering up.

Space race iconography in these ads relate back to the meaning of deafness I identified in chapter four- that of connection to the nation. During the Cold War between

the United States and the Soviet Union, the space race was a nationalistic program (Davenport 2019) that sought to position the first country to reach the moon as the world's primary "Superpower." The ads that focus on space, and the space race in particular, are leveraging this nationalistic narrative to appeal to people's desire to connect with, and be a part of, the nation state.

One cochlear implant company, Advanced Bionics (2020), features language on their website promoting the advanced science used by their brand. For example, on their page "Top 10 Reasons to Choose AB," (2021) they write the following; "With the combination of AB innovations and proven Phonak technology, you can enjoy all of the modern convenience of wireless streaming right to your ears" On the same page, they mention (2021) "AB's groundbreaking innovations will literally bring music to your ears. Using the highest sound resolution available, we'll help you appreciate all the nuance of music and understand lyrics more clearly than ever before."

All of the materials highlighted in this section, whether space-age advertisements from the 1950's or websites from hearing aid and cochlear implant companies, focus on cutting-edge technology. When coding the data, an advertisement was identified as leveraging "modern" themes if it portrayed the product as being new or revolutionary, up-to-date, or ahead of its time (Zhang and Shavitt 2003). It has been demonstrated that

advertisements are informed by cultural values (Zhang and Shavitt 2003; Caillat and Mueller 1996), including modernity. Advertisements that reflect modernity (Pollay 1983; Britt 2020) have been shown in previous research to be reflective of “new, improved, advanced, progressive, introducing, [and] announcing.” (Pollay 1983).



Figure 9. Advertisement featuring “space electronics.” Kenneth Berger Hearing Aid Museum.

The lure of science and modernity is what lies behind these ads (Freud 1961; Garvey 2021). Freud famously said, “civilization, despite being ostensibly intended to

protect humanity from misery, is paradoxically a great source of unhappiness (1961). Now, of course, hearing aid and cochlear implant manufacturers aim for the opposite of Freud's observation. They aim to demonstrate that the supra-modern hearing device they market will improve your life in many dimensions. In the late 1960's and the space race, anything associated with science, modernity, and space was attractive to people. The lure of the modern continues to exist, as will become clear as we move throughout this chapter. Advertisements that associated the product with space were able to capitalize on the excitement of the mission to the moon and other advancements in space travel. This can be clearly seen in Figure 9, in which the ad states, "From the Science of Space Electronics." One interesting aspect of this particular ad is that it seems to combine historical— either Greek or Roman— imagery with advanced space science. The figure in the advertisement blends modern technology with tradition, which may have sought to reassure the reader that, while, supra-modern, these hearing aids are accessible to even those who are not part of the advanced technological revolution. The image in Figure 10 does not clearly identify that it is for a hearing aid, but below this image, cut off in my photograph, it said, "Remarkable new hearing aids give birth to the future!"

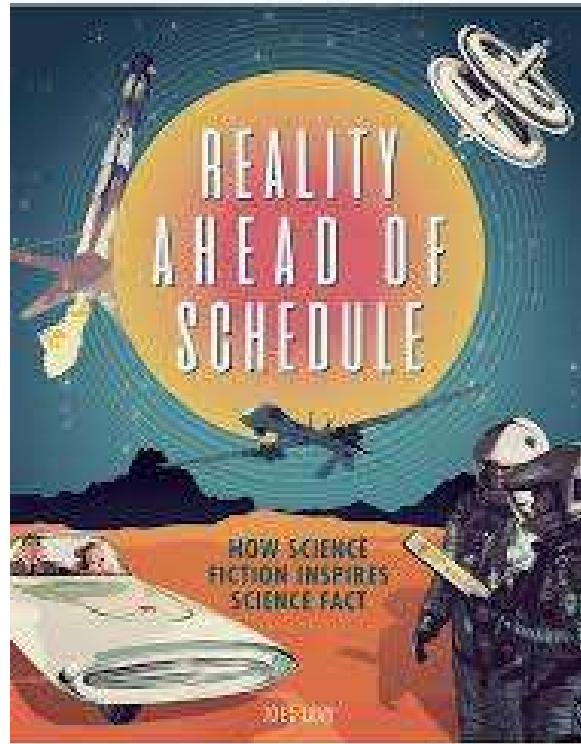


Figure 10. “Space Age” advertisement. Kenneth Berger Hearing Aid Museum.

None of the images in the “modernity/space age/supra modernity” category appear to relate to themes of normality, medicalization, or stigma, however, as discussed above, these ads can be connected to the meaning of deafness of connection to the nation. These ads are advertising something supra-normal. Going to space, science fiction/science fact and “space electronics” are all “better” than normal— they propel you into the future where only “special” people can go. A person buying a hearing aid or

cochlear implant based on one of these ads would likely be attracted to the futuristic imaging and might have thought that they were “getting early to the game.”.

Audibel’s (2021) hearing aid website highlights needs specific to the modern-age (the website promotes a hearing aid that can amplify speech that is muffled through the use of face masks), as well as promoting the future of hearing aid science. Figure 11 proposes that their product is on the “leading edge” of hearing aid technology, and it emphasizes the science behind the aid.



Figure 11. Technology’s leading edge. Audibel 2021

Moving to cochlear implant websites, the first thing one notices about the Advanced Bionics website is the company's name. Bionics refers to the act of applying biological methods and systems to the world of engineering. With this definition, bionics as a marketing theme is similar to the space age hearing aid advertisements shown previously. As with those advertisements, bionics implies advanced technology and high-tech science. The advertisement portrayed in Figure 12 shows a compelling mixture of high-tech science (through use of the company's name), and low-tech activities such as dance. This combination could be understood as "high-technology can enhance your normal, low-tech life." High-tech and low-tech exist comfortably together in this ad. Although normality as an explicit theme did not appear in either the historical or contemporary modernity/space age/supra modernity hearing aid advertisements, an argument could be made that the portrayal of a common, "normal" activity such as sharing time with children, and dance, implies that the advanced technology offered by Advanced Bionics can make possible these "normal" activities. The future—high-tech language used by Advanced Bionics and other hearing aid and cochlear implant manufacturers are relying on people's attraction to high-tech. In the words of one technology blogger, Jane Jelbacani, (1997):

I love technology because it allows me to multiply my efforts in ways that are remarkable. I can stay connected with friends and family, while

simultaneously working on a critical component of work—in any city, in any country, anywhere. Technology eliminates problems otherwise posed by geography and time.

The modernity/space age/supra-modernity hearing aid advertisements and cochlear implant websites imply that the supra-modern device they offer will allow one to lead a “normal” life. These devices can provide “normal” hearing, and therefore allow for normal relationships and activities— this can be seen in Figure 8— two people enjoying music together, which would conceivably only be possible if one or both of them were not wearing cochlear implants.



Figure 12. Science Fact and the Modern in a cochlear implant advertisement.

Advanced Bionics 2020.

CONNECTION WITH FAMILY AND COMMUNITY

The theme of connection demonstrated in this section is related to the “problems of deafness” identified in chapter four. The first 3 problems of deafness that I identified have to do with themes of connection.

The third central theme was one of (re)connecting with society, family, or church. In these ads, solitude is seen as abnormal. Recall from the last chapter that, from the 1700’s—until the FDA approval of cochlear implants in the 1980’s, the meanings of deafness were about isolation and alienation— either isolation from God, or isolation from the nation and humankind. Hearing aid and cochlear implant advertisements and websites that focus on connection with others are a direct response to these meanings of deafness. These ads either focused on the loneliness of deafness and demonstrated how buying a hearing aid or cochlear implant could connect you back with the world, or they focused on connection and relationship as an alternative to loneliness and isolation.

The third theme to emerge from the data is escape from isolation and connection with community and family. This theme was seen in the historical advertisements as well as the contemporary hearing aid and cochlear implant websites. Deafness was understood in the 1940s to separate the deaf individual from his fellow citizens (McAndrew 1948). Deafness was understood to lead to lower—than-average IQ, an inability to participate in

the neighborhood, an inability to socialize, and the inability to maintain close relationships (McAndrew 1948). More recent studies have also found, that, among those who live outside of Deaf communities, it is perceived that there is some degree of isolation among deaf people (Charlson et al. 1992; Taylor 1999).

As can be seen in the partial advertisement shown in Figure 13 below, deafness was associated with loneliness and social tragedy. Hearing advertisements that used this theme were marketed as rescuing the deaf person from a lifetime of banishment and loneliness.

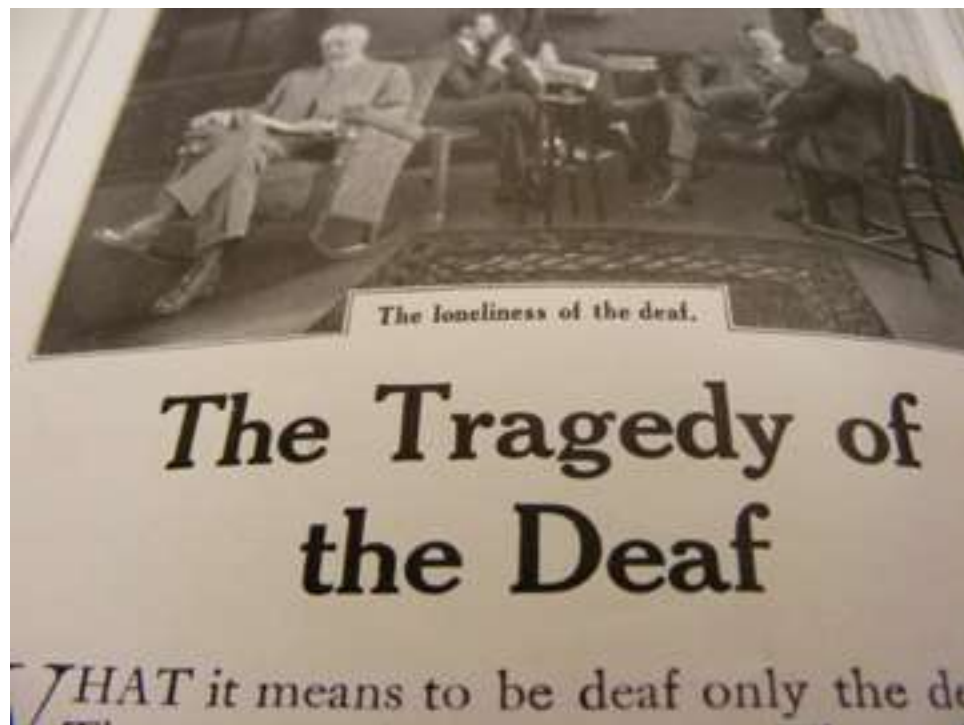


Figure 13. Deafness as loneliness and isolation. Kenneth Berger Hearing Aid Museum.

Attempts to eliminate the isolation of the deaf, either through hearing aids, or by other programs such as employment for those with disabilities (Schur 2002), were present as early as the 1700s with the development of Deaf schools, and continue into the present day. These advertisements relied on a maybe exaggerated claim of isolation of the deaf person and focused on the presumed and imagined image of the sad and lonely deaf person (see Figure 13). The historical document found in the Kenneth Berger archives along with the advertisements shown in Figure 14 is a listing of everything the deaf person has presumedly lost since becoming deaf— including happiness and health.

