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Cochlear implants and codas: the impact of a technology on a community

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Thesis

**COCHLEAR IMPLANTS AND CODAS:
THE IMPACT OF A TECHNOLOGY ON A COMMUNITY**

by

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DEDICATION

I dedicate this thesis to my participants.

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ERIN MELLETT

ABSTRACT

There has been a great amount of debate between the medical community and the Deaf community regarding cochlear implants. Indeed, some factions of the Deaf community have reacted with hostility to the development of the technology and have protested its implementation. Existing literature examines Deaf individuals' perceptions of cochlear implants, however there has been a significant lack of academic attention paid to the hearing children of deaf adults (codas). As children of deaf parents, codas grow up simultaneously inhabiting two worlds: the Deaf world of their parents and the hearing world of their peers. It is codas' unique position and loyalties between the Deaf world and the hearing world that make them important to the cochlear implant debate. This study investigates codas' perceptions of cochlear implantation using standard ethnographic methods, including in-depth, open-ended interviewing with codas, and immersion in the research population through ongoing participant-observation at a deaf school. The findings suggest that (1) codas' interstitial identity impacts their perceptions of and attitudes towards cochlear implantation and (2) cochlear implants have contributed to a refinement of Coda identity in relation to the Deaf community.

TABLE OF CONTENTS

TITLE.....	i
COPYRIGHT PAGE.....	ii
READER APPROVAL PAGE.....	iii
DEDICATION.....	iv
ACKNOWLEDGMENTS	v
ABSTRACT.....	vi
TABLE OF CONTENTS.....	vii
LIST OF FIGURES	x
INTRODUCTION	1
Who are codas and why do they matter?	6
BACKGROUND:	10
The Deaf Community: a brief history	11
Who are codas?	16
Cochlear implantation	23
Hearing advocates' discourse about cochlear implants	26
Deaf discourse about cochlear implantation	37
Aversion to the disability identity	41

Questions about risk, efficacy, variability of outcomes, and long-term impacts	43
The threat of ethnocide	48
Sign language as an endangered language	50
Children: issues of agency	52
Why study codas?	53
METHODS	55
Initial design	55
CHAPTER 4	65
The Deaf Community as a biosociality	65
Biological citizenship	67
On the periphery of biological citizenship	69
Fictive kinship	75
Fictive kinship founded upon biosociality	77
The birth of a community	82
Discovering coda	84
CODA organizations as liminality	87
The construction of a community and sense of belonging	90
Conclusion	93
CHAPTER 5	95
Third Culture Kids	95
Codas talk about TCKs and the children of immigrants	102

The TCK Profile and its relevancy to codas	105
How are codas unique?	121
Conclusion	126
CHAPTER 6	127
Coda discourse about cochlear implants	127
The advantages of cochlear implantation as articulated by codas	128
The disadvantages of cochlear implantation as articulated by codas	136
Codas conceptualize decision-making	140
Conclusion	152
CONCLUSION	155
The impact of misinformation and lack of information	155
Recommendations	164
Codas and implantees - points of parallel	172
Why is it important to continue studies of cochlear implantation?	174
REFERENCES	176
CURRICULUM VITAE	198

LIST OF FIGURES

Figure	Title	Page
1	Fingerspelling of "coda"	16
2	Cochlear Implants: Why wouldn't you?	33
3	Cochlear Implants: Before and After	39
4	<i>Killing My Deafness</i> by Leon Lim	40
5	<i>Ameslan Prohibited</i> by Betty Miller	50
6	<i>Milan, Italy 1880</i> by Mary Thornley	50
7	<i>No! Not My Baby Sister!</i> by David Call	52
8	Chart of Deaf and hearing attitudes	73
9	The Third Culture Model	96
10	Third Culture Kids: Online Comments	100
11	31 Signs You're a Third Culture Kid - BuzzFeed	101
12	The Cross Cultural Kid Model	125
13	Infant Implantation	144

INTRODUCTION

It's 6:30 p.m. on a Thursday night in January and I'm in the basement of the early childhood center at Bay State School for the Deaf.¹ I'm here for the weekly ASL night class, offered to hearing people who want to learn American Sign Language. I watch as other students trickle into the classroom, signing "hello" to one another and to me as they shed layers of coats, scarves, and hats. I've been attending these classes for about a year now and have progressed to the sixth level. There are familiar faces from previous levels here tonight, but some new ones as well. We're a varied bunch, ranging widely in age and in reason for taking the class. Some are high school students thinking about a career in interpreting, some have deaf family members who they hope to better communicate with, some are hearing parents with deaf children, others are hearing people who work or volunteer at the school. I even met a pastor and his daughter who are learning to sign for deaf members of their congregation.

The room is silent, except for the occasional creaking of a chair leg or quiet laughter. Seven of us—sometimes there are more, sometimes there are less, depending on people's schedules—sit in metal folding chairs arranged in a semi-circle around our instructor Dev, a Deaf man who teaches math to high schoolers during the day. We start class with the usual greetings: “how are you?” “what's up?” “how was your week?”

This week, a new student has joined the class. Dev asks us to introduce ourselves. The new student goes first, fingerspelling her name "Eve" and explaining that her son just started at Bay State.

¹ Pseudonyms are used for all names and places.

My turn comes. I position my body towards Eve so she can see my hands clearly.

“My name is Erin.” I sign.

Eve nods, confirming she understands my fingerspelling.

“I’m a medical anthropologist.” I continue.

“What?” she signs back, looking at Dev and then back to me. “Again?” she requests.

I repeat the sign for medical, placing the middle finger of my right hand into the center of my open left palm and wiggling it. I raise my eyebrows to see if she understands. She nods. I repeat the sign for anthropologist, placing my hand face down against my forehead, moving it away from my head a few inches, twisting it so the palm faces outwards, and then placing it back against my forehead. I finish with the sign for person.²

I raise my eyebrows again. Eve furrows hers.

“Anthropologist” I finger spell the word.

“Again?” She signs. She didn't catch what I spelled.

I finger spell it again, slower this time, pausing between each letter. Eve shakes her head still.

“I don't know” she signs.

“It's fine” I reply. This isn't the first time someone hasn't know the sign for anthropologist. A number of the fluent ASL-signers I've met were unfamiliar with the sign as well.

² See here for a visualization of how to sign anthropologist: <http://www.lifeprint.com/asl101/pages-signs/a/anthropology.htm>

Eve looks towards Dev. He takes a dry erase marker from his bag and writes anthropology on the board, pointing to it.

“I study different cultures” I sign, trying to come up with the easiest way to explain what it is I do with the signs that I know.

“Oh” says Eve softly out loud, closing her eyes and nodding her head in a moment of realization. “Yes. Yes. I understand” she signs.

“She studies Deaf culture.” Dev, who is familiar with my research, adds.

Another student, Nelly, waves her hand up and down to get my attention.

“Why medical?” She asks.

“What do you mean?” I reply.

“Why is it medical anthropology, not just anthropology?”

“Oh. I’m studying cochlear implants” I sign back.

“I see” Nelly signs. A couple other heads slowly nod as they recognize the sign for cochlear implant.

The already quiet room grows quieter somehow. Hands that were once signing, now sit still in laps. People have sat back in their chairs. No one asks any more questions. It seems the mention of cochlear implants has frozen the room. Dev looks at me and the others, nods, and starts today’s lesson.

I first became interested in cochlear implants in 2013, the senior year of my undergraduate career, when I stumbled upon a YouTube video of a young woman getting her implant activated for the first time. Like many others, I thought the device was amazing, miraculous even, a testament to the strides science and technological innovation

have made. Many of the comments on the video reflected what I felt: sentiments of happiness and wonderment. As I scrolled further down through the comments, however, I noticed that not all were so positive. Other commenters did not appear as awestruck as me, and a different narrative of cochlear implants emerged. So, I did what any other millennial would do: I googled it. Much to my surprise, I learned that not all deaf people support cochlear implantation. How could they not want to hear? I wondered. I googled more. That's when I stumbled upon Deaf culture, and I learned about those who do not believe deafness has to be a disability; it can be something much more.

Commercially introduced in the 1980s, cochlear implants continue to be a controversial and divisive issue in the Deaf community and, as evidenced by the reaction of my ASL evening class, they are still a topic that causes discomfort and tension. Cochlear implants entered onto the scene during the height of the Deaf Civil Rights movement, a time when the Deaf community mobilized and campaigned for recognition as a minority cultural and linguistic group. As Deaf scholar and activist Paddy Ladd remembers:

"Looking back through the literature on deafness, I arrive at the mid-1970s. In the writings I find there I find us, Deaf and hearing alike, timorously suggesting as if for the first time, that such a thing as a 'Deaf community' exists" (2003).

This time period was marked by important historical events like the Deaf President Now! Movement at Gallaudet University³ and revolutionary academic Deaf writings like

³ Gallaudet University is the most well-known Deaf university in the world. In 1988, students protested and shut down the school, demanding the next president of the university be a deaf person. An excellent book on this historical movement is *The Week the World Heard Gallaudet* by Jack R. Gannon, Jeff Beatty, and Chun Louie. The book presents 200 full-color and black-and-white photographs depicting, day by day, the protest as it unfolded March 6 - 13, 1988.

Harlan Lane's (1984) *When the Mind Hears* and Carol Padden and Tom Humphries (1988) *Deaf in America: Voices from a Culture*. Padden and Humphries elegantly summarize the movement for recognition of Deaf culture, explaining that:

"The medical community's narrow focus on deaf people as patients to be alleviated of their affliction has always been a source of anxiety within the community. The idea of 'culture' outlines the terms of a counterargument. It demands considerations of equal treatment, justice, and political voice for a group of people who find themselves in a highly politicized environment such as medicine and disability" (2005:162).

Journalist Lydia Denworth adds, "the message of the emerging deaf civil rights movement was this: Deafness is not a disability; it is a difference. It is not something to be 'cured' or 'fixed.' It is even something of which a person can be proud" (2014).

There is a schism between those who see deafness as a medical condition and those who see it as an identity: "In the medical model disability is an impairment located on the body and a medical problem. The social model, however, asserts that one is disabled by social structures and ideologies in society that do not accommodate or accept those with disabilities" (Mauldin 2012: 531). These conflicting ideologies underlie the debate over cochlear implantation; and when cochlear implants received FDA approval in 1984, many in the Deaf community reacted negatively. I will explore the Deaf critique in greater detail in the background chapter but, briefly, there are four Deaf objections to cochlear implantation. These include: (1) an aversion to the disability identity (2) fear of ethnocide (3) reservations about infant implantation (4) and questions about risk, efficacy, variability of outcomes, and long term impacts.

As far as my fieldwork has revealed, there are three signs used to signify cochlear implant. The first is the original, with two curved fingers placed behind the ear. Bonnie

Poitras Tucker, a deaf lawyer and supporter of cochlear implantation, argues that "the hatred culturalists view cochlear implants with is expressed in the ASL sign implant, which includes a two-fingered stab to the back of the neck, indicating 'vampire in the cochlea'" (1998:9). In conjunction with this "vampire" allusion, I have also read this sign described as "snake bite behind the ear." Suggestions that the sign was originally intended to be derogatory have not been corroborated by any Deaf informants during my fieldwork. In fact, an anonymous poster on an ASL-Cochlear Implant Community blog forum argues that the sign for cochlear implant is not meant to evoke images of vampires or snake bites, but was "created to show the old one-channel implants that had holes and no magnet."⁴

The second sign for cochlear implant is an evolution of the original. Instead of placing two curved fingers behind the ear, the fingers are straightened into the "U" handshape. The final sign is a fingerspelling of the letters "CI." My ASL instructor Dev confirms that this is the most politically correct sign to use when talking about cochlear implants. Although I cannot confidently speak to the true etymology of the sign for cochlear implant, the fact that the sign itself is debated speaks to the contentiousness of the issue.

Who are codas and why do they matter?

"I must have been about four the time Grandma Wells and I were cuddled up spoonwise in her bed. Grandma had her arms around me and the new ballerina doll I'd just received for Christmas. Grandma started humming, her voice, quiet and low, cracked. She breathed between words. Then her humming floated into a

⁴ See aslci.blogspot.com/2008/04/what-are-yout-thoughts.htm for the forum.

lullaby: 'Sleep, my child, and peace attend thee, all through the night. Guardian angels...Soft the waking hours are creeping, hill and dale in slumber steeping....'

Mom and Dad picked me up from Grandma's the next day. That night as Mom tucked me into bed, I asked her to sing me a lullaby, even though I knew she couldn't."

—Lou Ann Walker, *A Loss for Words: The Story of Deafness in a Family*

Hearing children of deaf adults, colloquially referred to as “codas,” are a relatively unexplored subpopulation of the Deaf community. Born to deaf parents, codas spend their formative years as inhabitants of the Deaf world, acculturated to a deaf way of life and often fluent in American Sign Language. Because of their unique positionality as part of the Deaf world, but with a capacity to hear, I believed codas would be an important population with which to have a discussion about cochlear implantation. With ties to both the Deaf and hearing, I anticipated codas would have noteworthy opinions about cochlear implants and would contribute to academic discourse about the technology. I also hoped they might serve as mediators in the cochlear implant debate. Thus, I set out with a tentative research question: What are codas' perceptions of cochlear implantation?

I discovered that cochlear implants have pushed a refinement of identities associated with the Deaf community. In particular, cochlear implants have impacted hearing children of deaf adults' sense of belonging and identity and, in turn, codas' positionality has colored how they react to the technology. This thesis will argue, in greater depth, that cochlear implants have impacted codas' relationship to the Deaf community and, conversely, that the Coda identity predicates specific attitudes towards the technology.

The background chapter provides a brief history of the Deaf community and the emergence of Deaf culture, a more nuanced explanation of hearing children of deaf adults, a technical overview of cochlear implants and how they work, and a detailed discussion of the hearing and Deaf sides of the cochlear implant controversy.

Chapter 1 explores the Deaf community as a biosociality and analyzes how codas, although biological relatives of deaf persons, are not biological citizens of the Deaf biosociality because they lack the necessary biological feature (deafness). I discuss how this fosters a conflicted identity and confused sense of belonging among hearing children of deaf adults and argue that to mitigate this ambiguous sense of belonging, codas have not only developed a “fictive kinship,” but have founded CODA organizations and utilized them as liminal spaces of identity transformation and community construction.

In Chapter 2, I use “third culture kids” as a conceptual framework against which to compare codas. I articulate both the parallels as well as the points of disjuncture between the two populations, and I explore how traits common to third culture kids, specifically open-mindedness, adaptability, and rootlessness, are also characteristic of codas. I argue that codas' sense of rootlessness results in a reluctance to stake a definitive claim in the cochlear implant debate. Finally I argue that, because of their distinctiveness, codas should constitute a new category of “cross culture kid.”

Lastly, Chapter 3 provides an overview of codas' perceptions of cochlear implantation. Specifically, I examine how codas' attitudes towards cochlear implantation are paradoxical and reflect their contradictory affiliation to both the Deaf and hearing communities. I conclude the chapter by introducing postphenomenological theory,

arguing that cochlear implants have acquired a moral dimension which influences how codas' conceptualize the decision-making process. The decision to implant is often a morally ambiguous one for codas precisely because of their interstitial positionality.

BACKGROUND:

DEAF CULTURE, CODAS, AND COCHLEAR IMPLANTS EXPLAINED

"Growing up I wanted to be deaf."

It's a warm day in early June and I'm sitting across from Tyra, a Deaf Education researcher and professor. Afternoon sunlight streams through the office windows, silhouetting Tyra as she talks about what it was like to grow up with a deaf father.

"I tried to jam pencils into my ears so that I'd make myself deaf."

"Did you want to be deaf because your dad was deaf?"

"I think he wanted. I knew he wanted. He would have preferred to have deaf kids. And within my social world and my...yeah, within my world the people who are at the core, who are, you know, the top of the social hierarchy are the deaf people. And everybody else is on the periphery. And so that's my frame of reference is being on the periphery where I'm not quite part of it. And never will understand what it means to be deaf."

Hearing children of deaf adults (codas) are a unique constellation of people whose community has been largely unexplored by academia. In the following chapter I first provide an overview of Deaf culture, including its origins and evolution. Next, I clarify who codas are and what the existing literature tells us about them. I then provide background information on cochlear implants, and I articulate the points of contention in the cochlear implant controversy. Lastly, I discuss why codas' opinions on cochlear implantation are worthy of attention.

The Deaf Community: a brief history

Deafness has existed for a long time, with the earliest known written references to deaf people dating as far back as biblical times (Nomeland & Nomeland 2012).⁵ In the United States, specifically, scholars trace the existence of deaf individuals to the 17th century. Outlining the origins of the Deaf community in America, Melvia and Ronald Nomeland explain that early deaf Americans were relatively isolated from one other because of a farming lifestyle, and "because there were limited opportunities for interaction among early Americans, it is doubtful if there existed a formal Deaf community prior to 1817, with the exception of Martha's Vineyard" (Nomeland & Nomeland 2012: 74; 76). On Martha's Vineyard—a small island off the coast of Massachusetts—a high rate of hereditary deafness resulted in a significant and concentrated population of deaf people. Because deafness was so common on Martha's Vineyard, both deaf and hearing people alike utilized sign language to communicate. The sign language born on Martha's Vineyard would later influence the development of American Sign Language (Groce 1985).

Over time, "as manufacturing progressively became dominant in America, cities grew larger; more people congregated in the cities [and] deaf people [. . .] moved to the cities where they could conveniently mix with their friends" (Nomeland & Nomeland 2012: 75). Where populations of deaf people congregate, communities are bound to develop. Unfortunately, "there is a lack of reliable recorded information about the Deaf

⁵ For a more information about the origins and history of the deaf through biblical times and the Middle Ages see Melvia and Ronald Nomeland's 2012 book *The Deaf Community in America: History in the Making*.

community's social life until after World War I" (Nomeland & Nomeland 2012: 76). For this reason, "many historians point to residential deaf schools as the beginning of a formalized Deaf community" (Nomeland & Nomeland 2012: 76). While there were many grass-roots Deaf individuals who were part of Deaf history and the development of Deaf culture, this synopsis will focus on some of the major players in the history of the American Deaf Community.

In 1817, Thomas Hopkins Gallaudet founded the Connecticut Asylum for the Education and Instruction of Deaf and Dumb Persons—the first public school for the deaf in the United States. American Sign Language (ASL) as it is known today was born at Gallaudet's school. Linguists hypothesize that ASL stemmed from an amalgamation of French Sign Language with indigenous signed languages (like the one from Martha's Vineyard) and self-created signs brought to Gallaudet's school by individual students (Singleton & Tittle 2000). As time passed and more schools for the deaf were established, "a full-blown, standardized sign language evolved, spreading from school to school as teachers and graduates moved away from Connecticut to establish new schools in other states" (Singleton & Tittle 2000:222). It was the development of this common signed language that united the deaf population and "contributed to the development of Deaf society and culture" (Lane et al. 1996:58).

Like sign language, deaf schools also became important focal points for deaf community development. As Thomas Holcomb explains, "when deaf people began to congregate at these schools, a new community of people was created among those who found they had a similar orientation toward life—a visual orientation" (2013:3). From a

common language and shared institutions, "an elaborate sociopolitical, linguistic framework for effective living was developed and fine-tuned by Deaf people themselves to maximize the use of their visual orientation to communicate, interact, and learn" (Holcomb 2013:3).

As the Deaf community grew, sign language became more refined and more Deaf institutions (like Deaf social clubs, Deaf literature, and Deaf art) emerged. With this growth came new conceptions of what it means to be deaf. Members of the Deaf community began to perceive themselves as united by more than just their physicality. As Stewart and Akamatsu (1988) argue, the Deaf community are a group of people who "share a common physical, psycho-emotional, and linguistic identification" (239). Although the experiences derived from being unable to hear are central to a Deaf identity, these biological commonalities are not the only prerequisite to membership in the community. Poplin explains that association with a community involves a "sense of identity and unity with one's group and a feeling of involvement and wholeness on the part of the individual" (1972:7).

Shared histories powerfully shaped early conceptions of Deaf identity. As Padden and Humphries explain, "the collective experience of Deaf people is not necessarily one that every Deaf person shares or even knows directly, but the residue of this history permeates the experiences of Deaf people" (2005:142). There are a number of seminal works that unpack the history of the community and the forces that have contributed to the formation of Deaf identity (Crouch 1997; Holcomb 2013; Lane et al 1996; Padden & Humphries 2005). In addition to shared histories, membership in the Deaf community is

also predicated on an individual's environment and interaction with other deaf persons (Corker 1996). Marcowitz and Woodard (1978) concur that being a part of the Deaf community is not an ascribed status, but is something that must be achieved; as Gregory and Hartley articulate "membership in a deaf community is achieved through (1) *identification with the deaf world*, (2) *shared experiences* that come of being hearing impaired, and (3) *participation* in the community's activities" (1991: 23).

Based on shared experiences, history, and language, many in the Deaf community began to recognize themselves, not as disabled individuals, but as members of a minority cultural group. The validation of American Sign Language as a legitimate language with its own grammar, syntax, and rules was a major stepping stone towards the recognition of a distinct Deaf culture. Previous definitions of language included speech as a prerequisite; as such, it was only recently that American Sign Language was recognized as an independent language. As Stewart & Akamatus explain: "until Stokoe (1960) revealed his linguistic analyses of the formation and structure of ASL, it was believed that signing was a visual form of broken English and indicated its user as being 'low verbal,' or "limited in linguistic ability" (1988:237). Five years after Stokoe's declaration of ASL as a true language in 1960, the *Dictionary of American Sign Language* was published. The book was revolutionary. It included, not only a linguistic analysis of sign language, but also a section that analyzed the social and cultural characteristics of deaf people who use American Sign Language (Gregory and Hartley 1991:40).

Language is deeply entwined with culture, and most definitions of culture stress language as an integral component. Edward Sapir's theory of linguistic relativity (more

commonly known as the Sapir-Whorf hypothesis) suggests that the structure of language influences how the speaker views the world. Most significantly, Sapir argues that the mental structure of language and culture are correlated—the one influences the other (Moore 2009). Indeed, the use of sign language among the Deaf community defines their worldview. As Stewart and Akamatsu articulate, "a language that can only be transmitted in a visual-spatial medium and has its own particular grammar is strongly symbolic of the uniqueness of the people who use it" (1988:243). In this respect, sign language has become a dominant characteristic of Deaf culture, and "to possess a language that is not quite like other languages, yet equal to them, is a powerful realization for a group of people who have long felt their language disrespected and besieged by others' attempts to eliminate it" (Padden & Humphries 2005:157).

On the heels of the recognition of ASL came the proclamation of a distinct Deaf Culture. In 1972, sociolinguist James Woodward proposed that individuals "use the lowercase *deaf* when referring to the audiological condition of not hearing, and the uppercase *Deaf* when referring to a particular group of deaf people who share a language—American Sign Language (ASL)—and a culture" (Padden & Humphries 1988:2).⁶ Since Woodward's proposal, many have campaigned for recognition of the Deaf Community as a cultural, not a disability, group. Thomas Holcomb makes this argument most deftly. Building from Daniel Bates and Fred Plog's (1990) anthropological definition of culture as "the system of shared beliefs, values, customs, behaviours, and artifacts that the members of society use to cope with their world and

⁶ Following Woodward's example, I will employ the D/deaf convention throughout the remainder of this paper.

with one another, and that are transmitted from generation to generation through learning," Holcomb constructs a conceptualization of culture that includes five hallmarks: language, heritage, customs, arts, and family or 'cultural players' (7). Holcomb demonstrates that all five of these hallmarks "exist within Deaf culture, and these serve to legitimize it as a distinct culture" (2013:18).

Who are codas?

"Mother father deaf" was the sign historically used to connote a hearing child born to deaf parents. More recently, some hearing children of deaf adults have adopted the initialism "coda."⁷ It is not uncommon for Deaf



Fig. 1: Fingerspelling of "coda"

adults to have hearing children; roughly 90% of children born to Deaf families are hearing (Hoffmeister 2008; Preston 1994). Despite there being an estimated 500,000 codas in each generation, little is known about the population; Robert Hoffmeister, Deaf Studies scholar and coda himself, explains: "What do we know about Codas? We know very little" (2008:191,190).

Hoffmeister contends that "we [codas] are invisible to those who study culture" (2008:212). Existing scholarly articles focus on the practical challenges of being hearing in a deaf environment, including issues of language acquisition, education, communicative strategies, and bimodal bilingualism (Pizer 2007; Pizer 2010; Pizer et al 2013; Bishop & Hicks 2005; Sachs et al 1981; Schiff & Ventry 1976; Critchley 1967). A handful of articles present suggestions for providers (specifically counselors and

⁷ It is important to clarify that not *all* hearing children of deaf adults utilize or even like these terms. Furthermore, not all hearing children of deaf adults use sign language or are fluent in sign language.

psychiatrists) on how to better care for their coda patients (Filer & Filer 2011; Myers et al 1999; Frankenburg et al 1985).

One of the most comprehensive anthropological studies about codas is Paul Preston's (1994) book *Mother Father Deaf: Living Between Sound and Silence*. Preston is a coda and anthropologist who, over a span of 4 years and 24 states, gathered the life histories of 150 hearing children of deaf adults. Preston uses a phenomenological approach to uncover what it means to grow up as the child of deaf parents, and through anecdotal stories he articulates codas' complicated existence situated between the hearing and the Deaf worlds. Additionally, Bishop & Shenks' (2008) volume *Hearing, Mother Father Deaf: Hearing People in Deaf Families* provides important insight into the coda population. Napier, Ataman, and Adams' chapters, in particular, focus on the subjective experiences of codas. These works present a portrait of coda experience upon which my research will build.

Biculturalism and bilingualism

Most codas can be considered bicultural. The degree of biculturalism can vary, however, as exposure to the Deaf and hearing worlds varies among codas. For example, codas who are not raised by their deaf parents (perhaps with minimal visitation) "may [only] have a very slight familiarity with Deaf culture and community" (Paul Preston, personal communication, October 27, 2015). However, for those codas with exposure to both the hearing and Deaf worlds, Hoffmeister maintains that: "all Codas grow up in two worlds, the Deaf world of their families and the Hearing world. Every Coda leads two lives: one as Coda and one as a hearing person. They may choose to only live one life,

but all of them have two" (2008:191). Codas learn Deaf culture from their parents, but are also enculturated by hearing family members and peers. As a result of this biculturalism, many codas are bilingual, learning ASL from their parents and spoken English through auditory exposure. Codas often sign more naturally than deaf individuals. Because 90% of deaf children are born to hearing parents they do not learn ASL from their parents, but from deaf peers later in life. Codas, on the other hand, learn ASL firsthand from their parents, meaning that "more Codas are fluent in a signed language than the majority of the Deaf world" (Hoffmeister 2008:195).

Codas as interpreters

"I spoke for my parents; I heard for my parents [. . .] I made their doctors' appointments. I interpreted in sign language for my mother when she went to the doctor and told him where it hurt and when he told her what medicine to take. I told the shoe repairman what was wrong with a shoe. I told the store clerk when we needed a different size. It was me the garage mechanic would hang up on when I called about a transmission for my father. I was usually the one to relay to Mom and Dad that a friend had died when we received a call. I was the one who had to call up other friends or relatives to give them bad news."

—Lou Anne Walker, *A Loss for Words: The Story of Deafness in a Family*

Because of their bilingualism, codas often serve as interpreters and cultural brokers for their parents. Codas have access to the hearing world and are thus relied upon to interpret, even in situations that may not be appropriate (i.e. doctor's appointments, interactions with police, conversations about finances, legal issues). Some suggest that the responsibility of handling family communication and exposure to inappropriate contexts creates "unwanted pressure and burdens that [codas] are too young to resist or negotiate," and they become "parentified children, taking care of duties

normally handled by a parent" (Singleton & Tittle 2000: 228). However, others argue that such responsibilities "can result in maturity, independence, and an opportunity to have rich experiences" (Singleton & Tittle 2000: 228). Interpreting may help codas develop "adaptiveness, resourcefulness, curiosity, and 'worldliness'" (Singleton & Tittle 2000: 228). Preston (1996) notes that birth order, temperament, and gender all play a role in who assumes the interpreter role, as older siblings and female siblings are more apt to interpret.

Straddling two worlds

As linguistic and cultural interpreters, "hearing children became the cultural link between two often separate worlds" and "the interpreter role itself [comes] to embody hearing children's ambiguous alignment between two distinct and often opposing cultures: the Hearing and the Deaf" (Preston 1996: 1683, 1681). Unlike most deaf children, codas learn Deaf culture from birth, and their "ability to move in the Deaf world, understand how it operates, and function as a Deaf person demonstrates that Codas are actually more culturally Deaf than many Deaf people" (Hoffmeister 2008: 196). Preston concurs: "unlike even their own deaf parents [. . .] these hearing children have been raised on the peripheries and often within the heart of an exclusively Deaf community" (Preston 1996: 1682).

Despite growing up in the Deaf world, biology makes codas de facto members of the hearing world. This complicated positionality is problematic for coda identity formation and cultural affiliation. As Hoffmeister articulates, "an interesting result of growing up in a Deaf family is that for Codas the identity issue is a psychological

division having no physical demarcation. So in essence we must borrow our parents' physical condition as part of our own identity process" (Hoffmeister 2008:196). Many codas experience confusion and frustration about where they "belong." The Australian movie *Passport without a Country* sums up the identity dilemma many codas face: "It's like you were born in a country, and you have a passport to that country, but no one will recognize your passport." Codas exist between the hearing and the Deaf communities, belonging to both and neither simultaneously.

Not Deaf enough?

Coda status in the Deaf community is problematic. Arguments about their positionality continue to this day. The literature talks of codas as existing between two cultures, in the borderlands. As described by Gloria Anzaldua, borderlands are "a vague and undetermined place created by the emotional residue of an unnatural boundary" (1987: 2-23). Codas "have the unique experience of being insiders, yet outsiders, in the DEAF-WORLD" (Singleton & Tittle 2000: 228). In this way, they challenge the binary of Deaf and hearing. They are a contradiction: "they display the knowledge of their parents—skill in the language and social conduct—but the culture finds subtle ways to give them an unusual and separate status (Padden & Humphries 1988: 3).

Some have argued that codas are members of the Deaf community: "The DEAF-WORLD includes sympathetic hearing people such as family members who accept d/Deaf people on their own terms." (Senghas & Monaghan 2002:80). Holcomb describes codas as belonging to the "Hearing-But" category, a "label designated for hearing people who have exhibited an extraordinarily positive attitude towards Deaf people and a deep

respect for Deaf culture in general" (2013: 48). Although hearing loss is a significant factor in membership in the Deaf community, many argue that hearing people can still be part of the culture: "characterized by experience and language, then surely Codas can be at least partially 'Deaf'" (Hoffmeister 2008:194). Others disagree, questioning codas' authority as members: "Hearing children of ethnically Deaf parents, whose socialization into Deaf ethnic patrimony may be extensive, may never be considered as members, no matter how "Deaf" they are able to act." (Johnson & Erting 1989:48).

Although raised in Deaf culture, the ability to hear erects boundaries that distances codas from the Deaf. It is the hearing community that has historically oppressed the Deaf: "Deaf people have been systematically deprived of power by hearing people who either thought they were acting in the interests of Deaf people, or by hearing people who simply exploited Deaf people for their own benefit" (Baker-Shenk 1991). Thus, although codas are raised in the Deaf world, "they also represent the hearing oppressor" (Shield 2004: 189). Because of a legacy of audism, coda's hearing identity makes their relationship to the Deaf community tenuous.⁸

"Codas are able to easily move across or between the two populations" and "this ability to travel easily across the border engenders suspicion and mistrust because those Deaf who cannot traverse the border easily do not have the same access to the information, purpose, or control of this border-crossing process. Hence, divisions within the Deaf world are created. Codas are viewed within these divisions and are suspect as to their purpose when residing on either side of the border" (Hoffmeister 2008:199).

Coda's unstable cultural affiliation has implications for cultural identity development. Shield discusses how some codas, "despite 'feeling Deaf' on the inside,

⁸ Audism is a term coined by Tom Humphries in 1977 to describe "the notion that one is superior based on one's ability to hear or to behave in the manner of one who hears."

have a sense that they do not belong in the Deaf World, and force themselves to learn hearing behavior" (Shield 2004: 191). Additionally, according to the Deaf Identity Development Scale "Codas are no more 'hearing' than deaf individuals of deaf parents [. . .] However, codas are more marginalized than their deaf peers" (Leigh et al 1998: 337). This study "suggests codas are experiencing more conflict between hearing and deaf values than deaf or hard-of-hearing individuals of deaf parents" (Leigh et al 1998: 337).

A number of scholars have problematized the "not Deaf enough" debate. In particular, Lennard Davis, a coda, argues that some definitions of "Deaf" have become too strict to the point of excluding people. Specifically, he speaks of the emphasis placed on ASL fluency as a requirement to admission in the Deaf community, explaining that:

"excluded are the hard of hearing, those who learned to lip-read and speak instead of sign, hearing children of deaf adults, those who never had a chance to learn sign language (because they were too poor, or the facilities weren't available), and deaf people with limb impairments or spinal injuries that make it impossible for them to sign" (Davis 2007).

To Davis "the minority model of deaf identity is too crude, too rigid, too limiting," suggesting that codas should occupy a recognized place in the Deaf community (2007).

Coda community

Over time, codas have developed institutions of their own. As Hoffmeister explains, "Codas had to claim and stake out the definitional territory of children of Deaf adults and our heritage on our own, where typically cultural identity and heritage is passed on from parent to child" (Hoffmeister 2008:210). Most significant has been the foundation of CODA International, a non-profit organization for adult hearing children of

deaf parents. CODA International "celebrates the unique heritage and multicultural identities of adult hearing individuals with deaf parent(s) [. . .] via conferences, retreats, publications, scholarships, resource development and fundraising to enrich the experience of Codas" (<http://www.coda-international.org/>). Organizations, especially summer camps for coda kids (or kodas) have also proliferated in recent years. The importance of these organizations will be further discussed in Chapter 1.

Cochlear implantation

Background

Embed video of 8 month old baby getting implant turned on for the first time
<https://www.youtube.com/watch?v=HTzTt1VnHRM>

Experimental research on cochlear implantation first began in France in 1957 when Professor Charles Eyries and his colleague Andrew Djourno surgically implanted an electrode in a deaf man's ear in the hopes of restoring his ability to hear (Blume 2010:30). Since that first experimental surgery, cochlear implant technology has progressed dramatically, resulting in "the first sensori-neural prosthesis to effectively and safely bring electronic technology into a direct physiological relation with the central nervous system and human consciousness" (Clark 2006:791). The FDA approved cochlear implants in 1984. Not long after, in 1989, they were approved for children two and older, and in 2000 they were approved for children as young as twelve months old (National Institute of Health 2013). Currently, there are three major cochlear implant manufacturers in the United States: Advanced Bionics, Cochlear Americas, and MED-EL. Originally crude single-electrode devices, today's cochlear implants are intricate, sleek, multi-channeled devices with up to 22 electrodes. Newer models come in various

colors and styles, and are even water resistant and Bluetooth enabled. As of December 2012, The Food and Drug Administration estimates that approximately 324,200 people have cochlear implants worldwide and in the United States roughly 58,000 adults and 38,000 children are implanted (National Institute on Deafness and Other Communication Disorders 2014).

Functionality

The cochlear implant is a surgically implanted device used to treat sensorineural hearing loss (the most common type). With this kind of hearing loss, the tiny hair cells located in the cochlea are damaged. Normally, vibrations from sound are transmitted through the external and middle ear to the organ of Corti, located on the basilar member in the cochlea (Clark 2006; Blake 2006). The basilar member acts as a sound filter by selectively vibrating to specific sound frequencies, and the inner hair cells in the organ of Corti convert these sound vibrations into electrical impulses that "provide temporal and spatial patterns of auditory nerve excitation in the higher brain centers" (Clark 2006:791). With sensorineural hearing loss, the hair cells are damaged and, consequently, sound is unable to travel through the ear to the auditory nerve. Cochlear implants direct electrical stimulation to the auditory nerve by bypassing the damaged hair cells entirely. The implant consists of three parts: an external microphone, a speech processor, and an internal implanted receiver-stimulator (Clark 2006; Blake 2006). The speech processor "filters the speech waveform into frequency bands, and the output voltage of each filter is then modified to lie within the narrow operating (dynamic) range required for electrically stimulating each electrode in the inner ear" (Clark

2006:792). Radio waves transmit the sound data through the skin to the receiver-stimulator, which is implanted in the mastoid bone. The receiver-stimulator decodes the signal and creates a pattern of electrical stimulus currents in a bundle of electrodes, inserted around the scala tympani of the basal turn of the cochlea. These electrodes then excite the auditory nerve fibers and higher brain center, where they are perceived as speech and environmental sounds (Clark 2006; Blake 2006). To see how a cochlear implant works, watch the video below of the RONDO cochlear implant from MED-EL.

<https://youtu.be/HTortNW0eel>

In a functioning cochlea there are approximately 10,00 inner hair cells and 30,000 outer hair cells. The inner hair cells send signals to the brain that are interpreted as sound and the outer hair cells exhibit electro motility and function as electro-mechanical transducers and amplifiers. In cochlear implant patients, the damaged hair cells of the cochlea are replaced with an electrode array. However, replacing thousands of hair cells with a mere 22 electrodes means that the sound an implantee hears is imperfect. Using electrodes, only part of the auditory nerve is stimulated—only about 500-5000 hertz is covered. However, most speech is 250-6800 hertz. Although cochlear implants allow deaf individuals to perceive noise, the frequencies of speech do not necessarily correlate with the correct location in the cochlea to produce the correct sound. As a result, the "sound image" received through an implant is often spectrally poor, compressed or distorted, making speech difficult to understand (Shipsey 2015). To listen to what speech and music sound like through an implant, watch the video below.

