# PARENTS OF DEAF CHILDREN WITH COCHLEAR IMPLANTS:

# DISABILITY, MEDICALIZATION AND NEUROCULTURE

by

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A dissertation submitted to the Graduate Faculty in Sociology in partial fulfillment of the requirements for the degree of doctor of Philosophy, The City University of New York

2012

This manuscript has been read and accepted for the Graduate Faculty in Sociology in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

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Abstract

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Changes in technology are radically altering how conditions are treated, transforming the way we understand diseases and disabilities, and creating new stakeholders and subjectivities. This dissertation is an ethnographic study of parents and professionals involved in cochlear implantation in and around New York City. In the last two decades, the cochlear implant (CI) has become a common treatment for deafness, and since deaf children born to hearing parents are the fastest growing demographic of recipients, this research focuses on pediatric implantation. By spending time in a CI clinic, parents' homes, and children's schools, I learned how these parents and professionals participate in a social world based on interconnected institutions and the integration of clinical aspects of care into the home. I found that the success of this was significantly correlated with a mother's style of parenting, which was influenced by her class position. Perhaps the most striking quality of this social world was how dependent it is upon neuroscientific knowledge. I found that parents saw themselves as engaged in a 'neural project' to overcome their child's deafness. I describe parents' desires to be successful at this, their willingness to comply with medical professionals, but also the ways they struggle to find their own agency in the middle of it all. Lastly, all of this must be seen within the larger context of social and technological change. There has been tremendous controversy over CIs; many in

Deaf culture argue against their use because they diminish the numbers of children that learn sign language. They argue that CIs ultimately represent a case of a technology destroying a community. I found that this technology also generates community. The battle has been characterized as medical knowledge versus Deaf cultural knowledge. However, this research shows that the world of implantation, while steeped in medicine and presumed 'objectivity,' is equally cultural and uses neuroscientific arguments that help to maintain controversy and division between the communities.

## Acknowledgements

I have been waiting a long time to write this section; it is the least stressful of them all. First and foremost, I challenge anyone to name a more supportive and generous dissertation committee than mine. Barbara Katz Rothman, Victoria Pitts-Taylor and William Kornblum: each of you has been incredibly wonderful to me. I especially thank Barbara for her tireless, merciless, and extremely detailed comments on every draft of this dissertation. In addition, I was privileged enough to be mentored by helpful colleagues at The Hastings Center and Yale University's Center for Bioethics. I especially thank Erik Parens for his kindness and generosity with his time.

I want to dedicate this dissertation to the late Jamie Harriet Finkelstein. She was the love of my life: my partner, my editor, my cheerleader, and my best friend. We met during my first year of doctoral studies. I still remember exactly what I was wearing the first time we arranged to meet for a drink and I, just a baby sociologist, was reading Marx at the bar. For the following five years, Jamie was my constant encouragement. She was by my side every step of the process, from completing my coursework and passing my orals exams, to my first day of teaching, my first conference presentation, my first publication, and my first day of fieldwork. Even though she died before the dissertation was completed, she always talked of my graduation and hoped she would live long enough to see it. I am profoundly sad and utterly heartbroken that I can't share it with her. This research is as much a product of her support, as it is a product of becoming her caregiver. Becoming a caregiver was the most brutal and most beautiful

experience of my life; I owe her a great debt for teaching me to see the world with new eyes. These eyes have helped me to be a better sociologist, and a better person.

This dissertation is the result of collective efforts and there are probably more people to thank than will ever even read it! I want to thank Cricket McLeod for being my confidant and ultimate supporter. Through all my writing, I have looked at the totem you gave me ten years ago: a small, plastic skull to place on my desk so I did not forget to be punk rock. Thank you Jane Dowling for reminding me that critiquing medicine *is* the new punk rock. I want to thank Kathryn Housewright for being a sister to me, ever patient with my ups and downs. Thank you Chris Castillo for your cross-country endurance. And Adrienne Sneed, thank you for your entertainment and support.

Of all the people in the world, I thank Brad Gibson for opening up the Deaf world to me. Without our friendship when we were just kids and none of this would even exist. You shaped the trajectory of my entire life. Thank you Byron Bridges for sending me to Gallaudet University in the first place, for telling me I could do more, and for giving me the confidence to do it. Thank you Dirksen Bauman for telling me so nonchalantly once I got to Gallaudet that I could go on to do a doctorate; no one had ever said that to me, much less with such matter-of-factness.

Thank you to the Deaf communities far and wide – from Austin, Texas to Washington, DC, Bristol, England, and New York City. I especially thank Gallaudet comrades Joseph Hill, Emilio Insolera, and Emily Steinberg. I must also thank the cochlear implant communities; many individuals displayed an enormous amount of trust and kindness. I am forever grateful to you for 'letting me in' as much as you did. I especially thank study participant J.L.: your openness and willingness to be emotionally authentic with me made this work what it is. Thank you to my fellow PhD seekers at CUNY, your camaraderie kept me sane. Crystal Bradley,

Lawrence Carter-Long, Christine Sun Kim, Fern Silva, and the entire Mate Family: you each hold such a significant place in my heart that is filled with gratitude for your constant love, understanding, and friendship. Without each of you, I would not have been able to carry myself through.

I also thank my parents, Stan Mauldin and Suzan Brown, for their constant, miraculous approval and support of me while I pursued my dreams. I must be one of the luckiest girls from Texas to have been born into the family I was. And I can only hope that all my life endeavors are done with as much grace, love and care as the late Helen Jane Hall Mauldin Dowling. Finally, I am especially grateful to my grandmother, Lois Murphy. Without her financial assistance, constant advice giving, and ability to talk me down from the ledge, this research would not have been possible.

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

It was a bright, sunny October afternoon. As I was walking up to Jane's[1] that day, there were Halloween decorations around front doors and leaves on the ground. We made tea and stood in her kitchen. I leaned against the counter and as she fed her youngest son, who was sitting in a high chair. She was waiting for her daughter Lucy to come home from school. She was four years old and had recently received a cochlear implant (CI).[2] Soon, she would get home from school, where she received extensive speech therapy and was placed in a classroom that was tailored for children with CIs. Jane told me that Lucy was progressing nicely in her speech articulation and comprehension and it was clear that Jane was brimming with excitement about it.

Over the last two decades, the CI was introduced as a medical device heralded by many as a cure for deafness. In the 1990s, however, the market for CIs "grew far more slowly than had been anticipated…Deaf people were not coming forward in anything like the numbers anticipated by professionals and manufacturers" (Blume 1997:38). In an analysis of the scientists and engineers who designed them, Blume showed how CIs moved from being thought of as 'experimental' to being routinely applied, largely because of certain conceptualizations of deafness. Namely, the scientists who developed the CI seemed to think that deaf individuals had

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[1] All names have been changed to protect the identity of the study participants.

[2] The CI is a tiny receiver attached to a silicon-covered array of electrodes. In surgery, the receiver is implanted into the skull and the array is inserted into the cochlea, a small, circular tube in the inner ear that translates mechanical sound waves into electrical signals. A microphone and speech processor is magnetically attached to the receiver via the skin behind the ear. This translates sound waves into electrical signals, which directly stimulate the auditory cortex (Clark 2003).

no other recourse but to sit in silence and wait for a cure. "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" (Blume 1997:39). Furthermore, the media continually promised the possibility of making the deaf hear.

The manufacturers and designers of CIs did not consider that deafness might be something a person may find acceptable, and even worth being proud of, and that sign language had a long history and culture associated with it. After the introduction of CIs, deaf persons went from being disinterested to actively opposing them. "The history that began to be written is one of oppression of deaf culture and deaf language" (Blume 1997:48). CIs were seen as a threat to a specific linguistic and cultural tradition and many utilized identity politics and diversity arguments characteristic of other new social movements.