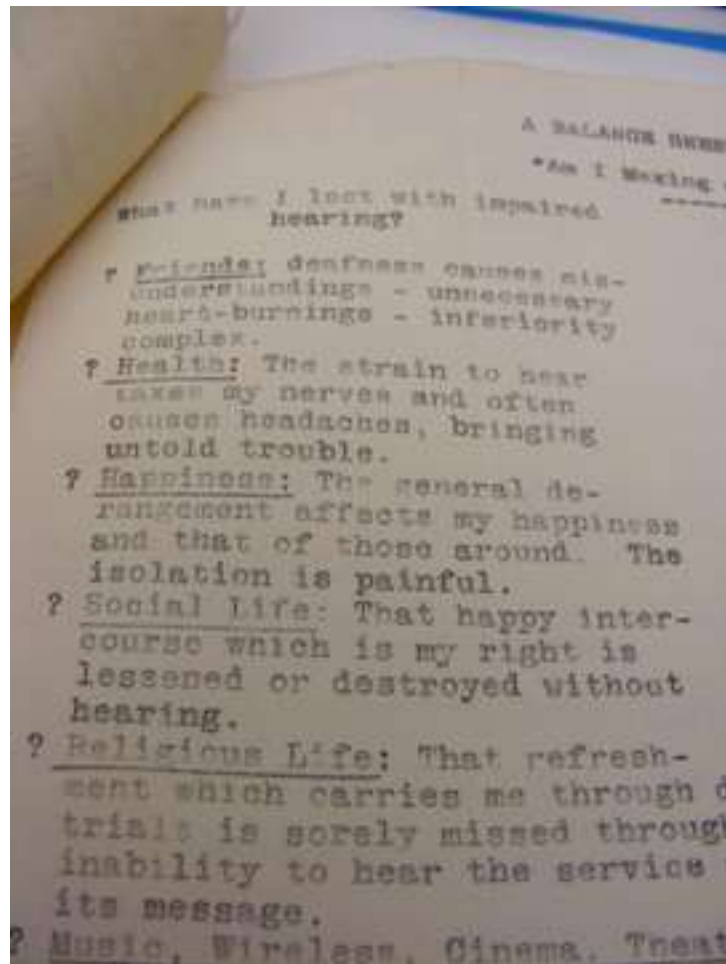


Figure 14. Undated list from the archive of all a deaf person loses when they become deaf. Kenneth Berger Hearing Aid Museum.

The list above in Figure 14, which was undated like all the other advertisements and material in the archives at the museum, emphasizes the isolation that people who are deaf experience. It lists isolation from friends, social life, and religious life as resulting

from deafness. This feeling of isolation is also clear in the discussion about the meanings of deafness throughout the eras— deafness was seen to cause isolation from God, the nation, and humankind.

The Phonak (2021) image seen in Figure 15 demonstrates that being a deaf child doesn't mean that one must be lonely or isolated. Instead, the website image shows several children together, learning together, with a teacher who is wearing a special microphone device called a "Roger" (Phonak 2021) that amplifies her voice directly into the student's hearing aids by use of Bluetooth technology. Although I selected this image to demonstrate how modern hearing aid website images explain that loneliness and isolation are not inherent in deaf life, and connection and relationships are possible through the use of hearing aid technology, this image also could be used to illustrate the "high-technology" theme seen in the previous section of this chapter. Many ads and website images contain multiple themes like this one. Figure 8, for example, which shows two people enjoying time playing music, could be included in the inconspicuous category (which it was), or, alternatively, the "connection with others" theme. I had to make categorical decisions, but that is not to say that each image only fits into one category. The "Roger" device is seen as cutting-edge technology, ahead of its time, futuristic. The teacher wearing the device could be seen by parents visiting the site as being particularly

mindful of her students' needs, and of having an advanced understanding of the types of technologies that will best assist their deaf or hard of hearing child.



Figure 15. The “Roger” device. Phonak 2021.

The first thing one notices when visiting the Cochlear Americas website (2020), is that the first page it takes you to is a “sign up for more information.” There are no graphics on the page, just a simple form. On top of the page are several drop-down boxes— with titles like “diagnosis and treatment,” and “products and accessories.” In looking through these drop-down boxes, one will find lots of pictures of people, adults, and children, enjoying life with a cochlear implant.



Figure 16. Playing with grandchildren. Cochlear Americas 2020.

Figure 16 is a picture of an older man with a cochlear implant playing with girls who are presumably his granddaughters. Once again, relationships, and lack of isolation, are featured, but so is fun. In the isolation hearing aid advertisements, “lack of fun” was emphasized—in these pictures, fun itself is shown as a result of having cochlear implants.



Figure 17. Child with a cochlear implant. Cochlear Americas 2020.

Figure 17 is a picture of a child with a cochlear implant. Again, relationships and having fun are emphasized here. It's important to note that the "other" person in these pictures are also getting something out of the cochlear implant— it's their relationship too. In this picture the man, presumably the boy's father, is enjoying his relationship with the boy. This picture proclaims, "everyone benefits from the cochlear implant, not only the user, but also everyone around them." There is a surfeit of scholarship on hearing

parents parenting deaf children (Kobosko 2021; Szarkowski & Brice 2020; Acar et al., 2020; Majorono et al., 2020). Majorono et al. (2020), even found that mothers' expectation of cochlear implant surgery had a direct result on their children's speech fluency three and six months after surgery. Children whose mothers were more positive about post-surgery outcome performed better on lexical tests than those children whose mothers were more mixed, or had more negative, expectations (Majorono 2020). The images in Figures 16 and 17 are in stark contrast to Figures 13 and 14, which emphasize the loneliness and desperation of deaf people. The images on the Cochlear Americas website demonstrate that deaf adults and children can experience connection and feelings of belonging with a cochlear implant.

The following text appeared on the Cochlear Americas website (2020):

Early intervention for children

If your child has hearing loss, getting treatment sooner rather than later has many benefits, including laying the foundation for fundamental language and social skills.



Figure 18. Early Intervention for children. Cochlear Americas 2020.

The headline in Figure 18 emphasizes early intervention, and implies that, for deaf children, the sooner the better to get implants. In this text, getting a cochlear implant is linked to language and social skills. From that perspective, this text emphasizes that cochlear implants can *expressly and specifically* improve social skills (and presumed, relationships). In addition to commenting about the relationship between cochlear implants and social skills, this text box also connects cochlear implant use with language skills. Recall that I propose that the meaning of deafness in the modern era is success. You must have language skills (either ASL or spoken language) for success, and notably, this text implies that one must have *verbal* language skills. Signed language skills such as

those employed by those who use ASL do not count here. It is interesting to note that all of these pictures showcase very “normal” activities— playing the guitar (Figure 8), going to school (Figure 15) and interacting with children (Figures 12, 15, 16 and 17). These website images, from both hearing aid and cochlear implant companies, appear to be telling the audience, “If you want to be normal and do these activities, you need a hearing aid or cochlear implant.”

The Advanced Bionics website also relies on imagery of isolation/connection on its website. On the Advanced Bionics site, it says in a text box, “The ability to hear is transformative. Without it, the world can feel isolating and disorienting” (Advanced Bionics 2020). Recall the meanings of deafness posited earlier in this dissertation, in which the meaning of deafness across all historical eras relate to isolation— isolation from God, country, and humankind. Seeing the theme of isolation/connection and community, in the Cochlear Americas and Advanced Bionics websites is not surprising, and it demonstrates how persistent some of these themes can be. As a theme, deafness is depicted as isolating, sad, and lonely. The hearing aid and cochlear implant websites have a cure for this loneliness: get a hearing aid or cochlear implant and go back to the world of family and friends! In this way, hearing is associated with positive relationships, and not-hearing is related to isolation and loneliness. It is interesting that the Cochlear

Americas website highlighted relationships and not technology, but Advanced Bionics highlights both— advanced technology and relationships.

Contemporary hearing aid and cochlear implant websites rely on the narrative of normality to sell their product. Whether it is “normal” to attend school, or hang out with children, “normal” images abound on the websites. This could be an example of normality in form vs. function. Both the cochlear implant and the modern inconspicuous hearing aid can claim that their customers are buying normality as well as technology, but the hearing aid advertisements are advertising normality more in *form*— one can “look” normal when wearing an inconspicuous hearing aid. However, a person wearing a hearing aid, no matter how advanced, is still just amplifying poor sound reception. The “fact” that the person still can’t hear is masked by the hearing aid. However, cochlear implant manufacturers advertise normality in *function*— hearing aids can actually make the deaf person sense sound, although they are not technically hearing through their ears. While cochlear implant wearers ears’ are still “broken,” the cochlear implant bypasses the ear and goes straight to the auditory nerve, where sound is processed. Hearing, in a manner of speaking, is achieved.

SUCCESS

There is some literature about the relationship between hearing technologies such as hearing aids and cochlear implants and success, although this literature mostly focuses on success with speech and hearing and academic success (Diaz et al., 2019), and does not address success in other life areas, such as friendships, romantic relationships, and parenting. Yigider et al., (2020) focus on quality of life of the deaf child and conclude that the success rate (on a series of questionnaires) and depression rate were lower (for the success questionnaires) and higher (for the depression scale) in children with hearing loss, whether they had a cochlear implant or hearing aid. This single finding, which has not been replicated in the literature, suggests that the “American Dream” version of “success” may be harder to achieve for deaf people. The hearing aid and cochlear implant websites promote not only normality, but success— perhaps as a direct argument to the nascent literature that deaf children are less successful than their hearing peers. The presence of “success” imagery on these websites support my hypothesis that success is the meaning of deafness in the current era.

The contemporary hearing aid website for AGX Hearing (2021) includes the following statement in a text box, “We believe that everyone deserves to live life to its fullest, to experience the moments that, one by one, illustrate a life well lived. Mountains

scaled. Goals achieved. Missions accomplished.” This quote exemplifies the exact opposite of the loneliness and isolation that are perceived to be problems for deaf people, and, importantly for our purposes in this section, demonstrate how a deaf person can be successful if they wear the “right” hearing aid. The AGX marketing proclaims that, with AGX hearing aids, one can “live life to the fullest,” and can accomplish social and personal goals in the exact same way as someone with normal hearing. The hearing aid manufacturers Widex (2021), Phonak (2021), and the cochlear implant company Med-El (2020), all had content that suggested their product would bring professional, academic, or personal success. Success can be considered as a normalizing theme— it is normal to have a job, normal to get married, and normal to do well in school. These websites all showed children and adults performing well academically or professionally by using the advertised product. Widex (2021), while it did not have any pictures on the site that reflect success, offered the below quote from a customer that focuses on the professional success the hearing aid brought him:

When I got my hearing aids, I thought they would make me look and feel older. In fact, the opposite is true; I look and feel younger. I am a lawyer, and I am in court frequently. Because I can't hear perfectly, I developed a habit of leaning forward, putting my head down, and turning my head so my ear would face the judge. In my first court appearance after I got my new Widex EVOKE CIC aids, I was able to stand straight as an arrow and look the judge straight in the eye when he spoke. As I did so, I realized my posture had changed over the last

10 years to account for my hearing loss. My only regret is that I waited so long to get the aids. They are life changers on every level.