<https://www.youtube.com/watch?v=SpKKYBkJ9Hw>

Hearing advocates' discourse about cochlear implants

Generally, the hearing population has favorable opinions about cochlear implantation. This positive portrayal of cochlear implants in public and political discourse aligns with Mary-Jo Delvecchio Good's (2001) concepts of "biotechnical embrace" and "medical imaginary." The biotechnical embrace describes "the affective and imaginative dimensions of biomedicine and biotechnology [that] envelop physicians, patients, and the public"; and the medical imaginary is "that which energizes medicine and makes it a fun and intriguing enterprise" (Delvecchio Good 2001: 397). Exposure to the medical imaginary is almost unavoidable as it pervades many aspects of daily life. As Delvecchio Good explains, "at more mundane levels, Americans live in a world in which the medical imaginary has star billing in medical journalism, television advertisements, and globally popular television productions such as ER" (2001: 398). In this way, whether the public recognizes it or not, the medical imaginary fuels and informs popular knowledge and discourse about medical innovations. The conceptualizations that fill the medical imaginary and envelop the public are what shape and direct cultural constructions of medical technology.

In his 2010 book, *The Artificial Ear: Cochlear Implants and the Culture of Deafness*, Stuart Blume explores how cochlear implants have been framed within public discourse and how the media has shaped people's perceptions of the technology. In short, he describes how the cochlear implant has been constructed within the medical imaginary. Since the earliest developments of hearing restoration technology, scientists knew publicity would be "vital" to the success of implantation (Blume 2010: 43).

Claude-Henri Chouard, one of the first implant scientists, emphasized the importance of advertising and the media, stating that "in front of the television, my patients have become performers" (Blume 2010: 39). Blume argues that cochlear implant advocates have purposefully utilized the mass media as a vehicle through which to construct specific positive interpretations of the cochlear implant within the medical imaginary. The mass media was, and still is, used as a tool to "systematically reinforce popular faith in what seems to be the limitless potential of modern scientific medicine" (Blume 2010: 67).

When the cochlear implant was introduced to the consumer market, it was called the "bionic ear."⁹ This rhetoric was purposefully selected to market the cochlear implant in a way that "reflect[ed] popular faith in medical science" (Blume 2010:71). By calling it the "bionic ear," scientists imbued the implant with symbolic meaning; the implant came to embody ideas about medical advancement and opportunity:

"the mass media embedded it in an account of medical progress that went far beyond the detail of technical achievement. Medical technologies are just as much a symbol of progress as, for example, space exploration. Both evoke human power over the unknown" (Blume 2010: 83).

Representations of cochlear implants presented in public discourse today continue to reflect similar ideals.

An analysis of the websites of the leading cochlear implant manufacturers in the United States (Advanced Bionics, Cochlear Americas, and MED-EL) speaks to the narratives about cochlear implants that circulate in the medical imaginary and that inform hearing people's understanding of the technology. The rhetoric employed by cochlear

⁹ Calling to mind pop culture references like the Bionic Man.

implant corporations is particularly significant. The Advanced Bionics web page is littered with phrases like "wondrous journey to hearing" and "miracle of hearing restoration." Likewise, Cochlear Americas talks of "the miracle of hearing" and how "sometimes the biggest miracles come in the smallest packages." These allusions to cochlear implantation as a "miracle" technology engender faith in the capabilities of modern medicine and foster a sense of hope; as Blume argues, this branding strategy intends the cochlear implant to be "resonant with hope: the hope of a triumph over deafness" (Blume 2010: 71).

The production of hope reaffirms what Carl Novas calls a "political economy of hope" (2006). Novas' work explores the concept of hope within a context of medicine. He argues that hope attains a political-economic dimension when "patients' associations invest in the possibilities of biomedical research to develop cures of therapies" (Novas 2006: 289).¹⁰ Through hope, objects of biomedical hope (like a device that can restore hearing) are brought into being and "rendered achievable" (Novas 2006:291). The simple hope that a medical "cure" for deafness could exist resulted in political and economic investments and led to the development of hearing aids and, subsequently, cochlear implant technology.¹¹

Cochlear implants differ from other medical innovations, however, because their intended users have reacted negatively to their conception. Novas argues that:

¹⁰ Cheryl Mattingly also explores this idea in her book *The Paradox of Hope*.

¹¹ Anthropologist Roy Grinker has made a similar argument about Autism Spectrum Disorder. He suggests that an Autism Industrial Complex has evolved in which "ASD is now, in some respects, a commodity that circulates in an industry of 'stakeholders,' such as therapists, producers of high-cost diagnostic tools, advocacy organizations, and new social movements" (Grinker 2015).

"Biopolitics today is shaped by individuals who identify themselves in biological terms, who form themselves into biosocial groups, and who demand a say in shaping the technologies and forms of knowledge associated with the new genetics. The direct involvement of patients' groups in biomedical research is a product of, and adds novel dimensions to, neoliberal inducements for individuals, families and communities to take responsibility for the management and provision of their own health" (2006: 290).

As will be argued in Chapter 1, the Deaf community does indeed constitute a biosocial grouping or "biosociality." However, despite being the "patient group" affected by cochlear implants, the Deaf community was not directly involved in the development of the device.¹² In reality, there have been significant clashes between the makers and intended users of cochlear implants. When the device first became available, "Deaf people were not coming forward in anything like the numbers anticipated by professionals and manufacturers" (Blume 1997: 38). Blume cites an industry representative who, at the time, suggested that perhaps "patients had become accustomed to a world of deafness and may fear the risk of entering the world of sound" (1997:38). This was a revolutionary concept as "it had simply been taken for granted that deaf people viewed their deafness in the same terms as medical and audiological professionals: as a loss of hearing. It stood to reason that those so deprived would seek the benefits of corrective technology" (Blume 1997:39). Indeed, in my own fieldwork I met many Deaf individuals who had no interest in being implanted. Because of this lack of interest, the cochlear implant was rebranded and the medical imaginary was reconstructed in an effort to mobilize the industry. Novas argues that the political

¹² In more recent literature, Mara Mills argues that implant users have indeed influenced the design of cochlear implant technology. As she argues, "the desires of early users, the conflicting demands of mainstream medicine and economics, and the mediated features of electrical listening — in other words, the politics attendant upon communication — can be found embedded in the design of electroacoustic objects" (2011: 339).

economy of hope allows patients to "become significant authorities who are engaged in the promotion of the health and well-being of individuals and populations, who directly contribute to the production of biomedical knowledge and to its capitalization, and who elaborate novel norms relating to the conduct of medical research" (Novas 2006: 290). In the case of cochlear implants and the Deaf community, however, this has not proven true.

Narratives about cochlear implantation presented by major manufacturers correlate the ability to hear with a better life. For example, Cochlear Americas talks of their commitment to "helping people hear and be heard," "empowering people to connect with others and live a full life," and improving "quality of life." These statements establish a connection between the ability to hear, power, and success. Furthermore, they suggest that, without the ability to hear, one is incapable of living a "full life." Cochlear Americas states that "hearing loss can be sneaky. It can steal your hearing so gradually, you may be tempted to ignore it and make do. But at the same time it's been stealing something else. Your connection with life." These statements are directed towards the "late-deafened" population—those with post-lingual hearing loss. However, the underlying implication is that a deaf person's life is dissatisfying and inadequate.

Within the medical imaginary, deafness has been medicalized . By that, I mean conceptions of deafness have been limited to strictly biological definitions.¹³

Medicalization has created "a construction of Deaf people within a very narrow frame, one which is totally focused on audiology" (Obasi 2008:459). A side effect of this medicalization has been the classification of deaf people as disabled and, consequently,

¹³ See Margaret Lock's entry in the Encyclopedia of Medical Anthropology for a more nuanced analysis of medicalization.

as inferior. Harlan Lane's *The Mask of Benevolence* (1992) touches upon how the medicalization of Deaf people has led to negative perceptions of deafness. Such attitudes are evident in the evolution of rhetoric regarding deafness:

"The original meaning of the term *deaf* - 'wholly or partially without hearing' - placed the concept firmly in the auditory sphere. Its common association with the terms *dumb* or *mute* established and reinforced phonocentric links between audition and linguistic competence. The meaning of *deaf* was then broadened to refer to any person who, regardless of whether they could hear or not, ignored, refused to listen to or comply with something or someone, and, likewise, *dumb* became equated with stupidity" (Shakespeare 1998: 224).

The hearing world's conception of deafness as disability, abnormality, and inferiority is known as the disability model of deafness.

Most cochlear implant advocates view deafness as a disability, which the technology can eliminate (or at least mediate). Edward Peters' argument is representative: "of course deafness is a disability, and those who deny it seem either to have literally no idea what they are talking about or to be partisans who are willing to wrench words from their correct and commonly understood meanings in pursuit of some agenda, worthy or otherwise" (2000:264). These advocates find support for their position not only in public opinion, but also under federal law.

The Americans with Disabilities Act (ADA) includes deaf and hard of hearing individuals. As the U.S. Equal Employment and Opportunity Commission states, "people who are deaf should easily be found to have a disability within the meaning of the first part of the ADA's definition of disability because they are substantially limited in the major life activity of hearing" (EEOC). Likewise, people with hearing loss are eligible for social security disability benefits. Hearing Loss is categorized in the Social Security

Administration Blue Book Section 2.00, *Special Senses and Speech*, and in Section 2.08, *Hearing Impairment* (Social Security Disability Help 2014). As a disability, deafness is thought to impinge upon a person's capabilities for success.

As a disability, deafness is thought to impinge upon a person's capabilities for success. Thus, the development of a technology with the capacity to eliminate disability is seen to be inherently positive. Indeed, much of the information presented on the Advanced Bionics and Cochlear Americas websites paints deafness as disabling and cochlear implants as the "cure." As Advanced Bionics states: "while hearing loss may leave you or your child feeling isolated and hopeless, AB's cochlear implant system can reconnect you with life and the loved ones around you." Cochlear Americas likewise condemns deafness, listing the negative effects deafness can have on the social, psychological, and economic development of children and adults:

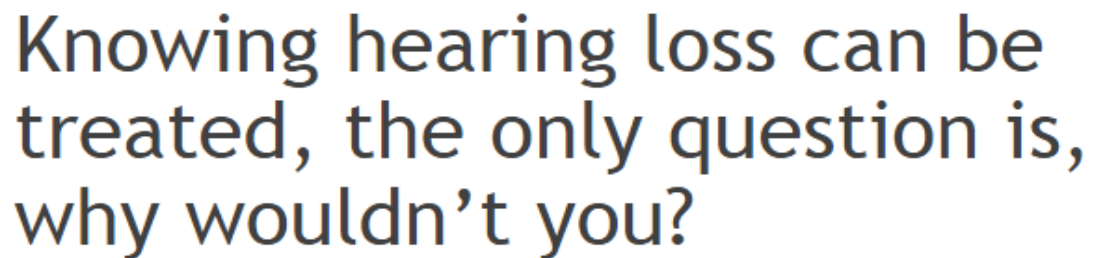
"If left untreated, children can experience difficulty in learning to talk and succeeding in school. This can make them feel isolated and lower their self-esteem, leading to behavioral problems."

"Hearing loss has been linked to loneliness, stress, depression, dementia and reduced job performance. Adults with hearing loss are less likely to take part in social activities and more likely to feel depressed or sad. And brain function can deteriorate faster. There's even an economic impact. It's been estimated that Americans who ignore their hearing problems lose at least \$100 billion a year in combined earnings. People with a profound hearing loss are more likely to be unemployed. Or make less money than people with normal hearing if they are employed."

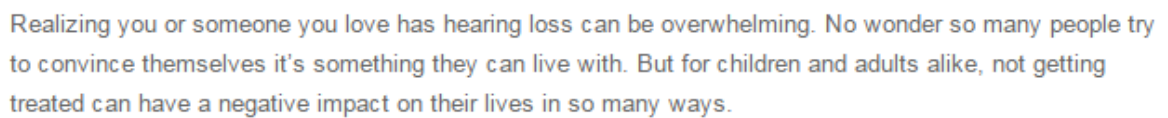
These representations present deafness as something limiting, harmful, and in need of fixing. Cochlear Americas also depicts deafness as abnormal, arguing that cochlear implants can make your child "normal": "That's why you want to address your child's hearing loss as early as possible. It's the best way to help your child grow up normally."

These advertisements perpetuate a “deficiency discourse” about deafness. By that, they do not emphasize what cochlear implants *do*, but rather focus on what deafness *deprives* (Dossa 2002).

Cochlear Americas subtly criticizes those who choose not to implant.



Knowing hearing loss can be treated, the only question is, why wouldn't you?



Realizing you or someone you love has hearing loss can be overwhelming. No wonder so many people try to convince themselves it's something they can live with. But for children and adults alike, not getting treated can have a negative impact on their lives in so many ways.

Fig. 2

Asking "why wouldn't you?" casts judgment on those who do not go the implant route. It paints cochlear implantation as the obvious and easy decision—the only choice that makes sense. As a result, those who refuse implantation come across as illogical, uninformed, or wrong. This argument echoes statements made by Dr. John Niparko, an ear specialist at Johns Hopkins Hospital. When asked, "so in the future, could deafness be a choice?" Niparko responded: "we're already there" (NPR 2012). The very idea of deafness as a choice speaks to the power of the medical imaginary to influence people's perceptions of the ease and effectiveness of cochlear implantation. In the public

viewpoint, cochlear implants have made deafness optional, and those who make the wrong "choice" are questioned.

Advocates also argue that cochlear implants are more cost-effective. Cochlear implants are covered by most insurance policies. According to the U.S. Food and Drug Administration, "in 2004, Medicare, Medicaid, the Veteran's Administration and other public health care plans cover cochlear implants [and] in 2004, more than 90 percent of all commercial health plans cover cochlear implants" (FDA 2014). In addition, advocates argue that cochlear implants are more economical than deafness. The National Institute of Health states that, in cases of child implantation, the benefits of cochlear implantation outweigh its costs. According to their estimates, a cochlear implant costs roughly \$60,000 whereas the special education and services required for a deaf child before the age of three costs more than \$1 million (NIH 2013). Similarly, a study by Cheng et al. exploring the cost-utility analysis of cochlear implantation finds that "the cochlear implant is highly cost-effective in children, with a net expected savings of \$53,198 over a child's lifetime" (2000:854). Based on these numbers, some have reprimanded deaf individuals who reject cochlear implantation. For example, Bonnie Tucker argues that "an individual who chooses not to correct his or her deafness (or the deafness of his or her child) should be held to lack the moral and ethical right to demand that others pay for costly accommodations to compensate for the lack of hearing of that individual (or his or her child)" (Tucker 1997:35).

For hearing parents in particular implantation is often presented as the "best choice" to ensure a deaf child's success and happiness. As Teagle explains, "when paired

with appropriate habilitation, cochlear implantation removes barriers for children who are deaf. This technology affords them the ability to circumvent the effects of deafness and participate academically, socially, culturally, and vocationally with their hearing family and peers" (Teagle 2012: 824). Cochlear Americas says:

"Every parent wants their children to grow up healthy and happy, bright and confident. you want to sing them nursery rhymes, watch them participate in sports and enjoy music. And then you're told your child can't hear and all that comes crashing down.

But it doesn't have to."

The hearing parent demographic is an important one to target, particularly because "the primary consumers of CI technology are not deaf persons but hearing parents" (Mauldin 2012: 530). Tied to decisions about cochlear implantation are expectations about being a "good parent." Because deafness is now considered a choice, what responsible parent would not choose to implant their child? Advanced Bionics even has an informational video targeted specifically towards children that tells the story of a monkey who receives a cochlear implant and becomes "the happiest monkey in the world!" and a "bionic buddy."¹⁴

In conjunction with the information provided by cochlear implant manufactures, the public receives positive information about cochlear implants through social media platforms like YouTube. "Activation day" videos are particularly powerful shapers of the medical imaginary. There are hundreds of videos on the Internet of individuals getting

¹⁴ http://www.advancedbionics.com/com/en/system/lightboxes/bionic_buddy_movie.lightbox.4c.html

their cochlear implant turned on for the first time. The videos are emotionally charged.

Cochlear Americas states:

"We're the people who help people hear. In fact, our Cochlear hearing implants have helped over 400,000 people hear. And no matter how many people we help, no matter how big that number gets, we still get choked up every time we see the priceless expression of someone being able to hear, either again or for the very first time."

Cochlear implant companies also include dozens of real world stories and testimonials on their websites, all of which are positive and highlight successful stories. These testimonies reinforce ideas about cochlear implants' ability to transform lives for the better. As Cochlear Americas boasts: "We've changed the lives of over 400,000 people. Here are just a few of their stories." In short, the Internet has been used to construct a rendering of the cochlear implant as an "apparently miracle technology" (Blume 2010: 7). By infiltrating and transforming the medical imaginary, the media has influenced people's cultural conceptions of the technology.

Deaf discourse about cochlear implantation

Questions for a Cochlear Surgeon

By Salvatore Parlato, Jr. (1994)

Your kind concern, Doctor of the ear,
 (though sincere and here respected)
 that Deafness-it is be corrected
 sooner may earn you a rich return
 if somewhere else re-directed.

For, seem we as those so childly naïve
 As so tolerate woes past our power to relieve?
 Or think you we lead lives somewhere in between
 Your world of words and ours of the seen?
 If so, of the few of us caught in-betwixt,
 How know you who of us ought to be
fixed?

Should we tell a youngster: Dearest one, we fear
 That, with your audio circuit naturally half-broken,
 Imperfect, may not freely hear,
 Every single syllable that someone else has spoken?

Must that minor therefore patient-ly endure
 Years of batteries and surgical assault
 Unsure that your probes of either of her lobes
 Can Lourdes-like cure her of her aural "fault"?

And isn't it true that the tactical premise
 Of your state-of-the-art high but crude electronics
 Base its case on the practical promise
 Of, at heart, only slightly better new sonics?

Also be I told: Will the hoped-for release
 To be gained, as sold, by such new-found noise
 Exceed the manufactured unnatural ill-ease
 Decreed by your medically magic sound-toys?

Thought: Still untaught, ought a trusting child feel
 As if caught in a world neither fowl's or fish's
 Confused over which of her two lives is real:
 Her won of that of some grown-up's wishes?

No wonder Deaf parents feel offended and nervous
 Almost as under a wait-for-me vulture:
 Kindly you offer a well intended service
 But blindly ignore their touch-and-see culture.

Finally, fine physician: Won't the bitter pill cost
 Of your highly positioned drastic drill so large
 Exhaust (as a lottery or Las Vegas lost)
 Their shiny plastic Visa or Master Charge?

So, if searching, Madam/Sir
For problems to be solved
 Why not find the answer to how *this* one first solved?

I'm sitting in Mac's office on a tepid June afternoon. He's seated, pushed back from his desk with his body turned towards me. His hands rest on his lap as he waits for the interpreter to finish relaying my next question. He nods his head as the interpreter signs.

How do you feel about infants being implanted?

Mac's hands spring back to life, gliding through the air in a flurry of signs.

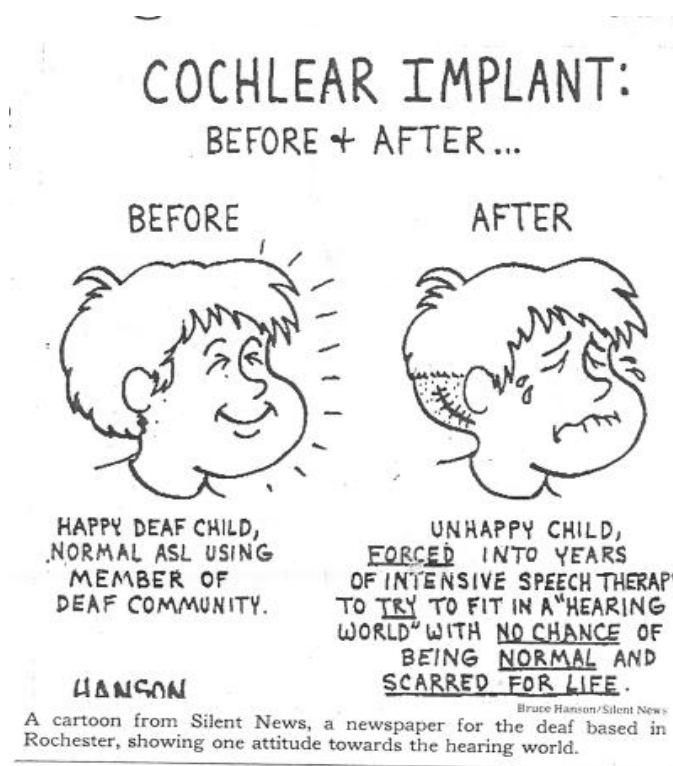
Can I be a little sarcastic and say well you know what? I want my daughter to become deaf. My hearing daughter. I want her to become deaf. What do you think the doctors would say? I want to drill in her ears. They would say "you're crazy." And what's the difference with a cochlear implant?

He repeats the question.

What's the difference?

The Deaf community has countered the narratives of the hearing medical imaginary with their own narratives about cochlear implantation. As discussed earlier, the Deaf community holds a different model of deafness than the rest of the world, one that rejects the disability identity: "Deaf people's lack of interest in the implant was due to the fact that most of them did not see their lives as unfulfilling or their bodies as defective in the way that doctors and manufacturers did" (Blume 2010: 61). As such, the bionic ear has become "a symbol of cultural oppression and medical dominance" to some of the Deaf community (Blume 2010: 105).

In contrast to the stories of successful implant cases showcased on YouTube and CI websites, tales of failed implantations are common throughout the Deaf community. During my fieldwork, more often than success stories I heard tales about implants that had malfunctioned, that had to be re-implanted, even one that dissolved. The most common stories I heard, however, were the ones in which individuals simply turned off their implants because they disliked them. Many found them to be a nuisance. I heard about implants getting caught as children raced down slides on the playground. I heard about earpieces getting snagged and pulled off when brushing hair, putting on a hat, or adjusting a scarf. People complained about batteries running out, being unable to get MRIs, and having to remove their implants to go to the beach or to shower.¹⁵ Other more



troubling reports about facial tics, facial paralysis, and debilitating headaches resulting from the surgery also circulate.

Other individuals simply find noise too overwhelming. As 23 year old Austin Chapman says: "I actually feel bad for hearing people, I wish that more people could experience the power and peace of utter silence" (Williams

Fig. 3

¹⁵ Newer models are water resistant, but older models were not

2012). Many people talk about how maddening noise becomes: the sound of the air conditioning running, cars beeping, a cricket chirping. So, they just turn the implant off and stop using it. My informant Mac told me about one individual who buried his implant in the back yard because he was so displeased with it:

Um you know even sometimes kids when they're 18 years old they say you know what I'm gonna get rid of this cochlear implant. They might bury it. They might throw it down the toilet. I've seen that. One of my friends actually did do that. They buried their cochlear implant.

The documentary *Hear and Now* by Irene Taylor Brodsky chronicles her 65 year old deaf parents' first year living with cochlear implants. The film provides a more realistic glimpse at the struggles some deaf people encounter when suddenly faced with sound. For example, Irene's father Paul "discovered that, far from being adorable, the voices of his grandchildren were rather shrill and often best experienced with the implant turned

off" (Williams 2012).¹⁶

Some platforms are more radical in their opinions about cochlear implantation. For example, www.cochlearwar.com is dedicated to stopping cochlear implantation and has declared "war" on the technology. Most Deaf individuals' objections to cochlear implantation are less drastic, however, and stem from four main sources: an aversion to



Fig. 4: *Killing My Deafness* by deaf artist Leon Lim

¹⁶ Michael Chorost's book *Rebuilt: My Journey Back to the Hearing World* likewise offers a first-hand narrative of the realities of the cochlear implant experience both pre- and post-surgery.

the disability identity, fear of ethnocide, reservations about infant implantation, and questions about risk, efficacy, variability of outcomes, and long term impacts.

Aversion to the disability identity

There is a cultural imperative to "fix" or "cure" disabled people. As Longmore argues, "the fear invoked by the presence of people with disabilities has produced two simultaneous and predictable responses: they have been stigmatized, and they have been subjected to relentless exertions to fix them" (1997:153). Indeed, the biomedical community views deafness as a pathophysiological disease that needs to be cured (Hoang et al 2011: 175). Historically, doctors have been unflagging in their pursuit of a treatment. Branson & Miller's (2002) book details some of the lengths doctors have gone to find a cure. For example, during the 1800s at the Paris School for the Deaf, "the school became [Doctor Itard's] laboratory; the students, his 'guinea pigs' in aural surgery [. . .] He applied electric shocks to ears, placed leeches and white-hot metal on pupils' Eustachian tubes; and applied blistering agents to necks, ears, and faces" (Branson & Miller 2002:115).

To most of the hearing community, deafness is not an acceptable state of being: "the disabled body does not properly fit in society, and it is the body—not society—which must be remade to rectify this problem" (Cherney 1999:28). There is a tendency in our society to reify disabled bodies through technological and medical intervention. Thus, medical devices like hearing aids and cochlear implants have been developed to "normalize" deaf individuals. Paddy Ladd's (2003) *Understanding Deaf Culture: In Search of Deafhood* and Harlan Lane's *The Mask of Benevolence* expertly

employ Foucault to analyze issues of bio-power and the medicalization, surveillance, and disciplining of Deaf bodies. For Deaf people of the 21st century, the cochlear implant is simply the newest in a long line of attempts to "fix" the disabled body. A history of unethical and harmful attempts to "cure" deafness has left a legacy of mistrust and anger towards the medical community, and that legacy continues to color the Deaf community's perceptions and opinions of cochlear implantation today.

Contrary to the disability model of deafness, the social model of deafness asserts it is not an individual's inability to hear that puts them in a disadvantaged position, it is "society's insistence on hearing as a prerequisite to full membership [in society]" (Oulette 2011:1257). The social model contends that "deafness can be eliminated when all deaf individuals have equal opportunity to access information, public educational and public services, as hearing individuals do every day" (Lee 2012: 823).

Indeed, there are communities where deafness is a non-issue. Examples include the Al-Sayyid Arab-Bedouin community and the deaf community of 18th century Martha's Vineyard (Kisch 2008; Groce 1988). In these communities, "both deaf and hearing people grow up familiar with deafness and sign language so that deafness is experienced as manageable and is not stigmatized or assumed to have other consequences than the need for a different communication mode" (Kisch 2008:308). When deafness is not medicalized, it is "merely a manifestation of human diversity" (Cooper 2010: 328).

Because the Deaf community subscribes to the social model of deafness, biomedical interpretations of deafness as disability are inherently demeaning. Indeed, "the pathological view of deafness and the Deaf is a kind of symbolic violence which

denies personhood to the deaf person, as well as delegitimizes the culture and language of the Deaf community" (Osborn 2005:61). The hearing community's ethnocentric insinuation that being hearing-able is "better" has become an issue of contention for many in the Deaf community, and the repeated attempts of the biomedical community to "cure" deafness through technological intervention has been interpreted as a form of discrimination and as an assault on Deaf culture.

Questions about risk, efficacy, variability of outcomes, and long-term impacts

Risks:

The Deaf community has voiced concern about the dangers associated with cochlear implantation surgery. The operation is major (involves drilling into the skull) and the potential side effects are serious. According to the U.S. Food and Drug Administration, the risks include: injury to the facial nerve resulting in facial paralysis, meningitis, cerebrospinal fluid leakage, perilymph fluid leakage, infection of the wound, blood or fluid collection at the site of surgery, vertigo, tinnitus, taste disturbances, numbness around the ear, and reparative granuloma (FDA 2014). Moreover, the surgery requires the patient to be put under general anesthesia, which is dangerous in its own right.

Another issue of concern is incidents of device failure resulting in the need for re-implantation (Lassig et al 2005). Approximately 2% of cochlear implants fail (Wiet & Mullins 2011). Reasons for device failure include: infection of the skin flap over the implant, the body rejects the implant (sometimes because of allergy), the implant extrudes, incorrect surgical placement of the device, damage to the electrode array during insertion, and electrode migration (Wiet & Mullins 2011). In more extreme cases,

defective implants have caused severe bodily harm. For example, 8 year old Breanna Sadler was implanted with a defective device and "suffered severe electric shocks inside her head due to excessive moisture in the device and was thrown to the ground, convulsing and vomiting" (Kosnar & Meyers 2014).

Along with these more serious side effects, cochlear implants also have some less dangerous consequences. For example, having a cochlear implant prohibits the implantee from getting an MRI. Implants can set off theft detection systems and metal detectors, can be affected by cell phone users or radio transmitters, have to be turned off during plane flights, and can interact with computer systems. Implantees must also be cautious of static electricity, which can permanently damage the implant (FDA 2014). Overall, these side effects are troubling to the Deaf community. To many, the risks associated with the procedure do not outweigh the benefits.

<https://www.youtube.com/watch?v=beKYEPfxhTY> - a comedic video parodying the unwanted side effects of CI

Efficacy and variability of outcomes:

The Deaf community also has concerns about the efficacy of cochlear implantation and the variability of outcomes. The current standards of success for cochlear implantation are dictated by the medical community, and these standards focus on audiological capability: "whether or not the implant 'works' is not a question of long-term results (these are questions of the brain, not the CI), but rather a question of whether the device is operational" (Mauldin 2014: 138). In a strictly sensorineural manner, cochlear implants work: they help the user perceive sound. However, the ability to

perceive noise is not the same as the ability to understand language. Cochlear implants do not guarantee the development of spoken language comprehension.

Cochlear implants also require extensive amounts of training to teach the brain how to interpret sound. The American Speech-Language-Hearing Association estimates that individuals with postlingual hearing loss need a few months to almost two years to learn how to interpret the electrical signals from the implant (2016). For those with prelingual hearing loss, the auditory mapping process is even longer. One implant recipient I met during the course of my fieldwork explained that he was in the hospital for two days following the surgery and then on bed rest for a subsequent month. Some individuals become frustrated with the tedious, time-consuming training; and some never gain the ability to understand speech. The fact that the cochlear implant does not immediately grant hearing often surprises people whose knowledge of cochlear implantation comes solely from the medical imaginary.

Cochlear implant efficacy varies, depending on factors such as age of implantation and type of deafness (born deaf, late-deafened, pre-lingually deaf, post-lingually deaf, etc). As Niparko explains, "one of the major remaining problems with CIs is the broad distribution of outcomes" (2009:122). Cochlear implants do not guarantee that implantees will be able to fully participate in hearing interaction (Sparrow 2005; Lane & Grodin 1997). In their position statement on cochlear implants, The National Association of the Deaf states that "while the implant may work quite well for post-lingually deafened individuals, this result just cannot be generalized to pre-lingually deafened children for whom spoken language development is an arduous process,

requiring long-term commitment by parents, educators, and support service providers, with no guarantee that the desired goal will be achieved" (NAD 2002).

Long-term impacts:

Because of the imperfect nature of cochlear implantation, there are questions about potential long-term cognitive, social, emotional, and psychological implications. In cases where the implant is less useful, the burdens of implant inefficacy outweigh any perceived benefits of being hearing-enabled. Crouch explains:

Placing prelingually deaf children in an environment where they can only learn oral language through an imperfect auditory system (even with cochlear implants) disadvantages many of them because not only do they fail to acquire an oral language, but perhaps more harmfully, their exposure to ASL is delayed, thus making their acquisition of ASL far more difficult and incomplete (1997:19).

Thus, accompanying cochlear implantation is the risk that children will be "trapped between cultures, unable to function effectively in a hearing context but also lacking the facility with sign language available to those who grow up with it as their first language" (Sparrow 2005:143). Deaf identity development and acceptance into the Deaf culture hinders on the use of sign language, an individual's exposure to and interaction with other deaf individuals, as well as participation in culturally deaf institutions. Those who receive cochlear implants are often excluded from these experiences. Consequently, when the cochlear implant is not entirely effective, individuals are marginalized in the hearing community as well as unable to fully participate in the Deaf community, leaving them in a state of limbo. This lack of inclusion in either cultural group and the inability to use either language efficiently could lead to social, psychological, and emotional problems. Alicia Oulette cites an undergraduate student who received a cochlear implant

as saying “it is emotionally exhausting to pretend to be a regular, hearing person” (2011:1260).

Although there are many studies that track language acquisition, speech recognition, and communication outcomes, there are far fewer studies that explore the social, emotional, and psychological outcomes of cochlear implantation. The limited studies that exist, however, are positive. A study by Nicolas & Geers (2003) of 181 school-aged implanted children finds that children are coping successfully in their social and school environment. Other studies have found that implanted children experience quality of life similar to their hearing peers, and have found that cochlear implants have no negative psychological outcomes on implanted children (Loy et al 2010; Knutson et al 2000; Filipo et al 1999). Percy-Smith et al (2008) find that implanted children score equal to or better than their hearing peers on matters of self-esteem and social well-being, and Schorr (2006) argues that implanted children are no more lonely than their hearing peers. In adults, cochlear implants have been found to improve quality of life (Maillet 1995; Klop et al 2007; Harris et al 1995). However, the longer an individual has been deaf, the less improvement in quality of life that is perceived (Maillet 1995). Other studies find that implantation decreases loneliness, social anxiety, depression, and distress for adult implantees (Knutson et al's 1998; Mo et al 2005).

Although none of these studies suggest long-term negative social or emotional impacts of cochlear implantation, many members of the Deaf community are skeptical. Some worry that participants in cochlear implant studies are not representative of the cochlear implant population as a whole. Specifically, there is concern that

"successful" implantees are cherry picked for these studies to paint a more favorable portrait of the technology. As one of my informants articulates:

"too often those studies are selective where they have these kids who are in special programs and whose parents are, you know, critically and wholly invested in making sure a kid becomes successful [. . .] but it is surely the majority of kids don't have the resources and input and support that kids that are typically involved in these studies get. And so the results for those kids are not so hot."

The National Association of the Deaf makes a similar argument, stating that "longitudinal research is critically needed, including a more thorough analysis of those for whom the implant is *not* working" (NAD 2002).

A study by Hayashi & Tobin finds that deaf Japanese children who attend a school that prioritizes Japanese Sign Language "are more socially and intellectually like their hearing counterparts in 'regular' preschools than are the deaf children in the public preschools who have spent a great deal of their time in preschool working on articulation and lipreading and on adaptation to cochlear implants and other assisted technologies" (2014: 44). Because implanted children dedicate so much time to spoken language development and audiological mapping, they may be less socially developed than their deaf counterparts. Further longitudinal research is required.

The threat of ethnocide

Deaf culture is unique in that most deaf people are born to hearing parents and subsequently have hearing children themselves;" thus, 'roots' in the Deaf community are virtually nonexistent" (Singleton & Tittle 2000: 224). Therefore, proliferation and transmission of what Ben Bahan (1994) calls "deaf world knowledge" occurs, not through the family, but through two primary channels: cultural institutions and

interactions with other deaf individuals. Irene Leigh, who is herself deaf, explains: "From early on, I was surrounded by deaf peers. 'Deaf' was a natural part of my environment, reinforced positively in the early years by my parents, who made sure I was connected with deaf friends" (2009:39). Integration into Deaf culture and the development of a Deaf identity is dependent upon an individual's exposure to and interaction with other deaf individuals—most of whom are met at schools for the deaf.

With the proliferation of cochlear implantation, more and more deaf children are being mainstreamed—integrated into hearing public schools. As a result, schools for the deaf are closing. Some scholars suggest that mainstreaming is a purposeful perpetuation of the oralism of the past.¹⁷ Monaghan et al. argue that "*integration* when used by oralists camouflages their unchanged goal of deaf assimilation into spoken-language society" (Monaghan et al 2003: 55). Osborn calls this the "epistemic violence of mainstreaming," arguing that mainstreaming "is oriented not towards the educational needs of the Deaf but towards the reinforcement of the dominant ideology of equality of access to educational resources, an ideology which is in fact the foundation for the reproduction of structured inequalities." (2005:60). Other scholars hint at a more sinister, eugenically-based, motivation for mainstreaming: "the central purpose of the large-scale oral education of Deaf children that began in the last century and continues today in many lands was, according to U.S. leaders, to discourage reproduction by Deaf people by discouraging their socializing and marriage" (Lane 2002:370).

¹⁷ Oralism was a movement that focused on teaching deaf students to lip read and speak instead of using sign language. In trying to make deaf children more like hearing children, oralism effectively denigrated Deaf culture and threatened its very existence.

Sign language as an endangered language



Fig. 5: Ameslan Prohibited by deaf artist Betty Miller (1972)



Fig. 6: *Milan, Italy 1880* by deaf artist Mary Thornley

Cochlear implantation threatens the viability of American Sign Language "because it seeks to ensure that deaf children grow up to use a spoken language rather than the signed languages of the Deaf" (Sparrow 2005: 136). As a cornerstone of Deaf culture, ASL is a major area of concern for the Deaf community. There are few native speakers—"only 5% to 10% of the community are native speakers of ASL as only this small percentage is born to Deaf, ASL-using parents" (Singleton & Tittle 2000: 224). As such, some argue that ASL is a vulnerable language. The fact "that ASL has survived nearly 200 years with so few native speakers is itself an amazing linguistic phenomenon" (Singleton & Tittle 2000: 223).

The Deaf community is frustrated that implanted children are discouraged from using ASL. Providers tell parents that learning ASL will impede their child's ability to learn spoken English. There is no evidence to support this claim. In reality, these claims are "in direct contradiction with neurolinguistic research" (Mauldin 2014: 145). To many in the Deaf community it feels as if the hearing community is imposing its language and values on the historically marginalized Deaf community. As a result, the right to sign language as a basic human right has become a central issue for many Deaf activists. As Lawrence Siegel argues:

The need for and right to communication and language is fundamental to the human condition [. . .] The importance of communication and language for deaf and hard-of-hearing children is so basic as to be beyond debate. Given the historic difficulties of deaf and hard-of-hearing children face, their compromised communication and language skills and the educational, social, cognitive, and psychological consequences, this note contends that a constitutional right to communication is both necessary and legally sound (2006:255).