Indeed, during the 1990s, as CIs became more sophisticated and more regularly used, a culture war between those who felt their deafness was not at all a medical problem - those who identified as Deaf[3] - and those who thought deaf persons should use a CI in order to hear and speak grew fierce. On the one hand, this device was thought to cure what was understood by medical professionals to be an isolating condition. On the other, those who used sign language to communicate felt that they simply used another language and were not in need of intervention. But no one *had* to get a CI if they did not want to, except for one major group: newborns and infants who were identified as deaf. And it is this group, according to the National Institute on Deafness and other Communication Disorders (NIDCD), that is the fastest growing group of recipients (2009). More than ninety percent of these children have parents who can hear (NIDCD 2009), which means that the consumer this device was intended for – deaf persons – is

[3] I will give a history of the use of capital 'D' deafness below, but it basically refers to a cultural identity that emerges out of the use of sign language.

not who is predominately consuming it. Instead, it is parents who can hear who are opting for the device for their child. As the age of implantation has steadily decreased, this complicates the debates that were already there. Now, the discussion often turns to parental rights, decision-making based on providing one's child the "best opportunities," and this all occurs in the context of more and more technological information. Throw in the emotional currency that parenting has, and an environment of dissension and anger is easily created. In fact, on one of my first days in the field, I was told a story of a parent who decided to get her child a CI had her tires slashed by those who opposed her decision.[4]

Parents and professionals that work in the field of implantation are well aware of the controversy. One evening, I was sitting in a conference room at a CI center where a support group for parents who were getting, or had already gotten, a CI for their child was about to begin. Gretchen, the facilitator, sits down with me and tells me about how the support group is really open-ended and unstructured, that it is intended to be a place for the parents to vent. There are not many chances to do this kind of venting and families are able to be mentored here because the people that attend are in all different stages – from the newly diagnosed and in crisis to old timer's that give support. She says she is really kept "on her toes; you never know what will walk through the door." Then, in comes Nancy, whom Gretchen would classify as an "old timer." They know each other well and have been friends for more than ten years. As we start talking about why I am at the meeting, I explain that I was intrigued by the Deaf community's argument against CIs. "Don't they understand their numbers are going down?" Nancy asks. "I

[4] I have no idea if the story is true or not, but nevertheless it struck me that the first time I attempted to conduct fieldwork, this was what I was told. I say 'attempted' because the person telling me this story worked in a CI center and, upon hearing my research interests, did not permit me access to that site, citing the controversial nature of the topic and doubts about me even 'being a graduate student.'

have one thing to say to them: culture's change," she continues. Gretchen nods, but quietly adds, "Well, I can understand, that's why they are upset, their culture is disappearing."

Another time, when sitting with a social worker at the CI center we talked about the controversial views around CIs, I asked her what she thought about the objections to CIs. She said that it was odd, "it's as though they think that signing is just like another language, so why are you taking this away? [Deaf people say] 'there's nothing wrong with us, we're different, it's not a disability.' But that's one point of view." Even Nancy, the old timer, told me stories over lunch one day of being warned how deaf persons would be coming up to her and telling her she had 'maimed' her implanted child. "I said fine, bring 'em on!" she tells me. "You know what? My answer to them is this: cultures evolve. If it didn't evolve we'd still be in the stone-age, the guy who decided to farm instead of going hunting and gathering, would still be out there."

Pediatric[5] implantation has been the hot-button topic of the CI debate and "opposition to pediatric implantation among certain members of the Deaf community continues unabated" (Christiansen & Leigh 2011:47). The issues were grappled with in 2000, when the documentary *Sound and Fury* followed one family's fight over CIs; half the family was deaf and used sign language and the other was hearing. In the film, there are two brothers, one deaf and the other hearing. The hearing brother, speaking of the increasing numbers of implanted children – including his own- says, "Deaf culture as they know it, is done" (Aronson 2000). This is followed by the deaf brother saying, "Maybe it's true: Deaf people will become extinct and my heart will be broken. Deaf culture is something to value and cherish. It's *my* culture. If hearing culture was wiped out, hearing people would cry and feel lost. Well, so would I" (Aronson 2000).

[5] In this dissertation, pediatric implant recipients are those between the ages of zero and six years of age.

I can relate. I am a member of this culture; I am not deaf, but I sign fluently. And where there is language, there is culture. I have known deaf persons for almost as long as I can remember. My school district growing up was the district that all the deaf children from the surrounding area were bussed to for the deaf education programs they provided. I learned sign language as I grew into my own identity throughout adolescence, studied the linguistics of sign language in college and maintained deep friendships with many deaf persons who, to this day I love, respect, and think of simply as people I use a different language to converse with. But I am also moved when surrounded by Deaf persons, feel comfortable, and intimately connected to this world. Like the deaf brother in the film, I would also cry if I was told that that part of my life experience was going to disappear.

Arguments over CIs are deeply emotional. They quickly become heated and often those on opposite sides of the debate have difficulty finding any common ground from which to work; debates are usually about language and whether or not one 'should' use sign or not. Part of the reason I undertook this project was to begin from the context of controversy and attempt, as a sociologist, to understand the social world of those who supported CIs not from an emotional place, but from a rational, 'researcher' position.[6] Rather than evaluate the saliency of either side's argument, I wanted to investigate the consequences that implantation was having on the lives of those who underwent it, especially the mothers (and some fathers) who obtained one for their child. This dissertation is my attempt to move beyond the heated back and forth over the idea of CIs, and instead to look at what CIs mean to one very important group: the parents who get one for their deaf child. Until now, the device itself – what it invokes and symbolizes - has been controversial. But what I want to focus on here are the outcomes and ongoing challenges of

[6] See Howard Becker's article (1967) on "Whose side are we on?" for a lengthy discussion on whether or not researchers should or could be neutral.

implantation, and I focus particularly on pediatric implantation.

The main thing to understand about the process of implantation is that it is not a one-time event. Children do not receive the implant and then are suddenly able to hear. Rather, they must undergo years of follow up therapies, adhere to intense and on-going methods of training, and continually program the device (a process called 'mapping'). It is long, it is arduous, and the results are highly variable.

Today, outcomes data on pediatric implantation are sparse and there are not hard measurements for determining the 'success' of it. Subjectively, a successful outcome would be one where the child seems to comprehend and articulate speech in a manner that is indistinguishable from a hearing person. But how can this be effectively measured? Aside from testing frequency discrimination, key word intelligibility, and using literacy assessments, how does one evaluate an individual's grasp of language (as opposed to speech)?[7] For whom does it "work" and when do we know it does not? As of today, there are no agreed-upon standards or numbers to tell us. While this dissertation does not attempt to answer these questions, it does attempt to show how deafness and being implanted is enacted through multiple, new social relations that have flourished alongside the increasing use of CIs. Perhaps through this, we may find avenues for developing such assessments. This would be much more useful than determining the rightness or wrongness of those on either side of the theoretical debates over whether or not CIs are a good or bad thing.

[7] Tobey (2010) summarized recent studies that have been undertaken in an effort to gather outcomes data. Because of the long-term nature of implantation, numerous years since implantation are needed for measuring outcomes, but CIs have only recently been increasingly adopted, leaving many unanswered questions. This is especially true for those children that it does not work for who silently disappear into sign language schools or educational programs; this presents a serious problem with hidden demographics and hinders our ability to understand what exactly the outcomes are.

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This dissertation draws from multiple approaches, including sociology of health and illness, science and technology studies, and disability studies. In its broadest sense, it is an ethnography that focuses on the social actors and organizational structure of an institution of medicine. But it is especially concerned with the interactions and technologies involved in the production, circulation, and consumption of medical and scientific knowledge, and the ways these processes extend beyond the clinic's walls. A focus on technology is increasingly being interwoven into medical sociology (Casper and Morrison 2010), mirroring a core area of concern in science and technology studies (STS): the ongoing, ever in-flux co-production of technology and society. Timmermans and Berg (2003) state that, "looking at technologies as central mediators in the construction and reproduction of novel worlds…should be high on our research agenda" (2003:104). Indeed, over the last thirty years, there have been drastic changes in the practice of medicine due to changes in technology, which Clarke et al (2005) assert move us from medicalization[8] to biomedicalization.[9]

In my fieldwork, I observed how changes in medicine are enacted through and alongside technologies, like the CI, such as how and when deafness is diagnosed in newborns, infants, and

[8] Originally conceptualized by Zola (1972), Conrad gives a working definition of medicalization as, "defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to 'treat" it" (Conrad, 2000).

[9] Clarke et al (2005) assert we have reached a "critical infrastructural mass…because capacities for clinical diagnosis and treatment are being technoscientifically transformed" (2005:442). Therefore, they argue for examining biomedicalization, the "increasingly technoscientific, complex, multi-sited, multi-directional processes of medicalization" (2005:442-3).

children, as well as how certain types of deafness are treated. The CI, a neuroprosthetic[10] designed to provide hearing in the hopes that a patient who is deaf may learn to speak and listen, is a device through which processes of biomedicalization can be studied. Both the science of and the long-term follow-up recommended with this device have been accompanied by a series of institutional changes, rising expectations for parents to adopt the CI, the development of emergent CI-related communities, and an increase in new forms of medical surveillance. As these changes continue, more and more deaf children are encouraged to strive for spoken language acquisition and their parents are the most common consumer of CIs. I also observed that rapid institutionalization is occurring, even though CIs remain a controversial technology. This institutionalization is not just occurring in the clinic, but also in schools, social service agencies, and hearing loss interest groups that are all linked together. But implantation cannot be seen outside of the politics of disability, the project of normalizing bodies, and the history and politics surrounding deaf persons and the disability rights movement. Thus, I will spend some time in Chapter Three talking about these historical and theoretical contexts.