This quote shows quite well that Widex suggests that using their hearing aid will bring professional success. It also implies that people who have untreated hearing loss are unsuccessful— so unsuccessful, in fact, that hearing loss can have a negative physical impact on the whole body. By using Widex hearing aids, this customer is now back to “normal” for a lawyer— standing up straight and looking people directly in the eye.

Academic success is one of the key debates within the Deaf and deaf communities. In fact, this debate goes back to the origins of American Deaf culture and the establishment of Deaf schools. The oral/ASL debate has always been a debate about academic success. Academic success, throughout a child’s entire education, from pre-school through college, is a key element in determining how “successful” that child will be as an adult. Phonak (2021) had several pictures on their site demonstrating that their product helped hard of hearing children be successful in school.



Figure 19. Hearing aids at school. Phonak 2021.

Figure 19 shows children, at least one of whom is supposedly wearing a Phonak hearing aid, participating in school, and being engaged in the lesson. Deaf children who are successful in mainstream hearing schools are more likely to attain professional success as adults (Zwolan & Sorkin 2006; Eckl-Dorna et al. 2004), as compared to Deaf children who attend ASL residential schools. Research suggests that students who attend ASL residential schools and use ASL as their primary language, read English at a 6th grade level (Allen 1986; Traxler 2000). Advanced hearing aids and cochlear implants intend to enhance and support the teaching of English speaking, reading, and writing skills at a much higher level, thus contributing to these students' later-life academic and professional success.

The below picture, taken from the Med-El website, shows a man with a cochlear implant in business attire consulting with a woman. This kind of business activity—consulting with others—is a key component of “normal” people in professions. These examples from hearing aid and cochlear implant websites all demonstrate that professional and academic success are outcomes of technological hearing assistance. These examples support my claim that success is the “meaning of deafness” in the current era.



Figure 20. Success at work. Med-El 2020.

CONCLUSION

The meaning of deafness is a socially constructed viewpoint of what deafness means, both to those who are deaf as well as to those who are hearing. As discussed in chapter four, different eras see different meanings of deafness, and these meanings influence the development of hearing technology, and the development of that technology influences, in turn, the meaning of deafness. Technologies are useless, however, unless people know about their availability and features. Advertisements for hearing technologies, including hearing aids and cochlear implants aim to inform people about the availability of their product and to try to convince them to buy their product. There are several different approaches to advertising hearing technology.

I found that the way technologies are marketed in advertisements map fairly completely over the problems of deafness introduced in the last chapter, so that advertisements are geared towards addressing the meanings of deafness. Hearing

technology advertisements changed throughout the years as the meanings of deafness changed. Hearing aid and cochlear implant advertising and marketing materials revealed four themes: inconspicuousness, isolation/connection, “normality/space age/supra modernity,” and success. Discretion, isolation/connection, futurism, and success were all found in the cochlear implant websites.

Meanings of deafness appear in advertisements for hearing technologies. For example, the advertisements that I coded as “connection with family and community,” connect back to the meanings of deafness that relate to connection with humankind and the nation. Connection, and its opposite, isolation, appear in the earliest ads and persist into the current-day cochlear implant websites. The meaning of deafness from the turn of the 20th century- connection with the nation- is related to the themes I identified in the “modernity/space age/supra modernity” advertisements. Again, like with the “connection” ads, these themes of “modernity/space age/supra modernity” persist, in a slightly modified form, into current-day hearing aid and cochlear implant advertising. Contemporary advertising utilizes themes of “high-technology” and supra-modern technology and do not mention the space race, but the overall theme of advanced science endures. The current-day meaning of deafness that I present- success- maps nicely over the advertisements that featured success in school and business. However, convincing

these relationships between advertisements and the meaning of deafness in different eras, and across eras, are, there was not a complete match between the advertisement themes and the meanings of deafness. Specifically, the advertisements that focused on “inconspicuousness” do not map neatly onto any meaning of deafness that I identified in chapter four. The inconspicuousness ads are related to stigma, which is one of the organizing principles of this dissertation, but I don’t see anything in the history of deafness and deaf technology that suggests that “inconspicuousness” is a meaning of deafness.

I suggest that the “meanings of deafness” (connection to God from 1750-1880, connection to humankind and the nation (from 1880-1920), and success (1980-current), can, but not always, translate to future time periods. These meanings of deafness map onto the types of technology that were developed to address these problems of deafness, but also, the meanings of deafness influenced the technologies used. For example, when cochlear implants became available, that helped move the meaning of deafness in the current era to be success— because cochlear implants could give people success in speaking and hearing. However, these meanings of deafness are not static objects— once a meaning of deafness appears, it tends to stay around, and bleed into the next era. For example, “space age” advertisements began in the 1950’s, but, as was shown with the

Advanced Bionics website, futuristic and supra-modern technology persists to this day. Not all of the meanings of deafness persist- “connection to God,” for example, is no longer leveraged in hearing aid and cochlear implant advertising, but it was present in the earlier ads demonstrated in this chapter.

I argue that some of these meanings of deafness (connection to humankind, connection to the nation, and success) have persisted since they first appeared in the second era (1880-1920). I think this speaks to their relevance across timeframes. Deafness as a “foreign” state may still be as relevant today as it was in 1910. Indeed, connection to humankind is also a theme that is still relevant today. Today’s science has the possibility for in-utero, or pre-implantation of zygotes that have been genetically modified to eliminate deafness (Géléoc & El-Amraoui, 2020; Leake, & Akil 2020; Blanc et al.,2020; Riddle & Butler 2019).The eugenics debate eluded to in chapter four continues today, and today, of course, we very nearly have the technology to very efficiently eliminate deafness, and many other disabilities. Jonathan Glover (2006) has highlighted the concerns emerging from disability-rights literature about a new form of eugenics; one designed to create a world without the disabled.

As revealed in my interview project, detailed in the next chapter, some children choose pink or red cochlear implant transmitters (the part that appears on the outside of

the head), or adorn them with stickers, as opposed to hair-colored transmitters which would more neatly mask them, and by doing so, they appear to be bucking the normality imperative— which is behavior that is excused in children but may be stigmatized if an adult had a pink or red transmitter. The hearing aid advertisements and cochlear implant websites also show themes of normality. For example, the inconspicuousness theme that ran through the hearing aid advertisements, imply that if no one sees you wearing an aid, then you can “pass” as normal. The next chapter in this dissertation will address children and cochlear implants, and how and why parents make the decision to implant their very young children, highlighting how thoughts of normality, medicalization, stigma, and the desire for communication are present in the cochlear implant decision.

Chapter 6. The Cochlear Implant Decision: How Parents Decide to Implant Their Deaf Children with Cochlear Implants

It was a no-brainer for us. We knew we wanted him to speak and listen, no doubt about it. We had no doubts. Very easy to make the decision, it was a no-brainer.

—Julie, mother of 12-year-old bilaterally implanted boy

Within hours of learning that their child was deaf, many parents in my study knew they wanted their child to hear and speak, and, even if they didn't know about the existence of cochlear implants, knew that they would do anything possible to allow their child to listen and speak. Mary said, "As we were driving home from the ABR [Auditory Brainstem Response test- a definitive test for detecting deafness], I was on the phone to the surgeon. We went from diagnosis to implant in 6 weeks." Other parents were much more ambivalent about the decision to implant their child or use ASL— they invited teachers of the Deaf into their home to teach the whole family sign language, they signed up for sign language classes, and they connected with Deaf communities. It wasn't until someone told these families about the cochlear implant that they changed their minds and went the route of the CI.

This chapter is about how parents make the sometimes— difficult decision to give their child a cochlear implant. It answers research question three: how do contemporary parents' decisions to get a cochlear implant for their children reflect the relationships

between social meanings of deafness, deaf technology, and social beliefs about normality?

Underpinning all of the interviews were undercurrents of medicalization, normality, and stigma. Merely by choosing cochlear implants for ones' children shows an adherence to medicalization. The very act of diagnosing a person as deaf, using state-of-the-art medical technology, and then medically implanting them, and sending them to schools that utilize medical theory about speech and hearing, is medicalization. This medicalization of deafness threatens the existence of the ASL-using Deaf community. The Deaf community does not consider deafness to be a "disorder" that needs to be treated, so members of this community don't medicalize the condition. However, if more and more deaf children born to hearing parents have their deafness medicalized, that puts the Deaf community at risk because more and more families are choosing the medicalized route, as opposed to the ASL route, for their deaf children.

In order to explore decision-making processes, I interviewed 33 individual parents or couples between March 2014-December 2014 who had decided to give their deaf children cochlear implants. Cochlear implants are a ripe location for studying decision-making processes because parents typically invoke both logical/rational decision-making narratives and emotional decision-making narratives, as well as invoke

conceptions of what it means to be normal. Deafness is in a unique position to explore people's relationship to normality. One reason for this is the fact that, in many people, cochlear implants can partially or completely eliminate the appearance of disability. People can literally choose to belong to a cultural disability community, in this case, the Deaf community, or to the apparently normal community of those without deafness. Few, if any, other disability groups are able to offer their members a choice to appear disabled or to not appear disabled. Based on the evidence presented in my interviews, I argue that the cochlear implant decision-making process is logical/rational *and* emotional. I also argue that powerful influence groups such as surgeons, oral schools, and national pro-cochlear implant organizations, play a large part in the decision-making process.

I'll first explore powerful influences in the decision-making process, such as national pro-cochlear implant organizations and oral deaf schools. I'll then examine how understandings of normality and the desire for communication influence parents' decisions.

POWERFUL INFLUENCES

The influence of powerful entities, including cochlear implant manufacturers, doctors, other medical professionals and hospitals, and even other family members, have a big influence on a parents' decision to give their child a cochlear implant. Alternatively,

the Deaf world has some influence on parents' deciding to implant their child, but arguably that influence is a lot less powerful than that from the cochlear world. Below I explore some of these influencers.

When parents find out their child is deaf, they are faced with a difficult decision— what type of communication style will their child use? Will they use ASL or hearing and speaking? It is at this stage that parents are presented with answers to that question from both ASL and cochlear implant focused individuals, companies, and institutions. Parents are presented with information on hearing aids and cochlear implants but are also offered the services of an in-home ASL Teacher of the Deaf who can introduce the parents to Deaf culture and teach the entire family sign language. The teacher-advocates try to expose the parents to the richness of Deaf culture and ASL. Parents, who want the best for their children, are not going to be swayed by pro-ASL arguments that cite the destruction of the Deaf community as reason enough to school their children in ASL. Parents want convincing, scientific-based knowledge that one option is better than the other, and because cochlear implants have advanced science on its side, very few hearing parents chose ASL for their child, even if they do use the services of an ASL teacher at first. Parents in my interviews saw most of these

encounters, both the ASL perspective as well as the cochlear implant perspective, as positive and in helping them make the cochlear implant decision.

As seen in the previous chapter, the cochlear implant manufacturers do a lot to promote their product. These companies emphasize relationships and community—and how a cochlear implant can restore both. Janet, a parent with a 3-year-old son with a unilateral implant, had a very positive experience with the implant manufacturer Cochlear Americas, “Our rep was there from the very beginning—from our decision stage to waiting in the waiting room while he was getting the operation. We still talk to him every four or five months and he gets us any parts we need.” Many cochlear implant reps are very “hands-on” and help parents make the decision to get a cochlear implant, and specifically a cochlear implant from the rep’s company. Many parents mentioned how helpful their rep was in helping them decide which implant to buy.