Children: issues of agency

Infants lack the ability to give informed consent; thus, the decision to implant is left to the parents. The child's lack of agency in this decision-making process is one of the most highly disputed issues in the cochlear implant debate. It is a parent's constitutional right to make medical decisions for their child. So long as parents are fit, "there will normally be no reason for the State to inject itself into the private realm of the family to further question the ability of that parent to make the best decisions concerning the rearing of that parent's children" (Troxel v. Granville 2000). Yet, approximately 90 percent of deaf children are born to hearing parents (National Institute on Deafness and Other Communicative Disorders 2015). Because deafness is seen as a deficit condition, "it should not surprise us that hearing parents, upon discovering that their



Fig. 7: *No! Not My Baby Sister!* by deaf artist David Call

child is deaf, perceive the child as essentially different and seek out any means available to remove this difference" (Crouch 1997:14). Many in the Deaf community feel that parents, because they are hearing-able, are incapable of

making an appropriately informed decision about their child. As Glenn Hladek (2009) articulates, "the Deaf community contends that since the parents of most deaf-born infants are hearing, they have no perspective upon which to base their decision regarding

cochlear implants, that without intimate knowledge of the Deaf culture, hearing parents can't make a 'best interest' judgment."

The Deaf community questions the ethicality of making decisions on behalf of children when hearing parents, influenced by the medical imaginary, are both un- and misinformed. Dena S. David (1997) argues that making the decision for the child traps him or her in a certain culture and risks consigning them to a life that they may not have chosen if they had had the agency to choose for themselves. The child's autonomy is violated and, as a result, the scope of his or her future choices is narrowed.

Why study codas?

As evidenced above, much is known about Deaf opinions on cochlear implantation; however less is known about the opinions of codas. Codas' dual perspective and intersectional identity make them ideally positioned to contribute to the academic and biomedical discourse concerning cochlear implantation. A previous study by Mand et al. (2009) explores coda's opinions of pre-implantation genetic diagnosis and prenatal diagnosis to select for or against deafness. The findings suggest that codas' opinions are generally in congruence with the Deaf community. My research builds upon this finding and the gap in the literature it suggests: will the same prove true in regards to cochlear implants? This study will, ideally, facilitate efforts to bridge the gap between the biomedical and Deaf communities regarding cochlear implantation.

Furthermore, there is minimal research on the experiences of codas. As Preston emphasizes, "researchers have rarely allowed these men and women to tell their own story. There has been no study that gives primacy to a broad cross-section of hearing

children of deaf parents'' (1994:5). This study will add to the academic literature on codas, providing insight into this enigmatic population.

METHODS

Initial design

In the initial research design, I planned to gather participatory observation data at the Bay State School for the Deaf, located in Massachusetts. I chose the Bay State School as the field site for this study because it allows for experiential language learning. Not only would I be able to observe people communicating naturally in American Sign Language, but I would be able to utilize ASL myself with native signers. Harvey Russell Bernard observes, "the most important thing you can do to stop being a freak is to speak the language of the people you're studying—and speak it well" (2006:360). For this reason learning ASL—a native language of my research population¹⁸—became an integral component of my research design. Establishing proficiency in the language not only reinforced my dedication to the subject, but also aided my efforts to establish rapport. Additionally, because of controversies in the Deaf community surrounding cochlear implants, developing my ability to sign facilitated access to the community. As Bernard has also noted, "fluency in the local language doesn't just improve your rapport; it increases the probability that people will tell you about sensitive things" (2006:361).

I also chose to conduct my fieldwork at the Bay State School because I would be immersed in a deaf environment and, as a result, would gain insight into the Deaf community's social norms, values, and beliefs. Gaining a more *emic*¹⁹ perspective of the community would allow me to speak with more authority about the Deaf community's

¹⁸ For many hearing children raised by Deaf parents, ASL is their first language.

¹⁹ As explained by David M. Fetterman, "An *emic perspective* is the insider's or native's perspective of reality" (2006).

opinions on cochlear implantation. Gathering data at Bay State would also serve as a point of triangulation, facilitating the validation of literature on Deaf cultural perspectives on cochlear implantation through cross verification.

In addition to participant observation at a deaf school, I also planned to conduct semi-structured interviews with hearing children of deaf adults. I chose to do intensive semi-structured interviews because I wanted to focus specifically on codas' opinions of cochlear implantation and "intensive interviewing permits an in-depth exploration of a particular topic or experience, and thus, is a useful method for interpretive inquiry" (Charmaz 2006:25). The initial interview guide consisted of broad, open-ended questions as opposed to rigid, structured questions because "by creating open-ended, non-judgmental questions, you encourage unanticipated statements and stories to emerge" (Charmaz 2006:26). I planned for the interviews to take place at a time and location chosen by participants and, if possible, the interviews would be conducted face-to-face. I planned for the interviews to last between 30 and 60 minutes, and would record them with a digital voice recorder.

I projected a minimum of 5 interviews and hoped to get 10. Given the limited number of codas in the greater Boston area, the difficulty of identifying and contacting them, the controversial nature of the research topic, the specificity of the research questions, and that qualitative medical anthropological methods would be used, I argued that a small sample was more than adequate to address the topic and to constitute a substantial contribution to extant data about the topic.

Hearing children of deaf adults are a difficult group to locate. There are no lists or databases of codas from which to draw a respondent sample. Indeed, codas' "Deaf heritage [is] invisible to most; their familial link to a separate culture and identity [is] not readily apparent" (Preston 1995:1464). Thus, the original inclusion criteria incorporated, not just codas, but also hearing individuals with other deaf family members or hearing individuals who worked with the deaf population. I believed such individuals might have life experiences similar to that of hearing children of deaf adults, making their opinions on cochlear implantation worthy of investigation in the event that I was unable to recruit any codas. Participants needed to be over the age of 18; I felt adults would be more appropriate to interview because they would have a greater understanding of cochlear implant technology.

Because codas are difficult to find, I chose to use purposive and respondent-driven sampling to recruit informants. I planned to recruit informants from my field site. I also planned to have staff at Bay State help distribute information about the proposed study through the use of a recruitment flyer.

Results

Participant observation

When I first began my internship at Bay State, I was provided with interpreters for two days. After that, I was on my own. Being completely immersed in a foreign environment with minimal language skills was challenging. I quickly learned the signs for "again?" and "I'm still learning." Plus, I think my constant looks of befuddlement

marked me as a newcomer. By the end of each field site day I found myself exhausted from the effort of trying to comprehend a new language.

During my participant observation at Bay State, I attended ASL Instruction Faculty Department meetings. There are four deaf ASL specialists who are responsible for teaching students the vocabulary, grammar, structure, meaning, and rules of American Sign Language. Sitting in on these meetings, I learned about the intricacies of ASL instruction, what an ASL curriculum looks like, and what challenges ASL instruction entails. During my time at Bay State, I also edited intake questionnaire videos. Each new student admitted to the school completes a questionnaire. The questionnaire is conducted in ASL and the student's signed responses are filmed. The student then completes the questionnaire a second time at a later date, and their progress is compared and noted. Watching and editing these intake videos not only helped me to improve my ASL skills, but also illustrated how quickly deaf students adopt signed language. As part of my internship, I was also allowed to attend ASL evening classes. The classes are offered to the general public and taught by Deaf instructors. I began in the Level 2 evening class in January 2015 and by the time I finished my fieldwork in July I had completed Level 4. Through observation and participation in these classes I was able to practice ASL and improve my vocabulary and conversational skills. Additionally I was able to observe how ASL is taught to individuals outside of the community and to observe interactions between Deaf and hearing people.

Lastly, as part of my fieldwork, I attended classes with a group of deaf high school students who were recent immigrants to the United States, most of them from

Central America. They faced the daunting challenge of having to learn both English and American Sign Language at the same time. Initially, I sat in on their ASL and ESL classes. As we established a relationship, however, they asked me to stay later each week and to accompany them to their Science, History, and Communications classes. Participating in these school days allowed me to not only develop rapport with the students, but to also improve my ASL proficiency. Because the students were unfamiliar with English, I could not rely on fingerspelling English words when I did not know the correct sign: a tactic I often resorted to with other bilingual deaf individuals. As such, I was forced to rely solely on ASL, which I believe facilitated my learning of the language. There were certainly moments of miscommunication and confusion, but the students' kindness, patience, and humor helped improve my language skills dramatically.

Through the time spent with these students and faculty, I became enculturated. I began to adopt the social norms and behaviors that accompany being in a deaf environment and that constitute Deaf culture. I learned to get someone's attention by stomping my feet and waving my hands. I learned to look at a person's face instead of their hands when they are signing. I learned that brightly colored nail polish and baggy sleeves are distracting when you're using your hands to communicate. I learned that knocking on the door of a building when all of its inhabitants are deaf and can't hear you is silly and will leave you subject to teasing. I learned that walking backwards while signing to someone is dangerous if you're walking down stairs. And I learned that a school for the deaf is anything but silent.

Recruitment

Although I originally planned to recruit informants through contacts I had made at Bay State, my recruitment actually began at Boston University. In the fall semester of 2014 I took an *Introduction to the Deaf World* course in Boston University's Deaf Studies program. At one point during the semester, two coda professors guest lectured. At the end of class I approached them, explained my research, and asked for their contact information. In spring of 2015 I sent an email to one of the professors asking if I could interview him. He agreed. From there, the snowball sampling stemmed as I asked him to recommend other codas to interview. Thus, despite my original research design, none of my informants were recruited through Bay State, and I never ended up using recruitment flyers.

Interviews

In total I interviewed eleven individuals. Six were male and five were female, their ages ranging from 22 to 48 years old. The interviews spanned from 31 to 59 minutes. Six of the interviews were conducted in person, five over Skype. Ten informants were codas and one was a Deaf man. My original inclusion criteria stated that my informants be hearing persons. However, when my closest contact at my field site (a Deaf man named Mac) offered to be interviewed, I could not say no. I interviewed him because I believed him to be what Bernard calls a "culturally specialized informant" — "people who can help you learn about particular areas of a culture" (Bernard 2006:200). To supplant my participatory observation data, I felt that an in-depth interview with a "capital D" Deaf man regarding his views on cochlear implantation would further inform

my research and could be used to corroborate existing literature about Deaf perceptions of the technology.

The interview with Mac was conducted with the assistance of an American Sign Language interpreter. First and foremost, I chose to use an interpreter for practical reasons. Using an interpreter and translating ASL into English "freezes a text that is otherwise in constant movement, thus making it amenable to content analyses that depend on the segmentation and rearrangement of a fixed written text" (Temple & Young 2004:165). In other words, the translation of ASL into English allowed me to transcribe and code the data because, as a visual language, ASL would not have been easily transcribable or codeable. Secondly, I chose to use an interpreter because I was concerned about my own level of ASL proficiency. In order

"to function in predominantly hearing society Deaf people make enormous adaptations to be understood and to understand. These often include modifying their [sign language] to include a range of English grammar constructions [. . .] in order for hearing signers to understand better. Such an adaptation is more than language hybridity because it once again raises the issue of acceptable and unacceptable modalities and the inherent power society subscribes to the spoken rather than the signed word" (Temple & Young 2004:169).

Although I had been learning ASL and was conversational in the language, I felt that my limited proficiency would inhibit my informant's ability to adequately express his thoughts on the topic. Lastly, I chose to use an interpreter to avoid the power inequalities that can result from the researcher acting as interpreter. I was wary about "reinforcing long-standing and dominant inter-community power relations - namely, that hearing society 'does' things to Deaf society (in this case research) and crucially that it is hearing

culture that negotiates and filters the meaning of Deaf people's lives (in this case through the act of presuming they can both research and translate)" (Temple & Young 2004:169).

Although I audio-recorded the interview and captured the interpreter's voice, in hindsight I wish I had video-recorded my informants' signed answers as well. Because of the Deaf community's history of oppression and the denial of ASL as a true language for many years, I worry that translating ASL into English and "quite literally writing out the source language, methodological expediency continues to reinforce the political invisibility of the language and its users" (Temple & Young 2004: 166).

Limitations of the sample

As discussed, codas are a difficult population to locate and contact. I used snowball sampling to identify informants, beginning with a coda who works in the Deaf Studies field. As a result, the subsequent informants I was referred to are distinctive in that many are actively involved with the Deaf community. As such, they exhibit an understanding of Deaf culture that may not be typical of all codas, and are generally familiar with a lot of the issues I raised in our interviews. For this reason, my particular sample is limited because it leaves out those codas who are not affiliated with academia, schools, or programs for the Deaf. The ability to include a wider range of coda informants with varying levels of interaction with the Deaf community would have strengthened the sample.

Data analysis

I engaged in modified grounded theory analysis. I selected grounded theory²⁰ because there is very little literature about the hearing children of deaf adults, and grounded theory is useful for exploratory research. Additionally, because grounded theory is an inductive approach it "allows understanding to emerge from close study of the texts" (Bernard 2006:493). Because cochlear implantation is a contentious topic, I wanted my research to remain grounded in the data. I wanted to allow meaning to evolve from the data itself in a more pure form, and to restrict preconceptions and stereotypes from influencing the emerging themes and conclusions.

After recording each interview with a digital voice recorder I transcribed the interviews using the transcription software Express Scribe. I choose to use this software because, not only is it free, but it allows the user to slow down audio, making it easier to listen and transcribe simultaneously. I employed the naturalistic method of transcription "where utterances are transcribed in as much detail as possible" (Oliver et al 2005:1275). I felt this transcription method would leave the least amount of room for misrepresentation as it most closely resembles actually-existing speech. Moreover, I choose the naturalistic method because "dialogue is rarely the simple exchange of ideas [. . .] talk is peppered with verbal and non-verbal signals that can change the tenor of conversations and meaning" (Oliver et al 2005:1276). Because I was interviewing individuals whose first language was a signed language, I felt it useful to use naturalistic

²⁰ Kathy Charmaz explains that, "A grounded theorist starts with gathering focused data and stays close to the data, while developing concepts that synthesize and conceptualize the collected data - in short, make analytic sense of these data. You study research participants' meanings, intentions, actions, and situations [. . .] Thus, you build levels of abstraction directly from the data and, subsequently, check and refine them by gathering further data" (2008: 82).

transcription in the event that any of them started code-switching or using ASL during the interview.

Following transcription, I used the qualitative analysis software NVivo to code. I choose to use a coding software instead of hand coding because the software allows all transcripts to be stored in a single file, keeping the documents in an organized, centralized, and easily portable location. Furthermore, the software allows users to code large amounts of text more quickly than if done by hand. Additionally, I used NVivo because it has the capability to run summary and analysis reports and because it has visualization tools to display data. Looking at data in varied forms allowed me to view the information from different angles, causing some previously unseen things to become apparent. The themes that emerged from the data analysis will be explored in greater depth in the ensuing chapters.

CHAPTER 4

BELONGING AND THE BIOLOGICAL RELATIVE

In this chapter I employ biosociality, biological citizenship, and fictive kinship to explore issues of belonging, identity, and community formation among hearing children of deaf adults. I explain the Deaf community as a biosociality and problematize codas as individuals raised within a biosociality, but who lack the identifying biological traits that would allow them to claim citizenship. I posit that, as a means of mitigating their bifurcated identity, codas have utilized organizations as liminal spaces for identity transformation and community formation, and have employed fictive kinship as a means of establishing a more concrete sense of belonging.

The Deaf Community as a biosociality

Paul Rabinow coined the term "biosociality" in 1996. In his discussion of the Human Genome Project and the emergence of "new genetics," Rabinow argues that humans will develop new ways of relating to one another based on shared biological characteristics and, from those shared biologies, communities will form. As he states:

"In the future, the new genetics will cease to be a biological metaphor for modern society and will become instead a circulation network of identity terms and restriction loci, around which and through which a truly new type of autoproduction will emerge, which I call 'biosociality.' If sociobiology is culture constructed on the basis of a metaphor of nature, then in biosociality, nature will be modeled on culture understood as practice. Nature will be known and remade through technique and will finally become artificial, just as culture becomes natural" (Rabinow 1996:186).

Rabinow paints biosociality as a process that rearranges social relations based upon biology, and he suggests that the resulting biosocially-derived groups "will have medical

specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and 'understand' their fate" (Rabinow 1996:188).

Although membership in the Deaf community does not hinge *entirely* on audiological status, hearing loss is an important factor of Deaf cultural identity. As Stuart Blume explains, "the frustrations of growing up in a world that largely barred them from easy communication formed part of the common culture of deaf people" (2010:63). Medical anthropologist Michele Friedner has made the argument that "the Deaf community can be seen as an example of Rabinow's biosociality as it is predicated upon a shared biological classification of deafness" (Friedner 2010:342). Deafness, whether sensorineural or conductive, is a biological trait shared among members of the Deaf community. Whereas scholars like Paddy Ladd and Harlan Lane have argued that the Deaf community formed in spite of oppressive power structures forced upon deaf bodies by a hearing majority, Friedner instead argues that the Deaf biosociality was "produced by and through, and not in spite of, the existence of power" (Friedner 2010: 337). As she articulates, "resistance exists and operates within power and should not be seen as the opposite of power" (Friedner 2010: 341). According to Friedner, structures of power "have created the conditions of possibility that are conducive to the emergence of the Deaf community, capital *D* Deaf identity, and community politics" (Friedner 2010: 339). The category of deafness was first introduced as a means to define and label deviant bodies. Over time, however, Friedner argues that the categorization of deafness evolved to become "productive"; it created identity and community. The very act of

labeling deafness set the stage for the deaf population to claim a deafness as an identity and for a Deaf community to emerge, produced *through* power not formed in spite of it.

Biological citizenship

Biological citizenship evolved from Rabinow's biosociality. The term was created by Robert Christopher Latiolais in 1998, but it was Adriana Petryna who first applied the concept in anthropological analysis. In her (2002) book *Life Exposed: Biological Citizens after Chernobyl* Petryna finds that the medical conditions shared by Chernobyl survivors have become the basis for a kind of social membership, and that those affected by the Chernobyl nuclear disaster utilize their biological status as radiation sickness sufferers to campaign for healthcare and social welfare. As Petryna articulates:

"the injured biology of a population has become the basis for social membership and for staking claims to citizenship. Government-operated radiation research clinics and nongovernmental organizations mediate an informal economy of illness and claims to a "biological citizenship"-a demand for, but limited access to, a form of social welfare based on medical, scientific, and legal criteria that recognize injury and compensate for it" (Petryna 2010: 261).

Rose and Novas further nuance biological citizenship in their (2003) article. They provide the following definition of biological citizenship:

"we use the term 'biological citizenship' descriptively, to encompass all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as a species" (Rose & Novas 2003).

Unlike Petryna's article which illustrates how biological citizenship can be used to collectively bargain for services, Rose and Novas argue that "in the West novel practices of biological choice are taking place within a 'regime of the self' as a prudent yet

enterprising individual, actively shaping his or her life course through acts of choice" (Rose & Novas 2003).

Based on these conceptualizations, it is clear that the Deaf community is both a biosociality and also a biological citizenship. Not only have Deaf individuals collectivized because of biological similarity (biosociality), but they have also purposefully used their shared biology to engage in political mobilization (biological citizenship á la Petryna) and to shape an understanding of their self identity (biological citizenship á la Rose & Novas). For example, following the path paved by the Disability Rights Movement, the Deaf community has campaigned for recognition, access to resources, and civil rights.²¹ One of the best known examples is the 1988 Deaf President Now! movement. Gallaudet University is the most renowned Deaf university in the world; however, until 1988 all of its presidents had been hearing and only 4 of the 21 board members were deaf. In a campaign for more equal representation, the students protested and shut down the campus until a Deaf president was elected.²² This movement is of particular significance because it exemplifies and reinforces the importance that biological deafness holds within the Deaf community. In this specific example, the Deaf community correlates most closely with Petryna's conceptualizations of a biological citizenship. During the time period of the Deaf President Now! movement, the Deaf community already existed as a biosociality; but by using their identity derived from

²¹ For a more detailed analysis of the Deaf community's problematic relationship with disability law, see Thomas Holcomb's *Introduction to American Deaf Culture*.

²² For further information about the American Deaf community's political movements in relation to other minority rights movements, see Karen Nakamura's *Deaf in Japan*.

shared biological characteristics, the community was able to demand (and successfully implement) systemic change.

On the periphery of biological citizenship

If the Deaf community is a biosociality and its members biological citizens, where does that leave codas? What happens to those individuals born within a biosociality but who lack the biological prerequisites needed in order to become a citizen? Hearing children of deaf adults grow up in the Deaf biosociality, but most do not have the hearing loss that unites the rest of the group. This contradictory existence has led to a confused sense of belonging. My informant Jen expresses the discordant identity of a coda most aptly. When asked about her relationship to the Deaf community, Jen responds:

"Where am I in all of that? I have no idea. So that's my relationship with them. It's just like I have no idea."

Within this statement, Jen expresses doubt about where she "fits" and admits she cannot confidently identify her affiliation. She feels ill-equipped to stake a definitive membership claim. She goes on to say:

"It's like all of these things [. . .] it's hard to really pinpoint what my relationship is to the Deaf community, cuz it's all of these things."

Again, Jen talks about the ambiguity of her relationship to the Deaf community.

However, in this instance, the uncertainty stems—not from a lack of knowing—but from too many variables. Her bond to the Deaf community is multifaceted, making her connections hard to isolate or unpack, and adding to a sense of perplexity.

"It's like being part of it, but am I really part of it? Cuz some people in the Deaf community don't see me as part of it. And where's the line between being an advocate for it and where I need to start pulling back? Because I don't fully, I

can only understand to a certain degree. So am I my own thing as a coda or am I part of the Deaf community?"

Jen problematizes "belonging." She expresses uncertainty about whether or not she can claim membership to the Deaf community for two reasons: 1) she is not deaf and therefore cannot fully understand the deaf experience and 2) there are some biologically deaf individuals who do not recognize her citizenship. Jen also questions whether or not "coda" can exist as its own identity, and whether or not that is an identity she can rightfully claim. She proceeds to talk about the ways in which she feels like a "coda:"

"I know that there are a lot of coda tendencies that I have that sometimes don't mesh when I talk to just hearing people who aren't cultured with the Deaf way or don't know anything about it. And so in those cases it's just like dang! In those cases I do feel very Deaf.

She describes intrinsic habits born from the Deaf experience that manifest in her interactions with hearing people as "coda tendencies." Although she does not elaborate specifically on what these tendencies look like, Jen notes that they alienate her from her hearing peers. Not only is she frustrated about being treated as a hearing person by other hearing people, she also expresses disappointment about being treated as hearing by members of the Deaf community:

But it sucks cuz it's like the outside world, even some people in the deaf community, still see me as hearing. So not really part of anything. And that's scary cuz it's like yeah I do hold a lot of Deaf tendencies, a lot of the Deaf spirit and heart that a lot of people will shun away or disregard because of my physical difference and a sense of having hearing as opposed to not having, you know?"

Here, Jen associates herself more closely with a Deaf identity than a hearing identity.

Jen's feelings align with earlier literature on codas: "despite appearing to matriculate within the Hearing world, a number of men and women suggested that they were not

always comfortable with hearing people, nor did they necessarily identify themselves as a Hearing person" (Preston 1995: 1464). Regardless of her feelings of attachment to a Deaf identity, Jen's capacity to hear distances her from the biologically deaf, resulting in frustration about lack of inclusion in the community and leaving her in a state of identity limbo:

Usually when we talk of deafness even that has a spectrum to it, you know? So the hard-of-hearing are still considered deaf, but then beyond that is that over the line? If you're part of hearing then you can't fully be a member. Like where? What constitutes being a member and not? Then it upsets me cuz if there are certain criteria for being deaf, being accepted in that that culture, how does the culture grow beyond that? You know?

The biological boundaries that distance codas from fully inclusive membership in the Deaf biosociality manifest as a reluctance to identify as part of the Deaf community. Despite having grown up in a Deaf family and being fluent in American Sign Language, most of my informants are hesitant to say they belong to the Deaf community. As James explains,

"It's kind of like you're a friend of somebody who brought you to a party. Like, you're not actually friends with everybody else. You're just kind of there. So it's one of those situations where..this is all from my perspective, rather than this is the Deaf people's opinion because I am not one. Although I do have a deeper understanding and am more involved than the average person. So yeah that's definitely a thing. I will never speak on the behalf of all the deaf people just like nobody should speak on the behalf of all their people. It's not, everybody's their own individual."

Informants often shift responsibility off of and away from themselves, indicating that it is not up to them to decide their citizenship status, but dependent upon the biologically deaf. This delineation of authority stems from the recent Deaf rights movement which, as Preston explains, "re-aligns the messenger with the message: to speak for the Deaf, you

must be deaf” (Preston 1995:1465). Preston argues that “status is contingent on the Deaf community's sense of them as culturally familiar. Because hearing children already occupy a paradoxical position within this culture, the risks of alienation are all the more perilous” (Preston 1995: 1465). As a result, Preston’s informants, like my own, “frequently described a sense of personal conflict” when it comes to speaking about Deaf issues (1995: 1465).

Borrowing concepts from Bourdieu, codas' ambivalent identity can be explained by a conflicted "habitus." Habitus "designates a set of generative and durable dispositions acquired through socialization" (Samuelsen & Steffen 2004:5). In other words, habitus are the set of values, dispositions, and tastes deposited within the individual through socialization. Habitus is acquired unconsciously and early childhood experiences carry a "disproportionate weight" in the development of habitus (Bourdieu 1977: 78). For codas, habitus is informed by two opposing spheres of influence: the Deaf biosociality of their family and the larger hearing society. Partially formed within a biosociality and partially outside of a biosociality, codas' habitus consists of different, and often clashing, dispositions and attitudes. In the chart below, coda Robert Hoffmeister outlines some of the contradictory worldviews that hearing children are inculturated with when they grow up with Deaf parents (Hoffmeister 2008:200).

SIDE OF BORDER	BELIEF
Deaf	Hearing is bad.
Hearing	Deaf is bad.
Deaf	ASL is good.
Hearing	ASL is bad.
Deaf	ASL is broken English.
Hearing	Broken English is bad.
Deaf	English is bad.
Hearing	Literacy is good.
Deaf	Can't read or write.
Hearing	Deaf are illiterate.
Deaf	ASL and English are <i>both</i> languages of the Deaf world.
Hearing	Bilingualism is bad.

Fig. 8

Not only do codas absorb narratives from their hearing peers about deafness as abnormal and inferior, but they also "listen to the countless stories and statements that imply a 'hate the Hearing' attitude [. . .] and it becomes a confusing mess, when we know that we are 'Hearing'" (Hoffmeister 2008:200). These opposing narratives result in a habitus that is polarized, leaving codas with a befuddled identity.

Codas' complex habitus manifests not only as equivocal attitudes about deafness and cochlear implantation, but also as bodily expressions. For example, codas have developed a communicative method specific to their population. Coda-talk, a term coined by Preston, describes codas' "highly creative combination of ASL and spoken English that is both voiced and signed" and that "alternately follows the grammatical and syntactic rules of both languages (1994:222, 223). As well as the simultaneous use of speech and sign, Coda-talk also includes "deaf voice." Deaf voice is "the recreation of the sounds of a person's deaf family members" (Bishop & Hicks 2005: 201). If you have

ever heard a deaf person talk, you know that deaf voice is marked by "pervasive nasalization, a distortion of prosody toward the extremes of highs and lows, strong assimilation processes that lead to a loss of syllables, and nonlinguistic vocal gestures (Bishop & Hicks 2005: 201). Coda-talk also includes some features of ASL, like an omission of subjects, modal verbs, the infinitive marker *to*, prepositions, and articles (Bishop & Hicks 2005). Coda talk is very private, generally only used in the presence of other codas, and Preston suggests that "Coda-talk was seen by proponents as a way of expressing two conflicting linguistic heritages" and "it is one way that some hearing children of deaf parents expressed the duality and marginality" of the coda experience (Preston 1994: 223).

Distinctly "coda" behaviors and mannerisms, like Coda-talk, demonstrate a hybridization of hearing and Deaf "bodily habitus." Jen provides another example:

Eye contact is so big and just like the way that—I mean this is not all codas, but this is definitely a lot of codas that I've met—of just being very animated in how we talk about things. Even the importance of eye contact is very much a deaf thing. But it's also something that a lot of codas take in as well and use in just like their everyday sort of interactions. But it's funny cuz hearing people will, I get this all the time, like [Jen] you're so animated! Or like why are you staring at me like that? It's just like oh my gosh, sorry! Like, it's just who I am—this is—that's a deaf thing!

As described by Horton and Barker, embodiment is the process in which people "literally incorporate biologically, the social and material world in which we live" (2010). What Jen describes as "coda tendencies" are the manifestations of a conflicted "bodily habitus." These coda behaviors are neither entirely Deaf nor entirely hearing; their tendencies display an embodiment of an interstitial identity.

Fictive kinship

There are many kinds of relationships at work within the Deaf community: between deaf parents and their hearing children, between hearing parents and their deaf children, between deaf parents and their deaf children, between deaf members of the Deaf community, and between codas with other codas. Some of these relationships are forged by genealogical connections, others by shared biologies, and yet others by constructed forms of kinship. One such form of constructed kinship is "fictive kinship." As will be explained below, fictive kinship functions both among the biologically deaf and among codas as a means of community creation and solidification. Fictive kinship is a tool that codas have employed to help alleviate their conflicted habitus.

Fictive kinship, a term originating with early anthropologists, describes "familial relationships with people who are not related by blood and who may or may not live with the nuclear family" (Kane 2000:693). Godparents are an obvious example of fictive kin, but other "friends or neighbors are likely candidates for fictive kin relationships and may be given kinship titles, such as aunt or uncle" (Kane 2000:693). Ebaugh and Curry define it as "a relationship, based not on blood or marriage but rather on religious rituals or close friendship ties, that replicates many of the rights and obligations usually associated with family ties" (2000:189). Found in a number of different cultures, fictive kinship has evolved because "human kinship implies much more than primary kin recognition and genealogical relationships" (Milicic 2013:10).

One of the earliest mentions of fictive kinship in the literature is Norbeck and Befu's 1958 article about kinship in Japan, which discusses the practice of assigning kin

terms to non-relatives, calling it "fictive usages among the unrelated" (1958:108). About a decade later, in Ballweg's (1969) U.S.-based study, 64% of questionnaire respondents admitted to using kin terms to identify people not actually related to them. These findings lead Adams to argue that "fictive kin may be to some extent replacing actual kin in the U.S." (Adams 1970:579).

Fictive kinship has been extensively cited among Black American family life. Indeed, there are a number of ethnographic studies that note fictive kin relationships in the African American community (Aschenbrenner 1973; Chatters et al 1994; Dilworth-Anderson 1992; Johnson 1999; Kennedy 1980; Martin & Martin 1978; Stack 1974; Tatum 1987). The assertion that fictive kinship is common among African Americans has been problematized by Nelson, who argues that "explicit references to fictive kinship among Whites [are] rare" and that scholars rarely "look for or even discuss fictive kinship among White populations unless those White populations include the elderly (and their caregivers) or some other "marginal" group (e.g., gays and lesbians; single mothers; people at risk)" (Nelson 2014:203). Indeed, existing literature about fictive kin networks primarily addresses older adults (Bedford & Blieszner 2000; Johnson 1999; Karner 1998; Rubenstein et al 1991), working class families (Coontz 1999), new immigrants (Ebaugh & Curry, 2000), gay and lesbian families (Muraco 2006; Weston 1991), and street families (McCarthy et al 2002).

Some scholars have contested the term "fictive," arguing that it suggests the relationships are not "real" (Weston 1991). As a result, other terms have been developed: imagined kindred, voluntary kin, families we choose, chosen kin, self-

ascribed kin, urban tribes, friend-keepers, othermothers, and ritual kin (Braithwaite et al 2010).²³ "Imagined kindred," in particular, is used by Rapp et al. to talk about the formation of communities based around individuals with shared hereditary disorders. Rapp et al. suggest that "those who 'share a gene' (or chromosome) for a disorder are felt to be related" (2001: 393). For example, "many people believe [. . .] that those with Down's syndrome have 'more in common' with one another than they do with members of their family of origin" (Rapp et al 2001:393).²⁴

Fictive kinship founded upon biosociality

Drawing from Rapp et al's conceptualization of imagined kindred forming around shared hereditary disorders, I argue that the Deaf community can be interpreted as a fictive kinship founded upon biosociality. Indeed, the Deaf community exhibits a strong sense of camaraderie between members, regardless of age, gender, ethnicity, and nationality. As Padden and Humphries explain, Deaf culture consists of a "group of people who [do] not have any distinctive religion, clothing, or diet—or even inhabit a particular geographical space they [call] their own" (2005:1). Likewise, as Lane et al. articulate, "unlike other cultures, Deaf culture is not associated with a single place, a 'native land'; rather, it is a culture based on relationships among people for whom a number of places and associates may provide common ground" (1996:5).

A measure of inherent kinship exists among members of the Deaf community based upon their biological deafness (Eckert 2010:2). In his 2005 study, Eckert asked

²³ Despite its contested nature, I employ the term fictive kinship in this chapter because it is the established term in the field of Anthropology.

²⁴ Rapp et al. also explore the sense of kinship among Little People.

Deaf respondents to compare meeting a Deaf person for the first time with meeting a hearing person for the first time. He found that:

"respondents described Deaf people as being those they felt instantly connected to and could be their real self around. The lack of connection to hearing people was also highlighted. One respondent (Jim) said, "It is different because the Deaf person feels like family" [. . .] The Deaf self-same ancestor, sometimes signed as "DEAFSAME," is not a matter of genetics" (Eckert 2010:2).

Deafness unites. I witnessed this sense of immediate kinship shared among biologically deaf individuals during participant observation. Below is an excerpt from my field notes wherein I reflect upon the arrival of a new student:

June 2015: All of the students in my classroom are immigrants. However, the newest student is different from the others. He is the only student to come from a country that is not Spanish-speaking (Kuwait). He is older than the other students (22). He looks older than the others students (he is taller and has a bit of a beard). He is Muslim. He knows Arabic and Arabic sign language, a little ASL, very little English, and no Spanish. Despite the physical, cultural, and linguistic differences separating the new boy from the current students, he has been immediately welcomed and accepted. The students show great interest in learning about Arabic Sign Language and about the differences between his culture and their own. They are eager to offer assistance and encouragement and to teach him. The students have a much closer connection to this deaf boy from Kuwait who arrived 3 weeks ago than they do to myself, who has been working with them since October. In this sense, there does appear to be a bond that unites deaf people, and it seems true that "Deafnicity" encompasses all, regardless of ethnicity, class, gender, or race. I believe the cross-cultural acknowledgement and respect I have observed among the students in my classroom is indicative of the accepting nature of the larger Deaf community.

To be clear, the Deaf community is not completely immune to divisions within – even if they share a biological feature. It is partially a matter of context. That is, when Deaf people are surrounded by hearing people, being Deaf usually overrides other characteristics. However, like most people, Deaf people prefer to socialize with other Deaf people who share not only biological deafness, but other features that are salient to

that group. Nevertheless, the excerpt from my field notes illuminates the hierarchical categories of belonging that exist within the Deaf community.

As an anthropologist, I establish a provisional sense of belonging through ethnographic fieldwork. To borrow from Alfred Shuetz, I am a “stranger”: “an adult individual of our times and civilization who tries to be permanently accepted or at least tolerated by the group which he approaches” (1944: 499). I gain entry and access to the community; however, my positionality as a hearing person in a Deaf world is of significantly lower stature than that of a coda. As Preston explains:

"Being culturally Deaf is interdependent on the individual's identification with the group and the group's evaluation and acceptance of the individual. This assessment is largely based on a sense of cultural familiarity: a breadth of life experiences associated with being deaf, routinely participating in social interactions with other deaf people; and sharing similar social behaviors, historical traditions and a common destiny" (Preston 1995: 1463).

Because I lack the requisite cultural markers, my status is more akin to that of other non-relative hearing people who exist within Deaf spaces, such as American Sign Language interpreters.

To describe the space that hearing people inhabit when they interact with Deaf individuals, Bienvenue and Sherwood have deployed the term "third culture."²⁵ Third culture is "not a full culture that people can identify as such. Third culture consists of people from two other cultures, for example, hearing and deaf people, coming together" (Bienvenue 1987). Not unlike anthropologists, interpreters "have a foot in both worlds," and third culture allows “Deaf and hearing cultures to 'meet in the middle' and as a

²⁵ The "third culture" discussed by Bienvenue and Sherwood is different from the concept of "third culture kids." Third culture kids will be discussed at length in the next chapter.

consequence establish mutual understanding" (Napier 2010: 144). Although interpreters, like codas, exist in the third culture, codas have a more thoroughly natural habitus because they are born and raised within Deaf culture. Non-coda interpreters can only approximate this habitus. As an anthropologist in a field site, I too exist within the third culture as I attempt to gain a more emic perspective of the Deaf community. We call this ethnography. Some of the interpreting literature has suggested interpreters adopt ethnographic techniques. For example, Sherwood argues for the use of ethnography to facilitate interpreters' cross-cultural mediation: "Germane to the task of cross-cultural mediation is understanding the cultural information of communicating groups from an ethnographic point of view" (Sherwood 1987:18). She argues that "ethnography shifts the focus of understanding from the perspective of the interpreter as an outsider, to the discovery of the Deaf insider's point of view" (Sherwood 1987:18). In this sense, interpreters and anthropologists are similarly situated along the continuum of hearing people in the Deaf world.