In this dissertation, I will offer a way to understand the changes the CI brings by asking why they have taken place and how they are enacted. To show these changes, I look at interactions between parents who choose to obtain a CI for their deaf child and the various professionals that work with them. I do this mostly in a CI clinic, but also in other sites, such as schools, parent support groups, and hearing-loss related organizations, that are linked to the CI clinic and those who utilize its services.

[10] Illustrative of changes in biotechnological capabilities, the CI is a neuroprosthetic or neural prosthetic, which replaces a sensory modality with a digitally simulated version. When the neural functioning for this process is damaged or diseased, neuroprostethics offer a simulated version of sensory information for the brain to utilize.

Most of my time in the field was spent focused on learning the clinical routines involved in implantation, as well as strategies employed by the center to attract and maintain their customers. The surgeon and director were upfront about their desire to be the clinic where parents came for initial diagnosis, follow up care, implant evaluations and candidacy, surgery, and on-going mangagement of the device. They did not want to 'lose' parents to other centers or surgeons, and even asked me to find out how they could have better retention rates. But I was focused on learning the routines, observing the interactions of the center staff amongst each other, and understanding the experiences of the parents who were coping with having a deaf child with a CI. On this final point, I followed up my observation in the field with interviews and additional observations with parents at home, support group meetings, or their child's school events. There are no other studies of these relations, the closest being Stuart Blume's study (2010) of the scientists, engineers and researchers involved in the design, dissemination of CIs. He also interviewed parents, although his focus was largely on the decision-making process and the industry side of the technology. Furthermore, the bulk of his fieldwork was conducted in Europe and spoke to the politics around CIs, especially in the Netherlands. My research is different because it focuses on the lived experiences of the medical professionals, parents, and educators who, together, enact the relations around this technology in an ongoing manner in one city in the US. It also, in part, seeks to address a gap in information that he raises:

> It is odd that ethicists and other scholars devote so much attention to clarifying how we should make decisions while so little attention is paid to how we can subsequently live with them. A decision is made once…It is not only a matter of making agonizing choices. It is also a matter of the context in which they are made and the context in which we then have to live with them" (2010:172).

***Deafness and the prevalence of cochlear implants***

Those who cannot hear may sometimes be called "hearing impaired" or "hard-of-hearing." Being deaf, as opposed to hard-of-hearing, indicates that the impairment is so profound that the person also may not speak and/or may be unable to understand or use spoken language.[11] As a result, many deaf persons in the US use a signed language, American Sign Language or ASL, to communicate. Throughout the rest of the world, deaf persons use sign language as well, although each country has its own. Being unable to hear and use spoken language is classified as an impairment or disability, although this is a contested idea.[12] While disability is a broad and wide-ranging category, deafness is usually institutionally categorized as a 'sensory disability.' This is seen in the Americans with Disabilities Act (ADA) of 1990, in the World Health Organization (WHO), and I the fact that deaf persons are also included under the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). Furthermore, deaf education in the United States is part of the special education system, which is responsible for educating students with disabilities.

According to the National Institute on Deafness and Other Communication Disorders, (NIDCD) more than sixty-seven thousand people in the US have a CI. CIs treat severe to profound hearing

[11] Deaf people do not prefer the term 'hearing impaired' and instead ask that, when their audiological status is being described, they simply be called 'deaf' instead.

[12] Most people consider deafness a disability, however, as I will discuss further below, members of what is known as Deaf culture or the 'DEAF-WORLD' typically do not identify as disabled and are even hostile toward the term. The use of all capital letters in DEAF-WORLD is what linguists call a 'gloss.' Because there is no graphic representation system for writing sign language, the concept being conveyed in a sign is capitalized in the closest available spoken language word. Here two concepts are linked with DEAF-WORLD and refer to what one might call in English, Deaf culture or the Deaf community. Davis (2008), however argues that this term is problematic; at once too elastic *and* too dependent on categories like deaf and hearing. Still, I think it important to invoke and use here as a guidepost or reference point.

loss associated with the inner ear (2009).[13] Although older children and adults do receive CIs, my research focus is specifically on implantation in infants and the subsequent quest to acquire spoken language. I chose this demographic for a number of reasons. Firstly, infant implantation is increasing at the most rapid rate. According to the NIDCD, children under the age of six are the fastest growing demographic of CI recipients (2009). In Chapter Three, I will provide the historical context of this, which is largely the result of drastic changes in both technological capabilities and health policy regarding the age by which hearing loss is identified in infants. For example, in 1993, only five percent of children were screened for hearing loss, while today that number has risen to more than ninety percent (Meadow-Orlans et al 2004). The second reason for looking at pediatric implantation is that hearing loss is the most commonly detected birth defect (Center for Disease Control 2010, American Association of Pediatrics 2010) and more than ninety percent of children diagnosed with hearing loss are born to parents who can hear (NIDCD 2009). The hearing status of parents strongly correlates with a desire for the child to develop spoken language and has been shown to be the most significant factor in the decision to implant (Archbold et al 2001, Christiansen and Leigh 2002, Bain et al 2004, National Association of the Deaf 2000, Okubo 2008). Once again, this shows that hearing parents are the primary consumers of CIs, and as I mentioned above, it is pediatric implantation that has provoked the strongest anti-CI sentiments from those who oppose implantation.

***Expanding CI markets***

In addition to medical services, social services and intervention programs are also available to infants and their families, such as state-funded early intervention services and district-level educational programs. As I will describe throughout this dissertation, these are now

[13] 'Severe' and 'profound' are degrees of hearing loss. Degrees are categorized according to the patient's ability to hear at particular decibel levels.

often tailored to and specifically developed for optimizing implantation, creating links between the clinical, social service, and education markets. And the market for implants continues to grow. Cochlear, one of the largest CI manufacturers[14], reported in 2008 that, "fifty percent of people implanted with a CI received it in the last five years, reflecting the exponential growth characterizing this intervention" (Cochlear 2008:1). Children are the most common recipients, and given the option to implant, parents are more and more often turning to implantation and the accompanying long-term therapies. This illustrates how "cochlear implants and neonatal screening have catapulted the deaf child into the auditory-verbal camp" (Luterman 2004). In this dissertation, I endeavor to show the day-to-day routines involved in the practical accomplishment of scientific and medical enterprises associated with implantation.

***The controversy over CIs***

The controversy over CIs is complicated. Like many medical technologies, CIs produce and are produced by social and technological changes that raise a host of ethical, social, and political concerns. Unlike other medical technologies, CIs raise questions in a specific and politically perilous aspect of culture: language. Before CIs, deaf persons often adapted to the condition through the social technology of sign language, but it has been well documented that along with CIs come institutionalized and corporatized goals and practices, which are predominantly enacted at the exclusion of sign language.

To illustrate: "Some states have documented that parents are choosing the listening and spoken language outcome as high as nine out of ten cases" (Murphy 2009:22). Murphy notes that in 1997, a mere sixteen percent of elementary and secondary students with hearing loss were aiming for spoken language acquisition. But this was before implantation became a common

[14] There are three implant manufacturers, Cochlear, Advanced Bionics, and MED-EL.

clinical practice. "Today seventy-three percent of elementary and sixty-eight percent of secondary students are learning through spoken language. That's a dramatic shift to occur over just one generation" (Murphy 2009:22).[15] It has not only resulted in changes in sign language communities and rates of usage that are not yet fully understood, but also a firestorm of political activism.

Deafness is a rich area of study, due to the presence of a shared language. This language, a signed language, is linguistically equivalent to any other language[16] and thus is accompanied by culture, history, and identity. For example, sign language is quite different from Braille, which is a tactile code representing the written form of a spoken language. Unless one is deaf and blind (deaf/blind), individuals who are blind or visually impaired can hear and speak the spoken language around them. To the surprise of some, many deaf persons do not want to be or become hearing and have in fact argued against CIs, particularly when it comes to the implantation of infants (Aronson 2001, Bahan & Lane, 1998, Blume 2000, 2010). The arguments leveled against CIs tend to center largely on the claim that sign language is a better solution to deafness than using CIs to acquire spoken language. Although there are more reasons articulated for and against CIs, it is important to understand that the CI has not clarified or "solved" deafness, but rather incited tremendous controversy.

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[15] It should be noted here that educational outcomes or measures of the CIs success – even though a high percentage are working toward spoken language acquisition- are not readily available, summarized or aggregated, and issue I take up later in the dissertation.