Families are influenced by powerful organizations, such as cochlear implant manufacturers and the John Tracy Clinic, an oral advocacy and educational organization. Two of my families had direct contact with the John Tracy Clinic, and both had very positive regard for it. Michelle, whose daughter was implanted at age 5, said,

We had been going to John Tracy for 6 months and she just wasn’t making any progress, and finally someone told us about CIs, and that’s all it took. John Tracy took care of getting us hooked up with a surgeon and everything. They just

didn't want to push it on us, but I wish they had told us sooner. That was 6 months lost.

Timing is one important, but not the singular, key to a successful cochlear implant in young children- prelingual implantation is usually considered the most optimal for language development, as it is significantly more difficult to learn hearing and speaking English as an older child or adult. The FDA approves cochlear implantation in children older than 12 months, but evidence is increasingly pointing to efficacy and safety of implantation in children younger than this (Miyamoto et al., 2017). Michelle's statement of, "That was 6 months lost," points to the fact that medical professionals such as surgeons and audiologists promote early implantation and parents worry about treating deafness as an urgent problem to be solved as soon as possible. Early implantation equals, in some parents' minds, "good parenting."

Within an hour of receiving the diagnosis that her son was deaf, the diagnostic audiologist took Denise next door to the oral deaf school that was attached to the auditory clinic. Denise said,

We were shattered, ruined. And then Lisa said, you must come see the children, you must come, and we were like, no, not now, and she said yes, now. We went to the playground and she called out "Austin, come over here!" and a little boy came running over. Lisa said, "This is Austin, he is deaf just like your son." We talked to Austin and you couldn't tell he was deaf. His speech was perfect. That's when we knew we had to go oral.

Denise's experience at the oral school and meeting children with cochlear implants was a common theme throughout the interviews. Several parents noted that meeting deaf children at the annual Alexander Graham Bell Conference (an annual pro-oral conference for parents with children who have cochlear implants or are considering them), was key to their decision to implant their child. In Denise's case, when she saw that a deaf child with a cochlear implant could hear and speak like a "normal" child, she saw that normality was possible for her son too. This shows her willingness to medicalize her son and his deafness- treating him with advanced medical technology in order to achieve "normality."

There are more than 32 oral deaf schools in the country, and they have a lot of influence over deaf and cochlear implant culture. Each oral school is different, but they share some ideological characteristics. oral schools believe that hearing and speaking, when possible, is the best form of education for deaf children. They promote cochlear implant and hearing aid use. Many oral schools have audiologists and speech therapists on site. Steph said, "I wanted her to get into Clarke school [a well-regarded oral school chain] so bad. I knew she would thrive there, but it's so hard to get in!" Another parent, Mirena, drove two hours each way to take her 8-year-old deaf daughter to an oral school. This trip included preparing her 2-year old hearing son for the trip, and then hanging out

with her son all day in the new city, then picking up her daughter and driving the three of them back home for the evening. Most oral schools go from pre-K to fourth or fifth grade, with the assumption being that after the child is in the oral school for several years, they are ready to be mainstreamed in a public school.

The Alexander Graham Bell society is the largest pro-cochlear implant organization in the country. It is named after Alexander Graham Bell, an early proponent of oral education for the deaf (Winefield 1987). AG Bell hosts an annual convention for parents and vendors to come together. During panel sessions, parents, and implanted children, answer questions about what it is like to have a cochlear implant and how their speech, academics, and social life has progressed. Also at the conferences are vendors—representatives from each of the three cochlear implant companies are there, as are vendors selling all other products for the deaf— adapters for cell phones, bed shakers, fire alarms, everything that a parent may want to buy for their deaf child. Parents reported to me that, for those that attended their first AG Bell conference before making the cochlear implant decision, that the conference really cemented in their minds that they wanted to go the cochlear implant route. If parents had already made the CI decision before attending the conference but had not chosen an implant brand yet, the conference helped them decide which implant to choose. Parents and children alike make life-long

friends and contacts at these conferences. Mark noted, “AG Bell was a godsend. We saw all these deaf kids who were talking and listening like any normal child. We definitely made our mind up after meeting these deaf kids.” Additionally, if parents had already made the cochlear implant decision before attending the conference but had not chosen an implant brand yet, the conference helped them decide which implant to choose. “They are all basically the same,” Sammy said. “It’s just a difference between special functions, like what swimming attachment they offer.”

Audiologists are usually the first hearing specialist parents encounter, usually even before their child is definitively diagnosed as deaf. It is audiologists who conduct the hearing tests and ABRs and audiologists who usually “break the news” to parents. Audiologists will often lay out the options to parents, including ASL and cochlear implants. Parents in my study had variable experiences with audiologists. Some parents had had the same audiologist from infancy to the teenaged years, while others suffered with poor audiologists, often changing audiologists several times. Changes in audiologists resulted in changes to the settings of the child’s cochlear implant, which often improved the child’s experience with the implant. Misty relayed her negative experience with an audiologist:

First of all, this woman was big. I mean just huge. Not that that has anything to do with it, but she walked with a walker she was so large. Secondly,

she didn't know what she was doing. She tried to put Brian to sleep for the ABR, but she didn't give him enough medicine, so he moved around the entire time. She read the audiogram wrong— she said it said that he was normal, but her assistant had to correct her and say that he was profoundly deaf. I'm just glad I never have to go back to her again!

Although most parents reported positive experiences with audiologists, Misty and one other parent, Allie, had negative experiences with audiologists that were resolved when they switched audiologists. In Allie's case, the first audiologist had turned up the gain on the cochlear device too high, and it was causing her child physical pain and she was unable to learn speech because the volume was too high. After several months of seeing no improvement, the family decided to try another audiologist, who, almost immediately discovered the problem, corrected it, and the child went on to develop speech and hearing without pain. These experiences demonstrate that although audiologists and other medical professionals have profound influence over parents' decision making, parents sometimes took "matters into their own hands," and exercised autonomy outside of the professional encounter. This phenomenon was also true of parents who did most of their research about cochlear implants on their own, either on the internet or in medical school libraries. These parents came to the surgeon fully informed about cochlear implants and therefore were able to exercise more self-determination in the professional relationship.

The Americans with Disabilities Act (ADA), through its policies, supports both cochlear implant users and people who use ASL. The ADA is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places (with the exception of religious institutions) that are open to the public (ADA National Network 2018). Many parents in my study cited workplace success for their children and the types of accommodations that the ADA would require from their child's future employer. Lillian noted that her husband was a police officer, and her 5-year-old bilaterally implanted son Joseph, said he wanted to be a police officer when he grew up. Lillian and her husband didn't have the heart to tell Joseph that he would never be a police officer, fire fighter, or be in the military. Although the ADA protects deaf people from unfair discrimination, there are some jobs that simply can't be done by someone without good natural hearing. The ADA requires employers to make reasonable accommodations (ADA National Network 2018) for disabled employees, and that could include special phones or deadening devices on chairs and on walls to cut back on background noise, which can cause a cochlear implant user to have difficulty hearing.

DECISION MAKING

Over a wide range of topics, parents in my study kept coming back to four key concepts: normality, risk analysis, being a good parent, and communication. Game theory shows decision—making is generally considered to be the result of a cost-benefit calculus (Li, Xin, et al 2018). However, I argue that dispositional factors such as the need to be “normal” and the desire for material success for one’s children moderate the cost-benefit calculus.

Normality

Parents often cited the fact that the Deaf world is totally different from the hearing community, and if they had made the decision to teach their child ASL and send their child to Deaf residential schools, their child would be in different community than the rest of the family. This sentiment recalls the meaning of deafness from the second era (as described in chapter four), in which connection to humankind and the nation was of paramount importance. Being an active part of a family and the community was important to parents, and these concerns reflect the meaning of deafness as being one of connection to others. Dana said “We’re all hearing. I wouldn’t want a child who could only speak and understand Chinese, and that’s what ASL is like. Chinese.” “We wanted listening and speaking, and we would do anything to get her there,” Julie explained. She

went on to say, “We only knew hearing people, and we understood how hearing people go about their daily lives. We had no idea how a deaf person would make a life for themselves in a hearing world.” As Dani, the mother of a 1-year old son with a unilateral CI said, “I’m hearing. My entire family is hearing. Why would I want to have a child that is living in a different culture that I do?”

All the parents in my study decided that speaking and listening is the route they wanted for their children. Marcia stated, “I wanted her to have a normal life, and if that meant ASL, then it meant ASL. But ultimately a normal life is not ASL.” Parents try to project into the future about what their lives would be like with a cochlear implant or with an ASL-using child. Bonnie said, “If she used ASL, she would be totally isolated from the rest of our family. She would go to a residential school and she wouldn’t know us. With the cochlear implant, she’s a functioning part of our family.” Sarah said, “We always knew we wanted him to speak and listen, to give him the most chances in life.” In Sarah’s case, the cochlear implant means options- the implanted child will have more “chances” in life than the non-implanted child.

In the decision-making process, parents must decide how likely it is that their imagined outcome of a cochlear implant vs. ASL is. Mark said,

With ASL, we thought he’d be limited. He’d need an interpreter all the time, and he would miss a lot of what goes on around him. With a CI, he’d be

plugged into the outside world and wouldn't need 2nd parties to help him communicate. We thought he'd have a better chance of success with the CI.

Mark's quote clearly demonstrates the theme of "success" as the problem of deafness in the current time period. Throughout the discussion of normality, success in varying environments- from childhood sports, to choosing a college, to choosing a marriage partner and ultimately parenting their own children, was raised as an important feature of the decision-making process. In sum, normality equaled success— "successful" college experience, for example, is code for "normal" college experience. When parents say they want their children to be successful, my data suggests that they are *also* saying they want their children to be normal. Julie said of her 12-year-old son:

If it weren't for the CIs, he'd have no friends. The immediate family, sure, we would have learned ASL, but grandma and grandpa, and cousins and aunts and uncles, are not going to learn ASL. So, he wouldn't have the full experience of family.

This quote demonstrates that an important reason for Julie getting her son cochlear implants was to eliminate that sense of isolation, which has been a prominent feature of the perception of deaf life, since at least the 1700s (Baynton 1996). We saw isolation/connection, in the hearing aid and cochlear implant advertisements of the last chapter.

When asked why they implanted their children, parents in my interview study cited “I want him to be good in school,” and “I want him to go to whatever college he chooses, not just Gallaudet.” Material and social success were key for these parents, who saw ASL as “Difficult. Deaf people have a tough row of it, hard to get anything accomplished,” according to Judi, the mother of a 7-year-old unilaterally implanted son. Suzanne, the mother of a 13-year old girl who is bilaterally implanted, said, “I want her to have a normal and successful life.” In Suzanne’s case, normality=success, and she views the cochlear implant as the best way to obtain normality and success. Janet said, “He has to be able hear to do well in school. ASL just won’t give him that.”

Being a good parent

Hays (1996), in a seminal study, reveals that the job of the mother is bifurcated: parent and woman who works outside the home. Women are pressured into intensive mothering (1996), and the child’s life outcomes are seen as mostly, or exclusively, the results of good (or bad) mothering. Research highlights how mothers across social classes express similar beliefs that good parenting adheres to the tenets of intensive mothering by being child-centered, time-consuming, and self-sacrificing (Randles 2020). Knoester & Fields (2019) wrote, mother–child interactions are positively associated with mothers’ perceptions of being a good parent.”