So, how do we differentiate between different kinds of hearing people? Napier suggests we use the D/deaf convention in regards to H/hearing. Hearing (with a capital H) = hearing people who are "ignorant or naive about the Deaf community and its culture and typically regard deafness from a pathological point of view; hearing people, however, are those who have internalized Deaf culture, ally themselves with Deaf people, and are regarded as members of the Deaf community" (Napier 2010: 144). Using this classification system, codas can be categorized as hearing, not Hearing, people. This shared category of belonging creates an environment in which kinship ties can be forged.

The literature provides a number of explanations as to why fictive kinship develops. For example, Braithwaite et al suggest that, "taken collectively, this research points to a variety of possible functions performed by voluntary kin, including a sense of belonging, emotional closeness, protection and security, and social support" (2010:391). Fictive kinships can develop because existing familial networks are inadequate in meeting material and interpersonal needs. Fictive kinship functions as a means to pool resources, extend familial networks, and extend social support.

Fictive kinship may also be a means to confront suffering. Michael Jackson talks of how "it is always easier to bear personal suffering if one can experience it as something shared by many others. This sense of kinship born of this identification with fellow sufferers one is able to find a common cause against a common foe" (Jackson 1998:140). This is similar to Victor Turner's earlier work among the Ndembu of Zambia. Turner found that certain healing rituals entered victims into a community of sufferers, or "cult of affliction," that bound members together in a shared identity:

“cult membership thus transects village and lineage membership and brings into temporary operation what may be termed ‘a community of suffering’—or, rather, of ‘former sufferers’ from the same type of affliction as now besets the candidate” (Turner 1969:14).

In a similar vein, Rapp et al argue that the development of imagined kindred is a "strategy for empowerment" and that "sculpting a collective identity through a hereditary disorder provides a way to cope with difference and normalize it" (Rapp et al 2001:393).

It could be argued that Rabinow's "biosociality" is a form of fictive kinship because both phenomena create social relationships and produce identity. However, more nuanced applications of biosociality, particularly biological citizenship,

differentiate the two concepts. A fellow "citizen" differs significantly from "kin" because, according to both Petryna and Rose and Novas' conceptualizations, citizenship operates within structures of power and entails a certain measure of activism. As Rose and Novas' argue, through biological citizenship "individuals are actively engaging with biological explanations and are forming novel relations with figures of scientific or medical authority in the process of caring for, and about, health" (2003: 13). Fictive kinship is less about achieving a political end, and more about the relationships that bind people in ties of affection, concern, obligation, and responsibility.

I seek to understand the role that fictive kinship has played in the emergence of a Coda community and Coda identity. Specifically, if the Deaf community is a fictive kinship founded on biosociality, where does that leave the biological relatives who are not biological citizens?

The birth of a community

Within the last decade or two, an identifiable Coda community and distinct Coda identity have emerged. Only recently has the term "coda" been used to talk about hearing children of deaf parents. However, while "coda" is more commonly used among Deaf people now, it is not universally used or accepted among hearing children of deaf parents. Indeed, there are some who disavow the term "coda" to refer to themselves. Although all of my participants accept coda as a means of talking about their identity, a number reveal they were unaware of the term until later in life, suggesting that Coda identity is a newly formed phenomenon:

Steven: Discovering coda as a way of being, as a person that apparently I am, I didn't really quite recognize it.

Steven: I'm the middle child of three. My aunts and uncles had hearing children that we would always hang out with as well, but the idea of coda, the idea of this way of being, or this label or identification has never really been applied.

Will: I honestly only understood what a coda was..really when I was looking for scholarships for college. They were like oh there's, you know you're considered a group of people and, you know, they give scholarships for it. And I was like "oh okay cool."

Victor addresses some hearing children's unfamiliarity with "coda" as "definitely a generational question," explaining that there are differences between new and older generations of codas:

We're basically what they would call the newest generation of codas, where we've grown up from a much younger age understanding our identity, understanding what it means to be a coda. Or at the very least just accepting that the identity exists. Whereas the older codas have grown up, not knowing themselves until they're 10 years into their marriage and they have to get a divorce because they're starting to realize that the other person's not recognizing that part of their identity. Or, they're getting to the point where they're still not able to make friends because they just don't understand their identity.

He continues, explaining that younger hearing children grow up with a far greater awareness of their identity as "coda."

For older codas, they're still really getting wet in that sense. They're still really submerging themselves in that identity. Whereas the younger generation, those of us that have been going to camp, that have been exposed to all of this, come out of it like "yeah we're so proud of both communities [. . .] I recognize that it was even harder for those that are only just beginning to understand their identity 30 years into their life 40 years into their life, some 60-70 years into their life.

It seems that, for the older generation of hearing children, coda is an achieved status, a status that is "not assigned to individuals from birth but are left open to be filled through competition and individual effort" (Linton 1936:115). For the newest generation, however, Coda identity appears to have become an ascribed status: a status which is

"assigned to individuals without reference to their innate differences or abilities. They can be predicted and trained for from the moment of birth" (Linton: 1936:115). This further illustrates that Coda identity is a new social construction, a newly available label or category through which to interpret and claim certain experiences of "difference."

Discovering coda

Presently, hearing children learn about coda and the existence of a Coda community through multiple pathways. For one informant, Steven, it was an American Sign Language interpreter who first introduced him to coda:

*"Oh yeah serving coffee, Starbucks. You know cuz that's what you do when you graduate college, you serve lattes. And late one night this lady comes in. It's like 8 o'clock, she orders four espressos, and I'm like: "Jeez what are you doing? It's like 8 o'clock at night."
She's like "oh I got a job."
"Oh wait what do you do for work?"
"Oh I'm an interpreter."
"Oh what do you interpret?"
"Oh sign language. I'm a sign language interpreter."
I was like "Oh cool I know sign language."
She's like "No you don't."
[Steven begins signing and speaking simultaneously] It's like yeah deaf yeah yeah.
She's "Oooo you're a coda."
And I was like "What? You're a coda? Like what's that mean, coda?"
She's like "you're a child of deaf adults."
I was like "what does that mean, I don't understand?"
And she was like "you're like in the deaf community, like you're praised, you sign all the time, like you have all these skills"
And I was just like standing there with my big fat degree serving coffee feeling like nothing but this lady, the way she just was so amazed and so appreciative and so like in awe of this thing, me. I won't even say me, but something that I guess I represented, just made something go hold on a second here [. . .]and everything just kind of opened up where I was like I gotta go pursue this, I gotta go figure this out. That's really uh a unique thing to experience and that just I was like entertained by it or just I enjoyed it so much.*

In Steven's case, it was another hearing person with ties to the Deaf community who informed him of his identity as coda. The way in which Steven recounts the experience frames it as an identity-affirming moment. The interpreter's reverence for Steven as a coda illustrates the elevated status that hearing children of deaf adults occupy in the hierarchy of hearing people in the Deaf world.

Even for those who are not actively involved in the Coda community or CODA organizations, the Coda identity holds importance. Coda is important to people on different levels. For example, two of my informants, despite not having strong connections to the Deaf community or to other codas, feel a relationship to one another. When I asked James if he identifies as part of the Coda community, he responded:

It's not as if I've actively seek them out, but I do occasionally find them. And it's an interesting connection because we have, you know, all the same things like "oh did this happen to you as a kid" sort of thing and alotta interesting things like that.

Although James does not search for other codas, when he does meet one he feels a sense of affinity towards them. For example, James speaks about one of the few other codas he knows, his friend Frank. He recounts the moment they met:

*He's friends with my roommate, and he came over one day and he goes "wait are your parents deaf?"
I'm like "yeah."
And he goes "oh that's so cool."
And everybody, like we were kind of at a party situation, and everybody was like "uhhh."
He's like "my parents are deaf too, it's cool."
And then he had a conversation with my parents and it was just one of those weird things.*

In my subsequent interview with Frank, he talks about meeting James' mother:

I mean the first time I met [James'] mom I was sitting, or we were standing on a deck, and she was behind a glass sliding door, totally closed. And I'm, you know, having a full conversation with her and everyone in the group is talking English, and then everyone kinda, you know, ten fifteen minutes later everyone kinda quiets down and she walks away and I'm like "your mom's really cool" and like I didn't say anything to anybody you know?

Despite their lack of serious involvement in either the Deaf or Coda communities, James and Frank still feel a bond to one another founded upon their lived experience as codas. Their entire friendship originated from and is strengthened by their shared identity. For some, discovering coda is an identity-affirming, life-changing realization, whereas for others it simply offers companionship.

Other hearing children learn about the moniker "coda" by virtue of interaction with CODA International, an organization founded in 1983 that hosts annual conferences to "celebrate the unique heritage and multicultural identities of adult hearing individuals with deaf parent(s)" (CODA International website):

Isabella: I was gonna be a Math teacher, and I was like oh totally fine with not having anything to do with the Deaf community. I didn't feel that connected or attached to it. After I graduated there's a woman, an interpreter, who was a coda in Vermont, who my mom met and connected with. And she got my sister and I into coda. And that summer we went to our first CODA conference, and I was hooked. Just meeting all of these people, just being surrounded by these other people that had the same experiences as me. It was so cool. So that's when I'm like I think I kinda wanna go into Deaf Ed. I ended up teaching for a year in Vermont, high school math, but I have a little bit of a hearing loss myself in my right ear so I noticed it was a little bit challenging for me. But ever since that coda experience I just kinda got drawn to that. So I applied to BU for their Deaf Ed program, their Master's program"

Jane: "I didn't know what a coda was until I was uh 15. And I only know that because CODA International was having a conference in my hometown when I was 15 [. . .] And then once I learned about the organization and, you know, the formal name and all that I started to kinda think about it more, and I went to my first conference for CODA International when I was 18. Um. And...that was

when I started to fully identify the differences, cultural and linguistic, and I've pretty solidly developed my identity as a coda after that."

As it was for Steven, a sign language interpreter played a role in introducing Isabella to coda. It was her exposure to CODA International, however, that had the most impact. She speaks of the fellowship she felt in the presence of other similarly-situated people at the CODA conference. For Jane, it was pure coincidence that she was introduced to coda. However, she credits learning about coda and being able to give a name to what she is as an important factor in the development of her identity. For both of these women, the introduction to CODA International was a turning point in their identity formation, and the organization offered a new way for these women to understand themselves. Based on the experiences of my informants, it appears organizations for codas play a significant role in the discovery, acceptance, and adoption of identity.

CODA organizations as liminality

One of my informants, Victor, talks about a "cultural revolution that's been going on for the last two decades" that has resulted in the "emergence of all these CODA organizations." The primary formal organization for codas is CODA International. However, there are also state, regional, and local "get-togethers" of codas. These are often loosely affiliated with CODA International. There are also several annual regional workshops that are advertised and (in some cases) may be partially sponsored by CODA International, and there is a subgroup/special interest group of coda interpreters in the Registry of Interpreters for the Deaf (RID). Lastly, there are agencies for "coda kids,"

commonly referred to as kodas, that offer summer camp programs.²⁶ Koda camps are independently operated and not formally tied to coda International.

A number of my informants speak about involvement in organizations for kodas in their interviews. For example, Victor has worked as a camp counselor at KODAWest in Los Angeles. He comments on how his experiences at koda camp have been integral to his identity formation:

To put it mildly, or to put it simply, it's an incredible experience where both the kids and the staff get to really explore their identities and get to bond over the commonalities of being a coda. And whether these are American kodas whose families have been here for years, whether their families are immigrants like mine, or whether they're mixed families, culturally, racially, whatever, there's still that common bond of being a coda.

Just like in general Deaf culture, it's the bond of being deaf and all the issues that come with that. And hardships and um definitely a lot of uh positive aspects for the most part people the negative aspects um but at least with coda West it's definitely very focused on the positive. And personally that's where I found my identity. I started there as a CIT and within two days of staff training I knew I was gonna come back. And I remember my mom came to pick me up and she asked me how camp was and I go alright sign me up for next year.

CODA organizations, in particular koda camps, can be interpreted as a form of liminality. Indeed, anthropologist Randal Tillery has already made the argument that "summer camp can be seen as providing a variation of the experience that anthropologists have termed 'liminality'" (Tillery 1992:379).

In his seminal work, Arnold Van Gennep argues that a rite of passage consists of three phases which Tzanelli summarizes as follows:

"(1) separation, when the individual or the group is distanced from their former identities; (2) liminality, the phase in-between two conditions (the one from which

²⁶ KodaWest in Los Angeles, Camp Mark Seven in New York, and Camp Grizzly in California are some of the most well-known.

the individual or group departs and the one which they will enter); and (3) re-aggregation (or incorporation), the final stage in which the individual/group is readmitted to society as bearers of new status" (2015).

Van Gennep further characterizes liminality as “the transitional stage” in “the rites of separation from a previous world” (1960:21). Expanding upon Van Gennep's work, Victor Turner focuses on the importance of the second phase of the rite of passage, liminality, which he defines as "any condition outside or on the peripheries of everyday life" (Turner 1974:47). Like other summer camps, koda camps exist in an environment removed—spatially and psychologically—from the workings of everyday life. In this way, the physical space of the CODA organization takes on special significance. As Jen describes,

"It's just like something that like can only really exist at that moment in time, like within the coda community [. . .] it's just like that's a unique cool thing to share, like safe space in that regard."

CODA organizations provide an ideal space for transformations or rites of passage to occur. Turner explains that rites of passage "accompany any change from one state to another [. . .] they also concern entry into a new achieved status, whether this be a political office or membership of an exclusive club or secret society" (Turner 1967:95). In koda camps, a transformation of status does occur. When codas enter the camp they fit the definition Turner provides for liminal entities: "neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremony" (Turner 1967:95). The individual enters the camp as a non-coda, with conflicting ties to both the Deaf and hearing worlds, but exits having adopted the new status of "coda."

Although not explicitly represented as a rite of passage, many koda camps pronounce that it is their mission is to transform hearing children's understanding of their place in the world. For example, the Koda Camp - MidWest webpage argues that it is important for kodas to go to camp "to participate in KODAtalk (a discussion where KODAs share their life experiences with deaf parents)" and "to promote the feeling of belonging and continue involvement with the deaf community once the child leaves their parents' nests as well as to be aware of the network in this big wide world." Similarly, KodaWest's mission statement is:

"to bring these KODA s (Kids Of Deaf Adults) together in a support/peer group type of environment, such as camps and cultural enrichment programs. With this unique fellowship, these children will gain confidence and wisdom which will help them develop a better understanding of, and ability to embrace their two worlds: the hearing and the deaf."

coda organizations function as a liminality where hearing children can adopt a new identity through an iterative process of interaction with one another.

The construction of a community and sense of belonging

Within the liminality lies the potential for permanent community formation. As Turner explains:

"Liminality can perhaps be described as a fructile chaos, a fertile nothingness, a storehouse of possibilities, not by any means a random assemblage but a striving after new forms and structure, a gestation process, a fetation of modes appropriate to and anticipating postliminal existence. It is what goes on in nature in the fertilized egg, in the chrysalis, and even more richly and complexly in their cultural homologues (Turner 1990:12).

The liminality of the CODA organization not only allows hearing children to undergo a transformation of status, but also fosters the creation of a Coda community. Turner uses

the term "communitas" to describe the bonds that grow among individuals experiencing the liminality together. As described by Tillery:

"Turner sees 'communitas' as the sense of spontaneous connection or group feeling that people in a social situation feel toward each other and the group. It is not the same as 'social structure' or 'social relations,' but it is more like a sort of 'social anti-structure' related to the spirit of the community-what binds community together aside from the range of positive structural assertions like obligation, garrulity, lineages, clans, et cetera" (Tillery 1992:381).

Tillery articulates that "the bonds of communitas are 'most evident in 'liminality' when societies or individuals in them are undergoing great transition. It is at those times when group identity is most important" (Tillery 1992:381). In the context of the koda camp or CODA organization, the similarities shared by codas are accentuated, and strong bonds based upon shared experience are formed.

A number of my informants articulated the feelings of connectedness they experience when with other codas. For example, Steven talks about his experience at a CODA conference:

Most critically is the fact that being in this room with 300 people that have all these unique experiences is something that I recognize like this is such a rare thing on this earth [. . .] it's just so stimulating and it's like blows me away everything. And it's sad to leave, and we all kind of share this experience, you know, like withdrawal syndrome or something.

Isabella makes a similar claim,

I mean it's just so so unique to our experiences. I mean I definitely notice, especially as I've gotten older, maybe part of it has to do with the hearing loss, but mostly just being drawn to the Deaf community more so than the hearing community. My husband jokes that I don't really know how to socialize and interact with hearing people. I do. It's just different [laughter]. It's just not what comes natural to me I guess. So I have a lot of deaf friends and I prefer to hang out with people that I feel comfortable with mostly for the language access and stuff [. . .] so I feel very strong in my coda identity because even though, like it's weird because I just feel like part deaf and part hearing but not really fully

belonging to one or the other. And that's why coda is so great, and I feel like I have that strong identity.

For codas, the ties that bind have emerged from a mutually shared positionality and relationship vis-à-vis the Deaf biosociality and fictive kinship. When I asked Victor what made attending summer camp with other codas so special, he explained:

Foundationally it's the fact that we get to bond over things that other people just can't understand without experiencing it. For example, something really simple and something you wouldn't really think about unless you had this experience, is going grocery shopping with your deaf parents. You go out there, you lose them because you just wanna lose them. You go look around, see what things you can throw in the shopping cart, they won't notice, and then you hear..every deaf person has a very particular voice, and codas know their parents' voices off the bat. Especially when they're yelling or just being loud. And you'll hear this yell for your name from somewhere in the store and you either ignore it or you come running and hope nobody else like has-hears it and...it's one of like the simple stories that people bond over is just how do you react when your parents call you in the grocery store. And that's just something you don't think about if you never deal with a deaf person. If you've never had a deaf parent growing up.

Isabella offered another experience shared among many codas that contributes to a feeling of shared identity:

You know there's a big joke in coda stories that almost every coda has suspected when they were young that were their parents really hearing and pretending to be Deaf? [laughter] How did they know like if we swore or yelled behind them?

Turner would describe the type of community formation that occurs within CODA organizations as normative *communitas*, "where, under the influence of time, the need to mobilize and organize resources, and the necessity for social control among the members of the group in pursuance of these goals, the existential *communitas* is organized into a perduring social system" (Turner 1969:132). The hearing child enters the coda organization, undergoes a transformation or identity enlightenment, and in the

process establishes a *communitas* that evolves outside of the liminality into a full-blown community.

When *communitas* forms, "structures fall apart, and differences arising out of the institutionalized socioeconomic and sociopolitical positions, roles, and status disappear" (Williams 2004:227). As a result, the bonds that form between members of a community supersede other forms of identity, like race, gender, or socioeconomic status. Indeed Millie Brother, the founder of coda International, argues that "our shared family experience has transcended global boundaries, languages and cross-cultural divides" (CODA International webpage). It seems apt, then, to stake the claim that, like the Deaf community, the Coda community functions as a form of fictive kinship. Codas feel, because of their lack of belonging to one community, a sense of belonging to one another. As a result of exclusion from the Deaf biosociality and fictive kinship, a new identity and community—a strictly Coda one—has coalesced. In short, codas' routine awareness of *not* belonging has resulted in the formation of a community where they do belong—a community of "non-kin who [. . .] conduct their social relations within the idiom of kinship (Stack 1974:40).

Conclusion

"We must understand not merely the contents and meanings of each side of the equation. We must understand that the dichotomy itself is a social creation"
(Preston 1995: 1466).

As a means of remediating a puzzled sense of belonging stemming from their existence as biological relatives in a Deaf biosociality, codas have used organizations as liminal spaces within which to construct community and, subsequently, have developed a fictive

kinship system providing them with the sense of belonging they were lacking as inhabitants of the borderlands between the Deaf and the hearing worlds. Although the Coda community is founded and hinges upon its relationship to the Deaf, the formation of a separate community solely for codas has provided hearing children with a sense of identity and cultural affiliation that is not contradictory or marginal in any sense. The founder of CODA International, Millie Brother, explains why she started the organization: "My life was full of constant movement between Deaf and hearing worlds. I felt comfortable in both but not fully immersed in either. The coda world would become my third option where I felt balance between my Deaf and hearing cultural experiences" (CODA International webpage). The Coda community has cultivated a sense of belonging.

CHAPTER 5

CODAS AND THIRD CULTURE KIDS: IMPLICATIONS OF A CROSS-CULTURAL UPBRINGING

In this chapter I utilize "third culture kids" (TCKs) as a theoretical model against which to compare and contrast hearing children of deaf adults, adding to existing literature about children who grow up in transcultural environments. Specifically, I analyze the parallels and disjunctures between codas and third culture kids, and discuss the "TCK Profile" as outlined in the literature, illustrating how codas share many attributes with third culture kids. I go on to argue that, because there are key points that distinguish codas from other similarly-situated children, hearing children should be incorporated as a new category in the "cross cultural kid" model.

Third Culture Kids

A Third Culture Kid (TCK) is defined as

"a person who has spent a significant part of his or her developmental years outside the parents' culture. The TCK frequently builds relationships to all of the cultures, while not having full ownership in any. Although elements from each culture may be assimilated into the TCK's life experience, the sense of belonging is in relationship to others of similar background" (Pollock & Van Reken 2009:13).

The term originated with sociologists Ruth Hill Useem and John Useem. In the 1950s, the Useems studied Americans who lived and worked overseas in India, including "foreign service officers, missionaries, technical aid workers, businessmen, educators, and media representatives" (Useem 1993). During the course of their fieldwork, the Useems noticed how groups of expatriates (from all countries, not strictly Americans) formed communities of their own, separate from the host and home cultures (Useem &

Useem 1967). They discovered that "each of these subcultures generated by colonial administrators, missionaries, businessmen, and military personnel—had its own peculiarities, slightly different origins, distinctive styles and stratification systems, but all were closely interlocked" (Useem 1973:122). To explain these communities of expatriates, the Useems used the term "third culture" (Useem et al 1963). "First culture" refers to the home or "passport" culture of the individuals living abroad. "Second culture" is the culture of the host country; to describe the interstitial or "culture between cultures" that expatriate communities formed, the Useems coined the phrase "third culture."

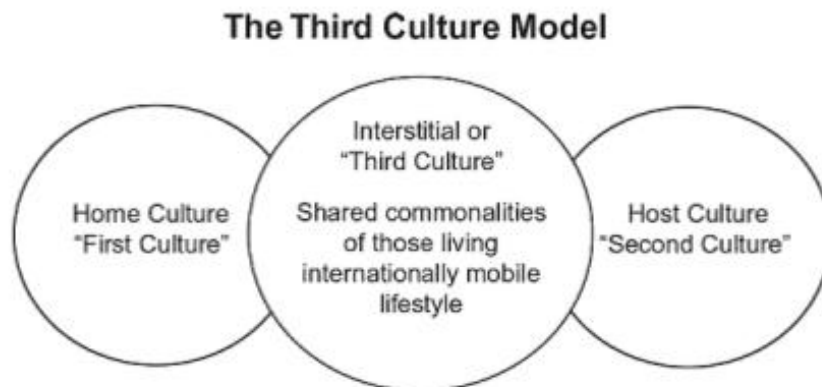


Figure 2-1 The Third Culture model
(© 1996 Ruth E. Van Reken)

Fig. 9

The Useems found children who had accompanied their parents overseas and who were raised within a third culture particularly compelling. These children became known as "third culture kids." As Ruth Hill Useem explains,

"In summarizing that which we had observed in our cross-cultural encounters, we began to use the term 'third culture' as a generic term to cover the styles of life created, shared, and learned by persons who are in the process of relating their

societies, or sections thereof, to each other. The term 'Third Culture Kids' or TCKs was coined to refer to the children who accompany their parents into another society" (Useem 1993).

In their book on third culture kids, sociologist David C. Pollock and adult TCK Ruth Van Reken note the importance of the Useem's pioneering work, arguing that

"The Useem's research wasn't in one expatriate subculture or 'sector,' such as corporate or military, but included them all. Because of that, as Dr. Ruth Useem studied TCKs of all backgrounds and did not isolate them into sector-specific groups, she was able to see the common threads that linked them" (2009: 15).

Subsequent research has focused primarily on the facets of TCK identity as well as issues of identity development (Dewaele & van Oudenhoven 2009; Fail et al 2004; Greenholtz & Kim 2009; Moore & Barker 2011; Lyttle et al 2011; Melles & Schwartz 2012; Walters & Auton-Cuff 2009). Pollock and Van Reken's (2009) book offers a comprehensive overview of TCKs, demonstrating how a childhood characterized by high mobility and many cultural worlds has affected parts of TCKs' personal and cultural being. Although the authors do not offer a definition for "cultural worlds," Pollock and Van Reken's conceptualization of the "world of TCK" is similar to Alfred Schutz's phenomenological concept of "lifeworld." That is, "the intersubjective world which existed long before our birth, experienced and interpreted by others" which is now "given to our experience and interpretation" (Schutz 1970:72). Pollock and Van Reken expand the list of potential TCKs to include children who "have parents with careers in international business, the diplomatic corps, the military, or religious missions [. . .] parents who studied abroad [and] families [that] live for a period of time outside their home culture because of civil unrest and wars" (Pollock & Van Reken 2009: 4). More recent scholarship on TCKs has critiqued existing literature for ignoring issues of diversity, especially socioeconomic

diversity, within the TCK population. As anthropologist Danau Tanu points out, too often “Third Culture Kids is conflated with children of expatriates - a conflation that overlooks the diversity of children growing up in transnational social spaces” (2015). Tanu argues that “it is important to treat the ‘third culture’ as dynamic and changing in relation to specific socio-historical contexts [. . .] only then can we begin to situate the existing study of Third Culture Kids within the broader study of migration and identity” (Tanu 2015).²⁷ In an attempt to demonstrate the dynamism of third culture, I will apply the "TCK Profile" developed by Pollock and Ven Reken to analyze another population raised within a trans-cultural environment: hearing children of deaf adults.

Third Culture Kids and codas - points of parallel

The parallels between TCKs and codas are striking. Because they spend their developmental years transitioning from place to place, TCKs are "raised in a neither/nor world. It is neither fully the world of their parents' culture (or cultures) nor fully the world of the other culture (or cultures) in which they were raised" (Pollock & Van Reken 2009:4). As discussed in the preceding chapter, codas are much the same. Raised in a Deaf world but biologically hearing, codas belong *neither* to the world of their parents *nor* to the world of their hearing peers. Codas only partially belong to either. Both groups, coda and TCK, exhibit an unclear and often conflicted sense of belonging. As Preston articulates, "[codas] represent a realm of ambiguity obscured by rigid

²⁷ For further reading on the ideologies behind the Third Culture Kid construct, see Benjamin and Dervin's edited volume *Migration, Diversity, and Education: Beyond Third Culture Kids*. This volume explores current debates around TCK literature from multiple disciplinary perspectives including sociology, anthropology, education, linguistics, and transnational studies, and revisits some of the key concepts associated with TCKs.

categorization; their lives incorporate two often conflicting systems of meaning" (Preston 1995: 1461). Similarly, because of their constant movement to new countries and cultures, TCKs experience a "paradoxical nature" and internalize a feeling of "not fully belonging anywhere in the world" (Pollock & Van Reken 2009: 40; 2).

Instead of feeling a sense of belonging to any of the multitude of cultures in which they were raised, TCKs' "sense of belonging is in relationship to others of similar background" (Pollock & Van Reken 2009: 13). This sentiment echoes statements made by many of my coda informants in the previous chapter. Just as codas feel more at ease around other codas, the literature suggests that TCKs feel most comfortable around other TCKs (Greenholtz & Kim 2009). As Moore and Barker state, "not only do they feel fully understood among those who have a similar mindset and worldview; TCIs²⁸ also tend to feel part of a special in-group who grew up with a sense that they represented something greater than themselves, be it their country, government, or God" (2011: 555). This kinship with like-minded and similarly-situated individuals can be seen in comments from a popular TCK webpage, *TCKids: A Home for Third Culture Kids*.

²⁸ TCI stands for Third Culture Individual, a term sometimes used to refer to adult third culture kids.

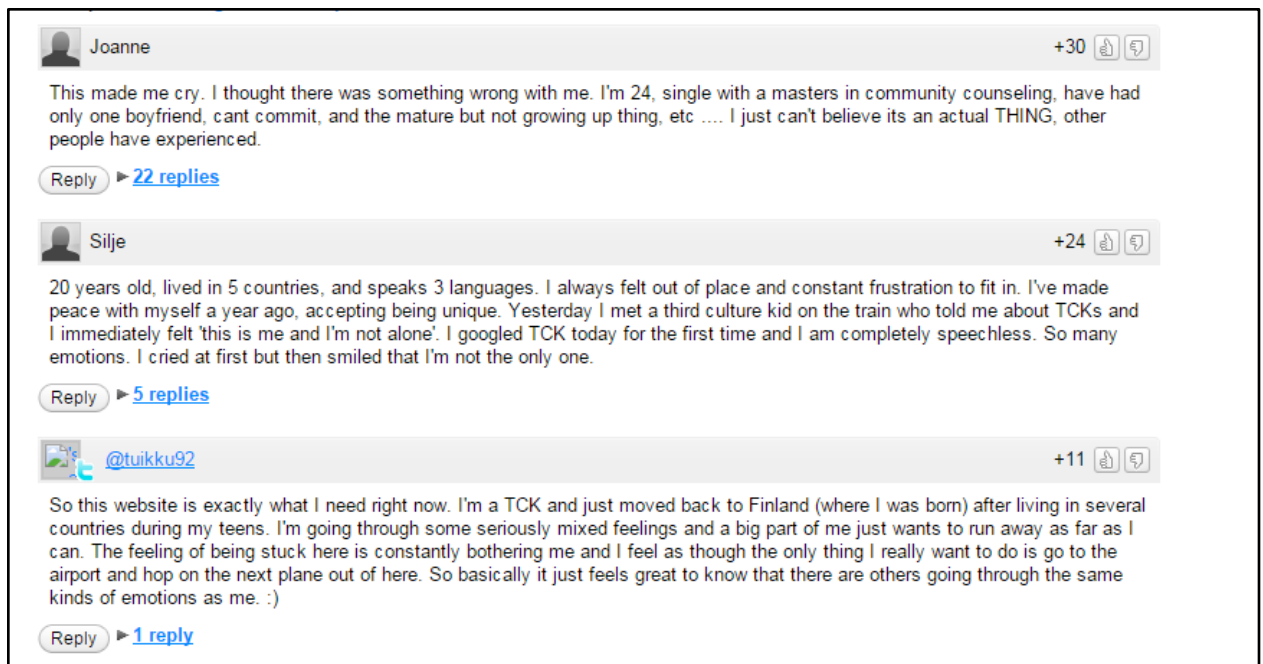


Fig. 10: <http://tckid.com/what-is-a-tck.html>

These comments illustrate the profound sense of loneliness, isolation, and restlessness that many TCKs experience prior to the discovery that there are others out there like them.²⁹ As Pollock and Van Reken explain, it is "obvious how delighted [TCKs] are finally to find a forum where simply naming how they have felt in various circumstances brings instant understanding" (2009: 26). TCKs hold an affinity and bond towards those who have experienced a similar lifestyle; there is "something about growing up in and among many cultures that creates an emotional experience and bond that transcends the details" (Pollock & Van Reken 2009:18). The supposed "magical connection" between TCKs is reminiscent of the fictive kinship among codas examined in the previous chapter

²⁹ It is important to note that not *all* codas or TCKs feel isolated or lonely, and I do not intend to generalize these populations as such. For example, when Ruth Sidransky (coda author of *In Silence*) spoke at the 1991 CODA International conference "she told the coda audience that while she appreciated the organization, she did not feel she 'needed it' anymore. The implication was that CODA was for those still struggling, conflicted, etc." (Paul Preston, personal communication, December 30, 2015).

(Pollock & Van Reken 2009:18). I would argue that TCKs have likewise constructed a fictive kinship network.

Similar to the development of CODA organizations and koda camps³⁰, TCKs have established communities of their own. Indeed, "both at home and abroad, adult TCKs seem to do best when they find their own community made up of expats and globe-trotters like them" (Lang 2002). In recent years, TCKs have become more vocal and connected to one another. Through organizations, websites,³¹ and social media, TCKs have constructed identifiable groups. They have even made their way into popular culture. For example, Barack Obama has been cited as a well-known example of a third culture kid, and BuzzFeed has compiled a humorous list of "Signs You're a Third Culture Kid."



Fig. 11: <http://www.buzzfeed.com/regajha/31-signs-youre-a-third-culture-kid>

³⁰ Koda camps are summer camps for "coda kids" more commonly referred to as "kodas."

³¹ There are a handful of websites for TCKs. <http://www.tckworld.com/> calls itself "the official home of third culture kids" and "the official home of Dr. Ruth Hill Useem." <http://www.tckid.com> is another well-known webpage. There is also the U.S. State Department's Foreign Service Youth Foundation.

Just as Coda communities are founded upon the mutuality of having grown up with Deaf parents, emergent TCK communities have been constructed upon the singular and shared experience having grown up in a cross-cultural and constantly mobile environment. For both groups, the formation of a discrete community offers a more concrete identity and a less muddled sense of belonging.

Codas talk about TCKs and the children of immigrants

Not only is the connection between codas and TCKs evident in an analysis of the literature, but it is also a theme that emerged organically from my interview data. A number of informants spoke about the fellowship they feel with TCKs. The term "third culture kid" first appeared when an informant, Steven, mentioned it in an interview:

A good example is uh third culture kid. Maybe someone whose parents have come from Mexico and are now living in America and they speak Spanish with their parents but English with everyone else. So it's this idea that I can see as like it's even more convoluted with deafness and sign language because of the stigmas, because of the lack of accessibility, because of just like the finite moment of sign language.

I asked Steven what language, English or ASL, he used among family members, and he explained that "we always sign to our parents and talk amongst ourselves." Steven likens this practice of code switching to experiences that TCKs also have. He makes a distinction between codas and TCKs, however, arguing that the uniqueness of American Sign Language creates a different scenario. He associates signed languages as being more stigmatized than spoken languages, and less accessible.

Steven's comments connect to larger arguments about codas as heritage language learners: "a language student who is raised in a home where a non-English language is spoken, who speaks or at least understands the language, and who is to some degree

bilingual in that language and in English" (Compton 2014:275). Tyra, another informant, specifically labels herself as such:

So it's called heritage language speakers. It's kind of a new term that's going around in respect to this community. It's not a new-well it's kind of a new term in general, but um definitely with respect to codas it's kind of a new thing. And so it means that you speak a different language at home than the majority language. And so for those of us who are heritage language speakers often we're not as fluent in the home language, just because you have less input and a lot of times you end up losing your proficiency all together.

Importantly, Tyra suggests that the term heritage language learner has only recently been used to talk about codas. Perhaps this is because both public discourse and academic literature have only recognized codas as a distinct population in recent years. Or, it could be that labeling codas as "heritage language learners" is a way to further assert that ASL is a "real" language, not just a gestural version of English. Regardless, the classification of codas as heritage language learners further likens them to TCKs and other similarly situated children, particularly the children of immigrants.

Indeed, a number of my informants talk not only about TCKs, but about the connections they feel to immigrant children. For example, as one informant, Maggie states:

EM: Okay and do you feel like there's a distinct Coda identity that's separate from a Deaf identity and from hearing identity?

Maggie: I do actually um I think it's one that's most similar to the experience of second generation immigrants. So I have a colleague next door, who does work on first and second generation immigrants. And sort of parental and language issues, and it seems to me that there's a lot more similarity in that we're doing a lot of cultural bridging, etc. The exception being that I think for codas they have to do the bridging, not only for their parents and the rest of the world, but they also have to be the bridge for the previous generation in a sense that they're the bridge between their parents and their parents' parents. Um I think that's the one exception that I see and that difference, but a lot of the other stuff is very similar.

Here, Maggie declares that the lived experience of being a coda holds similarities to that of a second generation immigrant because both groups have to practice "cultural bridging." Indeed, as discussed in the background chapter, codas often serve as cultural brokers and interpreters for their deaf parents. Existing literature further supports comparisons between deaf-parented families and immigrant family structures (Pizer 2013: 75). Maggie differentiates the experiences of children of deaf adults from children of immigrants, however, by emphasizing how codas' kinship relationships are compounded by an element of deafness. In an immigrant family, presumably both the parents and grandparents speak the native tongue and it is the children who learn the host country's language. In a deaf family structure, though, it is far more likely for the grandparents to be hearing, the parents to be deaf, and the child to be hearing. Thus, the child must act, not only as interpreter between the parents and the hearing world, but also between the deaf parents and the hearing grandparents. As my conversation with Maggie continued, she (with my prompting) spoke about TCKs:

EM: Okay yeah I've read a lot in my literature review-I've picked up a lot of stuff with second generation immigrants

Maggie: Yeah.

EM: Or third culture kids.

Maggie: Yeah.

EM: A lot of that.

Maggie: That's exactly right. That's where I feel like a lot of affinity. So indeed I actually have a lot of friends who are also third culture kids. Um who are-their parents were immigrants so a lot of my friends have that. We have that in common

EM: So you think that connection just comes from the shared experience?

Maggie: I think it does come from the shared experiences, a lot of the shared experience. Um it also is, a lot of it is also similar class background too. So they're um..I mean even though both my parents went to college that sets them apart from a lot of people. They're employment status was never...con-never like

consistent, my mom's was always consistent, my father's wasn't consistent. And so we had very fluctuating income levels growing up.

EM: The similarities.

Maggie: Yeah similarities there.