[16] William Stokoe studied and transcribed ASL and proposed a linguistic system that would "do for manual signs what phonology had done for spoken words" (Rée 1999:310). He is widely credited with initializing the formalization of ASL and revealing its linguistic complexity in his essay, "Sign Language Structure" (Stokoe 1960). Since then, dozens of studies have confirmed that ASL and other signed languages are linguistically equivalent to spoken languages (Liddell, 2003, Valli et al 2005).

***Deafness & disability***

Although deafness is considered by government agencies and educational institutions to be a disability, the condition of deafness and the concept of disability have long had a contentious and blurred relationship. Deafness is a conundrum: because there can be no language without an accompanying culture, deaf persons can be both seen as disabled and as potential members of a legitimate language-bound *Deaf* culture. This is reflected in the use of 'deaf' and 'Deaf,' a distinction that began in the 1970s in the US, following a variety of identity-based new social movements in the latter half of the twentieth century. (Humphries & Padden 1988). The word 'deaf' defines an audiological state while 'Deaf' indicates a cultural identity stemming from this state. Being 'Deaf' is an identity primarily characterized by one's use of American Sign Language (ASL) and embodiment of a set of distinct cultural values (Humphries & Padden 1988).[17]

For those in Deaf culture, the CI raises a host of questions about the values that are embedded in technologies and which communities and identities are valued in society: What does it mean when a technology like the CI is introduced that is claimed to have the potential to render a social technology like sign language unnecessary or irrelevant? Should we be rushing to protect an endangered language? Or should we embrace the idea of a technological future it represents, one where sign languages are obsolete? These questions are not unlike other questions we are asking about how technologies should be incorporated into and used in society.

[17] Throughout this dissertation, I will be using deaf and Deaf where appropriate. To be inclusive of both terms, or when referring to their coexistence, I will use "d/Deaf."

While there is certainly a long history of medical intervention into deafness, none have held the promise or sophistication that CIs do. CIs are already associated with a decline in the use of sign language due to implantation and its accompanying values that promote ambition for spoken language. The language politics involved here, however, also emerge from deeper ideologies that those with disabilities, including deafness, are in need of medical intervention. There are different threads of thought on how to theoretically deconstruct and critique disability, medical technologies, and practices. In Chapter Four, I will contextualize these theoretical approaches within the social history of disability, the Deaf movement, and the academic fields emerging from each of them.

***Prevalence deafness: Do Deaf people count?***

Not only does the duality of d/Deafness as both a condition considered a disability and a cultural identity place the deaf community at a heavily contested intersection, but it also complicates attempts to measure the American d/Deaf community. Do we measure the prevalence of persons with a certain degree of hearing loss or the prevalence of a language? Is it both? Do we measure the prevalence of a condition or the prevalence of an identity? Should we count being Deaf as an ethnic group? The presence of language hinders even a straightforward set of data that can adequately give a picture of the d/Deaf community in the US, and thus adequately give a picture of how it is changing due to the CI.

Multiple problems persist in simply counting deaf people. For example, the US Census does not provide statistics on the number of deaf people in the country because "the sensory disability question on the census (Question 16) did not separate those who are deaf from those who are blind" (Mitchell et al 2005). The preeminent place to find statistics on deaf persons is Gallaudet University in Washington, DC, the only liberal arts university for the deaf in the

world. The Gallaudet Research Institute (GRI) has estimates of the deaf population and its characteristics, but even defining what we mean when we refer to the "deaf population" in order to measure it seems quite the complicated affair, as seen in the box below from GRI (2005).

***A Brief Summary of Estimates for the Size of the Deaf Population in the USA Based on Available Federal Data and Published Research:***

- About 2 to 4 of every 1,000 people in the United States are "functionally deaf," though more than half became deaf relatively late in life; fewer than 1 out of every 1,000 people in the United States became deaf before 18 years of age.
- However, if people with a severe hearing impairment are included with those who are deaf, then the number is 4 to 10 times higher. That is, anywhere from 9 to 22 out of every 1,000 people have a severe hearing impairment or are deaf. Again, at least half of these people reported their hearing loss after 64 years of age.
- Finally, if everyone who has any kind of "trouble" with their hearing is included then anywhere from 37 to 140 out of every 1,000 people in the United States have some kind of hearing loss, with a large share being at least 65 years old.

**Table 1: Federal Census Data Estimates of the U.S. Deaf Population (Mitchell et al 2005)**

Based on the amalgamation of a number of different surveys available, many of which are unfortunately known to be outdated, the GRI estimates that deaf signers would "number in the hundreds of thousands today (360,000 to 517,000)...this final estimate is just that, an estimate (and a very rough one at that), and is not based on any new data" (Mitchell et al 2005). So, even though we may have some idea of the number of deaf persons, it is unknown if they are necessarily members of the Deaf community per se.

Tracing the community of ASL users is even more difficult since deafness is "predominantly treated as a matter of public health and social welfare policy in the United States, not primarily as a social and linguistic phenomenon within the general population" (Mitchell et al 2005). Thus, it is equally as difficult to estimate how many people use American Sign Language as their primary mode of communication. Furthermore, "None of the above

federal survey activity inquires about special language use or social identification among those who are deaf (or hard of hearing). That is, there are no questions about ASL or any other signed language use on federal surveys" (Mitchell et al 2005). Despite the "overwhelming evidence that signed languages are among the world's natural languages" (Lane, Hoffmeister and Bahan1996:43), the acceptance of ASL as a foreign language in universities, the professionalization of sign language interpreting, and claims of deafness an ethnic group, deafness has remained a purely medical phenomenon in government institutions like the US Census.

***Language politics and CIs***

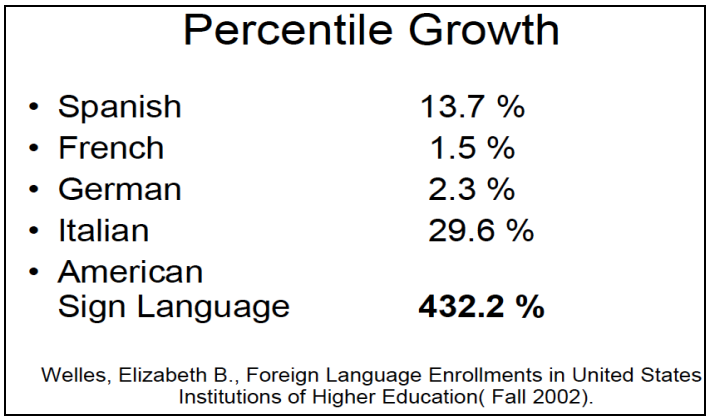
As I stated above, the role of language is the most significant practical issue being debated in the controversy over implants. Sociolinguists have studied language promotion, revitalization, or preservation, as well as languages of marginalized groups and language suppression (Milroy 2001, Garrett 2010) and their influence on language policy or planning (Reagan 2010). They have found that in general, the status of a language often indicates the status of the group who uses it. Garrett (2010) writes:

> It is generally difficult to distinguish attitudes to language varieties from attitudes to the perceived groups and communities members who use them. Language varieties and their forms are often not simply characteristic of a community, but even enshrine what is distinctive in the community and in a sense 'constitute' that community (16).

Furthermore, misconceptions about the nature of ASL tend to "feed the skepticism about the linguistic status of ASL and this is not helped by the fact that ASL is a minority language in the country where spoken English is the language of the majority" (Hill 2011:35). Deaf studies scholars and Deaf activists have developed the term 'audism' to critique this skepticism, the hierarchy of linguistic modalities, and the devaluation of sign language.

> Audism is attitudes and practices based on the assumption that behaving in the ways of those who speak and hear is desired and best. It produces a system of privilege, thus resulting in stigma, bias, discrimination, and prejudice—in overt or covert ways—against Deaf culture, American Sign Language, and Deaf people of all walks of life. (www.audismfreeamerica.blogspot.com)

Interestingly, at the same time that implantation was gaining popularity in the US in the 1990s, ASL also became increasingly marketable, suggesting that the relationship between American culture and the DEAF-WORLD is much more complicated than an expression of a nation's views on minority cultures. For example, universities began accepting ASL as a foreign language; schools then offered courses in ASL and were in need of qualified professionals to teach them. (See the chart below). Additionally, because of the Americans with Disabilities Act (1990) requiring interpreters in certain settings, hundreds of Interpreter Training Programs (ITPs) at community colleges and universities cropped up across the country. Lastly, and perhaps most ironically, using sign language with hearing infants emerged as a popular trend for new mothers, especially in the mid-2000s, to encourage their child's linguistic development,[18] even as mothers with deaf children were not encouraged to do so.




[18]See www.babysignlanguage.com or www.babysigns.com for research articles and justifications for baby sign language, which include 'reducing fussiness,' improving development, and strengthening the parent-child bond. Both cite National Institutes of Health studies. Ironically, sign language remains taboo for deaf children.