In this study, all but two of the respondents were mothers, and mothers demonstrated intensive mothering. For example, Mirena, the mother who drove two hours each way with her hearing 2-year-old son to take her deaf daughter to a well-known oral school, demonstrated intensive parenting, in that all of her daily effort went towards her daughter's schooling. Other mothers mentioned having to go out of state several hours away to cochlear implant centers and audiologist appointments. Louise said, "I need a secretary just to keep track of all of Benji's appointments! And a chauffeur would be nice!" In most of the families in my study, mothers had an unequal burden in managing their deaf child's appointments and other needs. Veronica quit her job as an advertising executive in order to manage the needs of her deaf daughter, and soon found herself volunteering in deaf organizations.

When parents imagine their child's life with a cochlear implant, they imagine a life that is very much like their own. Sammy said, "She'll go to a normal college and marry a hearing man. We'll have a real relationship with her and her family." Sammy emphasizes parent-focused elements of the cochlear implant decision— parents are concerned about their relationships with their adult children (and grandchildren), but it also focuses on the parent's desire for themselves, not only on what is best for the child. This is notable because the concept of *good parenting*, which is underscoring all these

decisions— parents want the best for their children—, is imagined as totally selfless and focused entirely on the wellbeing of the child. These quotes demonstrate that the parent is focused on their own outcomes, not just the child's, and outcomes relating to *what makes a good family*.

The parents in my study agonized over the idea of being a good parent and helping their children meet their full potential. Mary said,

It's such a major responsibility, to give someone else basically brain surgery so they can hear. Big responsibility. But even bigger responsibility if you chose to not let that child hear. You are damning them for the rest of their life to a life of silence. It was just the right thing to do. If he decides to go ASL when he's a teenager, then that's his choice, and we made it possible for him to make that choice.

Mary's commentary reflects notions of what it means to be a good parent. In her conception of "good parenting," a good parent gives their child all possible options, so that child can choose among options when they are older and can make autonomous decisions about their communication preferences.

The emotional-centered decision-making approaches focus in part on "being a good parent." These parents perceive that pursuing normalizing technologies for their children will set their children up for a good future, and that as good parents, they are obliged to do anything in their power to help give their child a good future. Of note is that most parents who used rational decision-making approaches to make the decision cited

how they would feel if their child was functionally deaf— e.g. was not able to communicate with the family. Alternatively, those who relied more heavily on emotional centered approaches imagined their child in the future going to college, getting married, having children of their own. Marge, the mother of a 3-year-old bilaterally implanted daughter, used an emotional decision-making strategy and said, “I just imagined her being in high school and not having any friends and only have two college choices to go to. I wanted her to have all the choices in the world, not only two.”

Parents want to have rewarding relationships with their child, and while, on one level, that is a practical concern, it’s also a very deep emotional concern. The parents in my study, such as Julie and Mary who made the cochlear implant decision while driving home from the audiologist’s office after getting the diagnosis, made the decision to go oral from a gut, emotional place. They knew instinctively that they wanted their child to speak and listen. These were not rational, practical choices— these were decisions made from the heart, not the head. I conceptualize rational decision-making as one that relies on a risk/benefit analysis (which is explored in the below section) and is borne out of logical reasoning. I understand emotional decision-making as one that is based on intuition, feelings, and emotions, and does not focus entirely on rational thought. Of course, the cochlear implant decision, for most parents, is a combination of rational and

emotional decision making. As an example of emotional decision making, Mary said, “After I called the surgeon, we were still 30 minutes from home, I cradled Joseph in my arms and cooed to him. You will soon hear my voice my precious baby, I said.”

Risk Analysis

Amy, the mother of a 15-year-old son with bilateral implants said, “We knew it was risky, but we wanted him to have every opportunity provided to him in college and a job and a romantic partner. We wanted him to have a normal life, so it was worth the risk.” Not all parents used this cost-benefit analysis that we see in Game Theory. Corrine, the mother of a 3-year old bilaterally implanted daughter, said “It wasn’t about trading this for that. It was the end decision.” In this case, Corrine specifically is not making a risk-benefit analysis, instead, she states that the cochlear implant is the end result she wants, regardless of the risk involved. In this stage, parents must determine how relatively important factors such as “isolation from family” or “risks from surgery” are. Each decision outcome has risks, and parents must decide how salient, probable, and likely those risks are. Jill’s statement weighs two risks: isolation from family vs. risks from surgery. She said,

It’s major surgery and I didn’t want my baby to have to go through that unless it was absolutely necessary. We learned baby sign and tried signing to her, but it soon became clear that my extended family wasn’t going to learn sign so if she was going to have a relationship with them, she needed to speak and listen.

In this example, Jill explored multiple communication methods for her deaf daughter, weighing the pros and cons of each (ASL vs. cochlear implant). This rational process compared two options, major surgery vs. relationships with family. In her conception of good parenting, a good parent weighs all options and makes the final decision based on facts and projected outcomes, not emotions.

Parents talked of their children having “dark futures” if they didn’t have cochlear implants, and they talked about the loss to the family if the deaf member could not communicate with the rest of the family. When the topic at hand involves cutting into the skull of an infant or young child, and when the alternative is believed to be a sad and lonely future, emotions are running high. Certainly, rationality plays a part, but I interviewed no family members for whom I think the decision was entirely rational. Mary said, “This was not logical. Cutting into my daughter’s head was not logical. But at the same time, it was the only decision that made sense.”

Parents use experiential knowledge of deafness to imagine what their children’s life would be like with or without the implant. For example, Sammy said,

We imagined that she would have to go to a Deaf college and marry a Deaf man, and we would not ever be able to really communicate with either one of them, because they would be ASL focused. It would be total isolation for everyone.

In the case of the parents in my study, they almost all imagined life as a Deaf child using ASL negatively. Brooke said, “ASL is like a prison. No way out. If Sam used ASL he would be trapped in his own little world. It’s not like the guy at the grocery store or library signs [with ASL].” Other parents imagine life with ASL more romantically but conclude that cochlear implants are the best approach for their family. Susan said,

ASL is beautiful, just beautiful. I’d love to be fluent in it, but I know I never would be. So, we had to choose CIs because we knew the whole family—grandparents, aunts, and uncles, would never learn ASL. But I look at people signing with envy—I’d love for me and Samantha to be in that world.

Susan’s ambivalence between ASL and cochlear implants is notable because she was one of only two parents (Jill, quoted above, is the other one), that considered ASL for their child. Both ultimately decided on cochlear implants because of issues relating to family and community communication. This demonstrates the critical importance of communication to these families, which I explore in more detail in the next section of this chapter.

Communication

At the core of the first two issues identified above—normality and being a good parent, is communication. Parents wanted to ensure good communication with their children—both within the family, including extended family, as well as at school, with friends, and in their career. Parents benefit from relationships with deaf children that

empower and promote good communication skills between parent and child (Nicastri et al., 2020). Cochlear implants, implanted at age two or earlier, have been shown to produce verbal communication skills comparable to typically hearing matched controls in approximately 50% of cases (Eisenberg 2019).

Parents in my study frequently mentioned improved communication across all spheres of the child's life as a primary reason to get a cochlear implant for the child. Amy said, "we wanted him to be able to talk with everybody he came across." Familial communication, and interpersonal communication between child and parent was especially emphasized, which I detailed in an earlier section of this chapter. As an example, Wendy said, "She's my baby. I want to be able to whisper into her ear before she goes to bed, and I want to hear her say, 'I love you Mommy.'"

The theme of communication is key to the entire *purpose* of getting a cochlear implant— as seen in this chapter, parents want their children to be able to communicate with their family, the local librarian, their hearing peers and teachers, their college mates, professional peers, future partners, and their own children. In discussions with these parents about normality, good parenting, and risk analysis, underlay the premise that cochlear implants improve communication and that the only reason parents would even

consider implanting their children is to enhance that child's verbal and auditory communication skills.

CONCLUSION

In this chapter I discussed factors of the decision-making process for parents deciding to implant their deaf child with a cochlear implant. There are several powerful groups that influence parents to choose cochlear implants for their children, and these groups have disproportionate power as opposed to the factors that could influence a parent to choose ASL for their child. Parents rely on social norms and the authority of experts to make this decision. Based on my analysis of my interview data, four main themes emerged: normality, the concept of being a "good parent," risk analysis, and communication.

Some parents invoked the language of normality when discussing their decision-making process. These parents talked about a "normal" childhood, "normal family experience" and "normal relationships." Concepts of normality fit well with the idea that parents make the decision with an idea of "what it means to be a good parent." Good parents try to imagine what the future will be like for their children and make the decision based on what they think is best for their child. These parents spoke about an "obligation" to do what's right for their child, in this case, giving them a cochlear implant. Some of

my data suggest that parents had more than only their child's wellbeing in mind— some parents also weighed their own values as part of the decision—making process. For these parents, having a good relationship with their adult children is beneficial to both the child *and* the parent. Underscoring all these decision-making factors is the idea that cochlear implants improve communication skills for profoundly deaf children, and parents want to capitalize on those opportunities for improvement.

Ableism is discrimination and prejudice against people with disabilities or who are perceived to have disabilities. Ableism characterizes persons as defined by their disabilities and as inferior to the non-disabled (Linton 1998). Implanting young children with cochlear implants, before they are able to speak for themselves, could represent a form of ableism. For example, some parents in my study cited the fact that they did not want their child to marry a Deaf spouse, and that cochlear implants are one way to avoid that outcome. These parents stated that they wanted their child to have a “normal” marriage. Parents appeared to worry about “losing” their child to a world they can't understand. This finding suggests that ableism is at least partly responsible for the decision to implant children with cochlear implants, and leads one to question— is ableism an accepted prejudice? Is it more socially acceptable to discriminate based on disability status than it is to discriminate against other personal characteristics, such as

race? My data shows that this indeed the case— no parent in my study hedged or sought to justify, statements that were clearly discriminatory.

In order to protect parents against being overly influenced by cochlear implant manufacturers or other ambassadors from pro-cochlear implant institutions such as Oral schools, I suggest that more be done to ensure the distribution of information on both cochlear implants and ASL to all parents whose child fails an ABR. Some parents in my study seriously considered both ASL and the cochlear implant— they engaged with teachers of the Deaf and learned ASL, however most parents were informed about cochlear implants right away and were not given the chance to seriously consider ASL. Parents should make an informed and full decision, and one that considers all options with equal weight.

This study supports the meanings of deafness that I first identified in chapter four of this dissertation. Several parents in this study reflected on concepts covered in that chapter such as the fear of isolation and the need for community. Isolation— from God, humankind, and the nation are key concepts in defining the meaning of deafness. Parents were afraid their deaf child would be isolated from others and would not enjoy true relationships with others. I identified isolation from God and others as key meanings of deafness throughout history, and this study suggests that isolation, although isolation

from God did not seem to be a preoccupation of the parents in my study, is still associated with deafness. Isolation from others— humankind, the nation, the city, and the neighborhood were all concerns for these parents. Isolation as a meaning of deafness is evident in the hearing aid and cochlear implant advertisements analyzed in the last chapter. Early hearing aid advertisements suggested that deaf people lived isolated and sad lives, but that hearing aids could bring back community to the deaf person. Modern cochlear implant websites almost always showed cochlear implant wearers in relationship with other people— with the cochlear implant, community vanquishes isolation. People depicted on these websites were engaged with others in meaningful ways. The parents in my study have internalized the meaning of deafness to be a life of isolation and see cochlear implants as the primary way to avoid that outcome.