Here, Maggie lumps third culture kids with children of immigrants as a group she feels attachment to. She suggests that the friendships she shares with such individuals stems from not only the shared experience of acting as "cultural bridgers" but also the reality of growing up with a lower socioeconomic status. This association with a poorer class background links codas more so with the children of immigrants than with TCKs because, generally, TCKs are of a higher socioeconomic standing; sometimes they are even referred to as the "global elite's children" (Desilets 2015:147). This demarcation is important because it suggests that codas, while similar to TCKs on many levels, are also different in important ways.

The TCK Profile and its relevancy to codas

Pollock and Van Reken (2009) have constructed a "TCK Profile" outlining the major traits that typify Third Culture Kids. Some of the characteristics "are primarily a result of the cross-cultural nature of the third culture experience. Others are more directly shaped by the high mobility of the lifestyle" (Pollock & Van Reken 2009: 88). Regardless, because of similarities in cross-cultural upbringing, many of the traits characteristic of TCKs also apply to codas. Although Pollock, Van Reken, and other scholars have collectively created a long list of attributes common among TCKs, the ones I will primarily focus on for the purposes of this discussion are open-mindedness, adaptability, and rootlessness because these characteristics directly impact how codas approach the cochlear implant controversy.

Open-mindedness

One hallmark of the TCK Profile is open-mindedness. Because of their highly mobile lifestyle, TCKs experience "cross-cultural enrichment" (Pollock & Van Reken 2009: 95). TCKs live "in other places long enough to learn to appreciate the reasons and understanding behind some of the behavioral differences rather than simply being frustrated by them as visitors tend to be" (Pollock & Van Reken 2009: 95,96). In other words, instead of just visiting the culture, TCKs are immersed in it and internalize its underlying assumptions. Through this process of involvement in multiple cultures, TCKs "learn how people view life from different philosophical and political perspectives," and consequently develop an "expanded worldview" that is more well-rounded than that of many mono-culture individuals (Pollock & Van Reken 2009: 88). TCKs' cross cultural experiences provide them with an "awareness that there can be more than one way to look at the same thing" which makes them inherently culturally relativistic and less apt to be prejudiced (Pollock & Van Reken 2009: 88). Indeed, a study by Melles and Schwartz confirms that the level of exposure to other cultures and amount of time spent among culturally and ethnically diverse people predicts levels of prejudice in TCKs (2012).³²

TCKs' bilingualism or multilingualism also contributes to their open-mindedness. The literature states that fluency in multiple languages is linked to an advantage in divergent thinking. As Dewaele and van Oudenhoven explain, "multilingual/multicultural experience allows individuals to perceive the world through

³² Pollock and Van Reken do warn, however, that some TCKs actually exhibit higher levels of prejudice because, historically, they were part of an elite, wealthy group which may have fostered feelings of entitlement and superiority (2009: 105).

the amalgam of two different conceptual prisms and view events with a wider range of enriched experiences" (2009: 447). In short, TCKs' cross cultural and mobile lifestyle creates a culturally enriched, multilingual individual with an expanded worldview who is intrinsically more open-minded because of their exposure to and understanding of multiple cultures.

As discussed earlier in the chapter, codas' background of cross-cultural upbringing holds many parallels to the lives of TCKs. Therefore, I argue that open-mindedness is also a hallmark of the "Coda Profile." When asked about the privileges of being a coda, many of my informants speak about the benefits of a bicultural identity and the well-rounded worldview that results from a cross cultural upbringing. For example, Frank argues that codas are naturally more sympathetic, caring, and accepting of difference because of the nature of their exposure to both Deaf and hearing cultures. As he states:

I think codas are genuinely good people and I'd say it's an advantage. I'd say it's uh you know depends on how you look at it. Sympathy can get you hurt a lot of times, but in our situation it just means we're, you know, we're caring people. We like helping others and everything so it's, I'd say that's probably the one biggest thing is the whole sympathy aspect.

Frank talks about a specific incident where his coda upbringing made him more sympathetic to the troubles of a deaf classmate who had gotten a cochlear implant. As he explains,

The kids standing behind him calling him shit. That kind of stuff was really sad. And part of this is going back to what you said about are coda kids a certain type of kid? I was I -because of what I had been through I went, you know, I'd always be following up to those kids that I saw do that being like "are you serious? Like come on, are we really gonna do this right now?" And just help him out a little bit [. . .] the only problem is that all those mean kids have a mentality that that kid's

like retarded. He just can't hear behind him, you know? It's just really, that part is sad.

Because of his exposure to the Deaf world, Frank knows about cochlear implants and their functionality. So, when he sees an implanted classmate being teased, he feels sympathy for him and uses his positionality as a coda to confront and educate the “mean kids.”

In conjunction with a sympathetic nature, interviewees also spoke of the advantages of bilingualism.

Scott: Your cognitive flexibility is greater for bilinguals. Your standardized test scores are greater if you're a balanced bilingual, you know. Not if you learn the word for, you know, "casa" and "amor." You know, I'm talking about real, not Sesame Street bilingualism, but real stuff. And I think that, you know, your orientation to the world in terms of discrimination and being open minded about difference and diversity, all those things that come with being a bilingual, that's balanced, that respects both cultures and both languages.

Here, Scott talks about the academic and cognitive benefits of bilingualism. But more importantly, he makes a direct connection between bilingualism and open-mindedness. He cites bilingualism as a feature which contributes to a more liberal, non-prejudicial demeanor. He goes on to say:

I think what ends up happening with being, you know, sort of bicultural or bilingual in any degree to, you know, using any sort of two cultures or any two languages um...is that you have perspectives that are perhaps more well rounded, you know what I mean? You can come from a multiple perspectives toward an issue that allow you to think about ways and alternate sort of realities. So I think that advantage sometimes is there. Like you have this credential as a hearing person who also has intimate access to the Deaf world. So I think that people are more likely to listen. Hearing people are more likely to listen to hearing people.

Scott claims status as both a bilingual and bicultural individual, and argues that a bicultural lifestyle creates more open-minded and enlightened people. Here, it is

important to note that my informants who speak specifically about third culture kids seem not to distinguish between being bicultural and being a third culture kid. There is certainly a difference between the two: being bicultural implies belonging to two cultures simultaneously while being a third culture kid implies having connections to a multitude of cultures without fully belonging to any of them. Despite using the word “bicultural,” the way codas speak about themselves—as neither fully belonging to one culture nor the other, but existing somewhere in between—aligns more closely to conceptions of third culture. Nevertheless, Scott suggests that bicultural individuals are better suited to tackle complex issues because of their nuanced worldview. Specifically, he alludes to the cochlear implant debate, and suggests that, because of their cross cultural positionality, codas can think about the debate in a more informed manner. Codas' open-mindedness allows them to see all sides of the issue with more clarity.

Scott's conception of codas as individuals who "people are more likely to listen to" connects with Pollock and Van Reken's argument that TCKs' cross cultural skill set is useful for those "who go into international or intercultural careers [because] this ability to be a bridge between different groups of people can be useful in helping their company or organization speak with a more human voice in the local community and be more sensitive to the dynamics of potentially stressful situations in the international work environment" (Pollock & Van Reken 2009: 112). In many ways, codas already act as cultural bridges between the Deaf and hearing worlds because they grow up acting as cultural and linguistic interpreters for their parents.³³ However, in the context of the

³³ For a discussion of codas' role as interpreters, see the background chapter.

cochlear implant debate, codas' positionality becomes all the more important. Pollock and Van Reken warn that the downside of open-mindedness is a confused sense of loyalty among TCKs. As they explain,

"More difficult than the questions of political or patriotic loyalties, however, are the value dissonances that occur in the cross-cultural experience. As we said earlier, TCKs often live among cultures with strongly conflicting value systems. One culture says female circumcision is wrong. Another one says female circumcision is the most significant moment in a girl's life; it is when she knows she has become an accepted member of her tribe [. . .] In each situation, which value is right? Which is wrong? Is there a right and wrong? If so, who or what defines them? Conflicting values cannot be operational at the same time in the same place. How do TCKs decide from all they see around them what their own values will and won't be?" (Pollock & Van Reken 2009: 92).

For codas, confused loyalties are a facet of daily existence. As outlined in the background chapter and Chapter 1, codas grow up trying to navigate a clashing set of value systems. The hearing world generally favors cochlear implantation while many in the Deaf world condemn it. As individuals with ties to both groups, codas' opinions of cochlear implantation are convoluted. For some, their identity as a coda endows them with a sense of responsibility to weigh in on the cochlear implant debate. Two of my informants expressed strongly negative opinions about pediatric implantation, likening the process to child abuse.

Tyra: You can't see that kind of abuse and not be compelled to do something about it, especially when you have the privileges that I have as a coda where I...you know, I have a...you know, unfair or whatever yea, unfair access to um to doctors and speech pathologists and people are willing to talk to me and give me the time of day and I also have um, you know, access to the Deaf community in, you know, a way that other people don't. And so with those advantages I feel like I have a responsibility to um...to do something about it.

Scott: You can't see the kind of...abuse that's happening to these kids that you know, by parents who are very loving, but mis-or under-informed. You can't see that kind of abuse and not be compelled to do something about it.

The comparisons Tyra and Scott make between cochlear implantation and abuse are striking and speak to the strong feelings some codas have regarding pediatric implantation. In this instance, Tyra and Scott's statements reflect loyalty to the Deaf community.

The feeling of needing to act in the face of a perceived injustice connects to yet another facet of the TCK Profile: "three dimensional view of the world" (Pollock & Van Reken 2009: 93). According to Pollock and Van Reken, "as TCKs live in various cultures, they [. . .] experience the world in a tangible way that is impossible to do by reading books, seeing movies, or watching nightly newscasts" (2009: 93). Yet, coupled with this three dimensional view of the world is "the painful reality that behind the stories in the news are real flesh-and-blood people—not merely flat faces on a TV screen" (Pollock & Van Reken 2009: 94). This "painful awareness of reality" is certainly relevant for codas. Because they are so heavily invested in the Deaf world, the fact that children are being harmed physically, emotionally, and socially³⁴ by cochlear implant technology is a painful reality that cannot be ignored and is the factor that can prompt some codas to align with Deaf cultural values instead of hearing values.

Adaptability

Lyttle et al argue that "TCIs need to be flexible and adaptive in order to deal with the transitions they experience" (Lyttle et al 2011: 688). Indeed, as TCKs migrate from community to community during their developmental years, they learn the different

³⁴ See the background chapter for a discussion of the negative physical and social effects of cochlear implants.

customs of each culture and, over time, learn to conform their behaviors to match whichever culture they currently inhabit. Pollock and Van Reken liken TCKs to chameleons, declaring:

"Over and over TCKs use the term *chameleon* to describe how, after spending a little time observing what is going on, they can easily switch language, style of relating, appearance, and cultural practices to take on the characteristics needed to blend better into the current scene. Often their behavior becomes almost indistinguishable from longtime members of this group" (2009: 100).

Strikingly, not only is "chameleon" a word used by TCKs to describe how they are able to culturally conform, but it is also a word used by codas to describe their role as interpreters. One of Paul Preston's (1996) informants, Gerald, explains:

"It's one of the first questions everybody asks me, 'What was it like being the child of deaf parents?' As a boy, I felt like a chameleon. I just adapted to every situation. I could be any role. And I was in that role—at least for a while. I mean I was my mother when I had to interpret for her. I was my father when I had to interpret for him. I was the mechanic, the teacher, the car salesman. I assumed the personality of whoever was speaking at any given time. I was that person. I was whatever anybody thought I should be. You know, I fit into that mold just like a chameleon" (1681).

Inhabiting the interpreter role, codas conduct a chameleon-esque routine similar to that of TCKs. Gerald's experience is distinct from the TCK experience, however, because he does not switch his behavior to match a culture, he switches his behavior to encompass the identity of whoever he is interpreting for. Regardless, the parallel between TCKs and codas remains because both groups must alternate personas and act differently in different arenas.

Although it is harder for codas to become "indistinguishable" from their Deaf family members and friends because of their fixed identity as a hearing person, they can

blend quite effectively into Deaf culture. For example, my informant Frank explains that from afar it is often difficult to distinguish a coda from a Deaf person:

Like you would go up to a group of people, everyone's signing, and you start kind of figuring out who is actually deaf and who isn't. You get surprised.

Frank admits that there is a process to determining who is and is not deaf, and that those differences are not immediately apparent. In communities like 18th century Martha's Vineyard or the modern day Al-Sayyid Bedouin in Israel everyone, deaf and hearing alike, utilizes sign language; the fact that "everyone here spoke sign language" makes it difficult for outsiders to discern who is deaf and who is hearing (Groce 1988; Kisch 2008). Similarly, Jane explains that when she was a child "*we didn't really distinguish deaf or coda.*" Certainly to outsiders, codas can appear to belong fully to Deaf culture. The "Coda Brothers," a YouTube duo who make videos about what it is like to be the hearing children of deaf adults, recently released a video about using your "Deaf card" (<https://www.youtube.com/watch?v=0WfZjsVlb8s>). In the video, the brothers talk about pretending to be deaf in order to get half-priced movie tickets, free video phones, better seats at concerts, and starring roles on ABC Family's *Switched at Birth*. Although this video is highly satirical and meant to be humorous, it does touch upon some real issues. To people unfamiliar with the Deaf community, codas can easily pass as Deaf.

Codas are also capable of passing as hearing when in a hearing environment. Because they are not biological citizens of the Deaf biosociality, when removed from a Deaf environment, codas' "Deaf heritage [is] invisible to most; their familial link to a separate culture and identity [is] not readily apparent" (Preston 1995:1464). As such, presumably anybody could be a coda. Outside of seeing them use ASL, there is virtually

no way of knowing who is or is not a coda. I even had an informant ask me if I was a coda during an interview. Both TCKs and codas, because of their experiences inhabiting multiple cultures, have developed an adaptability that allows them to navigate and, to some measure, blend into different environments. Moore and Barker describe this as "shifting identities" or "intercultural literacy": the ability "not only to communicate but also to shift between different cultural identities and operate from the standpoint of an insider" (Moore & Barker 2011:555).

Pollock and Van Reken problematize the adaptability of TCKs, arguing that:

"although in the short term the ability to 'change colors' helps them fit in with their peers day-by-day, TCK chameleons may never develop true cultural balance anywhere. While appearing to be one of the crowd, inside they may still be the cautious observer [. . .] always a bit withdrawn and checking to see how they are doing" (Pollock & Van Reken 2009: 101).

As explored in the previous chapter, codas do experience a lack of cultural balance. Just as TCKs are "cautious" about their outsider status, so too are codas. As explained by my informant James:

"If anything I would come to the Deaf community and feel a little inept in my abilities because um I, the way I sign, even though I understand the language structure, is very hearing-like where I would, I speak, I sign in most, not all the time but uh a lot of the times, I speak as if I'm hearing in sign language. So there's a sign for, it's this [he does the sign for hearing-minded] so if you're, you know, you're talking it's you're hearing.

James describes feeling self-conscious about his signing and worries that his hearing identity impacts his signing in a way that marks and distinguishes him from Deaf signers and calls attention to his difference.

Not only do codas have trouble fitting seamlessly into the Deaf community, they are also insecure about their status in the hearing world. As mentioned in Chapter 1,

Victor explains that some codas have difficulty connecting with Hearing people. He remarked that some codas who are married to a Hearing person "*have to get a divorce because they're starting to realize that the other person's not recognizing that part of their identity*" or "*they're getting to the point where they're still not able to make friends because they just don't understand their identity.*" Likewise, Isabella explains how "*my husband jokes that I don't really know how to socialize and interact with hearing people*"; and Jen talks about the "*coda tendencies that I have that sometimes don't mesh when I talk to just hearing people.*" This is not unlike the experiences of transgender individuals who must navigate gender expectations in order to "pass" as female or male. Sandy Stone comments that "passing, of course, is not an activity restricted to transsexuals. This is familiar to the person of color whose skin is light enough to pass as white, or to the closet gay or lesbian...or to anyone who has chosen invisibility as an imperfect solution to personal dissonance" (2006: 232). Undeniably, like TCKs, codas have the ability to switch from culture to culture, but sometimes they have difficulty flawlessly "passing." Codas do not purposefully try to "pass" as deaf; however, adaptability that they do have is useful in efforts to "fit in" more comfortably in the Deaf community. For codas, the goal of "passing" is not to hide, but to mitigate some of the differences that can alienate them from the Deaf community.

Rootlessness and its implications for the cochlear implant controversy

Accompanying TCKs' open-mindedness and adaptability is a sense of rootlessness. As Dewaele and van Oudenhoven explain, TCKs are known for "having a global perspective, being socially adaptable, intellectually flexible, able to think outside

the box and reconcile different points of view. Yet, also somewhat rootless and aloof" (2009: 445). The rootlessness characteristic of TCKs stands in direct contrast to Yi-Fu Tuan's conceptualizations of "rootedness," which he defines as "being at home in an unself-conscious way" (1980:4). Because of TCKs' highly mobile lifestyle, "home" is a complicated concept, something that does not come effortlessly: "no matter how home is defined in terms of a physical place, the day comes for many TCKs when they realize it is irretrievably gone" (Pollock & Van Reken 2009: 126). Although codas are generally domestic and do not live a transient lifestyle, I argue that they reflect a sense of rootlessness similar to that of TCKs. Codas' rootlessness stems, not from a highly mobile lifestyle, but from a conflicted sense of belonging (explored in the previous chapter). When Pollock and Van Reken talk of TCKs' as rootless, they discuss rootlessness in terms of physical "places" and equate rootedness with a sense of "home." They argue that, because TCKs move around so much, they are unable to form a significant attachment to a singular place that they can identify as "home." Other definitions of rootedness likewise denote a sense of attachment to a physical place. For example, environmental psychologist Francis McAndrew states that rootedness "results from long habitation at one locality" (1998: 411). Here, Edward Relph's (1976) phenomenology of place and conceptualizations of "existential insider" and "existential outsider" are helpful. Existential insiderness describes "a situation of deep unself-conscious immersion in place and the experience most people know when they are at home in their own community and region" (Seamon & Sowers 2008:45). In contrast, existential outsidership is "a sense of strangeness and alienation, such as that often felt by newcomers to a place or by people

who, having been away from their birth place, return to feel strangers because the place is no longer what it was when they knew it earlier" (Seamon & Sowers 2008:45). Based on these definitions, I argue that TCKs' sense of rootlessness aligns with feelings of existential outsidership. Because they move from place to place so often, TCKs do not feel "insiderness"; they never feel as if they are fully at "home" in any one place. Because codas are generally domestic, physical place is less important in discussions of rootedness. However, codas still reflect a sense of rootlessness similar to that of TCKs. While codas may feel "at home" with their deaf parents, they still express feelings of "existential outsidership" in regards to their place within the larger Deaf and hearing communities. They never feel truly comfortable either in the Deaf nor the hearing world and (as discussed above) often feel self-conscious about their positionality. Codas' lack of roots and their feelings of only *partially* belonging anywhere has resulted in a reluctance to accept a definitive role in the cochlear implant debate.

During interviews informants are quick to point out, and remind me, that they are not in fact Deaf. As such, they feel that they do not have the authority to speak about certain issues, including cochlear implantation. This contrasts with Scott's earlier comment that "*people are more likely to listen [to codas]. Hearing people are more likely to listen to hearing people.*" To other hearing people, codas have the authority to speak about Deaf issues because of their ties to Deaf culture. However, codas do not always accept the authority afforded to them by other hearing people. As exemplified by Steven below, many codas are hesitant to even declare whether or not they can be considered part of the Deaf community.

EM: So do you definitely identify as being part of the Deaf community?

Steven: I don't think that's for me to decide.

EM: Okay.

Steven: I think if they're willing to accept me and have me and allow me access, great. Am I fighting for it? Nah.

[. . .]

Steven: Deafness is its own separate issue that I don't truly comprehend. I have an opinion on it, I have a perspective on it, but I don't live it.

EM: Right.

Steven: I don't speak from a point of authority.

As Paul Preston explains, "the recent Deaf rights movement re-aligns the messenger with the message: to speak for the Deaf, you must be deaf [. . .] informants frequently described a sense of personal conflict" (1995: 1465). Being biologically deaf, it would seem, affords a certain amount of "cultural capital" (Bourdieu 1986).

I argue that deafness is a form of embodied cultural capital, or "long-lasting dispositions of the mind and body" (Bourdieu 1986:82). Embodied cultural capital differs from objectified cultural capital (material possessions) in that it is innate, like a dialect or accent. Cultural capital can be acquired "quite unconsciously" and its transmission "is always heavily disguised, or even invisible" (Bourdieu 1986:84). Indeed "the transmission of cultural capital is no doubt the best hidden form of hereditary transmission of capital" (Bourdieu 1986:84). Lotte Meinert would further characterize this type of cultural capital held by biologically deaf individuals as "bodily capital." As she explains,

"The fact that human beings are born into the world in specific, different physical bodies is an important resource [and] at birth the body is already a predisposed mixture of social and biological resources, and through the course of life the body is nurture and 'worked upon' in a social context to accumulate more bodily capital" (Meinert 2004:22).

The body of the deaf person is a form of capital that holds weight within the Deaf world—a very specific and narrow “field.” Wacquant and Bourdieu explain the social field as “a space of play”:

“A field is simultaneously a space of conflict and competition, the analogy here being with a battlefield, in which participants vie to establish monopoly over the species of capital effective in it—cultural authority in the artistic field, scientific authority in the scientific field, sacerdotal authority in the religious field, and so forth—and the power to decree the hierarchy and “conversion rates” between all forms of authority in the field of power” (1992: 17).

Codas inherit some measure of embodied cultural capital from their Deaf parents—most importantly knowledge of American Sign Language. Yet, because they are hearing-able, codas cannot truly acquire the “bodily capital” or cultural experience and education as experienced by those who cannot hear. This incomplete transmission and inheritance of Deaf cultural capital and bodily capital subsequently results in reduced social capital, or diminished networks of influence in which the coda is positioned. This leaves codas wary of their authority to speak about certain issues.

Without the proper capital, codas feel rootless and, as a result, feel ill-equipped to state whether or not they should have a role in the cochlear implant debate. My informants were noncommittal in responses to the question: Do you think codas have a role to play in the cochlear implant debate?

Isabella: Oh I don't know. Yeah I'm not sure. I've never really thought-I always kind of felt like...that's for deaf people to decide and be more involved in than me. I try to be more careful about how involved [I am].

Frank: Uhhmm [long pause] I don't think, in my opinion I don't think it's really our place. I-I understand that we're like really close to it and everything, but it should be an individual opinion or, you know, choice [. . .] I would I would say we don't really need to touch it?

Vlad: Um, but I don't really have an op-a determined opinion on whether codas should have any sort of authority on the question I don't think. I don't think it's, I dunno. Kinda expands on the whole topic of like well if the Deaf community will let us make those decision, then maybe.

These comments speak to a distinction between legitimacy and authority. As defined by Morris Zelditch Jr., "something is legitimate if it is in accord with the norms, values, beliefs, practices, and procedures accepted by the group" (2001: 33). As cross cultural individuals who are raised in the Deaf world and who know Deaf norms, values, beliefs, and practices, codas do hold legitimacy within Deaf culture. As Scott noted earlier, "*Like you have this credential as a hearing person who also has intimate access to the Deaf world.*" Yet, legitimacy does not always connote authority. The *Stanford Encyclopedia of Philosophy* states that "a theoretical authority in some area of intellectual inquiry is one that is an expert in that area," and argues that "the judgments of theoretical authorities give people reasons for belief " (Christiano 2013). Because their biological deafness offers them insights unattainable to codas as hearing individuals, Deaf individuals are considered theoretical authorities by codas. As "experts," Deaf individuals hold "authoritative knowledge." According to Brigitte Jordan:

"for any particular domain several knowledge systems exist, some of which, by consensus, come to carry more weight than others, either because they explain the state of the world better for the purposes at hand ('efficacy') or because they are associated with a stronger power base ('structural superiority'), and usually both" (1993: 152).

Deaf individuals are firmly rooted within Deaf culture and the Deaf biosociality. As such, they are associated with a stronger power base and can explain the state of the cochlear implant debate more aptly than "rootless" codas. They have the cultural and biological authority to speak about Deaf issues. Such authoritative knowledge is

politically contested and Deaf claims to authority rest on different structural and symbolic footings than the claims made by the biomedical community. While Deaf "authority" is respected by codas, many hearing people fail to recognize the authoritative knowledge of the Deaf community and instead favor the authoritative knowledge of the biomedical community, especially when it comes to discussions of cochlear implantation.

How are codas unique?

As demonstrated by informants' remarks earlier in the chapter, although codas share a number of similarities with TCKs and the children of immigrants, deafness is a compounding component that distinguishes codas from other similarly-situated children.

Paul Preston remarks:

"Although many of the issues and struggles of hearing children of deaf parents parallel children of other ethnic and racial groups, there is one important difference. Within the Deaf community, the critical measure of cultural identity is neither degree of language proficiency nor shade of skin color nor knowledge of customs. It ultimately depends neither on declarations of allegiance nor degree of interaction. Above all, to be Deaf is to *not* be Hearing. This exclusivity underscores why the emphasis on parental linkage is so crucial. Because hearing children share neither their parents' functional hearing loss nor, in many cases, their parents language, the primary source of cultural identity and community entrée is their connection with their parents. Only by association do hearing children have access to this exclusive identity and this community: 'mother father deaf'" (Preston 1995: 1466).

Just as codas' experience of *not* belonging has resulted in the formation of a Coda community where they do belong, TCKs have expressed similar sentiments: "our identity is an anti-identity, the only way we can define ourselves is how we are not" (Walters & Auton-Cuff 2009: 755). Yet, as Preston argues, codas differ from TCKs and immigrant children because of the rigidity of biological categories. Feasibly, TCKs and immigrants' children can learn about and integrate themselves into the cultures they are

raised in; they can learn the language and the customs. For codas, however, this is not enough. As biological relatives, but not biological citizens, codas can never truly claim Deaf culture. Despite their knowledge of Deaf customs and American Sign Language, codas' ability to hear places boundaries between them and true cultural inclusion.

Some articles make comparisons between deaf-parented families and trans-racial adoption families. As Singleton & Tittle argue, "deaf parents raising their hearing children are not unlike other parents who are not a member of their child's *native culture*" (2000: 227). The literature on transracial adoption further elucidates the differences between codas and other types of cross cultural children. Because of "apparent and immutable racial and ethnic differences between parents and children," the process of cultural socialization in transracial adoptive families is complicated (Lee 2003:721). This is known in the literature as the "transracial adoption paradox" (Lee 2003). Because of the biological differences between Deaf parents and hearing children, cultural socialization is similarly challenging and paradoxical in Deaf families. However, Deaf families differ from transracial adoptive families in significant ways.

Lee (2003) outlines four strategies for cultural socialization employed in transracial adoptive families: racial inculcation, cultural assimilation, enculturation, and child choice. According to the "racial inculcation" strategy, parents teach "coping skills to help children deal effectively with racism and discrimination" (Lee 2003: 722). Most transracial adoption cases discussed in the literature involve parents who belong to a majority culture and an adoptive child who is a minority. In Deaf families with hearing children, however, the roles are reversed. Deaf parents are members of a minority

culture; thus, hearing children automatically learn coping strategies to combat prejudice aimed at their parents, not at themselves. Hearing children learn the strategies used by their parents to battle discrimination against deafness. The second strategy is cultural assimilation which involves "parenting behaviors that reject[] differences or downplay[] the unique racial and ethnic experiences of children" (Lee 2003: 721). In particular, Lee discusses "a variant of cultural assimilation [. . .] that emphasizes a 'colorblind' orientation or a view of humanity without reference to ethnicity and race [where] the child's ethnicity and race are intentionally denied or deemphasized" (Lee 2003:721). Deaf parents differ here because it is almost impossible to exclude children from the hearing world. Children are surrounded by hearing culture: they have hearing family members, they are educated in hearing schools, and by default they learn the language of the hearing world. Next, in the "enculturation" and "child choice" strategies, parents either "make a concerted effort to teach their children about their birth cultures and heritage" or "provide their children with cultural opportunities" (Lee 2003: 721; 723). Deaf parents are excluded from the hearing world because of their biology. As such, they do not necessarily have the same option of becoming involved with the child's birth culture as hearing adoptive parents do. Whereas the parents of adoptees, TCKs, and immigrant children can feasibly learn about the native language and culture of the child, for Deaf parents of hearing children this is nigh impossible.

Biology hinders Deaf parents' ability to traverse cultural landscapes. As Isabella explains,

Jane: Yeah, I think there are a lot of similarities there [between codas and TCKs]. Um with the exception of those kids, their parents can like matriculate or they can become a culture.

EM: Okay.

Jane: Right? Whereas coda kids, their parents, you know you can get implanted, but that's still doesn't change the constitution of who you are.

EM: Right.

Jane: Right, so my parents could be oral deaf right and use spoken language, but they're still going to be deaf, they're still going to be that element of who they are and so that part can't ever change like you can mask an accent but you can't necessarily, you know [laughter] there's a slight difference in that way but yea I think it's a good comparison.

Deafness is a permanent state, one that even cochlear implants cannot alter.

EM: So to you implanted people are still deaf?

Jen: Yea, yea. And I would think that a lot of cochlear imp-those with cochlear implants would not, would also like to be respected as people who are still Deaf.

A Deaf individual, implanted or not, cannot claim membership to hearing culture. In this way, implanted individuals do not have the same parallels to TCKs as codas do. Whereas codas can make claims to both Deaf and Hearing culture, implanted individuals have a more difficult time attaining a Hearing identity. Mac, a Deaf man, validates these sentiments:

When you take the cochlear implant off the person, what do you call them? They're deaf. And then they put the cochlear implant on, are they-is it a different name? You know? So I don't know? I can say that all deaf when they're sleeping they take off their cochlear implant. They are all deaf you know?

Because codas' relationship to deafness makes their situation different from that of TCKs, adoptees, or the children of immigrants, I argue that codas should constitute a new classification under the umbrella term "cross-cultural kids" (CCKs). As explained by Pollock & Van Reken, "a *cross-cultural kid (CCK)* is a person who is living or has lived in—or meaningfully interacted with—two or more cultural environments for a

significant period of time during childhood" (Pollock & Van Reken 2009: 31). Codas, with their interactions with both Deaf and Hearing culture, certainly fit this definition.

What differentiates CCKs from TCKs is that

"the CCK definition is not dependent on the question of where CCKs grow up, such as outside the passport culture or overseas. This definition focuses on the multiple and varied layering of cultural environments that are impacting a child's life rather than the actual place where the events occur" (Pollock & Van Reken 2009: 32).

So, a TCK is always a CCK, but a CCK is not always a TCK. Pollock and Van Reken provide the following illustration to showcase the many different types of CCKs:

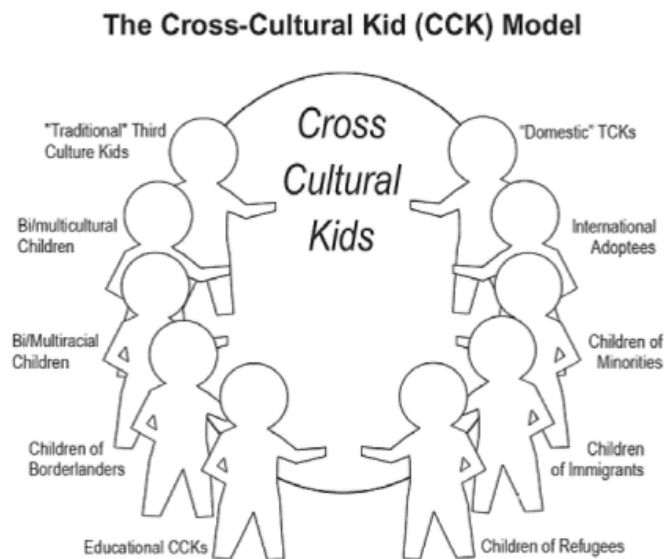


Fig. 12

Domestic TCKs, "those who have moved in and among various cultures right within their homeland," seem to be the category that fits most closely with codas (Pollock & Van

Reken 2009:36). However, based on the differences outlined above, it seems apt to revise the model to include hearing children of deaf adults as their own category of CCK.

Conclusion

To summarize: both codas and third culture kids experience a similar transcultural upbringing, fostering attachments to multiple cultures without fully belonging to any. The cross culturalism that characterizes codas and TCKs' developmental years has implications for both groups in terms of personal and cultural being, resulting in individuals who are inherently more open-minded, adaptable, and rootless. Notably, codas' feelings of rootlessness mean that they are often wary of staking a claim in the cochlear implant debate. I argue that as legitimate but not authoritative players in the cochlear implant debate, codas can have strong opinions about cochlear implantation but cannot claim to speak with any manner of "authoritative knowledge" about the controversy. The biological differences that distinguish codas from their deaf family members constrains their ability to claim membership or authority in the Deaf community. As such, codas differ significantly from TCKs and for that reason, I argue that codas should be included as a separate category in the "cross cultural kid" model.

CHAPTER 6

DISCOURSES AND DECISION-MAKING

In the background chapter, I outline the Deaf and hearing discourses about cochlear implantation, I explore how these discourses differ, and I discuss how the medical imaginary³⁵ positively influences hearing people's perceptions of the technology. In this chapter, I extend the discussion of discourses and perceptions, however I focus specifically on codas' attitudes towards cochlear implantation. As discussed in the preceding chapters, codas have ties to both the hearing and Deaf worlds. As such, codas have a unique perspective on (and perception of) the biotechnology, and I argue that codas' attitudes towards cochlear implantation signify an outgrowth of their identity as individuals situated between the hearing and Deaf worlds. I conclude the chapter by applying concepts from postphenomenological theory to investigate the particular ways codas conceptualize the decision to get a cochlear implant.

Coda discourse about cochlear implants

I contend that Coda identity³⁶ is extended through their interactions with and perceptions of cochlear implant technology. Hearing and Deaf perspectives both influence coda discourse about cochlear implants. On the whole, narratives about cochlear implantation among the hearing public are positive, while representations of the cochlear implant experience in the Deaf community are more critical. Because they are

³⁵ As a reminder, the "medical imaginary" is part of the "biotechnical embrace," concepts developed by Mary-Jo Delvecchio Good. The medical imaginary encompasses the ideas and knowledge about medicine and medical technology that circulate within public discourse and that influence perceptions of medical innovations.

³⁶ I use identity in this sense to mean "a core aspect of (individual or collective) 'selfhood' or as a fundamental condition of social being, 'identity' is invoked to point to something allegedly *deep, basic, abiding, or foundational*" (Brubaker & Cooper 2000: 7).

positioned between and have access to both worlds, codas receive information about cochlear implantation and the cochlear implant experience from either side of the controversy. Codas are inundated with romanticized ideas about implants from the medical imaginary; yet their perceptions are tempered by an intimate knowledge of and familiarity with the Deaf discourse. Indeed, because they were raised in the Deaf world, have strong familial ties to the Deaf community, and often have first-hand relationships with people who have been implanted, codas are more informed about cochlear implantation than most hearing people.

The advantages of cochlear implantation as articulated by codas

Codas' commitment to the Deaf discourse about cochlear implantation is complicated. As discussed in the background chapter, codas often become interpreters and cultural mediators for their parents. They also witness the discrimination and suffering their parents endure because of their inability to hear. As explored in chapters 1 and 2 respectively, being the hearing child of deaf parents can result in a confused sense of belonging and feelings of rootlessness. For these reasons, codas' childhoods can be difficult. Thus, it is understandable for them to see the usefulness and desirability of cochlear implants. My informant Frank, for example, shares how being a coda negatively impacted his childhood:

Uhm growing up was really tough because I was just, it was just me [. . .] So it was basically me against them [his parents] all of my childhood. Just because there was a language barrier. There was really strict rules and mindsets in our family. Like they were raised very Catholic and it just, it was tough, you know? And I ended up being pretty rebellious because of it [. . .] Yeah, a lot of communicational barriers and frustration and a lot of counseling and stuff to help with that, but you know it was really hard. I don't know if everybody dealt with that, but for me it was tough. Even if I was fluent and still it was always also this

feeling that you have to be there. You always have to be there to interpret. You always have to be there to, you know, when your dad's struggling with ordering a number 2 off the menu it's just easier to just say it behind his back to the person. Just be like Big Mac you know? Just let's hurry up. So I was pretty impatient that way, and it took me a long time to figure out that they've done well without me so there's no need for me to get so involved in everything and try to hurry things along so much.

Despite the fact that he is fluent in ASL, Frank felt there were communication barriers distancing him from his parents. He later explains that "*sign language is hard thing to kind of grasp, you know? A lot of the emotional mindsets that you might have. And it's just hard to say what you want to say. Sometimes you don't even want to sign it you know?*" During his childhood, Frank's parents' deafness was an obstacle, a biological difference that alienated Frank from his parents and caused turbulence in their relationship. He speaks about his childhood as a "me versus them" scenario, and describes feeling frustrated (and maybe even resentful) because of his parents' deafness. He would become irritated because, as the hearing child, he felt obligated to interpret for and assist his parents in their interactions with the hearing world.

Because of his negative experiences growing up with deaf parents, today Frank perceives deafness as detrimental. Further contributing to his poor perceptions of deafness are narratives Frank heard from his parents:

I'd say they're proud of what they are, but they're resentful for all the shit that's happened to them. Cuz, you know, Boston School for the Deaf and all that stuff.³⁷ It's just like horror story after horror story. So that was really sad to see them have to go through in the 50s and all that. So they've just, they've always been resentful about a lot of stuff because of that.

³⁷ Boston School for the Deaf is famous for having been a strict oral program. Children underwent arduous training to learn how to speak and lip-read. Students were forbidden from using American Sign Language, and would be physically hit if caught using their hands to communicate.

Learning about the "horror stories" his parents endured because of their deafness has made an indelible mark on Frank's opinions. Frank's parents' history of suffering, coupled with Frank's difficult childhood years, has painted a portrait of deafness as tragic, disabling, and undesirable in Frank's mind. As a result, he looks positively upon cochlear implantation as something that ameliorates deafness.