**Table 2: Percentile Growth of Foreign Language Enrollments**

In 2008, the Center on ASL/English Bilingual Education and Research held a National ASL/English Bilingual Early Childhood Education Advisory Focus Group meeting and presented the following:

- More hearing people are learning ASL than deaf people
- Less than 1% of deaf people are learning ASL
- More teachers are teaching ASL to hearing people than to deaf people
- More hearing parents are using sign language to communicate with their hearing children
- More hearing parents are using spoken English to communicate with their deaf children
- No formalized ASL curriculum and assessment exists for deaf children the US

As stated at the beginning of this chapter, most parents of children with CIs opt for them to be educated in spoken language environments (Murphy 2009). One can surmise the correlation between the rise of CIs and the decline of ASL usage in deaf persons. Interestingly, this also coincides with the rise of ASL in different – that is, hearing – communities.

The Deaf community, however, sees the CI as a threat to the strides made by the Deaf social movement, which advocates the use of ASL in deaf children. In short, the controversy over implants is a lot of things, including controversy over language, the value of disability, the role of technology in society, and the goals of medical intervention.

***The war over CIs***

CIs have been highly contentious and the vitriol is easy to find. In June 2006, one parent posted the following to the website The Straight Dope, in response to the anti-CI position of the Deaf community:

> My 4-year-old daughter is deaf. She is **not** "Deaf" with a capitol D. She simply has no hair cells in her cochlea, she has no functioning inner ear. Even though she is deaf, she is not automatically part of your little world of shame and exclusion, and her native language is **not** ASL. It is not child abuse if we decide to raise her in a household that speaks English. So: fuck you for claiming her as your own, without a second thought to the wishes of her parents (boards.straightdope.com).

Exchanges like these are easily found on the internet. One site, www.cochlearwar.com, organizes forums, which are divided into threads for Deaf persons, parents, and professionals. While not all exchanges are as heated, there remains a level of animosity around this technology that is striking and persistent.

For those against the widespread use of CIs in children, implantation and the goal of spoken language acquisition is hegemonic, normative, and a direct threat to sign language and Deaf culture (Lane and Bahan 1989, Crouch 1997, Sparrow 2005). For those that support the use of CIs, the idea of being able to acquire spoken language despite one's deafness is deeply attractive, simply pragmatic, and even an ethical act of care toward the child and an individual's responsibility to society (Tucker 1998). Over the last two decades, increasingly antagonist communities emerged on either side of the intertwined CI and language debates. I found that the CI community is marked by vastly differing values with regard to language and deafness.[19] I also found the CI center to be a meaningful site of meaning-making and thus significant facilitator of social change for d/Deaf persons, hearing parents of deaf children, and a variety of professional fields that accompany this technology. In order to further situate this study against the backdrop of Deaf culture and controversy, I will also elaborate further in Chapter Three on the history of sign language in America and of the academic work being done in Deaf studies.

[19] I do not wish to give the illusion that these communities are neatly separated or homogenous in their views. Although there are clear 'sides' to the argument in that some identify as pro-CI, others as anti-CI, perspectives are evolving and not all persons on either 'side' are totalitarian in their views.

Despite the persistence of debates over CIs and resistance of the Deaf community in the US, however, rates of implantation continue to rise. *The New York Times* reported that there are "debates across the country as technology creates new possibilities for deaf people through cochlear implants" (Schemo 2006). In 2000, the documentary film *Sound & Fury*, which showed the rift in a family with deaf and hearing members over implantation in deaf children in the family, was so gripping that it received an Academy Award nomination. Ten years later, a news story about a deaf father in Washington who faced charges of contempt "for refusing to force his deaf daughter to wear cochlear implants" garnered national attention (Boggs 2010).

I observed how the CI reshapes and challenges the politics of parenthood, in addition to transforming clinics, social service agencies, and schools. "There is increasing discussion in signing deaf school settings of the influx of implanted children and the changes this will bring to the entire approach to education in their schools" (Johnson 2006:31). I also observed how implants are accompanied by new modes of education, new areas of specializations and professions, and industries. The *New York Times* (Davey 2011) recently asked "Will sign language and the nation's separate schools for the deaf be abandoned as more of the deaf turn to communicating, with help from fast-evolving technology?" The conundrum of deafness, steeped in controversy around the issue of language, is now materialized in an artifact of technology: the CI.

**

Given the controversy over CIs and the heated debates going on in Deaf culture, why do research in a clinic? One reason is that there is certainly not a pressing need for further elucidations on the arguments; these have been spinning for some time and this dissertation is

not intended to be one more argument thrown on the pile. In an effort to go beyond the abstraction of the politics, I believe going into a clinic provides the best opportunity for understanding the consequences that implantation is having on the parents and the professionals involved. From here, it may be possible to not just have a better grasp of the social changes caused by technological change, but also to have empirical evidence from which we can view the arguments over implants in new ways. But, perhaps more meaningful than this, it is my way of shifting the discussion from the CI to the practices surrounding it:

> If practices are foregrounded there is no longer a single passive object in the middle, waiting to be seen from the point of view of seemingly endless series of perspectives…The body, the patient, the disease, the doctor, the technician, the technology: all of these are more than one. More than singular. This begs the question of how they are related (Mol: 2002:5).

***The actors***

The actors involved in the collective lives I describe had various roles. I observed audiologists, who often have a doctorate in audiology, but are not physicians. They specialize in both the anatomy of the ear, disorders in hearing, as well as counseling families on dealing with hearing loss and may or may not be involved in federal newborn hearing screening programs. Some of the audiologists in my study were young, in their twenties, but most of them were in their forties and were experienced audiologists who were highly trained and comfortable working with children with CIs.[20] But the center staff also consisted of administrative assistants, those who worked in the hearing aid dispensary, the ENT doctor who is also the CI surgeon, newborn hearing screeners, speech therapists, and the social worker. The people I have listed above are those that I spent the bulk of my time observing, though I had interactions with other employees who had different roles, as well as educators at outside institutions. By far, the

[20] To preserve confidentiality, I alter slight details of the site or the persons in my descriptions.

people I interviewed the most were parents. Out of all of them, mothers overwhelmingly were present. In only two interviews with two different couples was the father also present. As I met parents in the clinic and interviewed them in their homes, I got to know "the moms[21]," especially two families in particular, Jane and her daughter Lucy, as well as Nancy and her daughter Anne. Sometimes I accompanied one to visits to their child's school, to training seminars put on my CI corporation representatives, another to parent dinners and support groups. Lastly, I observed that references to Deaf culture and Deaf persons seemed to conjure up opposing 'implicated actors'[22] within the social world of implantation. Thus, I consider this amorphous referent an 'actor' of sorts. Here is a list of 'characters' and their role in the study and in the community.

| **Name** | **Role** |
|---|---|
| Sharon | Center Director & Audiologist |
| Annette | Chief of Audiology |
| Monica | Audiologist, Pediatric CI specialist |
| Dr. Brown | ENT doctor & CI surgeon |
| Sonya | Social worker |
| Margaret | Newborn screening coordinator |
| Gretchen | Speech pathologist & support group facilitator |
| Shelly | Audiologist |
| Lisa | Audiologist |
| Holly | Audiologist |
| Jane | Mother of Lucy |
| Carol | Mother of Jeremy |
| Nancy | Mother of Anne, AKA "The old timer" |
| Becky | Mother of Amy |
| Kelly | Mother of Nathan |
| Linda | Principal of local school program |
| Tina & Jim | Parents of Amanda |
| Julia & Paul | Parents of Morgan |

**Table 3: List of participants and their roles in the community**

[21] The phrase "the moms" is taken from center staff conversations. It was a rare exception when fathers came to the clinic, reflecting gender norms around caregiving. At times, the newborn hearing screening director or social worker would just say, 'the moms' and so I follow their lead.
[22] Clarke et al (2005) and Clarke & Montini (1993) conceptualized 'implicated actors', writing, "there usually exists a multiplicity of perspectives, heterogeneous voices, meaningful silences, and silent implicated actors in an arena" (1993:68).

**

I have selected portions of my fieldwork to present in this dissertation because I believe they give the best descriptions of the social world and collective lives I got to know. My interpretations are solely my own and shaped by my life experience, understanding of ethnographic methods, and theoretical underpinnings. I will go into further detail on this in the following methods chapter.

In Chapter Three, I provide a brief history of the unfolding of the Deaf cultural movement and provide the theoretical context that I was steeped in as I conducted this research. Chapters Five through Eight are a series of thematic chapters based on my fieldwork. Chapter Five illustrates the organization and culture of the clinic. Chapter Six looks at the socialization of mothers and integration of the CI into parenting styles. Chapter Seven focuses on how neurological discourse is used in the medicalization of deafness, resulting in specific neurocultural phenomena. This is followed by Chapter Eight, which is a brief description of how the CI is transforming deaf education and spawning related educational industries and service markets.