The theme of inconspicuousness was present in hearing aid and cochlear implant advertisements. Cochlear implants can be inconspicuous, especially for people with longer hair, but for people with short hair, the transmitter, which sits on the side of the head, is fairly obvious. The parents in my interview study spent a fair amount of time talking about their children's choices for this visible piece of the cochlear implant. Some children chose neutral brown colors that would blend in with their hair, but, as mentioned earlier, other children chose bright colors such as red and pink. Some kids chose to

personalize their implant by placing stickers on this visible piece. These stories suggest that inconspicuousness in hearing technology is no longer as important as it was in the 20th century. I propose that the reason for this is that using medical technology to address a deficit is no longer as stigmatized as it once was. In fact, *not* addressing deafness with advanced medical technology is more stigmatized— for example, Deaf signers using ASL in a public place are stared at by hearing people, but people wearing cochlear implants or hearing aids are normalized. As deafness continues to be medicalized, the medical and technological treatment of deafness will become ever more normalized and it will become even more stigmatized to *not* treat it as a medical problem. In fact, this was demonstrated in my interview with Deborah, who said, “There’s no reason nowadays to let deafness hold you back. We can fix it now, and if you can fix it, I mean with a hearing aid or cochlear implant, you have an obligation to.”

In chapter four, I identified the modern meaning of deafness to be a problem of success. In this conceptualization, people who are deaf struggle in school and work, and don’t have successful or meaningful relationships. Parents in my study were very specific about the fact that they believed cochlear implants would lead to academic, professional, and personal success. Almost every parent mentioned that with a cochlear implant, a deaf child can have their choice of friends, college, and marriage partner. Earlier in this

dissertation, I hypothesized that success was the meaning of deafness in the current era, and this was demonstrated in the cochlear implant and hearing aid advertisements examined in the last chapter, and combining that data with my interview data reinforces the concept that I am correct in the proposal that success is the meaning of deafness in the current age.

Chapter 7. Discussion and Conclusion

In modern western cultures, deafness has two general conceptions: Deafness, with a capital 'D' refers to the cultural group of people who are deaf. Deaf people do not see deafness as a disability, instead they see it as a cultural difference to be celebrated. Conversely, deaf people, with a lower-case 'd', consider deafness to be a disability that should be fixed by medical science. Although both Deaf and deaf people use hearing aids, Deaf people generally do not use cochlear implants, although they are very common amongst deaf people. This is important to note because although hearing aids amplify existing hearing, cochlear implants can actually provide a simulation of hearing, and can be used to transport otherwise Deaf children to the hearing and speaking world. Hearing aids don't generally make someone culturally hearing, but cochlear implants can do that. Understanding that the medicalization of D/deaf people as a choice is key to understanding the cochlear implant saga. Deafness didn't have to be medicalized—reification tricks us into believing that it has always been this way—always been medicalized – but that is simply not true. With the exception of Luigi Galvani's failed surgery in 1790 (Lane 1999), there is no evidence that deafness was medicalized until the meaning of deafness turned to isolation from humankind and the nation, when it began to be treated with aggressive oral education and effective, medical establishment produced,

hearing aids. In this discussion chapter, I am first going to summarize the main points and findings of the dissertation, then I will discuss some methodological and sampling issues, and conclude the chapter with a discussion about normality, medicalization, and stigma.

SUMMARY OF FINDINGS

In the first findings chapter, chapter four, I looked at the meaning of deafness through three eras, demonstrating how the medicalization of deafness came to be, and shedding light on time periods in which it was not medicalized. The research question I asked for chapter four was: “Drawing on historical accounts of deafness from the early 1800s to contemporary times, how have the social meanings of deafness, deaf technologies, and social beliefs about normality changed?” Using evidence from primary and secondary sources, I found that the meaning of deafness has changed throughout history, and that there are three distinct “eras” in which deafness is understood differently, and different technology is applied to address the problem as it is conceptualized in that era.

In the first era (from the mid-1700s—up to about the 1880s), deafness was considered a spiritual problem, not a medical problem. The deaf were perceived as not being able to communicate with God, and so ASL as a language technology evolved to meet this need. In every era, technology arises to meet the “problem” of deafness, and

conversely, the “problem” of deafness influences available technologies. In the second era, starting in the late 1800’s, people became concerned about “positive evolution” and making sure that the gene pool was “clean.” Coinciding with this concern, was a worry, slightly later in time, about immigration, and who deserved to be called an “American.” The hearing solutions devised during these time periods focused on speaking and hearing English— ASL was no longer sufficient because it did not allow immersion in the American nation or, more broadly, humankind. Technologies developed during this time frame included the remarkably disappointing audiphones and dentaphones, and, later, the more promising micro-battery that finally allowed discrete hearing aids. These technologies fit the problems of the era, but again, the problems of the era— fitting in with humankind and the nation— influenced which technologies would be developed.

I’ve proposed in this dissertation that the meaning of deafness in the current era (starting in the 1980s), is lack of access to success. This translates into success at school, success with friendships, success in college, success in dating and marriage, and success in parenting. I’ve used evidence from my interviews to back up this claim, and I’ve also found advertisements for hearing aids and cochlear implants that suggest that “success” is the problem to be solved in the current timeframe. Keep in mind that the meaning of deafness drives the technology available, but also the available technology drives the

meaning of deafness. In the first era, when the problem of deafness was conceived of as not being able to connect with God, ASL was an available technology that could address this problem. If surgical techniques were safe and efficacious in the 18th and 19th centuries, it is possible that the “meaning of deafness” in that time period may have been different, but the available technology- ASL- informed the meaning of deafness. In the modern era, cochlear implants are the perfect “fix” for the problem of reaching success, because they address both hearing and speaking, and some children who are implanted early have speech so clear it is difficult to distinguish them from hearing children. This is the kind of success that parents want when they chose a cochlear implant for their child.

In chapter five, I examined historical advertisements (from around 1910-1970) for hearing aids, plus contemporary websites for hearing aids and cochlear implants. Recall that the research question for this chapter was, “how does advertising and marketing strategies for deaf technologies from the 1900s to the present reflect the changing social meanings of deafness and social beliefs about normality?” The themes that emerged from this analysis answered this question by tracing the different social meanings of deafness across the years as represented in the advertisements and websites. Four main themes arose from this analysis: inconspicuousness, isolation/connection, modernity/space age/supra modernity, and success. Two of these themes map nicely onto the problems of

deafness identified in the fourth chapter. Isolation/connection are major historical themes in the meaning of deafness across all three eras. For example, in the first era, deafness was considered a spiritual problem, because the meaning of deafness was isolation from God. Likewise, in the second era, the meanings of deafness were isolation from humankind and isolation from the nation. Hearing aid and cochlear implant advertisements leveraged these problems of deafness in their advertising— early hearing aid advertisements focused on the desperate loneliness experienced by deaf people, and later, in the third era, cochlear implant websites focused on the connection with others that people with cochlear implants can achieve. These advertisements map onto all three historical problems of deafness— isolation from God, isolation from nation, and isolation from humankind— because they all deal with isolation and connection.

The other theme that maps nicely onto the problems of deafness is achieving success, which, if you'll recall, I propose is the meaning of deafness in this current era. Hearing aid and cochlear implant websites (and notably, *not*, historical advertisements from the second era), have pictures of people being successful— in school and in work. Many advertisements fit multiple categories, and there are images from websites that show people with hearing aids or cochlear implants being successful in their social and personal lives. The fact that images of success are specifically *not* included in the

historical advertisements gives credence to the idea that the meaning of deafness as success is a new and unique meaning that is true for this era and none other.

The question arises, why are isolation/connection and success problems with deafness that map onto the advertisements and websites, whereas modernity/space age/supra modernity is not a problem of deafness that I identified in chapter four? Marketing and advertising can influence the meanings of deafness, and can contribute to the normalizing, medicalization, and destigmatizing of a condition. Several recently medicalized conditions, such as adult ADHD, erectile dysfunction, Pre-menstrual Dysphoric disorder, and andropause, among others, (Conrad and Bergey 2004; Conrad and Leiter 2008; Conrad 2007) have relied on advertising, most of it coming from pharmaceutical companies, to promote the new medicalized disorder. This medicalization is distinctly related to modernity, and in fact is a feature of modernity (Santos 2020; Santos & Gottschang 2020; Shaw 2012). Advertisements for hearing technology serve to further medicalize deafness, as they place the treatment of deafness squarely on the shoulders of medical devices. Advertisements for treatments for medicalized conditions can make those conditions seem more normal, by bringing discussion of them into the mainstream.

It is worth noting the modernity/space age/supra modernity advertisements did not appear until the 1950's and have continued on in hearing aid and cochlear implant advertising, although the modern ads focus more on science fact than science fiction (Sankova 2020). During the US/Soviet space race, which reached its height in the 1950's and 1960's, the entire country was obsessed with reaching space first (Osborne 2015; Jones 2004). Jones wrote,

Before the launch of Sputnik in 1957, although space was present in popular culture, it was generally aimed at a specialized audience. In the 1960s, interest in space became widespread and reached unexpected corners of popular culture such as pop music.

Those far reaches of the culture that it reached included consumer electronics in the form of hearing aids. The space age advertisements from the 1950's and 1960's were a direct result of Cold War politics and the US/Soviet space race. In the third/current era, space race advertisements no longer exist, but modernity/supra modernity themes in advertising do. Cochlear implant and hearing aid companies want to be seen as forward thinking and technologically ahead of the curve. These ideas are present in the futurism—themed websites.

Although I did not find a correlation between the inconspicuousness advertisements that spanned the entire time period of the research and one of the “problems of deafness” identified in chapter four, this marketing theme is related to

stigma, which is one of the main theoretical concepts of this dissertation. Deaf people who choose inconspicuous hearing aids and cochlear implants may be responding to the stigma related to being deaf and try to hide the technology associated with their disability (Woodcock, Rohan, and Campbell 2007).

The last research question I posed in this dissertation is addressed in the third findings chapter: “How do contemporary parents’ decisions to get a cochlear implant for their children reflect the relationships between social meanings of deafness, deaf technology, and social beliefs about normality?” These last findings chapter focused on the 33 interviews I conducted with parents whose children were implanted with cochlear implants. In these interviews, parents’ narratives mimicked the problems of deafness seen in the fourth chapter: one of their main motivations for getting their child implanted was reducing isolation and enhancing connection and communication with others. They viewed deaf life as being isolating and lonely and wanted their children to have fruitful relationships with others. In addition to connection, however, parents in my study strongly echoed themes of success when speaking about the reasons they wanted their children to have cochlear implants. They spoke about success with school, college, work, marriage, and parenthood. Since success was also a theme in the contemporary advertisements, I argue that success is in fact a primary meaning of deafness in today’s

era. Parents used one of, or a combination of, four themes when talking about why they implanted their child. First, normality— parents talked about wanting their children to go to a “normal” college (this was frequently contrasted with the apparent “abnormal colleges” of Gallaudet and Rochester Institute of Technology, the other “deaf” school in the US), have “normal” marriages and have “normal” jobs. For these parents, the cochlear implant meant their child would have a normal life. The second theme that parents utilized was a narrative of “good parent.” A “good parent,” and likewise, a “good family” meant that parents had an “obligation” to “fix” their child’s deafness if they could. The good parent narrative is strongly related to medicalization- the good parent utilizes medical technology decisively. They understood that if their child was an ASL-using adult, they would be isolated from the family and would have limited relationships with extended family members. In this case, we see the theme of isolation again, which is sprinkled throughout the entire dissertation. Thirdly, parents used the theme of “risk analysis” when choosing a cochlear implant for their child. These parents weighed the risk of surgery with the potential benefit of hearing and speaking. These parents often took more time to make the implant decision, often having teachers of the Deaf come to their house to teach their family ASL. Lastly, and perhaps most broadly and most importantly, is a theme of communication. Wanting good communication with their

children and wanting their child to have good communication with others, was woven throughout all the interviews. Concerns about normality and good parenting are ultimately concerns about communication.