Any kid who's ever seen what happens to someone who is just, you know, fully deaf, the day to day activities like everything about it. Everything about it has just, it would make you want to not be deaf. Like why would you want to be deaf? Why would you want to be handicapped? Why would you want to be color blind or mute? Like those, that's not a good decision to make. [. . .] I understand there's a risk involved with the surgery and all that. That's something to think about, but I would say for the most part it should be on the parents to say I want a kid who can function in the real world and communicate intelligently to most people or I wanna deal with the responsibility. Like I'm, I sound like unsympathetic in that case, but that's the situation. Like being deaf is not fun. It's a great thing you should be proud of it if you are, but if you have a choice, don't, why would you wanna be deaf? Doesn't make sense.

Much like the cochlear implant advocates who argue that implants have made deafness a choice and the cochlear implant manufacturers who question "why wouldn't you [get an implant]?" Frank asks, "If you have a choice, why would you wanna be deaf?"

Despite Frank's strong negative feelings about deafness, he still harbors values of Deaf culture. This is reflected in his concern about sounding "unsympathetic" and his assertion that deafness, "It's a great thing you should be proud of it." Regardless of Frank's ideas about deafness, the Deaf discourse still influences the way he speaks about cochlear implants. When I ask Frank about the benefits of cochlear implantation, he says:

Uhm the benefits definitely are that you're more aware. You can hear things you never heard before. That stuff's great. Like short story, my mom didn't even know what a cricket was and then she heard a cricket for the first time and we went and

found the cricket and everything like th-those stories are cool cuz, you know, she's just she'd never been exposed to those things which is great but uhm the...well I-I'm gonna answer this as like an old person and a young person getting it. The older person, that's basically the only benefit to it uh because like I said you're already fully developed. You're not gonna change everything about yourself.

Frank recognizes the practical (and safety-related) benefits of cochlear implantation, suggesting that being able to hear makes a person more aware of their surroundings. He also talks about one of the more whimsical benefits of cochlear implantation, one that is often highlighted in activation videos³⁸: the curiosity and awe that accompanies hearing something new. However, while Frank presents the advantages of implantation, he also makes a point to acknowledge that cochlear implants are an imperfect technology. Especially for older deaf persons, the technology is less "effective" in terms of speech comprehension. Frank is the most "pro-cochlear implant" informant I interviewed. Yet he is not an unequivocal advocate of the technology; he balances the pros and cons of cochlear implants in his discourse.

I found that, like Frank, my other informants similarly talk about the benefits of cochlear implantation in a paradoxical way. A pattern has emerged in which my informants seem incapable of talking about the advantages of cochlear implantation without also mentioning its drawbacks. They continually couple positive statements about cochlear implants with negative ones, presenting a view of the technology that reflects a combination of hearing and Deaf discourses. The way codas speak about implants reflects their cross cultural positionality—their existence between the two opposing worlds.

³⁸ Videos that show people getting their implants activated for the first time.

For example, when asked about the benefits of cochlear implantation, Steven states:

I think it's a unique advancement of, like you say, the merging of human interaction with biotechnology. Does that make deaf children guinea pigs of a larger scientific experimentation? Perhaps.

Steven admits that the biotechnical capabilities of cochlear implants are remarkable. He seems impressed by the advances of modern medical devices and their ability to interface with human senses. However, in the next sentence he likens deaf children to guinea pigs in a scientific experiment. By simultaneously praising and criticizing the implants, Steven can admit that the technology has its benefits while retaining his commitment to the Deaf discourse. James and Vlad employ a similar type of rhetoric.

James: I think for those who it will actually work for? Um it gives them an opportunity to not feel outcasted, to not to feel included and to be quote [he uses air quotes] the same as everybody else.

Vlad: If there's enough guarantee that the person in question will be able to hear enough to make the implant useful, I think it's...uh a worthy option in life, to be able to use it as the person wants. Um I think it allows...for that person to be able to reach their potential, in a different aspect of life that they wouldn't be able to without the implant [long pause] I think those are the main aspects.

Saying "for those who it will actually work for" and "if there's enough guarantee that the person in question will be able to hear enough to make the implant useful," Steven and James clarify and reiterate that the technology is faulty. The implants do not always function perfectly and they do not work for everyone. Once again, James and Steven utilize a discussion about the benefits of cochlear implantation as an opportunity to also point out its disadvantages. Additionally, using air quotes when he says "the same as everybody else," James implies that he disagrees with society's constructions of

normality. In this way, James subtly conveys that he does not believe deafness equals abnormality.

Another of my informants, Tyra, also talks about implants in a paradoxically positive and negative way:

I guess you know maybe in some they give you access to a different kind of sound than hearing aids do. I'm not really 100% sure if its better or worse or you know I'm not really sure what the upsides are to cochlear implants over hearing aids.

Tyra admits that cochlear implants do influence a deaf person's ability to hear more sounds, however she modulates this praise by likening them to hearing aids, implying that they are not exactly what they are presented to be within the medical imaginary—they are not a miraculous "cure-all".³⁹ My Deaf informant Mac similarly equates cochlear implants and hearing aids. Indeed, he often speaks about hearing aids as the "Chevy" model to cochlear implants "Cadillac" model. For Mac, a cochlear implants is simply a more complex and more expensive type of hearing assistive device. This directly contradicts representations of cochlear implantation put forth by cochlear implant manufacturers. Advance Bionics claims that cochlear implants are different and superior to hearing aids, calling them "A Solution Beyond Hearing Aids." As Advanced Bionics urges:

"It's important to understand the difference between cochlear implants and hearing aids. Hearing aids merely amplify sound, which does not necessarily make it clearer or easier to understand. Cochlear implants are medical devices that restore the sense of hearing. Considered a medical miracle by many physicians, the cochlear implant is the only device that restores one of the five senses."

³⁹ Other informants also likened cochlear implants to hearing aids, suggesting that cochlear implants exist on a spectrum of assistive hearing technologies.

Tyra and Mac's failure to identify a significant difference between hearing aids and cochlear implants reinforces their perceptions of the technology as simply the newest in a long line of attempts to "cure" deafness. This subverts the medical imaginary's constructions of cochlear implants as miraculous.

Other informants speak about the ability of implantation to improve communication as a potential benefit. For example, Scott says:

I think that the uh obviously the benefit is that if you can gain the ability to speak and listen, you know on to some sort of reasonable degree that's like a skill that you can leverage to become successful in the world. So fine, you know, you can access information that way.

Within the medical imaginary, being able to restore hearing and develop the ability to speak are presented as the ultimate goal of implantation. Cochlear implant manufacturers portray deafness as tragic precisely because it prevents people from communicating and connecting with others in a normative way. Scott's comments, however, depict the ability to speak and hear as simple tools, almost like something you would list in the "special skills" section of a resume. Scott makes speaking and hearing seem advantageous, but in no way *necessary* to success. At another point in the interview he likens the ability to speak and listen to being good at painting: "*if the deaf kid can speak and listen with a cochlear implant, fantastic. Just like if a kid could be a fantastic painter. If you have this ability to paint, why not?*" He suggests talking and hearing are nothing more than nonessential skills people can utilize to access information; they are not necessary for fulfillment, happiness, or well-being as the medical imaginary touts. In talking about the ability to hear and speak in such a dismissive way, Scott undermines the idea of cochlear

implants as the only “logical” choice to ensure a successful life and he implies that cochlear implantation is an unnecessary procedure.⁴⁰

Like Scott, Maggie also spoke about the advantages of better communication:

Um uh I think there is a lot of benefit in one-on-one communication. Um uh...and...a little bit of a alleviating especially alleviating a lot of the lip-reading effort..in the one-on-one communication. Um my understanding from those three [the three implanted individuals she knows] is that group conversations are extremely difficult.

Once again, the informant talks about the advantages of cochlear implantation, however she mitigates this by acknowledging that conversations involving more than one person are difficult for implanted individuals to follow. In talking about the implants’ benefits, she creates a forum in which she can also remark upon the technology’s limitations.

My informant Jane took this back-handed complimenting even further. When I asked what she thought the benefits of implantation are, she stated:

Jane: Um it depends on who it's for. I think that there are all kinds of I mean perceived benefits. I don't know in actuality or just because I...personally would never experience that um at this point in my life um..I think that there are benefits to others...not um so immediately I would think that it would benefit others more than it benefits the individual

EM: So people around the individual?

Jane: Uh huh.

EM: Okay.

Jane: Um as far as helping them to communicate better with the individual.

Jane’s description of the benefits as “perceived” makes a powerful point about the purpose of cochlear implants and their effectiveness. Jane subtly criticizes the larger hearing community when she says that cochlear implants do not assist the deaf

⁴⁰ Jen makes a similar statement, saying: “I can understand these things [cochlear implants] being helpful as like further tools to maybe help the skills of learning hearing and speech, but they never take priority.”

individual, but the hearing people who interact with the deaf individual, suggesting that it is the hearing individuals who need “fixing,” not the deaf person. She questions whose limitations are really addressed with cochlear implant technology. Jane suggests cochlear implants are “for” the hearing world more so than the Deaf, subverting the deaf-as-disabled narrative.⁴¹

What the above examples illustrate is that codas' conflicted sense of belonging resulting from their existence as biological relatives but not biological citizens of the Deaf biosociality (chapter 1), coupled with feelings of rootlessness stemming from their cross cultural upbringing (chapter 2) manifests in paradoxical attitudes towards cochlear implantation. Codas are neither wholeheartedly for or against the technology. This is not to suggest that all deaf individuals or hearing individuals are unanimous in their attitudes towards cochlear implantation. Indeed, stances on cochlear implants vary significantly within both the Deaf and hearing communities; there are deaf individuals who support the development of cochlear implants and there are hearing individuals who condemn its development. What I maintain is that, because of their identity as hearing individuals raised within the Deaf world, codas formulate particular perceptions of cochlear implants, and these perceptions reflect their identity as inhabitants of a metaphorical "borderland."

The disadvantages of cochlear implantation as articulated by codas

As mentioned in the background chapter, activation videos are influential harbingers of how cochlear implants are constructed within the medical imaginary. The

⁴¹ The film *Audism Unveiled* similarly subverts the deaf-as-disabled discourse. The film's opening states that it is "subtitled for the signing-impaired." In this way, the film suggests that it is the hearing population that is impaired and limited, not the Deaf.

videos depict cochlear implants as helpful, powerful, and metamorphic devices. Because codas are immersed in Deaf discourse about the cochlear implant experience and are often acquainted with individuals who have undergone the procedure, they tend to be less swayed by the glamour of activation videos. As journalist (and coda) Lilit Marcus writes in her opinion piece *Why You Shouldn't Share Those Emotional 'Deaf Person Hears for the First Time' Videos*: "the 'deaf person hears for the first time' videos don't make me smile. They make me want to throw my computer out a window" (2014). Marcus argues that "these 'inspiring' videos continue to push one of the most problematic narratives in the history of the Deaf community: that deaf people are broken and therefore need to be 'fixed'" (Marcus 2014).

Like Marcus, my informants also critique the representations of cochlear implantation that suffuse the medical imaginary. For example, Jen speaks about how activation videos can be interpreted differently:

I remember, I don't know if you ever saw this video but it's really heartbreaking. There's this young girl who's like maybe about six or seven, your stereotypical cochlear implantation miracle story, which is not really a miracle at all. Like they're just hearing higher frequencies but really if someone were to speak to them they wouldn't be able to distinguish those sounds. Anyway, different subject. Anyway, the girl, when she got fitted for a cochlear implant and they started bringing up the noise she started crying, but it wasn't [. . .] She was like saying "stop stop stop it hurts it hurts." But like I swear I feel like people would just be like "oh my gosh look she's crying cuz she's so happy."

Jen finds the activation video "heartbreaking" because she construes the girl's reaction as a sign of pain and discomfort. For many, however, the girl's tears symbolize joy at being able to hear for the first time. In telling this story, Jen makes a point to discredit the idea of the cochlear implant as a miracle technology, drawing attention to the fact that the girl

is simply "hearing higher frequencies" and, at this stage, cannot comprehend spoken language. Jen's need to clarify that cochlear implants are "not really a miracle at all" speaks to her frustration about the misinformation that permeates the medical imaginary. Like Jen, Lilit Marcus is equally as frustrated by the lack of factual information presented in the medical imaginary. As she states

"What bothers me are the maudlin videos produced out of someone's intense, private moment that are then taken out of context and broadcast around the world. What bothers me is how the viewer never learns how the individual came to the decision about their implant, which factors they took into account, whether their medical insurance covered it. Sometimes we don't even learn their names" (2014).

Misinformation is something many of my informants find highly significant in any discussion of cochlear implants. When asked about the disadvantages of cochlear implantation, my informants focused more so on the harmful effects of inaccuracy than the cochlear implant itself. While there is an abundance of information available about cochlear implants in the medical imaginary, much of this information is tangled within biomedical narratives and does not represent an unbiased portrait of the implant experience. As my informant Tyra says, "*there's a lack of information and, at the same time, there's a lot of information.*"

The codas I spoke with do not despise cochlear implants. They are, however, frustrated by how uninformed people are about the technology. As Jen explains, "*they're [cochlear implants] more so bad because they're happening and society isn't educated about it.*" In particular, a major issue for my coda informants is the misconception that cochlear implants are a "cure-all." Growing up within the Deaf community and hearing Deaf narratives about the cochlear implant experience, codas know full-well that implants

are not fool-proof. They do not work for everyone. The idea that implants work immediately and completely has been fostered and perpetuated in the medical imaginary; and this misconception is upsetting for many codas. As Jen says, "*what pisses me off is that it's still a mass idea that these things are cure-alls when really it's just like no they're still deaf.*"

Maggie likewise laments how cochlear implants have been presented as infallible:

There is a message out there that this is going to fix it [. . .]the person you're talking with may tell you A-Z the real details out there but all you hear [. . .] It's gonna fix it. And so you know I think the problem is is that the early intervention specialists have to work against the sort of the individual psychologies of parents. Um and their message, so they may, you know, say all the right things, but it's not necessarily going to be absorbed.

Maggie emphasizes the power of the medical imaginary, suggesting that it has the ability to influence the "individual psychologies of parents." Maggie reiterates the idea that hearing people subscribe to a "political economy of hope"⁴² that makes them *want* to believe that cochlear implants eliminate deafness, and the desire to "fix" leads them to disregard narratives that suggest otherwise. This also echoes Jane's earlier arguments that cochlear implants are more for the hearing community than the Deaf. My informant Vlad makes a similar argument:

I think that's where some of the misunderstanding comes. That doctors and parents who just are desperate for some sort of solution because they don't understand the culture, the issue, uh are just looking for a quick fix. It'll make them feel better, they don't really understand the implications.

⁴² Please see the background chapter for a discussion of how a "political economy of hope" has influenced hearing perceptions of cochlear implant technology.

Sometimes, even Deaf individuals can be consumed by the medical imaginary's idealistic constructions of cochlear implantation. For example, Frank's parents have both undergone cochlear implant surgery.

Erin: Do you know anybody with a cochlear implant?

Frank: Yeah they both have it.

Erin: Your parents do?

Frank: Yep.

Erin: Do you know why they got it?

Frank: Uhm because it was fairly new and they thought that it was gonna change their whole world. They thought they were just gonna like get up one morning and be able to talk on a phone and all that.

Erin: And that wasn't the case?

Frank: No. I mean they were the two oldest candidates at the time for the cochlear implant. So by the point, by the time they got it in their sixties they had already fully developed all their mannerisms and weren't gonna change. So they got the implant. It helped them hear things like it opened their eyes to stuff, but nothing that they did, nothing, the way they spoke, the way they communicated, none of that changed.

Like many hearing people, Frank's parents—whom he describes as having been "capital D" Deaf—subscribed to ideas about cochlear implants as a miracle technology. The discourses that exist in the medical imaginary are strong enough even to influence those in the Deaf community.

Codas conceptualize decision-making

As evidenced above, codas are more informed about cochlear implantation than the average hearing person because of their unique positionality. Consequently, because codas are more informed, they conceptualize the decision-making process differently. To examine how codas' relate to cochlear implantation (and the decision to implant) I borrow concepts from postphenomenology.

Postphenomenology is a branch of phenomenological inquiry that seeks to illuminate human-technology relations. Described by its most well-known practitioner (Don Ihde) as "a modified, hybrid phenomenology," postphenomenology expands the scope of traditional phenomenology to understand the ways "technologies mediate the human experience, of oneself, other, and our lifeworld" (Ihde 2009: 23; Ihde 2008: 8). Most existing postphenomenological work focuses on intentionality—"the directedness of human beings toward their world"—and how technology mediates the way human beings relate to the world (Verbeek 2008: 13). As Verbeek explains, "virtually all human perceptions and actions are mediated by technological devices, ranging from eyeglasses and television sets to cell phones and automobiles" (Verbeek 2008: 13). Recent postphenomenological literature has analyzed cochlear implant technology. Indeed, building upon Don Ihde's work and Peter-Paul Verbeek's (2008) conceptualizations of "cyborg intentionality," Kirk Besmer argues that cochlear implants constitute a distinct form of technological embodiment and intentionality (2012). Besmer's work on cochlear implants focuses specifically on the relationship between the cochlear implant and its user, scrutinizing how the implant mediates the way its user experiences the world. What this literature fails to address, however, is how the technology impacts and influences people who do not physically "embody" it. Verbeek calls attention to this:

"Human intentionalities can not only be operative 'through' embodied technologies, but that in many cases 'intentionality' needs to be located in human-technology associations - and therefore partly in artifacts as well - without being able to entirely reduce the resulting intentionality to what was explicitly delegated to them by their designers or users" (2008:14).

There is a difference between interacting with a technology that functions as an extension of your own body versus interacting with a technology that functions as an extension of *someone else's* body. In line with Verbeek's comments, I explore how codas engage with cochlear implants without bodily interacting with them.

Codas do not utilize cochlear implants themselves, but they do interact with the technology and the technology does influence how they experience the world. Specifically, cochlear implants mediate how codas (and other hearing people) interact and communicate with deaf individuals. However, cochlear implants differ from other types of technology that people interact with (like eyeglasses) because they have become imbued with moral significance. Eyeglasses are not morally meaningful; thus, the decision to get glasses holds no moral weight or consequence. People have no qualms about saying "Oh, you need glasses" to someone. Cochlear implants, however, have acquired intricate layers of moral meaning, which hold moral consequence in relation to decisions about deafness.

In his 2011 book, postphenomenologist Peter-Paul Verbeek argues that technologies can develop moral significance. He examines the interplay between ethics and technology, stating:

“This active contribution of technologies to our daily lives has an important moral dimension. First of all, the quality of their contributions to our existence can be assessed in moral terms. Some roles played by technology can be called ‘good’ and other roles ‘bad’—even if it is not possible to blame technologies for the ‘bad.’ And second, by helping to shape human actions and experiences, technologies also participate in our ways of doing ethics” (Verbeek 2011:1).

Verbeek argues that technologies "embody morality and help to constitute moral subjectivity," and claims that "technologies help to shape human perceptions and

interpretations of reality on the basis of which moral decisions are made" (2008: 11, 13). In short, technologies can mediate how humans make moral decisions. The example Verbeek provides is speed bumps: they "help us make the moral decision not to drive too fast near a school" (2011:2). In another example, Verbeek posits that ultrasounds function in a mediating role, influencing moral decisions about abortion:

"the technology in the ultrasound practice clearly had moral significance, it did not directly steer our behavior. Rather, it helped to shape our experience of our unborn child and the interpretive frameworks that guided our actions and decisions. By establishing a very specific form of contact between the fetus and us, this technology had not simply granted us a 'peek into the womb'; it had reorganized the relations between or unborn child and ourselves" (Verbeek 2011: viii).^{43,44}

I suggest that, in a similar way, because cochlear implants have now made deafness a "choice," the technology has assumed a moral role that mediates decisions about deafness.

Poel and Kroes (2014) argue that technologies can "embody values." As evidenced by the different discourses about cochlear implantation, the technology is indeed value-laden, holding different meanings for different communities. As such, the decision to receive a cochlear implant or not can be constructed as a decision of moral consequence. Is it more moral to remain deaf or to achieve technologically-mediated hearing? Based on which representation of the cochlear implant you subscribe to, your ideas about the moral course of action will be different. For most hearing people, the

⁴³ It is worthwhile to note that the organization ANSIRH (Advancing New Standards in Reproductive Health) has found that "ultrasound viewing does not change women's minds about abortion" (2015). However, this does not negate the point Verbeek is making about how technologies can acquire moral significance.

⁴⁴ Other scholars, including Rayna Rapp (1999) and Janelle Taylor (2008) have made similar arguments about the impact of reproductive technologies.

morally sound decision would be to implant your child to ensure their future success, normality, and happiness. The opposite is true for many Deaf people. For codas, however, the moral character of cochlear implants is sometimes unclear. Cochlear implants pose a new choice, one with moral consequence not only for oneself, but for others as well.

Infant Implantation

Where this moral significance is of most consequence is in discussions of infant implantation. As explained in the background chapter, infant implantation is one of the most contentious issues in the cochlear implant debate. Many in the Deaf community condemn the implantation of infants because children lack the autonomy and agency to make the decision for themselves.⁴⁵ On the whole, the codas I interviewed disapprove of infant implantation.



Fig. 13

⁴⁵ This controversial picture by Deaf artist Daniel Winship depicts a dramatization of a child undergoing implantation surgery. This is a provocative piece that sparked controversy and debate on the artist's Facebook page. Although dramatized, it does speak to the strong opinions held by some members of the Deaf community: <https://www.facebook.com/winshipcreations/photos/pb.197181996996363.-2207520000.1369953236./514866838561209/?type=3&theater>

As Steven expresses:

EM: So if you had a deaf child you wouldn't implant them?

Steven: Oh god no. No. I mean would I prevent them when they're old enough to comprehend the decision they're making? No. But would I like take this child's..undeveloped free will and say "you're gonna strap it on cuz that's what I think is better for you"? Absolutely not.

The only informant who definitively states he *would* implant his hypothetical deaf child is Frank. This positionality is not surprising based upon Frank's thorny history with and negative perception of deafness (discussed earlier in the chapter). Most of my informants proclaim they would *not* implant their deaf child (if they were to have one); however, they express sympathy for hearing parents and exhibit an understanding of the medical community's motivations. As articulated by Scott, "*I personally would never implant my child. You know, I would not. I have no inclination to do it. I have no, you know, I have no ill will for people who decide to do it, but I just would never decide to do it.*" Once again, this dual discourse reflects codas' conflicting ties to both the Deaf and hearing worlds. My informants adhere to the Deaf discourse in their disapproval of infant implantation and assertion that they would not choose implantation for their own child, yet they reflect hearing values as they sympathize with hearing parents and hearing medical professionals.

Codas question the ability of uninformed hearing people to make decisions about cochlear implantation on behalf of their offspring. As Scott says, "*Epecially for parents who opt for cochlear implants um I think too often they're misinformed.*" Maggie elaborates, "*The problem is that there's no way they [hearing people] can be as fully informed as we'd like them to be precisely because they're coming at it from a different*

angle [. . .] they're hearing what they want to hear." For Maggie, hearing people are poorly-equipped to make knowledgeable decisions on behalf of their children because they are deeply entrenched in the medical imaginary's model of deafness as disability, inferiority, and abnormality. Jen expresses similar concerns about the power of the medical imaginary and its influence on hearing people's decision-making:

They often rely on doctors to tell them what to do. Doctors do not know about the issues, you know? [. . .] Hearing parents, doctors think that these are the solutions that are needed because there's no other alternative. And it's like no there are. And that's a thing, I feel like hearing parents and doctors think that they know what's up with how they're managing their kid, but it's like are you really in a position to say that? Have you really done the research? Like do you know? And I can't blame you if you don't because it's we don't have enough of these people in powerful positions.

Despite her statements criticizing hearing parents and doctors' ignorance, Jen does not assign blame. Instead, she points to the Deaf community's lack of representation and voice in the medical imaginary as the root of the problem. Tyra similarly refuses to place blame on the medical community:

You're getting the information from a speech therapist who doesn't think [. . .] Surgeons cut, right? Speech therapists do speech. And so, they're better equipped to talk about the things that they know. Audiologists know about hearing, so those people aren't necessarily as equipped to talk about the other options.

Tyra harbors no ill will towards medical professionals, and her comments like "speech therapists do speech" suggest a recognition that these individuals are constrained by the need to do the job assigned to them.

Codas are hesitant to vilify the medical professionals or hearing parents who are implanting infants, but do acknowledge they are problematic. For example, Tyra talks about the "*abuse that's happening to these kids by parents who are very loving, but mis-*

or underinformed." Tyra commends the parents' good intentions, but uses loaded words like "abuse" to express her strong disapproval of child implantation. Jen says "*I can respect their desires, but it boils me on the inside because I know that they're not informed enough.*" Similarly, Scott believes that "*this infant business is just scary,*" but he says "*I get it. I know why [hearing parents implant their children]. I'm not oblivious to this sort of rationale.*" He goes on to say:

"Obviously it's shocking and traumatic and there's grief that goes along with having a child who is different than you and who you consider to be special needs. There's no doubt about it, and that's like real. And I'm not glossing over that fact. But what we do is we capitalize on that, and I think that it makes it worse and we reinforce this notion of a child as incapable."

Scott sympathizes with hearing parents, indicating an understanding that having a deaf child can be a distressing event. Indeed the literature confirms that hearing parents often experience grief when learning that their child is deaf, and parents can have difficulty coping with the reality of having a deaf child (Feher-Prout 1996; Kurtzer-White & Luterman 2003). Scott implies that hearing parents are not entirely at fault, however, because the medical imaginary reinforces conceptions of deafness as tragic and capitalizes on parent's fears. From a postphenomenological view, the cochlear implant becomes a technological coping mechanism for hearing parents, mediating how they interact with their deaf child. Tyra likewise identifies that, for many hearing people, the news that their child is deaf is upsetting:

This is fraught territory because I don't intend to be critical of what parents are doing [. . .] And it's, I can't even fathom being a parent and getting, you're suddenly in the crossfire, you know? And it's a terrible place to be.

Tyra recognizes how difficult it must be for hearing parents, most of whom have no real knowledge about deafness or exposure to the Deaf community, to suddenly have a child who is deaf. She also acknowledges that parents get caught "in the crossfire," meaning they are presented with two disparate paths—get a cochlear implant for your child or do not—both of which are bound in moral value and judgment.

Codas' intimate and multifaceted knowledge of cochlear implantation influences how they "morally" conceptualize the decision to implant infants. On the one hand, they draw from the Deaf discourse that presents cochlear implantation as harmful. In this reality, the cochlear implant acquires a negative moral dimension, and the decision to implant is constructed as morally "bad." Yet, because of their ties to the hearing world, codas are able to recognize that, for hearing parents and medical professionals, cochlear implants embody a different set of values and mediate a different relationship to deafness. In this case, the decision to implant is the morally sound one.

Personal choice

In situations that do not involve infants and children, codas are strong proponents of personal choice (as long as the individual is adequately informed). For example, as Steven says:

Steven: I don't agree with implants.

EM: At all?

Steven: At all.

EM: Okay.

Steven: But

EM: But if it was somebody's personal choice as an adult over 18?

Steven: Sure.

EM: You respect the choice.

Steven: Yes.

Despite his personal dislike of implantation, Steven does not condemn others' decisions to be implanted. He feels the choice is the responsibility and right of the individual.

James and Scott express similar sentiments:

James: I think with my classes that I've taken obviously headed by Deaf people, their opinions on the cochlear implant as well as my previous experiences make it a very solid point that I would be against it [cochlear implantation]. But, then again, me personally I'm all about you having choice. You wanna do something, you go do it. Like I'm not gonna be the one to stop you.

Scott: I think it's, I mean totally up to them. That to me is, I have no concern about that. You know to me it's like, it would be like if you decided to get contacts or if you decided to get braces later on. Like, if you want to do it later on, you know, you make the decision for yourself. You're sort of interacting in the world. If you have, hopefully, a strong L1 [first language] and your friends and your life is set, and you're happy, then great [. . .] Initially I would be like if there was a deaf person who was culturally Deaf, who had Deaf friends, and Deaf family, if they got an implant I would be like "Woah! That's surprising!" You know? That's like weird. But like alright. That's fine, you know? You made the decision. You're an adult, you're well informed, and you're fully capable of making decisions for and about yourself. That's good.

Other informants echoed these affirmations of personal choice. Frank says "*it should be an individual opinion or, you know, choice;*" Maggie says "*I think it's personal choice;*" Tyra proclaims "*That's a personal choice if they're gonna do it.*"

In this exchange with Isabella, she explains her support for her deaf cousin and Deaf friend's decision to get implanted. She also proclaims that she would support her brother's decision to get an implant in the future (if he chooses to get one):

My strong feeling is I would, I totally support it and respected my cousin's decision to get an implant. My mother had a very difficult time with it. Feeling like she [the cousin] doesn't have a Deaf identity and that's why. But yet my friend at work has a very strong Deaf identity, uses an ASL interpreter all the time and has an implant. I totally respect her choice and I would not implant my daughter or myself, but I would respect her decision to do it later on in life when she's aware of the risks involved.

EM: So personal choice you have no problem with?

Isabella: Yeah exactly. And so with my brother I would respect his choice. I mean it's his life. It's his body. And I don't know what, how it works for him. And you know what I mean? I would choose not to do it for myself, but I wouldn't make a big deal of him choosing to do it for himself. Does that make sense?

Isabella notes that her mother, a Deaf woman, had a "difficult time" accepting her cousin's decision to implant and, earlier in the interview, she states that her mother does not want her brother to get implanted. Isabella, however, adopts a more neutral positionality.

When asked if they would consider an implant for themselves, three of my informants say yes. Two informants, Frank and James, answered quickly and confidently. The third, however, took a longer time to deliberate::

EM: Would you consider getting an implant or would you get an implant?

Tyra: Oh god. Ummm.

EM: Hard question.

Tyra: Yea I mean...I would have to consider it. Umm. But that's how I approach.

EM: Everything?

Tyra: Everything [laughter]. Um would I get one? [long pause] I don't know [long pause] I mean I am very aware of all the privileges that come along with my ability to hear.

EM: Mmmhmmm.

Tyra: Um, and I guess it would depend you know how much, was I born deaf? And when do I get the cochlear implant? Am I getting it as an adult or not as an adult? You know, if I went deaf now.

EM: Mhmm?

Tyra: Umm..my understanding is that cochlear implants in adults who have had speech before that can actually be fairly effective. Um. And so I might consider..I guess I might consider that.

Conversely, five informants state that they would *not* get an implant. Four—Scott, Jen, Isabella, and Vlad—all respond with a quick and confident "no." Steven, on the other hand, hesitates and wavers before answering. For him, it is not an easy question to answer:

Ahhh..no. And like, and I hate to even hesitate at that. Cuz it's like that "woah if I lost the faculty." No I think I would fully embrace that and appreciate the reality of that happening cuz then I can fully realize my own lineage and this long line of deafness and now truly be deaf and whatever whatever.

Like Tyra and Steven, Maggie has difficulty answering the question, and looking back at my interview data, I realize she never provides a definite answer:

EM: And if you were suddenly deaf tomorrow, would you consider one for yourself?

Maggie: Um that's a good question. Um I've had a migraine only once in my life and I thought it was really miserable so to me the idea of having migraines a lot really turns me off to the the thing, the idea. Um but I don't know how I would feel if I were suddenly in my workplace and didn't have auditory access.

EM: Mhmm

Maggie: But I also don't know what I would, what that auditory access is like.

EM: Right.

Maggie: Is it like overwhelming? Is it weird? Is it like you know? So I don't know.

EM: Okay, that's always a tricky question for people.

Maggie: Yea.

EM: It's a lot of I don't knows.

Maggie: No, I'm sure! I mean right now the biggest thing is like I don't ever want a migraine again.

EM: Yeah the risk doesn't outweigh..

Maggie: Um but I guess I don't know what it would feel like to not have, I mean had I lost my hearing I'd be a great candidate for it but...

Similarly, Jane leaves her answer at a noncommittal "maybe":

EM: Um so if you were suddenly deaf today or tomorrow, would you consider an implant for yourself?

Jane: [sigh] maybe? I I think I would be more likely to go the hearing aid option.

EM: Okay.

Jane: Right, if that weren't really successful I work and live in an environment where I could probably adapt. Not saying it wouldn't be hard but I I could and I don't think I would necessarily do that...yeah.

The difficulty that some of my informants exhibit in definitively expressing whether or not they would choose an implant for themselves reflects the moral ambiguity

surrounding the cochlear implant decision. In the same way that "a sonogram does not provide a neutral 'window to the womb' [. . .] but actively mediates how the unborn is given in human experience," cochlear implants do not provide an unbiased window into deafness (Verbeek 2008: 15). The view through this metaphorical "window" varies based upon who is looking through it. Yes, cochlear implants mediate how deafness is morally constituted. The difficulty is that, in different contextual worlds, the implant is imbued with different meanings which subsequently influences the moral decision-making process in dichotomous ways. Because they inhabit both the Deaf and hearing worlds, codas' view of deafness through the "window" provided by cochlear implants is multiple and conflicting. Thus, when trying to make a moral decision about implantation, codas' attitudes are convoluted. The choice is not clear-cut. For codas, the moral ambiguity is tied to the paradox that personal choice does not only affect the individual, it also affects others. Specifically for codas, the decision affects individuals they deeply care for: their parents. If choosing a cochlear implant for oneself or for one's child implies a negative valuation of deafness or the Deaf community, then the decision *matters* beyond the scope of personal choice. The decision has moral consequence.

Conclusion

Because of the different values and meanings ascribed to deafness (either deafness as a disability or deafness as a culture), the decision whether or not to get a cochlear implant acquires a moral dimension, and the cochlear implant itself becomes a moral force that influences how decisions about deafness are made. This is an interesting phenomenon when one considers how medicalization typically functions. Generally,

medicalization removes the moral overtones of certain conditions; it changes "the moral into the medical" and results in a "medical moral neutrality" (Conrad 1992: 223). A good example of this is addiction—a condition previously condemned as immoral that is now recognized as disease. The medicalization of deafness, however, has had the opposite result. Instead of removing morality, the development and use of cochlear implants has introduced morality, creating a moral choice over a therapeutic intervention.

I do not want the discussion above to imply that codas are passive actors influenced by technology. As Verbeek argues:

"Recognizing that our experiences and actions are inevitably mediated by technology, the choice is here to explicitly "shape" and "stylize" these mediations, in order to help to shape one's own subjectivity" (Verbeek 2008: 22).

Codas can develop "a specific attitude to technology in which the technological constitution of moral subjectivity is explicitly reflected upon and actively reshaped" (Verbeek 2008:25). I believe codas attitudes towards cochlear implantation and the decision-making process are purposefully developed and reflect their subjective identity. Codas' subjectivity is constituted not only by their stance toward the technology, but by their relationship to significant others. Borrowing from relational identity theory, "the self is relational—or even entangled—with significant others and [. . .] this has implications for self-definition, self-evaluation, self-regulation, and, most broadly, for personality functioning, expressed in relation to others" (Andersen & Chen 2002: 619). As Aron and Aron (1986, 1996) argue, individuals in close relationships expand the self to include their partners *in* their selves. Furthermore, "the cognitive processing of each operates to some extent as if the partner's resources, perspectives, and identities, along

with one's own, are accessed and are affected by the outcomes of any action one might take" (Aron & McLaughlin-Volpe 2001:89). Indeed, coda *and* their parents are affected by the outcome of a cochlear implant decision. Thus, codas support individualism, yet they waver in their opinions about cochlear implantation because they are not independent of the Deaf community. Codas have expanded the self to include their significant others: their deaf parents. While they have the ability to see the world from different perspective simultaneously, they are deeply invested in both.

Not surprisingly, then, codas' attitudes towards both the technology (and the moral decision associated with the technology) lie somewhere along the continuum of the discourse, reflecting an acknowledgement of both the Deaf and hearing sides of the controversy. In this way, codas' attitudes of cochlear implants become symbolic of their interstitial and rootless identity, allowing them the freedom and the space to navigate both the hearing and Deaf worlds.

CONCLUSION

As this thesis has demonstrated, cochlear implants engender a modification of identities within the Deaf community, having a particular impact on hearing children of deaf adults. This research reveals two parallel phenomena: (1) cochlear implants influence codas' identity and sense of belonging and (2) codas' identity and positionality influences their attitudes towards and conceptualizations of the technology.

The impact of misinformation and lack of information

As both the background chapter and third chapter reveal, discourses surrounding cochlear implantation are often incomplete, offering only partial representations of the reality of the cochlear implant experience. In their narratives, my informants are particularly frustrated by the misinformation about cochlear implants circulated in the medical imaginary. Specifically, they criticize the popular notion that cochlear implants can instantly afford the ability to comprehend spoken language. For example, both Maggie and Tyra are frustrated by the "illusion" of cochlear implants as an immediate and fully effective cure for deafness.

Maggie: Maybe the drawbacks, one of them is the illusion that they [implantees] have greater access than they really have. That what they're getting is some sort of perfect speech, which isn't the case.

Tyra: Even if you can get enough speech to basically understand what's going on, you still aren't gonna get the peripheral sorts of conversations. You're not gonna necessarily have access to everything. Maybe, maybe you will. But a lot of times you could understand somebody if you're facing them, if you're doing lipreading, whatever. But, it's still not the same kind of access as hearing people have. And it's not the same kind of access that people have when they're signing where you could pick up, you can be following multiple conversations or, you know, incidental learning kinds of things that happen with your peers or with things like that.