In the clinic, I unearthed much data confirming what I already knew: differing views on deafness are historically fraught, ideologically perilous, and extremely powerful. But, I also unearthed much that was surprising, and even conflicting for me. While I hope to convey the ethos of the Deaf community's views on deafness in order to contextualize this research, I also hope to equally convey the ethos of the CI community's views through ethnographic description, despite the fact that they are quite different and even at odds with each other. It is my goal to

show these views, as well as to show the social forces shaping them. I do not leave out sympathies or criticisms, but rather engage with the jumbled mess that modern biotechnologies leave us in today.

## Chapter 2: Methods: Ethnography in Awkward Places

*Both sides to a dispute have opposing and unshakable convictions as to who are the heroes and the villains involved and where truth and justice lie*.[23]

Because of the controversy over CIs, my background in Deaf culture, and the site I chose for my fieldwork, this was ethnography in places one might call awkward; these social relations were not easy to navigate. Though all ethnographers must wrestle with their position, I want to be explicit about the specific ways I had to deal with mine. For example, anthropologists tend to describe far-flung cultures and then market these descriptions to home audiences. Meanwhile sociologists tend to write about local, maybe even mundane, cultures (Katz 1997). Here we may have a kind of inverse of this, as my knowledge is more akin to 'anthropological knowledge'; the Deaf-World has qualities of being a far away culture right under our noses. This knowledge shapes me. Plus, any ethnography is by definition full of awkward social relations[24] and it is the job of the ethnographer to navigate these.

In 2004, while I was studying at the University of Amsterdam, my adviser commented that because of my life experience, I had done an "incidental ethnography"[25] in the Deaf community without even knowing it. Indeed, it is a world where different cultural rules apply, use of the body is nuanced and quite different from the hearing world, and language conveys information in three dimensional, simultaneous form. I did not think of my experiences or membership in it as a study, but rather as part of my upbringing. Learning sign language was a

[23] From Scott, Richards and Martin (1990:490) writing about social science approaches to controversies over scientific knowledge in their article "Captives of Controversy: The Myth of the Neutral Social Researcher in Contemporary Scientific Controversies."
[24] See anthropologists Hume & Mulcock's (2004) edited collection on ethnography in awkward social spaces, how some spaces are more difficult to inhabit than others, but how these may be the most productive.
[25] Thank you, Han ten Brummelhuis.

crucial part of the adolescent experiences that shaped my adult self.[26] During my time in the Deaf community for almost two decades, I have gotten to know many Deaf persons, became a professional sign language interpreter, and graduated from Gallaudet University. Despite these things, I will make no claim that I am considered 'native' there,[27] but my knowledge of that community and its culture influences me as a sociological researcher.

I chose to conduct research in what will be for many, especially for those who are unfamiliar with the Deaf-world, a rather mundane and uncontroversial site: a clinic where children with hearing loss are treated. But, it was my far away land and some of my colleagues – and myself at times - even categorized it as 'enemy territory.' The conceptualizations of deafness in this space were foreign to me. In my life, I approached d/Deaf persons as persons that I simply needed to switch into my other language to engage with. They were a community that gave me the gift of embodying a different sensorial space, and people who gave me the privilege of witnessing a community linked by language and particular experiences of oppression that I, in my middle-class, southern, white, able-bodied experience, had never known. That is not to say that Deaf persons do not have their problems and that Deaf communities do not have their schisms. They do. There are ugly parts, but the point here is that I had never seen d/Deaf persons as in need of any kind of medical intervention. More than that, I am emotionally invested in and politically sympathetic to the Deaf-world. I was at times uneasy. This deserves further scrutiny

[26] I learned sign at age fourteen as a result of forming a fond friendship with a fellow student in my school who was deaf. To this day, I am greatly indebted to him and the path his friendship has lead me down. Thank you, Brad Gibson.

[27] There is a long history of tenuous relations between hearing people that know sign language to one degree or another, and their acceptance in the Deaf-World. At times I was introduced as "hearing, but…" giving me a pass for being hearing because I can sign well. But I can make no authentic claim of being a native of this world, no matter how "comfortable" I feel in it or how skilled my sign.

and I address this much more below when discussing reflexivity and doing research on controversial topics.

In the last two decades, the discussions involving CIs in the d/Deaf community has been intense. One could not escape talk of this 'new technology' that would 'make robots' out of people and 'destroy an entire culture.' Being against CIs, or at least thinking they were unnecessary, was often derided and attacked by those that supported them. But the d/Deaf community is not homogenous. For example, some individuals lose their hearing later in life. Individuals who become deaf later in adulthood may share a condition with people in the DEAF-WORLD, but their viewpoint and experiences vary a great deal. These 'late-deafened' individuals often opted for CIs if they were an option, saw them as restorative, and celebrated them.[28] Other Deaf persons I knew were engaging in mudslinging against those that supported CIs. Much work has been put into explaining *why* people have such differing opinions about the CI. But there has not been work on *how* meanings surrounding deafness and the CI happen and how these perspectives are maintained. I hope to address that void by using ethnography to make what was a strange phenomenon to me – the medicalization of deafness and adoption of CIs – familiar. This quest to satisfy my own curiosity merged with my professional identity as an ethnographer and I set out to do the work that ethnographers do: reveal the strangeness of the familiar that encompasses us.[29]

***Ethnographic intent***

My ethnographic intent is characterized by two desires that are more art than science; although each speaks to particular schools of thought about the methodology of ethnography,

[28] See the memoirs of Tucker (1995), Romoff (2002), Biderman (1998) and Chorost (2006).
[29] I take this from Lesley Sharp (2007), who eloquently framed her ethnography of organ transplantation as a process of making the familiar strange and the strange familiar.

they also echo the work of the sociologists who have shaped me (Liebow 1995, Myerhoff 1980, Mills 1959, Rothman 1993, 2001). The first desire is to translate observed moments into tangible artifacts marking what it is to be human. By human, I am referring to the inconvenience of the fact that interactions and experiences are sometimes full of conflicting qualities; moments may be sad, hopeful, resolute and ambivalent all at once. Capturing this is the essence of capturing what is human, even if it may not fit neatly into current modes of analysis. In doing this, however, I also focus on connecting micro-level phenomena to the structures surrounding and shaping them. I aim to describe persons and places in a way that reveals their humanity, but not at the expense of dynying the social, cultural, and institutional structures shaping them. Ethnography is one of the most powerful ways that sociology can slow down social processes in order to acknowledge the humanness that is at the core of our social reality. Perhaps society needs time to think and ethnography gives us this chance.[30]

My second desire is to write honestly. Perhaps my greatest concern in this research was my own uncertainty and discomfort. I take responsibility for my own thoughts on the matter and the ways I represented my participants. I take seriously the task of reflexivity. I do not just integrate it into my descriptions as best I can, but I try to maintain reflexivity as part of the method. The interpretive license that ethnographers have is both a challenge and an opportunity to be honest. To write honestly, I acknowledge and include my uncertainty to honor both my position as the researcher, as well as the participants in my project. I take the thoughts, feelings, and motivations of the participants for what they tell me they are, even as I situate them within

[30] I am thinking here of various slow movements. For example, the Slow Science Manifesto's slogan is "Bear with us while we think," proclaiming that science needs time to think, to fail, and that room must be made for justice. I take up this idea again in subsequent chapters. See slow-science.org for further information.

social forces and point out contradictions.[31] It is a balancing act; I must toggle between what I see and where my sociological imagination, an imagination that has been shaped by my experience, takes me. It is this process of extrapolating from the moments that happen in front us when the scholar "must sometimes ask the reader to make a leap of faith" (Duneier 1999:343). I hope my struggle to be honest about the interpretive license I take is clear throughout this research.

***Ethnographic influences: grounded theory***

Throughout my research, I pieced together useful aspects of more than one approach. I borrowed from grounded theory, the work of Katz and Duneier, as well as work of those in medical ethnography and science and technology studies (STS). Grounded theory begins from general data collection and one of its hallmarks is that the researcher goes into field without a specific hypothesis to prove or disprove (Corbin and Strauss 1990, Charmaz 2006). Rather, the site chosen by the researcher has been determined to be a space where significant social processes are occurring and where rich data can be mined. I chose an audiology clinic and while medical ethnography has a rich history, each condition and treatment is unique. Little is known about CI-related social relations and grounded theory is also particularly well suited for exploratory research. For example, because I had little idea of what to expect when entering the clinic, grounded theory gave me an open orientation to the field where I adopted the tactic of listening to and recording everything.