LIMITATIONS AND SUGGESTIONS FOR FUTURE RESEARCH

It is important to note that I think a thorough analysis of this topic is not complete unless it includes parents who chose ASL for their children. I attempted to reach out to Deaf schools in the same way I reached out to the oral schools, as described in the methods chapter. Some users of ASL believe that cochlear implants are tantamount to genocide, or at the very least, glottocide (Lane 1999). Since approximately 90% of deaf children are born to hearing parents, if all, or most, of those children use cochlear implants and not sign language, the Deaf ASL community will slowly dissolve. With a fewer number of Deaf children joining Deaf culture and adopting ASL, the language will not be passed onto newer generations, and eventually, the culture, by way of the loss of the language, will disappear. Parents who use ASL may have distrusted a cochlear implant researcher and refused to participate for this reason. In order to engage more fully with this community a researcher who is fluent in ASL and one who clearly preferences ASL would be ideal. Understanding why people chose ASL for their child would be a useful addition to the current study.

In addition to reaching out to ASL families, this study would be greatly enhanced by including families of color, especially because I posit that the meaning of deafness in the current era is influenced by white middle-class values of success. These values were first developed in the post WW-II era and the availability of the GI Bill to returning soldiers, although it was generally not easily available to Black soldiers (Faber 2020). This cemented and further deepened the wealth gap (Faber 2020) between white and Black families through the practice of homeownership that the GI Bill afforded white families and has almost certainly influenced the concept of “white middle class values of success.” Black families are more likely, by representation in the population, to have Medicaid than white families (National Committee to Preserve Social Security & Medicaid 2021), and although Medicaid covers cochlear implants, the reasons for these families getting cochlear implants for their children is an un-studied topic. Tampio et al. (2018) studied the rates of cochlear implants in different sociodemographic groups and found that whites and Asian-Americans were more than twice as likely to implant their deaf children with cochlear implants than Black and Hispanic families. “White middle-class values of success” may not have bearing on why, or why not, families of color choose cochlear implants for their children. In other words, the “meaning of deafness” for

families of color may not be the same— success— as I suggest it is for the white families in my study. This topic, not covered in the literature, is a ripe location for future research.

Another area ripe for future study are the technologies that come “after” the cochlear implant- cochlear implants are not going to be the last technology at the end of a long string of technologies. Gene therapy (de Joya et al. 2021), and other techniques that can be employed while the fetus is still in-utero, or pre-implantation of zygotes that have been genetically modified to eliminate deafness (Géléoc & El-Amraoui, 2020; Leake, & Akil 2020; Blanc et al.,2020; Riddle & Butler 2019) are promising technologies on the near horizon.

SO WHAT?

This dissertation contributes to sociological thought in the areas of normality, medicalization, and stigma. Normality, medicalization, and stigma have been studied in the context of deafness before (Mauldin 2016; Horwitz 2016; Davis 1995; Branson & Miller 2002; Lane 1999), but what I bring to the discussion is the “meanings of deafness” and how these meanings contribute to normalizing and medicalizing technology. The study of the meanings of deafness as they relate to normality, medicalization, stigma, and emergent technology, is a new contribution that I make to this literature. Lastly, I provide a novel approach to stigma, that relies on the scholarship of Goffman (1963; 1959) but

goes further by examining how technology can either diminish or enhance stigma. I will examine each of these constructs — normality, medicalization, and stigma in turn in the rest of this chapter.

Normality

Normality has many different definitions, which are explored in chapter two. I utilize each definition presented in chapter two throughout the dissertation— the social construction paradigm (Goffman 1963; Canguilhem 1989; 1994; Foucault 1994; 2009; and Conrad 2007) , the interactive theory (Hacking 1986; 1999), and the Harmful Dysfunction model (Horwitz 2002; Horwitz & Wakefield 2007). References to normality are found in historical documents, in hearing aid and cochlear implant advertising, and in parents’ narratives.

In the advertisements that focus on connection, they show people engaging in normal, everyday activities such as playing with children, working, and involvement with others. These images all say, “if you use our product X, you can be normal like the people in this picture!” The isolation/connection advertisements from the 20th century proposed the alternate view: “If you do not use our product X you will be isolated and abnormal.” Isolation was not only shown as a negative condition, but it was shown as an “abnormal” condition, placed in contrast with the “normal” condition that the ads were

selling. These advertisements largely used the social construction of normality in the advertisements. Generally, these advertisements focused on the *perception* of normality.

Parents also utilized conceptions of normality in their discussion about how they made the decision to give their deaf child a cochlear implant. By and large, these discussions were couched using the language of the Harmful Dysfunction model of normality (Wakefield 2007). In this model, every body part has a function, and if that body part is not working properly, then it may be considered a “harmful dysfunction.” However, this model is not entirely biological in nature, there is also a social component, which makes it ideal for studying physical phenomena that are also social in nature. In this case, the ears are “dysfunctional,” but the social component is what makes it “harmful.” If families are not able to operate in a typical way, if students aren’t able to go to school in a typical way, if relationships to others and to the world around the deaf child are impacted, then this would be considered a “harmful dysfunction.” In the interviews, parents utilized all the conceptions of normality. For example, some parents focused on other people— “other people” do not use sign language, therefore, their child, if signing, would be isolated. This is an example of the social construction paradigm of deafness. Other parents talked about the fact that their children’s ears were “not working properly” and a cochlear implant was the solution to this dilemma. This construction falls in line

with the Harmful Dysfunction model of normality. No parent utilized the interactive approach to normality, which would have paired physical realities with social norms—parents used the Harmful Dysfunction model instead, which is similar because it includes both the medical and the social.

Regardless of what normality model the parents and advertisements used— social constructionism or the Harmful Dysfunction model, technology is poised as the answer to the abnormality. Each of the three meanings of deafness across time— isolation from God, humankind and the nation, or success are each answerable by technology. Certainly, the meanings of deafness inform what technology will arise to address it, but also, the technologies themselves inform what the meaning of deafness is. For example, in the first era, medical technology (including hygiene, electric lights and antibiotics) were not available to support a medicalized/surgical view of deafness. However, a prototypical ASL *did* exist, and was used as the solution to the problem of deafness in that era, which was isolation from God. Presumably, God could understand ASL. So, in this way, you have a dialectic between the meaning of deafness and the technology available to support that meaning. Normality was possible by providing deaf students with ASL because the available technology matched the problem as it was conceived. As another example, the meaning of deafness in the current era is success, as I have demonstrated throughout this

dissertation. This success is posited by parents to include success in all areas of life—from success in school, friendships, career, marriage, and parenting. Since success in all of these diverse areas of life are the meaning of deafness, the technology that has to emerge to meet this problem must provide success in all of these areas. Cochlear implants arose as a direct answer to the meaning of deafness in the current era, as, when they are successful in providing speech and hearing, they provide meaningful assistance in all areas of normal social, educational, and professional areas.

Defining normality has presented a puzzle to medicine and society. Normality remains an obscure concept particularly in the medical field, which is historically reductionistic and its practitioners trained to recognize and treat pathology. The word normality derives from the Latin word *norma*, which referred to a tool used to show a square angle and by extension to mean a rule, standard, or principle. Over time, the definition of normal came to mean ordinary, usual, or “naturally occurring.” Interestingly, if one applied the “naturally occurring” definition, many individuals born with “anomalies” or “birth defects” or with behaviors different from mainstream could be considered normal. But most societies did not take this definition. Instead, a departure from the typical physical or behavioral characteristics was usually seen as abnormality or deviance.

Although terms such as normal and normality serve some purpose in medicine and the study of human behaviors, they also perpetuate labeling and discrimination. The utility of the normality concept can be seen in how it benefits or contributes to the well-being of and services to the full range of human beings. Several attempts at defining normality are worth reviewing to examine examples of traits felt to be abnormal. Two different models of normality relevant to disability are the medical and social. Both have merits as well as limitations; attempts at integrating these models would be useful. The main proponents of these two theorists are Michel Foucault (1996), Jerome Wakefield (2007) and Stephen Gould (1996). Foucault questioned the timelessness of many taken-for-granted aspects of normality. This is certainly seen in my data, as it is evident that the meanings of deafness shift over time and are decidedly *not* static. This perspective is the social construction perspective which I think this dissertation amply demonstrates. However, theorists from a more biological point of view such as Gould (1996) and Wakefield (1997), argue that disability is “baked-in” to a person and that the bodily difference experienced by some, if it poses social or medical disabilities, is a disability that should be treated by advanced medicine (Gould 1996; Wakefield 1997).

Allan Horwitz, who ideologically straddles the border between social constructionism and the Harmful Dysfunction model wrote:

Sociologists typically study phenomena that stand out from the commonplace. They pay more attention to crime than conformity, homosexuality than heterosexuality, blackness than whiteness, or holidays than regular days. The conventional, usual, and expectable is usually taken for granted and more rarely studied. Despite its general neglect, normality has an extraordinarily powerful effect on how people behave. Even those who want to be different use a conception of the normal as a guide.

Sociologist Emile Durkheim (1912) gave an unusual twist to the statistical conception of normality. He postulated that the needs of specific social groups, rather than statistical forces, generate distributions of normality. Because all groups need to construct definitions of normal behavior, they single out behavior at the tails of statistical distributions as “deviant” to ensure behavior within the tails is normal.

Because of these problems, sociologists are more likely to view normality as some sort of ideal or social norm. The normative approach drops the statistical aspect of normality and treats what is normal entirely as conformity to a standard or ideal. In contrast to statistical conceptions of normality, normative conceptions imply that everyone, or no one, in any particular group can be normal. Another difference from the statistical conception is that when we consider normality valuable, we can determine whether or not a person is normal by measuring the qualities of that person without knowing anything about the distribution of the trait in question among other members of the group.

Normalizing may be defined as (a) acceptance of people with disabilities and (b) offering people with disabilities the same conditions that are offered to others. The normalizing principle therefore means making available to all people with disabilities conditions of everyday living that are equal to (or as close as possible to) the regular circumstances and everyday way of life of society. This includes providing to individuals with disabilities the ability to live a life with normal rhythms, including daily routines. It also includes providing to such individuals the opportunities to interact within the normal conditions of life (e.g., regular housing, schooling, employment, exercise, recreation, and independent living).