Both Maggie and Tyra stress that there is a discrepancy between cochlear implants' perceived and actual functionality. While Tyra admits that implants aid one-on-one communication and can facilitate lip-reading, she also makes it clear that implants do not allow communication access akin to the kind of access available to naturally hearing people or deaf people who utilize sign language.

Not only do my informants criticize the inaccurate information perpetuated in the medical imaginary, they also express concern about the repercussions of such inaccurate information. For example, Scott worries about the implications these misconceptions can have on implantees' real world experiences:

Even some kids who can speak and listen to a degree are assumed to be able to understand everything and that's a problem. I think that the environment plays a big role in it. Like if there's a crowded room, if there are more than two or three or four communicative partners that's very difficult [...]. What ends up happening is that there are assumptions made about how much access you indeed have, and sometimes that access is not as natural as say you and I would have to the world.

As Scott's statements demonstrate, the misinformation that floats through the medical imaginary has tangible impacts on implantees' lives and their relationships with other people. According to Scott, hearing people's suppositions that implanted individuals can both hear and understand spoken language easily is problematic. Jen shares a similar sentiment:

Often I feel like it [having a cochlear implant] becomes more of a detriment because people see it still as like "Oh okay this person has a cochlear implant. Sweet, they can hear" [...]. So then it's a cycle right? So you have these cochlear implants or whatever, hearing assistive technology. Then people thinking that this is the cure-all solution. Then having to go about life theoretically being treated as hearing because they now do have these assistive technologies. And people thinking like "Oh no you didn't, you should be able to learn this because you have a cochlear implant." Or like "we're putting a lot of resources into you becoming hearing so make the effort" [...]. A lot of people not being able to

reach that point cuz who can blame them? Like those things only work to some degree and they're not, again, this cure-all thing. And then because of that you run into issues probably with being able to obtain a foundational language. Cuz, again, you can't hear. You can't. Like even with cochlear implants some deaf children, deaf people still only get fragments of what you're saying. They're not getting the full spoken language. So they don't, they still don't understand spoken language.

The impression that cochlear implants have a 100% success rate can create a negatively reinforcing cycle with adverse outcomes. People believe implantees can hear and understand spoken language perfectly, and treat them correspondingly. In reality, however, the process is much more complex. When people's assumptions do not align with reality, problems can arise. For example, Jen suggests that cochlear implants can hinder an individual's ability to acquire a foundational language. As discussed in the background chapter, implanted individuals (especially infants and children) are sometimes discouraged from using American Sign Language and are pushed to develop only their spoken language capabilities. In cases where cochlear implants are less effective than anticipated, however, the individual does not acquire spoken language fluency. With only limited spoken language abilities, and no knowledge of sign language, implantees are left with no solid language skills and are vulnerable to cognitive, social, and psychological developmental delays (NAD 2014; Humphries et al 2012; Mayberry 1993; Newport 1988, 1990). This is an noteworthy paradox; a device of so-called “medical progress” for society creates developmental delays for the individual. Not only is this device for the individual, but it is "for" society. It functions to make the deaf body—an "unruly body"—amenable to society (Bridges 2011).

Like Jen, my informant Scott also worries about the effects inaccurate perceptions about cochlear implantation can have on implantees' wellbeing. As he articulates:

Like the worst thing that I worry about is a school says "They have an implant. They don't need a special school. They don't need special services." That's the thing. That's what I fear the most is that there is this illusion that I've been seeing for the last 20 years that if they have an implant you can just put them in kindergarten and it's fine [. .] And that is not the case. So to me that's the biggest worry is again this notion that it's a magic bullet. And that you don't, there isn't this circle of support that is also needed to make that child successful.

Scott worries that cochlear implantation can negatively impact or eliminate a child's educational and social service support network. In particular, this raises questions about the efficacy of mainstreaming. If an implanted child is placed in a hearing school, and the school assumes that child has the same kind of access to sound as a naturally hearing child, there can be serious consequences for both educational development as well as social and emotional well-being. For example, in a study of thirty two implanted children in mainstream schools, Damen et al (2006) found that "the CI group scored significantly less well than their normal-hearing peers on most questionnaire domains of both the AMP and the SIFTER" (551).⁴⁶

The perception that cochlear implants instantly and flawlessly bestow the ability to comprehend spoken language can lead to confusion and frustration for both the implantee and the hearing people who interact with the implantee. When speaking about her Deaf friends who have received cochlear implants, Maggie shares the following:

Maggie: Several have chosen not to use them.

⁴⁶ AMP is the Assessment of Mainstream Performance, and SIFTER is the Screening Instrument for Targeting Educational Risk.

EM: Okay.

Maggie: In certain situations and other. So I know because all three of them are hardcore ASL signers and would say that they are capital D Deaf. Um but they...so they often make conscious decisions when they use their implant or they don't use their implant.

EM: Depending on who they're with?

Maggie: Depending on who they're with and depending on what their needs are.

EM: Okay.

Maggie: And they also, a lot of it is about not wanting to give other people the illusion that they have complete access when they don't have complete access.

EM: Okay.

Maggie: Do you know what I mean?

EM: Yeah.

Maggie: So if they have an implant other people, hearing people, assume they can get more than they really can. So there's a lot of not wearing it to make sure that assumption isn't being made.

Assumptions about cochlear implant efficacy are not just harmless misconceptions; they can have a direct effect on implantees' lives, causing them such stress and irritation that some make the decision not to use their implant at all, or to conceal their implant in certain environments. For some, while the implant grants the ability to hear sounds, it also inadvertently positions the individual in a borderland between hearing and deafness.⁴⁷ Existing in such an interstitial place can cause exasperation for many. As Jen shares:

I remember a deaf woman told me it's the worst position to be in as a hard-of-hearing person as opposed to a completely deaf person. Because if you're completely deaf, people will find their way to go to cater to you. But if you're a hard-of-hearing person you're still considered hearing culture and so you have to rise to the occasion. But like obviously you're not there yet. So everyone's gonna get frustrated with you.

Jen draws a comparison between implanted individuals and those who are hard-of-hearing. In similar ways, both implantees and hard-of-hearing people are often wrongly

⁴⁷ As discussed in the previous two chapters, codas similarly inhabit a “betwixt and between” positionality, although their experience is different from the experiences of implantees and hard-of-hearing individuals.

categorized by others as "hearing." Yet, because these populations cannot hear as naturally and clearly as others assume, this classification creates tension. For implantees, because the reality of the implantation experience does not match with what is portrayed in the medical imaginary, device failures are sometimes blamed on the individual instead of the device itself.

Anthropologist Laura Mauldin argues that blame gets assigned because cochlear implants have redefined deafness; where deafness was previously categorized as a sensory loss, cochlear implants have now made it "a neurological (processing) 'problem'" (2014: 131). To explain: cochlear implant technology requires the implantee to "train" their brain to perceive, and more importantly *comprehend*, sounds. Consequently, "the CI is then a method of retrieval, of cultivating the hearing brain inside," and the cochlear implants' success hinges upon the brain's ability to be trained (Mauldin 2014:139). Mauldin argues that "this redefinition has multiple implications; most notable it shifts responsibility *from the device to the individual*" and "this redefinition of deafness from a sensory problem to a neurological one then ushers in an ensuing responsibility to 'train the brain,' subsequently displacing 'failure' from the device onto the individuals' ability to train his or her brain" (Mauldin 2014: 131; 132). For this reason, when a patient is hearing but not successfully processing and comprehending sounds (like spoken language), blame can easily be assigned to the individual, not the device itself. Implantees can be condemned as uncooperative or "not trying hard enough," which can have harmful effects on self esteem and can further perpetuate negative stereotypes of deaf individuals as inferior. This result is antithetical to portrayals of cochlear

implantation in the medical imaginary. Instead of saving and curing the individual, the implantee is harmed.

Along with cochlear implant misconceptions, codas also bemoan the stereotypes about Deaf people that exist within the medical imaginary. My informants often speak about how misinformed hearing people are about the deaf experience. For example, as Steven recounts:

Steven: This technology [cochlear implantation] is just like furthering a lot of that. And I think the ignorance and I dunno? What's the word? Like...like uh these blunt people who can't perceive any other way besides like "Oh my baby can't talk to the cashier at the grocery store if they can't hear." And it's like, okay, then they're just that rude customer that day. But they're gonna go meet someone and have a signed conversation with them and be that person's best friend and learn about nuclear science, you know nuclear physics, and they're a renowned like Nobel prize winning physicist, but they couldn't talk to the cashier at the supermarket.

EM: Tragedy.

Steven: Yea... yea! Oh my god. It's like we can paint all these situations in which having the faculty to hear will make their life better, and it's like that's, you can create any situation and make it seem like it's a doom or gloom type of situation and that ticks me off.

Steven is particularly frustrated by the commonly-held idea of deaf people as less capable than their hearing counterparts, and he dislikes the idea of deafness as something tragic and limiting. He believes the downsides of deafness are often exaggerated, and deaf people's capabilities and accomplishments are overlooked. In alignment with Deaf discourse, Steven asserts that a deaf person can do anything a hearing person can (except hear). Isabella agrees, stating that "*Deaf people can do so much. And I wish that hearing people could see more of that.*" Tyra makes a similar argument:

I think there's a lack of information. I don't think that parents are necessarily totally aware of the fact that it's possible to talk about politics and statistics and you know all of these complicated concepts in sign language. That it's possible to

have a really rewarding career and never learn to speak. Like I don't think people necessarily know that sign language is as risk free and benefit-ful option as it is. In part because they're getting information, not from people who are directly familiar with that.

As discussed in the background chapter, American Sign Language was only recently recognized as a true language in 1960s. Many hearing people still have misconceptions about ASL, believing it is nothing more signed English or pantomime. In reality, however, ASL is as complex as any spoken language, with its own grammar, syntax, and rules; and it allows for highly advanced and intellectual conversations.

The perceptions of deafness as inferior and disabling can create rifts between the medical community and Deaf individuals. For example, my Deaf informant Mac shares a story about a doctor who got angry at a Deaf family for celebrating the birth of a deaf child:

One story. A friend of mine. They were seventh generation deaf. And the first child who was born, this is the 8th generation, they had to have the hearing newborn screening because in Massachusetts there's a law for the newborn screening. And the doctors, the nurses, they came over and said "I'm sorry. We have bad news. Your son is deaf." And they [the Deaf family] were jumping for joy. And the doctor got pissed off. Pissed off, he got!?

Mac's outrage and disbelief that a doctor would get angry at a family for celebrating their son's deafness speaks to Mac's strong capital D Deaf inclinations. Mac does not identify deafness as a disability. For him, having a deaf child is a blissful occasion, not a grievous affair. The very fact that a child being deaf is presented to the family as "bad" news sets up and reinforces the idea of deafness as something dreadful. Laura Mauldin notes a similar phenomenon in her fieldwork:

"The NBHS coordinator, who coordinates the newborn testing in the clinic's affiliated hospital, describes the protocol for carefully communicating with

parents. She emphasised how she has developed a very 'non-threatening way of communicating to moms about it to not scare them'. This is the first indicator that deafness is undesirable and news to be broken gently" (2012:534).

The presentation of a deaf child as "bad news" is what Mauldin calls an anticipatory structure: "persons, practices and protocols in the clinic that are already in place, triggered by a particular event and deployed to reduce resistance to medical intervention" (Mauldin 2012: 533). Mauldin argues that the medical community employs anticipatory structures, like presenting deafness as bad news, to ensure parent compliance and position cochlear implant technology as the favorable and logical choice.

Stereotypes about deafness can also impact deaf individuals who are isolated from the Deaf community. For example, Isabella speaks about her cousin who was pressured into getting an implant by her mother. As Isabella explains:

As I've gotten older and I'm working with students that are deaf and I look back and I wonder. Her [Isabella's aunt] only experience with a deaf person is her sister, my mom, who did not have a strong language. She [Isabella's mom] had whatever she could pick up at Boston School for the Deaf, a very oral program. She ended up going to Austin School for the Deaf where she learned sign at like 14. So she does not have a strong first language. And so even her writing, I mean if you've interacted with deaf people you know. You can see that their grammar isn't super great. So her limited experience with deaf people, with somebody like my mother, she probably thinks that that's all deaf people are capable of.

Isabella's aunt had very limited knowledge of the Deaf community; the only deaf person she knew personally was her sister, Isabella's mother. This resulted in a narrow perception of deafness as restricting and harmful. As a result, Isabella's aunt choose cochlear implantation for her deaf daughter in the hopes that her daughter would be more successful than her sister. In another example, Isabella talks about one of her Deaf friends who "didn't think that she would live very long because she'd never met a deaf

adult before." A young girl literally thought she would *die* because she had never met an older deaf person before. Both of these anecdotes speak to the power of representation. Exposure (or lack thereof) to the Deaf community and Deaf role models is an incredibly important influencers in shaping perceptions of deafness among both the hearing and deaf.

In conjunction with the misinformation about the Deaf community, there is also a lack of *misinformation* about what it means to be Deaf. As Will explains:

The knowledge about deaf people in general is so limited. Anybody I've talked to that hasn't taken a class or doesn't know anybody who is [deaf] they have no idea what it's like. They just don't. They don't get it [. . .] Um..so it-it's so easy if you don't know about it. You're not going to pay attention to it because obviously how you gonna pay attention to something you don't know about?

Not only does Will think the hearing community lacks knowledge about the realities of the Deaf community, he is also skeptical that hearing people will ever be adequately informed.

Recommendations

"My job as the son of deaf parents was not just to be a son but, rather, also an ambassador of deaf culture to all of the boundary-less idiots of the world.

"Now, can your mother read?" a ranger asked us once as we pulled into a state park, handing me the maps she was sure would baffle my mother.

"Yes," I replied, handing them back over to my mother defensively, "she is deaf, not retarded."

It seemed, though, like everyone else was. Some people shot me looks of pity when they saw me walking down the street, signing to my mother. I got looks of heroic admiration from other people.

"Is she speaking English when she talks?" they'd ask, blissfully unaware that I might not be interested in answering their trivia about what my life was like.

"No, actually, its Crypto-Cyrillic. My mother is from the faraway past, sent here to warn us all!"

—Moshe Kasher, *Kasher in the Rye: The True Tale of a White Boy from Oakland Who Became a Drug Addict, Criminal, Mental Patient, and Then Turned 16*

As my informants articulate, misconceptions about deafness and cochlear implants that infuse the medical imaginary can have a direct effect on people's lives. As such, there is a dire need for people to be better informed about the reality of the cochlear implant experience. One way to address these issues would be to promote better communication between the Deaf, hearing, and biomedical worlds. In particular, hearing people need an easier (and less intimidating) way to access information from and about the Deaf community. Deaf children need Deaf role models, but so do hearing people.

As discussed in the second chapter, codas' feelings of rootlessness mean they are often wary of staking a definitive claim in the cochlear implant debate. However, I argue that codas could play a pivotal role in transforming the discourse about cochlear implantation. Their unique position and loyalties between the Deaf world and the hearing world makes them potentially powerful brokers and mediators in the cochlear implant conversation.

As my Deaf informant Mac explains: *"I think coda has three worlds. They can support the Deaf community. They can take over and oppress. And then they can disappear."* For Mac, the role of support is the most important a coda can fill. However, the threat of oppression is a reality that many of my coda informants express concern about. Linguist Charlotte Baker-Shenk explains that, as hearing people, "by birth, we are members of the class that has hurt them" and "Deaf people have been systematically deprived of power by hearing people who either thought they were acting in the interests of Deaf people, or by hearing people who simply exploited Deaf people for their own

benefit" (1991:121). The existence of this inherent power imbalance between deaf and hearing is supported by my interview data. A number of my informants speak about the authority granted to them simply because of their hearing status. For example, when asked if she feels hearing people give her words more authority than they would a deaf person's, Jane responded: *"Um that's tricky. It's unwarranted privilege that I have. It's an automatic trust or respect that I have that it is just there. I can't really help it and so I try really hard not to take advantage of that."* In a similar vein, Scott feels that *"you have this credential as a hearing person who also has intimate access to the Deaf world. So I think that people are more likely to listen. Hearing people are more likely to listen to hearing people."* Likewise, Tyra explains:

The privileges that I have as a codas where I...you know, I have a...unfair or whatever yeah, unfair access to um to doctors and speech pathologists. And people are willing to talk to me and give me the time of day and I also have um, you know, access to the Deaf community in, you know, a way that other people don't. And so with those advantages I feel like I have a responsibility to um...to do something about it.

These quotes demonstrate that other hearing people see codas as being like them. Consequently, hearing people afford codas a greater amount of authority than they would a deaf person whom they view as being "disabled."

Little research explores the power dynamics between codas and deaf people specifically; however, there are a number of articles analyzing the relationship of power between American Sign Language interpreters and deaf people. As another population of hearing individuals involved with the Deaf community, ASL interpreters are a useful comparison to codas. A number of articles talk of the "helper model" of interpreting in which the interpreter intervenes "by taking control and making decisions for Deaf people,

rather than enabling Deaf people to gain access to the needed information so they could make decisions for themselves" (Baker-Shenk 1991: 123). The power inequality inherent to the helper model is something that many of my informants express concern about. They are cautious about "stepping on the toes" of the Deaf community. For example, Jen worries: *"where's the line between like being an advocate for it and where I need to start like pulling back? Because I don't fully, I don't, I can only understand to a certain degree."* As discussed in the second chapter, my informants stress that they do not have the authority to speak on behalf of the Deaf community; and this concern about overstepping bounds manifests in a wariness about adopting a "helper model" type of attitude when it comes to issues of cochlear implantation. This apprehension is exemplified in Tyra's comments:

"Trying to make sure that I'm not...that I'm not stepping on toes or doing things that are not fully in service of others. So yeah. So I think certainly we have, we could have a role to play. I think we have to be careful about not taking over. And making this about us or making it, you know...driving or putting our opinions and ourselves and our, you know, savior mentality and all of the sort of ways that that can feel good. I think we need to make sure that we keep those in check and make sure that we're actually doing this in service of others."

Instead of adopting a helper attitude, my informants speak about acting as advocates or ambassadors. As one informant says, *"there's a role to play as an informed advocate as someone who, you know, comes from the hearing world, as someone who is able to take advantage of all the bilingual abilities and bicultural sort of orientations."* Likewise, Maggie talks about codas *"continuing their work as ambassadors."* The literature supports the idea of the interpreter as an ally or advocate as an alternative to the helper model. As Baker-Shenk states, "an ally is one who supports the goals of the community

and accepts leadership from that oppressed group (ibid). It means candidly acknowledging the limitations of our own knowledge and experience in relation to Deaf people, and also trusting Deaf people to assume decision-making roles" (1991). I argue that, like interpreters, codas can navigate their relationship with the Deaf community as allies. Codas can leverage the privileges granted to them by nature of their birth right to be advocates *of* the Deaf community, not *for* Deaf community.

Cultural Bridging, Education, and Exposure

The privilege and the authority granted to codas vis-a-vis their status as hearing persons would make them effective agents in an effort to educate the larger hearing community. Specifically, codas can leverage their positionality to open the gates of communication between the hearing and Deaf worlds, acting as a cultural bridge of sorts. For many hearing people, a coda is more approachable than a deaf person; and, as stated by Scott, "*hearing people are more likely to listen to hearing people.*" Mac speaks comically about hearing people's reactions to him, categorizing them in four ways: (1) deer in the headlights (2) confused (3) curious (4) embarrassed. Indeed, hearing people often act awkwardly or uncomfortably around deaf people because they are uninformed or unsure of how to behave. I have heard many stories of hearing people talking loudly or over-exaggerating their mouth movements when speaking to a deaf person because they believe it will help the deaf person understand them better. Mac told me of a time he encountered a particularly rude hearing man who asked "can you read my lips?" Mac responded with a sarcastic "can you read my hands?"

Jen argues that, as hearing people who are well-versed in Deaf culture, codas can better connect with the larger hearing community and mediate interactions between the two groups. As she explains:

Deaf culture and these alternative perspectives on deafness is already a weird thing for a lot of people to comprehend. And a lot of people still think deaf people to be inferior because they're not used to that way of communicating. They're not used to lack of sound. See this is where I think codas can play an important role [. . .] a lot of deaf people always talk about this, but it's like a lot of hearing people aren't listening because it's just something so foreign.

Codas are a "tamer" and more accessible link to the Deaf community. Hearing people with no prior exposure to or knowledge of Deaf culture may feel more comfortable and willing to seek information or support from another hearing person than from a deaf individual. As Vlad explains:

For the most part, if it's the only way they can be advocates, is by being a member of both communities, of both the hearing community and the Deaf community. It allows them to advocate so much more effectively, I think, because the people really usually in charge are afraid of the "other" person [. . .] And so if you can get somebody who is in some way like you to explain to you this topic which you're not familiar with you're gonna be more comfortable at least listening to it, if not agreeing with it. I think that's where codas really come in.

In this way, codas could increase the hearing population's exposure to Deaf discourse and could promote a better understanding of the Deaf community as a culture. As Jen says, "*I feel like we're at the prime spot as codas to be able to bring more hearing people in and like show them and expand Deaf culture*" and "*I feel like codas can change [deafness] from being not perceived as a disability anymore, but a difference. Like a difference and then like a positive one.*" Codas can educate hearing people about the Deaf community, dispel some of the myths about what it means to be deaf, and provide a more realistic glimpse into what it is like to grow up in the Deaf world.

In regards to the cochlear implant debate specifically, codas are uniquely situated to represent both sides of the discourse, contributing to a more realistic portrait of the technology. As Jane explains, codas are "*versed in both sides*" and could "*at least kind of provide a different perspective.*" Will argues that codas can inform hearing people that cochlear implantation is not the only viable path; there are other available options:

We need to...show the other side of it. Um from the hearing world we assume deafness is the disability and it's, you know, horrible and you don't ever want to subject your children to it. But in actuality there's a loving culture and people there that really care about everybody who's within it [. . .]To say...yeah sure you have the opportunity of joining the hearing world and potentially being average and being the normal if you wanna call it that, but there's opportunity, there's chances where it's not gonna work and then you've shunned yourself from both communities [. . .]So I think, I think definitely we have to work at it, to, at least inform the the general public of the hearing people of what it is, what's going on and at least the positives and negatives about it. Cuz no doubt there are positives if it works for you, but if it doesn't then there's quite a few negatives there.

Will emphasizes a need to educate people about both the positives and negatives of cochlear implantation, and posits that codas are adequately equipped to do so. Scott similarly argues that, because of their cross-cultural upbringing, codas have perspectives "*that are perhaps more well rounded, you know what I mean? You can come from multiple perspectives toward an issue that allows you to think about ways and alternate sorts of realities.*" For those hearing people who are only exposed to the cochlear implant narratives presented in the medical imaginary, codas could represent a means of accessing more nuanced information about the device.

Will talks of the ability of codas to represent both the hearing and Deaf worlds as "*bridging the gap.*" He argues that codas, because of their history of interpreting for their parents, are particularly well suited to "*communicate effectively with both sides.*" He

suggests that the Deaf community can benefit from "*hav[ing] somebody that sees it from their side, but can communicate effectively with the other side.*" In this sense, codas can become a communication agent, a literal cultural interpreter helping to build bridges between the Deaf and hearing worlds. As Steven explains:

EM: What role, if any, do you think codas have to play in this cochlear implant discussion or debate?

Steven: [long pause] A very unique one. An important one. I won't give it so much weight. But I think they have the potential of representing another side of things. The antithesis to it all.

EM: What do you mean by that?

Steven: Coda is varied and numerous and diverse in all its ways, but to represent this person who has a capacity to hear, the faculty for sign language, can really be this, I dunno, representation. I don't wanna say beacon of hope or something. It makes it seem too like egregious or something. But it's like this idea of this person that has the ability to voice for the unspoken or to represent a language that may be otherwise misunderstood. Could be I'd like to believe...an icon. For both sides. For all parties involved. But these are things I'm figuring out for myself as well [laughter] I think a lot of certain, I think a lot of codas are in a number of ways.

Tentatively, Steven expresses hope that codas can become a positive symbol of both the Deaf and hearing communities.

In conjunction with representing both sides of the hearing and Deaf worlds, codas can also educate by example. Jen explains how codas can create interest in and increase exposure to the Deaf community:

My boyfriend is also a coda and it's so cool cuz we like sign to each other through windows and what not [. . .] and then start talking and people are just blown away by like "wait you guys can talk, but you're signing. Why are you guys signing to each other? You guys can talk." [. . .] Those interactions alone are just totally upset the system. But those are only instances in time, now imagine it if more people were to do that, more codas were to do that, more hearing signers.

Increasing coda visibility can become a teaching point for hearing people. For instance, Jane, who works providing resources to hearing parents with deaf children at a Deaf

Commission, has encountered situations where hospitals are reluctant to release hearing children to deaf parents because they question the ability of deaf people to be sufficient parents. As she explains:

And sometimes the hospitals will contact for information because they don't want to discharge the parents because they're not sure if the parents will provide this baby with adequate development for their spoken language and so then I have to educate you know "oh no it's actually going to be okay."

In these situations, Jane employs her identity as a hearing child of deaf adults to convince uninformed hearing health professionals that deaf parents are perfectly capable of raising a fully-functioning hearing child; she is able to use herself as an example of a successful hearing child raised by Deaf parents. She becomes a "poster child" of sorts, illustrating Deaf people's ability to socialize, parent, and live "normally." In a similar way, Scott admits:

I guess the more you think about it, what these parents want is somebody who would be more close to me than they would be to a deaf person. Who can use the spoken language and sign language, so I think that there is an interesting and probably important role that codas could play.

Codas represent "success stories" to hearing parents. By being successful products of a "deaf" childhood, codas prove that American Sign Language is not detrimental to cognitive or emotional stability, and that bimodal bilingualism is beneficial. Codas prove that children raised in a Deaf world can turn out alright.

Codas and implantees - points of parallel

Chapter 1 discusses how codas, despite being biological relatives of Deaf individuals, are not biological citizens of the Deaf biosociality. I go on to argue that, as a means of managing this existence between the Deaf and hearing worlds, codas have

created a fictive kinship and have utilized organizations as spaces of community formation and identity construction. To extend that discussion, I would like remark on how cochlear implants were a catalyst for further polarizing the Deaf and hearing worlds' view of deafness and the moral implications of implanting or not. The cochlear implant controversy highlighted the differences between the hearing and Deaf worlds. The contentiousness of the debate placed the boundaries between the two worlds in high relief, making codas even more acutely aware of their complicated positionality situated between the two communities. The debate made codas' affiliation with the hearing community more visible, and their biological ties to the hearing world would have been problematic as the hearing were seen as an "enemy" of sorts. The controversy would have exacerbated codas' awareness of all the ways in which they did *not* belong. Interestingly, the timing of the first cochlear implants coincides with the emergence of the first CODA organizations. It is unclear whether the emergence of cochlear implants caused the development of Coda communities, or whether the timing is just coincidence. However, it can be said that cochlear implants enhanced codas' conflicted status, and perhaps increased the need to find others with whom they could share common experiences and perceptions.

I also propose that an identity has coalesced around implantees. As the first round of implantees reach adulthood, it is worthwhile to examine the nature of any implantee communities that have emerged. As discussed earlier, implantees are not unlike codas in that they are located in the borderland between the hearing and Deaf worlds. My informant, Isabella ponders:

"it'll be interesting to see what happens as they [implantees] get old. Are they gonna kinda have their own-are they gonna feel so separate? You know, kinda like codas are from the Deaf community and the hearing community? [. . .] Cuz they're not really, are they fully accepted in that community? They're not really hearing."

In future research, it will be interesting to analyze "cochlear implant communities" and how and if such communities will interact in meaningful ways with the Coda community. Is there a sense of camaraderie between the two populations because they are similarly situated betwixt and between the hearing and Deaf worlds?

Why is it important to continue studies of cochlear implantation?

Cochlear implants are still a relatively new technology. As such, research on the outcomes and long-term impacts of implantation is still needed. Additionally, cochlear implants are important to study because rates of implantation continue to increase. As Mac expresses:

We have about 10 or 15 new students that come every year to the [Bay State School for the Deaf]. And you know you might have only 1 or 2 that have a cochlear implant. And then you see kids that are born and that have the cochlear implants, and it's happening often. But now it's just like it's like a machine. It's like a factory. They just are continuing to have these cochlear implants implanted into these kids.

The relationship between the Deaf community and cochlear implantation is complicated, and an anthropological perspective can bring both theoretical and methodological insights that offer more nuanced analyses of cochlear implantation beyond that which other disciplines can offer. Studies of cochlear implantation and its implications for the Deaf community should continue to be an area of anthropological inquiry because, as Scott says, "cochlear implants are not going away. There's no doubt about it. I mean there

are more and more kids that are getting implanted [. . .] Having kids get cochlear implants is gonna be sort of the new normal. The new reality."

REFERENCES

- Aschenbrenner, Joyce
1973 Extended Families Among Black Americans. *Journal of Comparative Family Studies* 4(2): 257-268.
- Adams, B
1970 Isolation, Function, and Beyond: American Kinship in the 1960s. *Journal of Marriage and the Family* 32: 575-597.
- American Speech-Language-Hearing Association
2016 Using Computerized Auditory Training Clinically for Adults with Cochlear Implants. <http://www.asha.org/aud/articles/auditory-training-adults-cochlear-implants/>, accessed January 3, 2016.
- Andersen, Susan M. and Serena Chen
2002 The Relational Self: An Interpersonal Social-Cognitive Theory. *Psychological Review* 109(4): 619-645.
- ANSIRH
2015 Research on Abortion: Ultrasound Viewing. <http://www.ansirh.org/research/ultrasound-viewing>, accessed March 14, 2016.
- Anzaldúa, Gloria
1987 *Borderlands/La Frontera: The New Mestiza*. San Francisco, CA: Aunt Lute Books.
- Aron, Arthur and Tracy McLaughlin-Volpe
2001 Including Others in the Self: Extensions to Own and Partner's Group Memberships. *In Individual Self, Relational Self, Collective Self*. Constantine Sedikides and Marilynn B. Brewer, eds. New York, NY: Routledge. Pp. 89-108.
- Aron, Elaine N. and Arthur Aron
1986 Self and self expansion in Relationships. *In Knowledge Structures in Close Relationships: A Social Psychological Approach*. Garth J.O. Fletcher and Julie Fitness, eds. New York, NY: Psychology Press. Pp. 325-344.
- Aron, Elaine N. and Arthur Aron
1996 Love and expansion of the self: The state of the model. *Personal Relationships* 3(1): 45-58.
- Bahan, Ben

- 1994 Comment on Turner: A view from the deaf world. *Sign Language Studies* 84:241-249.
- Baker-Shenk, Charlotte
 1991 The Interpreter: Machine, Advocate, or Ally? *In* *Expanding Horizons: Proceedings of the 1991 RID Convention*. Jean Plant-Moeller, ed. Pp 120-140. Silver Springs MD: RID Publications.
- Ballweg, John A.
 1968 Extensions of Meaning and Use for Kinship Terms. *American Anthropologist* 71(1): 84-87.
- Bates, D. G. and F. Plog
 1990 *Cultural Anthropology*. New York, NY: McGraw-Hill.
- Bedford, V. H., and R. Blieszner
 2000 Personal relationships in later life families. *In* *Families as Relationships*. R. M. Milardo & S. Duck, Eds. New York: Wiley. Pp. 157-174.
- Benjamin, Saija and Fred Dervin, eds.
 2015 *Migration, Diversity, and Education: Beyond Third Culture Kids*. New York, NY: Palgrave Macmillan.
- Bernard, Harvey Russell
 2006 *Research Methods in Anthropology: Qualitative and Quantitative Approaches*. Lanham, MD: AltaMira Press.
- Besmer, Kirk
 2012 Embodying a Translation Technology: The Cochlear Implant and Cyborg Intentionality. *Techné: Research in Philosophy and Technology* 16(3): 296-316.
- Bienvenu, MJ
 1987 Third Culture: Working Together. *Journal of Interpretation* 4:1-12.
- Bishop, Michele and Sherry Hicks
 2005 Orange Eyes: Bimodal Bilingualism in Hearing Adults from Deaf Families. *Sign Language Studies* 5(2): 188-230.
- Bishop, Michele and Sherry Hicks
 2008 *Hearing, Mother Father Deaf: Hearing People in Deaf Families*. Washington, D.C.: Gallaudet University Press.
- Blake, Wilson

- 2006 Engineering Design of Cochlear Implants *In Cochlear Implants: Auditory Prostheses and Electric Hearing*. Fan-Gang Zeng, Arthur N. Popper and Richard R. Fay, eds. New York, NY: Springer Science+Business Media New York. Pp. 14-52.
- Blume, Stuart
1997 The Rhetoric and Counter-Rhetoric of a "Bionic" Technology. *Science, Technology, & Human Values* 22(1): 31-56.
- Blume, Stuart
2010 *The Artificial Ear: Cochlear Implants and the Culture of Deafness*. Piscataway, NJ: Rutgers University Press.
- Bourdieu, Pierre
1977 *Outline of a Theory of Practice*. Cambridge, UK: Cambridge University Press.
- Bourdieu, Pierre
1986 The Forms of Capital. *In Cultural Theory: An Anthology*. Imre Szeman and Timothy Kaposy, Eds. Hoboken, NJ: John Wiley & Sons. Pp. 81-93
- Braithwaite, Dawn O., and B. W. Bach & L.A. Baxter
2010 Constructing family: A typology of voluntary kin. *Journal of Social and Personal Relationships* 27: 388-407.
- Branson, Jan and Don Miller
2002 *Damned for Their Difference: The Cultural Construction of Deaf People as Disabled*. Washington D.C.: Gallaudet University Press.
- Bridges, Khiara
2011 *Reproducing Race: An Ethnography of Pregnancy as a Site of Racialization*. Los Angeles, CA: University of California Press.
- Brubaker, Rogers and Frederick Cooper
2000 Beyond "identity." *Theory and Society* 29: 1-47.
- Charmaz, Kathy
2006 *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. Thousand Oaks, CA: Sage Publications Inc.
- Chatters, Linda M. and Robert Joseph Taylor and Rukmalie Jayakody
1994 Fictive Kinship Relations in black extended families. *Journal of Comparative Family Studies* 25(3): 297-312.

Cheng, Andre K. and Haya R. Rubin, Neil R. Power, Nancy K. Mellon, Howard W. Francis, and John K. Niparko.
2000 Cost-Utility Analysis of the Cochlear implant in Children. *The Journal of the American Medical Association*. 284(7):850-856.

Cherney, James L.
1999 Deaf Culture and the Cochlear Implant Debate: Cyborg Politics and the Identity of People with Disabilities. *Argumentation and Advocacy*. 36(Summer): 22-34.

Christiano, Tom
2013 Authority. *In The Stanford Encyclopedia of Philosophy*. Edward N. Zalta, ed. <http://plato.stanford.edu/archives/spr2013/entries/authority/>, accessed December 13, 2015.

Clark, Graeme
2006 The multiple-channel cochlear implant: the interface between sound and the central nervous system for hearing, speech, and language in deaf people—a personal perspective. *Philosophical Transactions of the Royal Society B* 361: 791-810.

Compton, Sarah E.
2014 American Sign Language as a Heritage Language. *In Handbook of Heritage, Community, and Native American Languages in the United States*. Terrence G. Wiley, Joy Kreeft Peyton, Donna Christian, Sarah Catherine K. Moore, and Na Liu, eds. Pp. 272-283. New York: Routledge & The Center for Applied Linguistics.

Conrad, Peter
1992 Medicalization and Social Control. *Annual Review Soc.* 18: 209-232.

Coontz, S.
1999 *American Families: A multicultural reader*. New York, NY: Routledge.

Cooper, Rachel
2010 Are culture-bound syndromes as real as universally-occurring disorders? *Studies in History and Philosophy of Biological and Biomedical Sciences*. 41: 325-332.

Corker, M.
1996. *Deaf transitions*. London: Jessica Kingsley.