[31] Duneier also raises this issue by invoking Stephen Steinberg's notion of the ethnographic fallacy. The ethnographic fallacy "begins when observation is taken at face value. Too often - not always - ethnography suffers from a myopia that sharply delineates the behavior at close range but obscures the less visible structures and processes that engender and sustain the behavior (1999:343)." I will say more later in this chapter about the precarious task adequately portraying participants' claims and feelings of agency, whilst pointing to the forces shaping their actions.

The second major characteristic of grounded theory is data collection that results in the production of analytic themes or 'codes.' By listening to everything I could, I amassed data to comb through to show me what the themes or concepts were that needed further attention. These do not come from any set, presupposed hypothesis I bring to the research, but from data itself. As one takes in data, themes are identified and then data is 'coded' accordingly. Concepts, intentions and meanings then drive each phase of subsequent data collection. Thus, there is a constant, almost real-time shaping of the research through periodic re-evaluation of emergent themes. For example, as I found recurrent themes, I realized that this fieldwork should be multi-sited. This is why I began to follow up on topics that appeared in one space and time (such as the clinic) in another (such as at the patient's home). Secondly, implantation is a fiercely controversial topic and I wanted to uncover what was true for the participants in this social world and not enter into the clinical setting to collect data to support one side or the other.

***Ethnographic influences: Katz, Duneier, Becker***

My first goal was to understand how participants made and understood interactions and meanings in this social world. Through adopting practices in grounded theory, I was able identify concepts and ideas directly from data, but I then looked to the models of Katz (1997), Becker (1982), and Duneier (1999) to connect these to meso and macro level forces by systematically moving outward from the interactions I observed. Like grounded theory, they prioritize observation, understanding meanings for the people in their social world, and linking method and theory. But they also look beyond the micro-event to explanatory conditions surrounding them, with the goal of unveiling the processes that constitute a particular experience (Katz 1997). As I moved along in my fieldwork, I was struck by how the repeated clinical motions producing the CI candidate and recipient had conveyor-belt-like qualities. These

predictable, mundane motions, however, accomplished something curious: they fostered parents' commitment to CIs, maintained faith in its potential, and provided entrée into communities where these sentiments continued. I wanted to focus on the structural environment shaping how individuals became committed to something, maintained a perspective on it, and had somewhat predictable experiences with it. I had certain theoretical ideas in mind as I made these connections, and in this sense violated the method of grounded theory. However, in Katz's discussion of ethnography's warrants, he states that the "moral reputation of a set of people or a type of activity as either deviant and disreputable or especially respectable and worthy of deference, can be invoked as a warrant for ethnography" (Katz1997:393). To approach this controversial topic, I favored his use of social framing for "analyzing the social relations that set up and support the subjects' world…to show the contingencies of the production of its distinctive culture" (Katz 1997:403). Drawing on theoretical concepts helped me link the dynamics between micro level observations and the social conditions surrounding them.

This plunged me further into multi-sited analysis and I began to investigate sites in addition to the clinic such as educational programs and homes, as well as researched related state-institutions, hearing-loss related organizations, and laws to understand how these interactions were situated within larger structures. Like Becker's (1982) study of the art world, my focus turned to describing the collective action surround the CI as a technological artifact. In other words, I wanted to move the discussion from the object, which garners such deference and engenders such faith, to the ways it is embedded in and produced through collective action. This reveals *how* our attribution of values and meanings, how we make sense of things, actually fulfills our own needs or projections.

My interpretation or social framing of this collective action offers important moments for being honest both about the political nature of theoretical choices, as well as slowing down or pulling apart of an important moment in ethnography. Duneier (1999) and Katz (1997) both criticize ethnographers like Buroway for skipping over this moment. Duneier argues that techniques like the extended case method just "collapses the importance of 1) constructing theory and 2) making the micro-macro link" (Duneier 1999:344). As I will discuss below, medical ethnographers such as myself witness interactions, but "interpret the moral conflicts that lie beneath the surface of an advancing technology" (Bosk 1985:10). I want to be explicit about my methodological approach, especially the interpretive process: I began through open inquiry guided by the principles of grounded theory, then socially framed the interactions by looking at explanatory conditions and moved outward to meso and macro-level structures. I will say more about theoretical ideas that influenced this process in the next chapter. But for now I will turn to a thicker description of my research site, then talk about specific applications of these ethnographic methods in the contested milieux of medicine and scientific controversies. I will then go on to describe how I gained access to the clinic and the details of what the day-to-day routines in the field looked like.

*

Most mornings I arrive at the clinic after it has officially opened; as I open the glass doors of the center's new building, the cold, air-conditioned air hits me. It is summer time, it is hot, and I feel overdressed in my office attire. I have my hands full with my coffee, my lunch, audio recorder, notebook and extra sweater for the often overly air-conditioned office. I walk into the quiet lobby, decorated with soft, pastel colors that soothe the eye. There are lots of

grays, interspersed with muted greens and blues. As I pass through the lobby and walk through the clinic's doors, I enter a waiting room. The furniture looks new and continues the cool color palate, except for the 'kids area' in the waiting room. It is filled with brightly colored toys, an elaborate and rainbow colored block set, tiny tables, and tiny chairs.

The clinic is nestled within the larger hospital system, whose buildings are in close proximity. The immediate environment where I did my fieldwork housed the audiology division, the specialization in medicine that concerns hearing, as well as the otolaryngology division (also known as ear, nose and throat, or "ENT"). The center staff informed me that ENT had only recently moved into the building a year before I arrived. There seemed to be a mild frustration with this, as more than one member of the audiology staff explained that they used to have the whole space to themselves. Now, they have to share it with ENT, which is completely separate. "It's different billing, different scheduling, different everything, we aren't in the same department," the clinic director's secretary, who works in audiology, told me. ENT was in the main hospital before, so they could be close to the operating rooms. But now they are here.

When I asked if ENT was happy with their new placement, she tells me, "They are happy about it when it suits them." She shared how difficult it was to patients, plus she says, "We're like the stepchild here." I was curious about this statement and quickly learned, to my surprise, that audiologists are not medical doctors, but one of many types of allied health professionals like physical or speech therapists. They cannot make medical diagnoses, but they do dispense hearing aids, recommend treatments, and program the implants their patients receive. In other words, they are the managers of hearing-related issues for their patients. But if their patient is to get a prescription, procedure or implant, they must refer them to ENT. Because of their

proximity to each other in this center and their need to work together with patients, I often spent my time with center staff in both audiology and ENT.

Some mornings are busier than others. On the days that I arrived early, there was usually no one but the hearing and speech department receptionists near the front door to greet me in the waiting room. At the back of the waiting room was a door and glass window that the ENT receptionist sits behind when the surgeon/ENT doctor is holding clinical appointments, which is usually one day a week. Patients for both divisions share this space. On the days I arrived after the clinic opened, the waiting room could be in any number of states. Sometimes the waiting room was filled with children of different ages, their parents, and other adult patients. If it was particularly busy that day, it would fill up further as the morning went on and appointments went over their allotted time. On these days, the traffic sometimes built up and the noise of children and the impatient looks on people's faces infused the waiting area with a slightly more stressful tone. Other times it was nearly empty with only one or two patients; the schedule was sometimes light. What kind of day it would be, however, was not always predictable. Even if there are a lot of appointments on the books, there were a few times when the parents of pediatric patients, harried with childcare and managing work, would cancel, reschedule, or not show up.

As I come in, I wave and greet the receptionists behind the fairly tall front counter, which comes up to the middle of my chest. Susie and Margie are sitting there, readying themselves for the task of managing the flow of patients for the day and answering the phones. I greet them and ask about how they are doing. We sometimes catch up for a minute about a recent vacation or plans for the weekend. These two women know about most of the goings on in the clinic and who is expected for the day. Because they know I want to talk to parents before appointments, if I know the name but have not met the patient yet and am not sure who they are, they will assist

me. Their willingness to point them out to me is helpful, since the audiologists are often too busy moving from one appointment room to another. Sometimes they also let me into the office behind the counter so that I can sort through files that had been pulled for all patients coming in that week. They are often the people who know how to get things done; they know how to get the gate in the parking lot open if it is locked, find files that audiologists have misplaced, if there is a special lunch-time presentation happening that day, or how to access and decode the patient appointment system. They are good people to know.