In considering normalizing deaf people, techniques, and technologies such as cochlear implants, Oral schools, and other approaches that aim to make children “normal,” what is the difference between normalizing and pathologizing? Does the very presence of cochlear implants mean that we are actually pathologizing deafness? By bringing kids into the mainstream with cochlear implants is that pathologizing or normalizing? I argue that it is both— by utilizing the technology you are saying that something is wrong with you— e.g. one doesn’t take medications unless one thinks something is wrong with them. Except for an annual physical that most people skip (American Association of Retired Persons 2018), you don’t go the doctor when you are

well. People go to the doctor to help feel better/feel normal again. So, from that perspective, it is pathologizing. However, if adopting the technology allows one to use mainstream communication methods, such as speaking and listening, then it is normalizing. So cochlear implants are both normalizing and pathologizing, and the people who promote cochlear implants; parents, doctors, and technology manufacturers, do in fact pathologize deaf people—they admit there is a problem with the deaf person blending into society. On the other hand, the same group of people just want their kids to be normal. You can't fix something that you don't admit is broken.

Medicalization

A clear example of medicalization is the difference between the definition of the meaning or problem of deafness in earliest era – disconnection to God – and the definition of deafness today – success. In the 1700's, deafness was not medicalized, it was spiritualized, and was treated as a spiritual problem not a medical problem. Contrast that with today, where deafness is conceived of as a medical problem to be treated with advanced medical technology.

I treat medicalization in a novel way in this dissertation, because not only do I discuss technologies that treat deafness, which is not a unique contribution (Mauldin 2015), but I also focus on concepts of morality, especially in the context of connection to

God and in terms of what it means to be a “good parent,” and how morality is intertwined with technology to create a form of moralized technology to treat deafness. There is a rich literature on medicalization and medical technology and morality that I am contributing to with this dissertation (Rimke & Hunt 2002; Obrist 2004; Evans 2006; Davis 2014; Lewin 2011; Pustovrh & Pirc 2016; Schirin 2016; Sáenz & Hoppe 2020). ASL as a technology was a particularly moral technology— in that it connected Deaf children to God and community (Baynton 1996)- and my analysis in chapter four of primary sources from this time period demonstrate that ASL was seen as the only way to “civilize” the “deaf savage” (Jastrow 1886) . If a parent eschewed the ASL school for their deaf child, one can imagine that they would be met with a moral/spiritual sort of scorn. This morality is now medicalized— one must do the right, “moral” thing for deaf children, and that means medicalizing their disorder and treating it medically. In this way, medicalization becomes a moralizing force. For example, the parents in my interview study who said they “had no choice” are using the language of morality. In this example, morality, and the concept of being a “good parent” are medicalized concepts— the only right, moral way to be a good parent is to give your child a cochlear implant.

My data show that when deafness meant “can’t connect to God— use ASL” in the 1800’s, now means “can’t have success— use a cochlear implant” in the current era

(post-cochlear implant FDA approval in the 1980's), demonstrating the medicalization of deafness across the years. I also demonstrate how deafness is understood differently in different places and in different time periods. Resistance to the medicalization of deafness, such as that often seen in the Deaf community, exemplified at Gallaudet University, is in stark contrast with the embracing of medicalization that is apparent at the John Tracy Clinic or the annual AG Bell conference. This variety and difference across time and space is evidence that deafness is indeed a medicalized social phenomenon.

Stigma

Stigma is closely related to normality and medicalization. Stigma, or, having a spoiled identity (Goffman 1963), is one result of not being normal. In many domains—from criminal background to medical illness (Goffman 1963), one can develop a “spoiled identity” that leads to stigma. Medicalization, on the other hand, can either ameliorate or cause stigma. In some situations, once a condition becomes medicalized, more, and better treatment of it can occur. For example, when erectile dysfunction was medicalized in the 1990s, it gave millions of men a voice to express their sexual problems (Conrad & Leiter 2008), and a solution to those problems. On the other hand, when postpartum mental health disorders were medicalized in the 2000's (Dubriwny 2010), not only did it open up

treatment options to women who suffered severe postpartum symptoms, it also medicalized a very normal experience that many postpartum women experience— mild to moderate postpartum depression. All of a sudden, in both of these examples, medical science took normally occurring bodily and emotional experiences (decrease in sexual ability as one ages, and postpartum depression), and turned them into medicalized problems.

The contribution I make to the stigma literature is that I pair it not only with normality and medicalization findings, but I contribute to newer applications of stigma theory to technology. To this end, I offer up technology as a way to understand stigma (see for another example of this in Birnholtz & Macapagal 2021.) To my knowledge, Goffman did not address technology head-on in his discussion of stigma and spoiled identities. Studying social technology through the lens of stigma, as I and Birnholtz & Macapagal (2021) do, moves Goffman's theory of stigma forward into the modern age of hyper-technology and sociologists should consider ways of applying Goffmanian theory towards technology, both medical and otherwise. Technology can either serve to enhance or decrease stigma, depending on a variety of factors. For example, some of the children in my interview study chose bright red or pink processors, so it was impossible for these children to "pass" as "normal." In this case, you can say that cochlear implants are not

stigmatizing, because these children willingly chose a brightly colored processor and, according to my interviews, were not shunned or embarrassed by it. Alternatively, hearing technology can be stigmatizing, which is apparent in the inconspicuousness advertisements explored in chapter five. In an interview with a deaf man who used cochlear implants, he told his manager at his job that he needed a Videophone to do his work and felt as though this request was considered a “reasonable accommodation” under the ADA (Burrows 2013). However, his employer did not buy him a Videophone, and instead, demoted him to a job that didn’t require him to talk on the phone. This kind of stigma is the kind of spoiled identity that Goffman (1963) writes about.

There was a program in the 2010’s on ABC called “What would you do?” Many of the parents in my interview study mentioned this program, because one of the episodes dealt with young deaf people. In this particular episode, two young deaf women who wore hearing aids and had good speaking skills (who were deaf actresses) walked into a coffee shop and asked if they could have a job application. The man at the counter said that they couldn’t do the job because they were deaf. When the actresses left the store, a customer in the restaurant (an HR manager), told the man at the counter that the more politically correct way to get “rid” of the girls would be to have them write an application and then write “not a good fit” on the application. Tens of people in the coffee shop

witnessed the manager's rude and discriminatory behavior, as well as the discriminating advice of the HR manager, but nobody did anything about it. The parents in my study who talked about this program all wanted their child to never have to go through such an experience. They were horrified that that kind of stigma existed, and they thought that cochlear implants were the best option to prevent that kind of stigma. These parents imply that the stigma of not being successful is worse than the stigma of wearing a visible medical device- reinforcing, again, my assertion that achieving success is the problem of deafness to be solved in the current, third era.

IN CLOSING

This dissertation has come full circle. It started with the meanings of deafness and how those meanings influence, and are influenced by, technology. All of the meanings of deafness— from connection to God, humankind and nation, and success, all have their origins in normality, medicalization, and stigma. These meanings of deafness appear throughout the dissertation. The findings chapters address all three of the research questions- how have the social meanings of deafness, deaf technologies, and social beliefs about normality changed (chapter 4), how does advertising and marketing strategies for deaf technologies reflect the changing social meanings of deafness and social beliefs about normality (chapter 5), and, finally, how do parents' decisions to get a

cochlear implant for their children reflect the relationships between social meanings of deafness, deaf technology, and social beliefs about normality? (Chapter 6).

Deafness is a useful and unique site to study normality, medicalization, and stigma, because deaf people, and the parents of deaf children, have the option of minimizing the impact of the disability by giving the deaf person a cochlear implant. Themes of normality run throughout the experience of being deaf— from advertisements that suggest you will be normal if you use their product, to parents who say definitively they want their children to “be normal.” In the current era, deafness is medicalized and treated with advance medical devices, but, proving that the social meanings of conditions vary by time and space, deafness has not always been considered a medical problem. Cochlear implants allow some deaf people to experience less stigma than their ASL-using peers, because many people with cochlear implants have near-normal hearing and speech. However, deafness is a marked status (Zerubavel 1999; Brekhus 2003), and many people try to hide their disability, or try to “pass.”

Glottocide, and the possibility of resultant culture death, is a very real and looming possibility for the Deaf community, and this is due in large part to cochlear implants. To preserve the ASL language and community, Deaf and cochlear implant activists could partner more closely and become more aligned. Preserving Deaf culture

and ASL language is not at odds with, or incompatible with, providing cochlear implants for deaf children. Cochlear implanted deaf children can learn ASL and attend ASL events while still wearing cochlear implants and speaking and hearing. This kind of arrangement is the only arrangement that will allow the Deaf ASL community to flourish while still respecting parents' desires to give their child a cochlear implant.

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Appendix

INTERVIEW QUESTIONS

Demographic Questions

1. What is your child’s age?

2. How many people are in your family?
3. What type of school does your child attend?
4. Can you describe your neighborhood?
5. Do you have health insurance that covers cochlear implants?
6. How would you describe your household income?
7. What is your highest education received?
8. Is your child deaf or hard of hearing (HH)?
9. How long has your child been deaf/HH?
10. At what age did you have your child implanted with the cochlear implant?
11. How was your child identified as deaf/hard of hearing?
12. Do you consider your child to be deaf?

When you first discovered your child was deaf

1. What steps did you take when you discovered he/she was deaf?

How did you decide to get a CI?

1. How did you decide to get a CI?
2. What information did you use to make the decision?

3. What role did the internet (if any) play in your decision-making?
4. Who taught you how to use the cochlear implant? What did they say?
5. How was your experience with the insurance companies when you got the CI (if has insurance?)? Give me an example of your dealings with the insurance company.
6. What was your experience with doctors in your decision making process?
7. How important were families with children with cochlear implants in making your decision?
8. What CI did you end up buying? How do you feel about your purchase.

Having Cochlear Implants

1. How are your relationships with your surgeon? What about with your audiologist?
Your speech pathologist?
2. How, would you say, have cochlear implants have contributed to your child's quality of life?
3. Walk me through an average day with the cochlear implant.
4. What did your morning routine yesterday look like? Would you say this is typical of your morning routine?

5. What did your evening routine yesterday look like? Would you say this is typical of your evening routine?
6. Are there day—to—day challenges in dealing with cochlear implant technology? Can you give me an example?
7. How have you adapted to your child's deafness?
8. How have you adapted to deaf technology?
9. What kinds of challenges have you faced in dealing with deafness or deaf technology? Can you give me an example?
10. How aware is your child that they are deaf or different? Can you give me an example?
11. How do the siblings (if any) react to your child's deafness and CI? Can you give me an example of their relationship?

Normality Questions

1. PROMPT: How, would you say, does your child compare to other children?
2. ONLY ASK THE FOLLOWING QUESTIONS IF #1 ELICITED THE WORD OR CONCEPT OF NORMAL
3. What does the word "normal" mean to you?

4. Do you think deafness is a “normal” condition? Why or why not? Do you think it is an “abnormal” condition? Why or why not?
5. Do you think somebody can be deaf/HH and normal?

Stigma & ASL

1. To what extent do you feel you/your child is treated differently because you/your child is deaf? What are some positive examples? Negative examples?
2. How do you feel about deaf/HH people who chose to use ASL as their primary means of communication?
3. How do you feel about signing once your child is implanted?
4. How do you feel about deaf/HH people who chose to use spoken English as their primary means of communication?
5. Do you think it is important for deaf people to fit in with the hearing community? Why or why not?