Critchley, Edward

- 1967 Hearing Children of Deaf Parents. *The Journal of Laryngology & Otology* 81(01): 51-62.
- Crouch, Robert A.
1997 Letting the Deaf Be Deaf: Reconsidering the Use of Cochlear Implants in Prelingually Deaf Children. *The Hastings Center Report* 27(4):14-21.
- Damen, Godelieve W. J. A., and Marilene H.L. van den Oever-Goltstein, Margreet C. Langereis, Patricia M. Chute & Emmanuel A. M. Mylanus
2011 Classroom Performance of Children With Cochlear Implants in Mainstream Education. *Annals of Otology, Rhinology & Laryngology*. 115(7): 542-552.
- Davis, Dena S.
1997 Genetic Dilemmas and the Child's Right to an Open Future. *The Hastings Center Report* 27(2):7-15.
- Davis, Lennard J.
2007 Deafness and the Riddle of Identity. *The Chronicle*. <http://www.odec.umd.edu/CD/ABILITY/DEAF1.PWill>
- Denworth, Lydia
2014 *I Can Hear you Whisper: An Intimate Journey through the Science of Sound and Language*. New York, NY: Penguin Group.
- Desilets, Gabrielle
2015 "Third Culture Kids" as Serial Migrants' Children: Understanding Some of the Impacts of a Highly Mobile Transnational Upbringing. *In Migration, Diversity, and Education: Beyond Third Culture Kids*. Sarah Benjamin and Fred Dervin, eds. New York, NY: St. Martin's Press LLC.
- Dewaele, Jean-Marc and Jan Pieter van Oudenhoven
2009 The effect of multilingualism/multiculturalism on personality: no gain without pain for Third Culture Kids? *International Journal of Multilingualism* 6(4): 443-459.
- Dilworth-Anderson, Peggye
1992 Extended Kin Networks in Black Families. *Generations* 16: 29-32.
- Dossa, Parin
2002 Narrative Mediation of Conventional and New "Mental Health" Paradigms: Reading the Stories of Immigrant Iranian Women. *Medical Anthropology Quarterly* 16(3): 341-359.
- Ebaugh, Helen Rose & Mary Curry

- 2000 Fictive Kin as Social Capital in New Immigrant Communities. *Sociological Perspectives* 43(2): 189-209.
- Eckert, Richard Clark
2010 Toward a Theory of Deaf Ethnos: Deafnicity. *Journal of Deaf Studies and Deaf Education* doi: 10.1093: 1-17.
- Fail, Helen and Jeff Thompson & George Walker
2004 Belonging, identity, and Third Culture Kids. *Journal of Research in International Education* 3(3): 319-338.
- Feher-Prout, Terri
1996 Stress and Coping in Families with Deaf Children. *Journal of Deaf Studies and Deaf Education* 1(3): 155-166.
- Fetterman, David M.
2006 Emic Perspective. *In Encyclopedia of Anthropology*. H. James Birx, ed. Washington, DC: Sage Publications.
- Filer, Rex D. and Peggy A. Filer
2011 Practical Considerations for Counselors Working With Hearing Children of Deaf Parents. *Journal of Counseling & Development* 78(1): 38-43.
- Filipo, R., and E. Bosco, C. Barchetta & P Mancini
1999 Cochlear implantation in deaf children and adolescents: Effects on family, schooling and personal well-being. *International Journal of Pediatric Otorhinolaryngology* 49 (Suppl.): 183–187.
- Frankenburg, FR, and L Sloman & A Perry
1985 Issues in the therapy of hearing children with deaf parents. *Canadian Journal of Psychiatry*. 30(2): 98-102.
- Friedner, Michele
2010 Biopower, Biosociality, and Community Formation: How Biopower is Constitutive of the Deaf Community. *Sign Language Studies* 10(3): 336-347.
- Good, Mary-Jo DelVecchio
2001 The Biotechnical Embrace. *Culture, Medicine and Psychiatry* 25: 395-410.
- Greenholtz, Joe and Jean Kim
2009 The cultural hybridity of Lena: A multi-method case study of a third culture kid. *International Journal of Intercultural Relations* 33(5): 391-398.
- Gregory, Susan and Gillian M. Hartley

- 1991 *Constructing Deafness*. New York: Continuum.
- Grinker, Roy
2015 *Who Owns Autism?: Singularity, Stigma, and Stakeholders*. Paper presented at the Annual Meeting of the American Anthropological Association, Denver, November 20.
- Groce, Nora Ellen
1985 *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard*. Cambridge, MA: Harvard University Press.
- Harris, Jeffrey P., and John P. Anderson & Robert Novak
1995 *An outcomes Study of Cochlear Implants in Deaf Patients: Audiologic, Economic, and Quality-of-Life Changes*. *Arch Otolaryngology Head Neck Surgery* 121(4): 398-404.
- Hayashi, Akiko and Joseph Tobin
2014 *The Power of Implicit Teaching Practices: Continuities and Discontinuities in Pedagogical Approaches of Deaf and Hearing Preschools in Japan*. *Comparative Education Review* 58(1): 24-46.
- Hladek, Glenn
2009 *Cochlear Implants, The Deaf Culture, And Ethics*. The Institute for Applied and Professional Ethics. <http://www.ohio.edu/ethics/2001-conferences/cochlear-implants-the-deaf-culture-and-ethics/index.html>, accessed October 29, 2012.
- Hoang, Lisa and Shela F. LaHousse, Melanie C. Nakaji, and Georgia Robins Sadler
2011 *Assessing Deaf Cultural Competency of Physicians and Medical Students*. *Journal of Cancer Education* 26: 175-182.
- Hoffmeister, Robert
2008 *Border Crossings by Hearing Children of Deaf Parents*. *In Open Your Eyes: Deaf Studies Talking*. H-Dirksen L. Bauman, Ed. Minneapolis, MN: University of Minnesota Press.
- Holcomb, Thomas K.
2013 *Introduction to American Deaf Culture*. New York: Oxford University Press.
- Horton, Sarah B. and Judith C. Barker
2010 *Stigmatized Biologies: Examining Oral Health Disparities for Mexican American Farmworker Children and their Cumulative Effects*. *Medical Anthropology Quarterly* 24 (2).

- Humphries, Tom and Poorna Kushalnagar, Gaurav Mathur, Donna Jo Napoli, Carol Padden, Christian Rathmann & Scott R. Smith
2012 Language acquisition for deaf children: Reducing the harms of zero tolerance to the use of alternative approaches. *Harm Reduction Journal* 9:16.
- Ihde, Don
2008 Introduction: Postphenomenological research. *Human Studies* 31(1): 1-9.
- Ihde, Don
2009 *Postphenomenology and Technoscience: The Peking University Lectures*. Albany, NY: State University of New York Press.
- Jackson, Michael
1996 Introduction: Phenomenology, radical empiricism, and anthropological critique. *In Things as they are: New directions in phenomenological anthropology*. Michael Jackson, Ed. Bloomington: Indiana University Press. Pp. 1-50.
- Jackson, Michael
1998 Myths/Histories/Lives. *In A Reader in Medical Anthropology*. Byron J. Good, Michael M. J. Fischer, Sarah S. Willen, Mary-Jo DelVecchio Good, Eds. Hoboken, NJ: Wiley-Blackwell. Pp. 137-142.
- Johnson, CL
1999 Fictive kin among oldest old African Americans in the San Francisco Bay area. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences* 54(6): S368-75.
- Johnson, R.E. and C. Erting
1999 Ethnicity and socialization in a classroom for Deaf children. *In The sociolinguistics of the Deaf community*. C. Lucas, Ed. San Diego, CA: Academic.
- Jordan, Brigitte
1993 *Birth in Four Cultures: A Crosscultural Investigation of Childbirth in Yucatan, Holland, Sweden, and the United States*. Long Grove, IL: Waveland Press.
- Kane, Connie M.
2000 African American Family Dynamics as Perceived by Family Members. *Journal of Black Studies* 30(5): 691-702.
- Karner, T. X.

- 1998 Professional caring: Homeworkers as fictive kin. *Journal of Aging Studies* 12: 69–82.
- Kennedy, Theodore R.
1980 *You Gotta Deal With It: Black Family Relations in a Southern Community*. New York, NY: Oxford University Press.
- Kisch, Shifra
2008 "Deaf Discourse": The Social Construction of Deafness in a Bedouin Community. *Medical Anthropology Quarterly* 27(3): 283–313.
- Klop, W Martin C., and Jeroen J. Briaire, Anne M. Stiggelbout & Johan H.M. Frijns
2007 Cochlear Implant Outcomes and Quality of Life in Adults with Prelingual Deafness. *The Laryngoscope* 117(11): 1982-1987.
- Knutson, J. F., and K. T. Murray, S. Husarek, K. Westerhouse, G. Woodworth, B.J. Gantz & R.S. Tyler
1998 Psychological change over 54 months of cochlear implant use. *Ear and Hearing* 19: 191–201.
- Knutson, J. F., and R. L. Wald, S. L. Ehlers & R. S. Tyler
2000 Psychological consequences of pediatric cochlear implant use. *The Annals of Otology, Rhinology, & Laryngology* 115 (Suppl.): 87–89.
- Kosnar, Michael and Lisa Myers
2014 Defective cochlear implants shocked kids—even though company had been warned. *Today Health & Wellness*. <http://www.today.com/health/defective-cochlear-implants-shocked-kids-even-though-company-had-been-2D79371793>, accessed September 20, 2015.
- Kurtzer-White, Ellen and David Luterman
2003 Families and children with hearing loss: Grief and coping. *Mental Retardation and Developmental Disabilities Research Reviews* 9(4): 232-235.
- Ladd, Paddy
2003 *Understanding Deaf Culture: In Search of Deafhood*. Buffalo, NY: Multilingual Matters LTD.
- Lane, Harlan
1984 *When the Mind Hears: A History of the Deaf*. New York, NY: Random House
- Lane, Harlan

- 1992 *The Mask of Benevolence: Disabling the Deaf Community*. San Diego, CA: Dawn Sign Press.
- Lane, Harlan and Robert Hoffmeister and Ben Bahan
1996 *A Journey into the Deaf World*. San Diego, CA: Dawn Sign Press.
- Lane, Harlan and M. Grodin
1997 Ethical Issues in cochlear implant surgery: an exploration into disease, disability, and the best interests of the child. *Kennedy Institute of Ethics Journal* 7:231-51.
- Lane, Harlan
2002 Do Deaf People Have a Disability? *Sign Language Studies* 2(4): 356-379.
- Lang, Gretchen
2002 At Home Abroad/Third Culture Kids: Often more accomplished, but sometimes more troubled. *The New York Times*. October 26.
http://www.nytimes.com/2002/10/26/news/26iht-rreturn_ed3_.html, accessed November 28, 2015.
- Lassig, AA and TA Zwolan & SA Telian
2005 Cochlear implant failures and revision. *Otol Neurotol*. 26(4): 624-34.
- Latiolas, Robert Christopher
1998 *The Body Politic: Naturalizing Biological Citizenship and Philosophical Reservations*. University of Chicago Midwest Seminar, March.
- Lee, Chongmin
2012 Deafness and Cochlear Implants: A Deaf Scholar's Perspective. *Journal of Child Neurology* 27:821-823.
- Lee, Richard M.
2003 The Transracial Adoption Paradox: History, Research, and Counseling Implications of Cultural Socialization. *The Counseling Psychologist* 31(6): 711-744.
- Leigh, Irene W. and Alan L. Marcus, Patricia K. Dobosh & Thomas E. Allen
1998 Modification of the Deaf Identity Development Scale. *Journal of Deaf Studies and Deaf Education* 3(4): 329-338.
- Leigh, Irene W.
2009 *A Lens on Deaf Identities*. New York: Oxford University Press.
- Linton, Ralph

- 1936 *The Study of Man*. New York, NY: Appleton-Century-Crofts, Inc.
- Lock, Margaret
2004 Medicalization and the Naturalization of Social Control. *In The Encyclopedia of Medical Anthropology*. New York, NY: Springer.
- Longmore, P. K.
1997 Conspicuous contribution and American Cultural dilemmas: Telethon rituals of cleaning and renewal. *In The Body and Physical Difference: Discourses of Disability*. D. T. Mitchell and S. L. Snyder, eds. Pp. 134-158. Ann Arbor: University of Michigan Press.
- Loy, Betty and Andrea D. Warner-Czyz, Liyue Tong, Emily A. Tobey & Peter S. Roland
2010 The children speak: An examination of the quality of life of pediatric cochlear implant users. *Otolaryngology Head and Neck Surgery* 142(2): 247-253.
- Lyttle, Allyn D., Gina G. Barker and Terri Lynn Cornwell
2011 Adept through adaptation: Third culture individuals' interpersonal sensitivity. *International Journal of Intercultural Relations* 35(2011): 686-694.
- Maillet CJ, and RS Tyler & HN Jordan
1995 Change in quality of life of adult cochlear implant patients. *The Annals of Otolaryngology, Rhinology & Laryngology*. 104: 31-48.
- Mand, C., and R E Duncan, L Gillam, V Collins, M B Delatycki
2009 Genetic selection for deafness: the views of hearing children of deaf adults. *Journal of Medical Ethics* 35(12): 722-728.
- Marcus, Lilit
2014 Why You Shouldn't Share Those Emotional 'Deaf Person Hears For The First Time' Videos. *The Wire*. <http://www.thewire.com/politics/2014/03/why-you-shouldnt-share-those-emotional-deaf-person-hears-for-the-first-time-videos/359850/>, accessed January 24, 2016.
- Markowitz, Harry and James Woodward
1978 Language and the Maintenance of Ethnic boundaries in the Deaf Community. *Communications and Cognition*.
- Martin, E.P., and J. Martin
1978 *The Black Extended Family*. Chicago, IL: University of Chicago Press.
- Mattingly, Cheryl

2010 *The Paradox of Hope: Journeys Through a Clinical Borderland*. Berkeley, CA: University of California Press.

Mauldin, Laura

2012 Parents of deaf children with cochlear implants: a study of technology and community. *Sociology of Health & Illness* 34(4): 529-543.

Mauldin, Laura

2014 Precarious Plasticity: Neuropolitics, Cochlear Implants, and the Redefinition of Deafness. *Science, Technology, & Human Values* 39(1): 130-153.

Mayberry, RL

1993 First-language acquisition after childhood differs from second-language acquisition: The case of American Sign Language. *Journal of Speech and Hearing Research* 36: 1258-1270.

McAndrew, Francis T.

1998 The Measurement of 'Rootedness' and the Prediction of Attachment to Home-towns in College Students. *Journal of Environmental Psychology* 18: 409-417.

McCarthy, B., and A. Hagan, and M. J. Martin

2002 In and out of harm's way: Violent victimization and the social capital of fictive street families. *Criminology* 40: 831-865.

Meinert, Lotte

2004 Resources for Health in Uganda: Bourdieu's Concepts of Capital and Habitus. *Anthropology & Medicine* 11(1): 11-26.

Melles, Elizabeth, A. and Jonathon Schwartz

2012 Does the third culture kid experience predict levels of prejudice? *International Journal of Intercultural Relations* 37(2013): 260-267.

Milicic, Bojka

2013 Talk is Not Cheap: Kinship Terminologies and the Origins of Language. *Structure and Dynamics* 6(1):

Mills, Mara

2011 Do Signals Have Politics: Inscribing Abilities in Cochlear Implants. *In The Oxford Handbook of Sound Studies*. Trevor Pinch and Karin Bijsterveld, eds. New York, NY: Oxford University Press.

Mo, Birger and Morten Lindbaek & Sten Harris

- 2005 Cochlear Implants and Quality of Life: A Prospective Study. *Ear & Hearing* 26(2): 186-194.
- Monaghan, Leila & Constanze Schmaling & Karen Nakamura & Graham H. Turner, Eds.
2003 *Many Ways to Be Deaf: International Variation in Deaf Communities*.
Washington D.C.: Gallaudet University Press.
- Moore, Andrea M. and Gina G. Barker
2011 Confused or multicultural: Third culture individuals' cultural identity.
International Journal of Intercultural Relations 36(2012): 553-562.
- Moore, Jerry D.
2009 *Visions of Culture*. Plymouth, UK: AltaMira Press.
- Muraco, A.
2006 Intentional families: Fictive kin ties between cross-gender, different sexual
orientation friends. *Journal of Marriage & Family* 68:1313–1325.
- Myers, Shirley Shultz, and Randall R. Myers, and Alan L. Marcus
1999 Hearing Children of Deaf Parents: Issues and Interventions within a
Bicultural Context *In Psychology with Deaf Clients from Diverse Groups*. Ed,
Irene W. Leigh. Washington D.C.: Gallaudet University Press. Pp. 121-150.
- Nakamura, Karen
2006 *Deaf in Japan: Signing and the Politics of Identity*. Ithaca, New
York: Cornell University Press.
- Napier, Jemina
2010 The D/deaf-H/hearing Debate. *Sign Language Studies* 2(2): 141-149.
- National Association of the Deaf
2000 NAD Position Statement on Cochlear
Implants. <http://nad.org/issues/technology/assistive-listening/cochlear-implants>,
accessed September 19, 2015.
- National Association of the Deaf (NAD)
2014 Position Statement on Early Cognitive and Language Development and
Education of Deaf and Hard of Hearing Children. [https://nad.org/position-
statement-early-cognitive-and-language-development-and-education-dhh-
children](https://nad.org/position-statement-early-cognitive-and-language-development-and-education-dhh-children), accessed January 31, 2016.
- National Institute of Health

2013 Cochlear
Implants. <http://www.report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=83>,
accessed September 11, 2015.

National Institute on Deafness and Other Communication Disorders
2014 Cochlear
Implants. <http://www.nidcd.nih.gov/health/hearing/pages/coch.aspx>, accessed
September 11, 2015.

National Institute on Deafness and Other Communicative Disorders
2015 Quick
Statistics. <http://www.nidcd.nih.gov/health/statistics/pages/quick.aspx>, accessed
September 20, 2015.

National Institute of Health
2013 Cochlear
Implants. <http://www.report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=83>,
accessed September 11, 2015.

Nelson, Margaret K.
2014 Whither Fictive Kin? Or, What's in a Name? *Journal of Family Issues*
35(2): 201-222.

Newport, E.
1988 Constraints on learning and their role in language acquisition: Studies of the
acquisition of American Sign Language. *Language Sciences* 10: 147-172.

Newport, E.
1990 Maturational constraints on language learning. *Cognitive Science* 14: 11-
28.

Nicolas, Johanna G. and Anne E. Geers
2003 Personal, Social, and Family Adjustment in School-Aged Children with a
Cochlear Implant. *Ear & Hearing* 24(1): 69S-81S.

Niparko, John (ed)
2009 *Cochlear Implants: Principles and Practices*. Philadelphia, PA: Lippincott
Williams & Wilkins.

Nomeland, Melvia M. and Ronald E. Nomeland
2012 *The Deaf Community in America: History in the Making*. Jefferson, NC:
McFarland & Company, Inc., Publishers.

Norbeck, Edward and Harumi Befu

- 1958 Informal Fictive Kinship in Japan. *American Anthropologist* 60(1): 102-117.
- Novas, Carl
2006 The Political Economy of Hope: Patients' Organizations, Science and Biovalue. *Biosocieties* 1: 289-305.
- NPR
2012 Cochlear Implants Redefine What It Means To Be Deaf. <http://www.npr.org/2012/04/08/150245885/cochlear-implants-redefine-what-it-means-to-be-deaf>, accessed January 2, 2016.
- Obasi, Chijioke
2008 Seeing the Deaf in "Deafness." *Journal of Deaf Studies and Deaf Education* 13(4): 455-465.
- Oliver, Daniel G. and Julianne M. Serovich and Tina L. Mason
2005 Constraints and Opportunities with Interview Transcription: Towards Reflection in Qualitative Research. *Social Forces* 84(2): 1273-1289.
- Osborn, Terry A.
2005 *Language and Cultural Diversity in U.S. Schools: Democratic Principles In Action*. Wetsport, CT: Praeger Publishers.
- Ouellette, Alicia
2011 Hearing the Deaf: cochlear implants, the deaf community, and bioethical analysis. *Valparaiso University Law Review* 45(3):1247-1270.
- Padden, Carol A. and Tom Humphries
1988 *Deaf in America: Voices from a Culture*. Cambridge, MA: Harvard University Press.
- Padden, Carol A. and Tom Humphries
2005 *Inside Deaf Culture*. Cambridge, MA: Harvard University Press.
- Percy-Smith, Lone and Per Caye-Thomasen, Mette Gudman, Jorgen Hedegaard Jensen & Jens Thomsen
2008 Self-esteem and social well-being of children with cochlear implant compared to normal-hearing children. *International Journal of Pediatric Otorhinolaryngology* 72(7): 1113-1120.
- Peters, Edward
2000 Our Decision on a Cochlear Implant. *American Annals of the Deaf* 145(3): 263-267.

- Petryna, Adriana
2002 *Life Exposed: Biological Citizens After Chernobyl*. Princeton, NJ: Princeton University Press.
- Petryna, Adriana
2010 *Biological Citizenship: The Science and Politics of Chernobyl-Exposed Populations*. In *A Reader in Medical Anthropology: Theoretical Trajectories, Emergent Realities*. Bryon J. Good, Michael M.J. Fisher, Sarah S. Willen, and Mary-Jo DelVecchio Good, Eds. Hoboken: Wiley-Blackwell. Pp 199-212.
- Pizer, Ginger
2007 "It's like he can't be bothered": Ideologies of effort in CODA family narratives. *Texas Linguistics Forum* 51: 126-133.
- Pizer, Ginger
2010 "We can hear": The role of attention-getting in the code choices of hearing children and their deaf parents. Paper presented at the Southeastern Conference on Linguistics (SECOL) 77, University of Mississippi, Oxford, MS.
- Pizer, Ginger and Keith Walter and Richard P. Meier
2013 "We Communicated That Way for a Reason": Language Practices and Language Ideologies Among Hearing Adults Whose Parents Are Deaf. *Journal of Deaf Studies and Deaf Education* 18(1): 75-92.
- Poel, Ibo van de and Peter Kroes
Can Technology Embody Values? *The Moral Status of Technical Artefacts, Philosophy of Engineering and Technology* 17: 103-124.
- Pollock, David C. and Ruth E. Van Reken
2009 *Third Culture Kids: The Experiences of Growing up among Worlds*. Boston, MA: Nicholas Brealey Publishing.
- Poplin, D. E.
1972 *Communities: A Survey of Theories and Methods of Research*. New York: MacMillan.
- Preston, Paul
1994 *Mother Father Deaf: Living Between Sound and Silence*. Cambridge, MA: Harvard University Press.
- Preston, Paul
1995 *Mother Father Deaf: The Heritage of Difference*. *Social Science Med* 40(11): 1461-1467.

- Preston, Paul
1996 Chameleon voices: Interpreting for deaf parents. *Social Science and Medicine* 42(12): 1681–1690.
- Rabinow, Paul
1996 Artificiality and Enlightenment: From Sociobiology to Biosociality. *In Anthropologies of Modernity: Foucault, Governmentality, and Life Politics*. Jonathon Xavier Inda, Ed. Princeton, NJ: Princeton University Press. Pp 181-193.
- Rapp, Rayna
1999 Testing women, testing the fetus: the social impact of amniocentesis in America. New York, NY: Routledge.
- Rapp, Rayna, Deborah Heath & Karen-Sue Taussig
2001 Genealogical Dis-Ease: Where Hereditary Abnormality, Biomedical Explanation, and Family Responsibility Meet. *In Relative Values: Reconfiguring Kinship Studies*. Sarah Franklin & Susan McKinnon, eds. Durham, NC: Duke University Press.
- Relph, Edward
1976 Place and Placelessness. London: Pion.
- Rose, Nikolas and Carlos Novas
2003 Biological Citizenship. *In Global Assemblages: Technology Politics, and Ethics in Anthropological Problems*. Aihwa Ong and Stephen Collier, eds. Oxford, UK: Blackwell Publishing.
- Rubenstein, R. L., and B.A. Alexander & M. Goodman
1991 Key relationships of never married, childless older women: A cultural analysis. *Journal of Gerontology: Social Sciences* 46: S270–S277.
- Sachs, Jacqueline and Barbara Bard & Marie L. Johnson
1981 Language learning with restricted input: Case studies of two hearing children of deaf parents. *Applied Psycholinguistics* 2(01): 33-54.
- Samuelson, Helle and Vibeke Steffan
2004 The Relevance of Foucault and Bourdieu for Medical Anthropology: Exploring New Sites. *Anthropology & Medicine* 11(1): 3-10.
- Schiff, Naomi B. and Ira M. Ventry
1976 Communication Problems in Hearing Children of Deaf Parents. *Journal of Speech and Hearing Disorders* 41: 348-358.

- Schorr, Efrat A.
2006 Early Cochlear Implant Experience and Emotional Functioning During Childhood: Loneliness in Middle and Late Childhood. *The Volta Review* 106.3: 365-379.
- Schuetz, Alfred
1944 *The Stranger: An Essay in Social Psychology*. *American Journal of Sociology* 49(6): 499-507.
- Schutz, Alfred
1970 *On phenomenology and social relations*. Chicago, IL: University of Chicago Press.
- Seamon, David and Jacob Sowers
2008 Place and Placelessness (1976): Edward Relph. *In Key Texts in Human Geography*. Phil Hubbard, Rob Kitichin, and Gill Valentine, eds. Thousand Oaks, CA: Sage Publications Inc. Pp. 44-51.
- Senghas, R. J., and L. Monaghan
2002 Signs of their times: Deaf communities and the culture of language. *Annual Review of Anthropology* 31: 69-97.
- Shakespeare, Tom (ed)
1998 *The Disability Reader: Social Science Perspectives*. New York, NY: Bloomsbury Academic.
- Sherwood, Bonnie
1987 Third Culture: Making It Work. *Journal of Interpretation* 4: 13-24.
- Shield, Aaron
2004 Ideological Conflict at Group Boundaries: The Hearing Children of Deaf Adults. *Texas Linguistic Forum* 48: 187-195.
- Shipsey, Ian
2015 Bionic Hearing: The Science and the Experience. Lecture presented at Boston University Physics Department Colloquia Series in the Metcalf Science Center, Boston. April 14.
- Sigel, Lawrence
2006 The Argument for a Constitutional Right to Communication and Language. *Sign Language Studies* 6(3): 255-272.
- Singleton, Jenny L. and Matthew D. Tittle

- 2000 Deaf parents and their hearing children. *Journal of Deaf Studies and Deaf Education* 5(3): 221–236.
- Social Security Disability Help
2014 Hearing Loss and Social Security Disability. <http://www.disability-benefits-help.org/disabling-conditions/hearing-loss-and-social-security-disability>, accessed September 11, 2015.
- Sparrow, Robert
2005 Defending Deaf Culture: The Case of Cochlear Implants. *The Journal of Political Philosophy* 13(2): 135-152.
- Stack, Carol
1974 *All Our Kin: Strategies for Survival in a Black Community*. New York, NY: Harper & Row.
- Stewart, David A. and C. Tane Akamatsu
1988 The Coming of Age of American Sign Language. *Anthropology and Education Quarterly* 19(3):235-252.
- Stone, Sandy
2006 *The Empire Strikes Back: A Posttranssexual Manifesto*. In *The Transgender Studies Reader*. Susan Stryker and Stephen Whittle, eds. New York: NY. Routledge. Pp. 221-235.
- Tanu, Danau
2015 Toward an Interdisciplinary Analysis of the Diversity of “Third Culture Kids.” In *Migration, Diversity, and Education: Beyond Third Culture Kids*. Sarah Benjamin and Fred Dervin, eds. New York, NY: St. Martin’s Press LLC.
- Tatum, B.D.
1987 *Assimilation blues: Black families in a white community*. Northhampton, MA: Hazel-Maxwell Publishing.
- Taylor, Janelle S.
2008 *The Public Life of the Fetal Sonogram: technology, consumption, and the politics of reproduction*. New Brunswick, NJ: Rutgers University Press.
- Teagle, Holly F. B.
2012 Cochlear implantation for children: opening doors to opportunity. *Journal of Child Neurology* 27: 824-826.
- Temple, Bogusia and Alys Young

- 2004 Qualitative research and translation dilemmas. *Qualitative Research* 4(2): 161-178.
- Tillery, Randal K.
1992 Touring Arcadia: Elements of Discursive Simulation and Cultural Struggle at a Children's Summer Camp. *Cultural Anthropology* 7(3): 374-388.
- Troxel v. Granville, 530 U.S. 57, 68.–69 (2000).
- Tuan, Yi-Fu
1980 Rootedness and Sense of Place. *Landscape* 24(1): 3-8.
- Tucker, Bonnie Poitras
1997 The ADA and Deaf Culture: contrasting precepts, conflicting results. *Annals of the American Academy of Political and Social Science* 549:24-37.
- Tucker, Bonnie Poitras
1998 Deaf Culture, Cochlear Implants, and Elective Disability. *Hastings Center Report* 28: 6-14.
- Turner, Victor
1967 *The Forest of Symbols: Aspects of Ndembu Ritual*. Ithaca, NY: Cornell University Press.
- Turner, Victor
1969 *The Ritual Process: Structure and Anti-Structure*. New Brunswick: Aldine Transaction.
- Turner, Victor
1974 *Dramas, Fields, and Metaphors*. Ithaca, NY: Cornell University Press.
- Turner, Victor
1990 Are there universals of performance in myth, ritual, and drama? *In* *By Means of Performance*. R. Schechner and W. Appel, eds. Cambridge: Cambridge University Press.
- Tzanelli, Rodanthi
2007 Rite of Passage. *In* *Blackwell Encyclopedia of Sociology*. George Ritzer, ed. Blackwell Publishing. Blackwell Reference Online. 07 November 2015
<http://www.sociologyencyclopedia.com.ezproxy.bu.edu/subscriber/tocnode.html?id=g9781405124331_yr2014_chunk_g978140512433124_ss1-70>
- U.S. Equal Employment Opportunity Commission

Questions and Answers about Deafness and Hearing Impairments in the Workplace and the Americans with Disabilities Act. http://www.eeoc.gov/eeoc/publications/qa_deafness.cfm, accessed September 11, 2015.

U.S. Food and Drug Administration

2014 Cochlear Implants: Frequently Asked

Questions. <http://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/ImplantsandProsthetics/CochlearImplants/ucm062866.htm#iq>, accessed September 11, 2015.

Useem, John, J.D. Donaghue and Ruth Hill Useem

1963 Men in the middle of the third culture. *Human Organization* 22(3): 169-179.

Useem, Ruth Hill and John Useem

1967 The Interfaces of a Binational Third Culture: A Study of the American Community in India. *Journal of Social Issues* 23(1): 130-143.

Useem, Ruth Hill

1973 Third Cultural Factors in Educational Change *In Cultural Factors in School Learning*. Cole Brembeck and Walker Hill, eds. Lexington, MA: Lexington Books.

Useem, Ruth Hill

1993 Third Culture Kids: Focus of Major Study. *Newslinks*, Newspaper of the International School Services 12(3).

van Gennep, Arnold

1960 *The Rites of Passage*. London, UK: Routledge.

Verbeek, Peter-Paul

2008 Cyborg Intentionality: Rethinking the Phenomenology of Human-Technology Relations. *Phenomenology and the Cognitive Sciences* 7(3): 387-95.

Verbeek, Peter-Paul

2011 *Moralizing Technology: Understanding and Designing the Morality of Things*. Chicago, IL: The University of Chicago Press.

Wacquant, Lois and Pierre Bourdieu

1992 *Toward a Social Praxeology: The Structure and Logic of Bourdieu's Sociology.* In *An Invitation to Reflexive Sociology.* Chicago, IL: University of Chicago

Walker, Lou Ann

1986 *A Loss for Words: The Story of Deafness in a Family.* New York, NY: Harper Collins.

Walters, Kate A. and Faith P. Auton-Cuff

2009 A story to tell: the identity development of women growing up as third culture kids. *Mental Health, Religion & Culture* 12(7): 755-772.

Weston, Kath

1991 *Families We Choose: Lesbians, Gays, Kinship.* New York, NY; Columbia University Press.

Wiet, R. Mark and Krystine Mullins

2011 Revision Cochlear Implantation. *Audiology*
Online. <http://www.audiologyonline.com/articles/revision-cochlear-implantation-834>, accessed September 20, 2015.

Williams, Sally

2012 Why not all deaf people want to be cured. *The Telegraph.* <http://www.telegraph.co.uk/culture/9526045/Why-not-all-deaf-people-want-to-be-cured.html>, accessed January 3, 2016.

Williams, Stephen

2004 *Tourism: The Experience of Tourism.* New York, NY: Routledge.

Zelditch, Morris

2001 Theories of Legitimacy. In *The Psychology of Legitimacy: Emerging Perspectives of Ideology, Justice, and Intergroup Relations.* John T. Jost and Brenda Major, eds. Cambridge, UK: Cambridge University Press. Pp. 33-53.

CURRICULUM VITAE

Erin Mellett

108 Cedar Street Walpole, MA 02081 - 508-404-4632 - emellett@bu.edu - DOB: 1991

EDUCATION

Boston University School of Medicine, Boston MA May 2016
Masters of Science, Medical Anthropology and Cross Cultural Practice
GPA 4.0

Elon University, Elon NC May 2013
Bachelor of Arts, Anthropology
Minor, Communications
Magna Cum Laude GPA 3.856

Study Abroad

Curtin University Perth, Australia February 2012 - June 2012

Elon University Hawaii: Nation or State? January 2011

- One month course exploring the heritage of the indigenous people of the Hawaiian Islands.
- Considered issues of identity formation and political reality in the Hawaiian Islands, including the native Hawaiian movement to secede from the United States.

RESEARCH EXPERIENCE

Master's Thesis

Codas and Cochlear Implants: Impact of a Technology on a Community

- Study exploring how cochlear implants have pushed a refinement of identities associated with the Deaf community.
- 10 months of ethnographic fieldwork in a Deaf school.
- 11 in-depth qualitative interviews. 10 conducted with hearing children of deaf adults and 1 with a Deaf man.

Undergraduate Research Thesis

Tourism as a Force for Cultural Revitalization: a case study of the Occaneechi Band of the Saponi Nation.

- Conducted as a member of Elon College Fellows, mentored by Dr. Tom Mould.
- 2 year study exploring how and to what effect a local American Indian tribe utilizes tourism.

- Attended Tribal Council meetings, Powwow Committee Meetings, and other tribal events.
- 8 in-depth qualitative interviews conducted with tribal members.
- Curated, designed, and installed an exhibit about the Occaneechi in a local museum.

RESEARCH INTERESTS

Medical Anthropology
 Disability Anthropology
 Linguistic Anthropology
 Deaf Studies
 Immigrant Studies
 Kinship

WORK EXPERIENCE

The Learning Center for the Deaf, Framingham MA October 2014 - July 2015
Intern

- Observed ASL Department faculty meetings.
- Edited intake videos.
- Attended classes alongside a group of deaf high school students, providing assistance to teachers when needed.
 - Primarily ASL and ESL classes, but also History, Science, and Communications.
- Observed and participated in ASL evening classes offered to hearing people.
- Conducted administrative work (data entry) on an as-needed basis.

Avedro Inc, Waltham MA October 2013 - August 2014
Customer Relations Duties

- Processed and took ownership of customer orders from PO receipt to delivery.
- Effectively managed and monitored critical order fulfillment details such as pricing, payment requirements, lead times, stock availability, and delivery.
- Created, maintained and filed order documentation (sales orders/pack slips/commercial & proforma invoices).
- Provided customer support such as responding to inquiries, communicating order related issues, processing samples and replacement parts.
- Supported returned material authorization (RMA) process for products and field service parts in accordance with internal processes.
- Served as point-of-contact for established international distributors.
- Communicated and interacted with cross functional departments such as sales, marketing, finance, manufacturing, and quality on a daily basis.
- Supported inside sales efforts and field service staff.

Administrative Assistant Duties

- Backup to the Executive Assistant.

- Answered and screened all telephone calls, and directed calls appropriately.
- Ordered and put away groceries/ensure kitchens remained stocked at all times.
- Ordered all office supplies and ensure supply areas remained stocked.
- Greeted visitors as they entered.
- Aided employees in preparing and sending UPS/Fedex shipments.
- Checked availability of conference rooms and scheduled conference rooms upon request.
- Handled all building maintenance work orders.
- Handled maintenance of Xerox copiers.
- Sorted and distributed all mail.
- General administrative duties—filing, scanning, organizing, etc.

Mebane Historical Museum, Mebane NC

September 2012 - May 2013

Producer and Curator

- Curated, designed, and installed an exhibit about the Occaneechi Band of the Saponi Nation entitled "Welcome to Our Land: The Occaneechi Yesterday & Today."
- Funded by a grant from the North Carolina Humanities Council.
- Exhibit stemmed from independent undergraduate research and was developed to assist the Occaneechi in their tourism and public programming efforts.

Mebane Historical Museum, Mebane NC

September 2010 - December 2010

Intern

- Coded transcribed interviews and conducted an oral history analysis of some of Mebane's oldest residents.
- Results of analysis resulted in the creation of an exhibit about play.

Enanta Pharmaceuticals, Watertown MA

May 2010 - October 2013 (intermittently)

Operations Management Assistant

- Responsible for purchasing, including chemicals, laboratory & office supplies, equipment, maintenance contracts, and outside services.
- Entered purchase orders into Microsoft Dynamics SL.
- Maintained up to date records of all purchases.
- Filed invoices & assisted in invoice reviews for NIAD Billing.
- Maintained relationships with vendors & established accounts with new vendors.
- Oversaw that all purchases were received and matched requisition slips to packing slips.
- Conducted fixed asset inventories.
- Ensured lab equipment maintenance.
- Ensured day-to-day lab operations ran smoothly.
- Communicated with scientists to ensure all needs were being met.
- General office organization.

PRESENTATIONS

2013 "Welcome to Our Land: The Occaneechi Yesterday and Today." Exhibit Opening. Mebane Historical Museum. May 9.

2013 "Tourism as a Force for Cultural Revitalization: a case study of the Occaneechi Band of the Saponi Nation." Spring Undergraduate Research Forum. Elon University. April 23.

GRANTS RECEIVED

2013 North Carolina Humanities Council Grant. "Creating a Permanent Museum Exhibit for the Occaneechi Band of the Saponi Nation." \$1200. With Tom Mould and Ethan Moore.

SKILLS

American Sign Language

Data analysis software including Nvivo, Atlas.ti, and SPSS

Ethnographic fieldwork - participant observation, qualitative interviewing

Transcribing

Grant Writing

IRB application

AWARDS AND DISTINCTIONS

Boston University School of Medicine Provost Scholarship recipient

Elon University Presidential Scholarship recipient

Elon University Outstanding Senior Anthropology Student

Elon College Fellow

Phi Beta Kappa, Honor Society

Phi Kappa Phi, Honor Society

Founding member of Elon University's Lambda Alpha chapter, Anthropology Honor Society

Pi Gamma Mu, Social Science Honor Society

Phi Eta Sigma, Honor Society Recognizing First-Year Students

2010 Debating for Democracy Finalist

- Wrote a letter to U.S. Senator Scott Brown urging him to support legislation that would fund the development of modular nuclear reactor technology.
- Out of 63 entries, was selected as 1 of 6 finalists to attend the Debating for Democracy National Conference in New York City.
- Presented letter to former U.S. Senators Bob Kerrey and Harris Wofford.
- Received a \$500 award which was used to fund environmental advocacy through Elon University's Sierra Club.

SERVICE

Habitat for Humanity, Elon NC

Burlington Animal Shelter, Burlington NC
Medfield Animal Shelter, Medfield MA
Walpole Special Needs Summer Program, Walpole MA