After walking through the waiting room, I turn left town a hallway, passing office administrators in a room attached to the receptionists' area. I then turn right down a longer hallway, lined with hundreds and hundreds of file folders in floor-to-ceiling shelves. As I pass by the wall of files, I come to a large room there are three cubicles. The center cubicle houses the secretary of the surgeon/ENT doctor (otolaryngologist); she also often doubles as the receptionist at the ENT window when the surgeon has clinic hours. The cubicle to the right of her is not occupied by a person, but piled high with boxes of files that need sorting. The cubicle to the left is where I sat. Tucked in a corner, I have a desk, office supplies, file cabinet, and computer. I usually start the day by going through appointments, which I access by logging into the hospital system's program for managing appointment information. But most of the time, it is easier and more informative to grab my pen and notebook and head back out to the receptionists to take advantage of their knowledge and quick ability to decode special notes or codes next to patient names. Sometimes they can tell me in just a few seconds what the appointment is for, while I would often labor through the software trying to remember the codes used, which ended up usually being there for the billing department.

The office across hall from mine belonged to the clinic's director and her secretary. Further down the hall, past a copy room, was the surgeon's office. It was piled high with stacks of files and shelves of books. This hallway met another, where if one turned right there were three 'therapy rooms' where appointments were held, each of them with an attached observation room behind a two way mirror. As you walk down this hallway and the therapy rooms are on the left, the ENT receptionist sits to the right, gazing out through a glass window into the waiting room in the middle of the center. Just past her, the social worker's office is to the right, along with another hallway. If you take the second right you come to another long hallway that ran the length of the building. Here was the electro-physiology room, where certain types of hearing tests were conducted. If one turned right and continued down this long hallway, there was a row of three test rooms on the left hand side, where patients sat and listened to the tones presented to them through headphones. These were adjoined to control rooms, where the audiologist manipulated the testing devices and took notes. On the right were additional test rooms and audiologist's offices. There were more audiologist offices at the end of the hallway. If one turned right there, you arrived at the chief audiologist's office and eventually, back to the waiting room. The hallways in the center, though they turned at right angles, made a large circle. On the following page is a diagram illustrating the clinic.

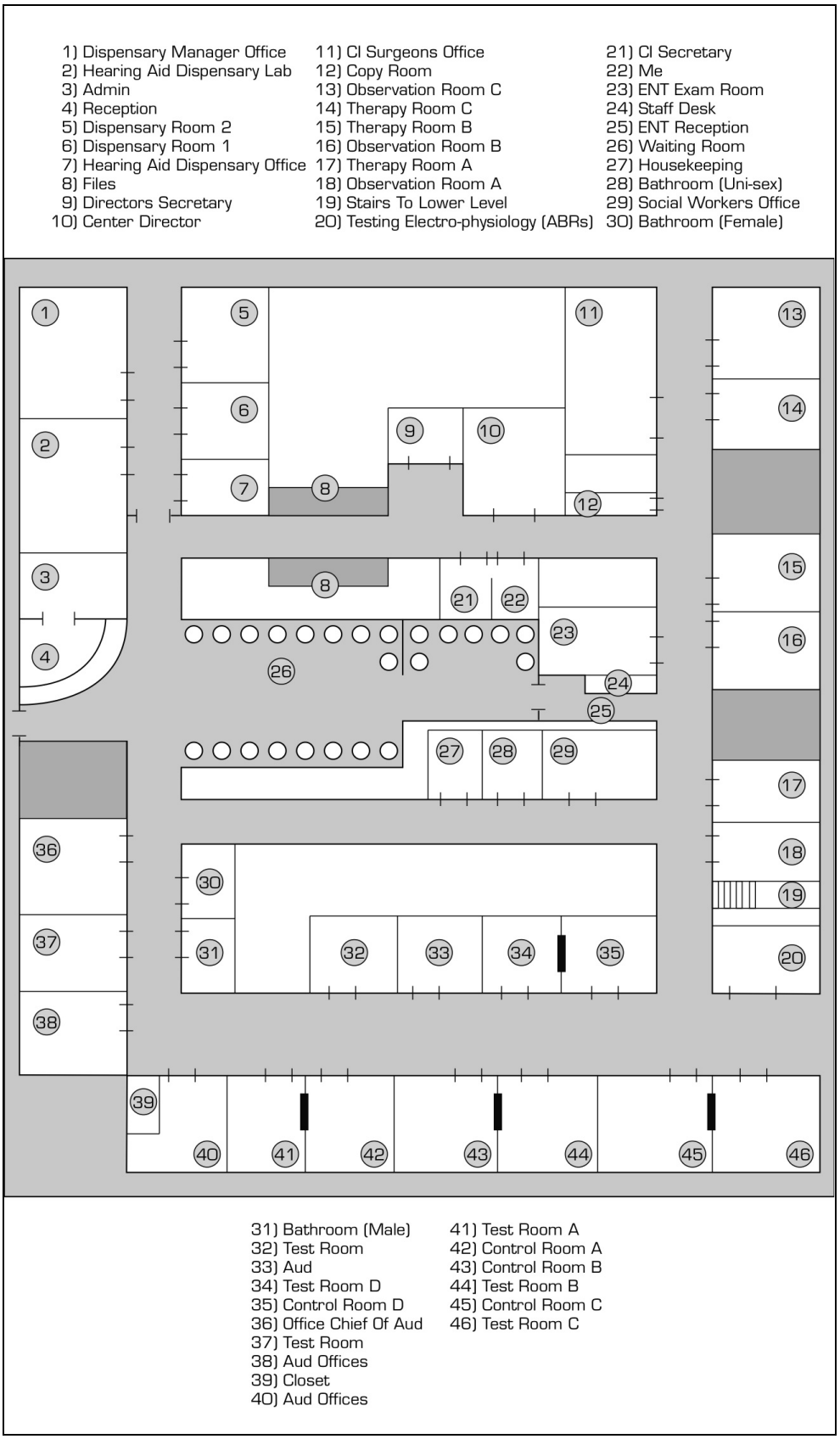



**Figure 1: Diagram of Clinical Fieldwork Site**

The center also occupied part of the basement floor below, although some of this floor contained offices that I did not ever go into. One corner housed the woman responsible for scheduling ENT surgeries in the operating room, two secretaries who worked for the newborn hearing screening program, as well as an office for the director of the screening program. There was also a break room, where I often ate lunch with the center staff. In the middle of the basement floor was a conference room, where I originally presented my research to the staff, as well as attended meetings and parent support groups. Another corner of this floor housed the speech therapists, where I also observed appointments, but less often than upstairs. The break room was lively at times, and if there was a significant lull in appointments around lunch time, the table would become full. The women (most of the center staff was women, aside from a part-time statistician and the maintenance man) would open their lunches they brought from home and talk about coupon cutting, news of the day like the death of Michael Jackson, and the other big topic: the sometimes terrible smells that wafted through the basement windows of the building, which always kept the conversations going.

I usually spent two to three days a week at the center, observing appointments, center staff as they interacted with each other, and conducting ongoing, casual interviews with staff who fulfilled a variety of roles. My purpose was to understand both the organization and interaction of the professionals that worked with children who received CIs, but also to meet, interview, and understand the experiences of the parents of these children. Rather than determine whether or not deafness *should* be medicalized, I sought to find out *how* it was medicalized, particularly in relation to CIs, and what the consequences were. Thus, as I conducted my fieldwork, I was guided by the question: how is the medicalization of deafness accomplished

through social practices in the clinic? What meanings do these practices generate and how are they reproduced outside of the clinic, such as in parent communities?

I originally presented my research to the audiologists, speech pathologists, newborn hearing screeners, social worker, and hearing aid dispensary staff at the clinic, but there were also many others on the center staff like the secretaries and billing administrators. They where largely unaware of my exact role or interest in the clinic, but because the director had taken me around and said that I was joining the center to do some research, they did not seem bothered by this. Few inquired about the nature of my work, and when they did ask, I explained that I was a medical sociologist interested in the experience of parents in the clinic as they went through the process of implantation with their child.

My position at the clinic seemed to be easily accepted by most of the staff, though how the audiologists, whom I spent the most time with, felt about me I do not know for certain. I was sometimes self-conscious doing this research, as my background as a sign language interpreter, which I will elaborate on in detail in the following chapter, was a source of anxiety for me at times. However, I was able to observe certain things, such as the day-to-day routines of this center, which have never before been recorded. I found that the day-to-day goings on, over time, became more and more predictable as I learned the clinical routines.

***Situating this research within the tradition of medical ethnography***

My methodological approach is considerably influenced by the rich history of ethnography in medical settings. As I mentioned in the beginning of this chapter, choosing a clinical site meant going into what felt to be 'far away land.' As Bosk writes:

> For the ethnographer in a medical setting, health care workers are an exotic tribe; the hospital is the bush. Our task is to report on the goings-on in this faraway province. At worst we are voyeurs seeking cheap thrills; at best we are witnesses reporting on the most profound dilemmas of the human condition (1985:10).

But as a sociologist trained in critiques of medicine, medical power and surveillance, this means openly walking into a minefield, a position Bosk goes on to astutely characterize. As a sociologist, I am acutely aware of the expectation of sociology of health/illness to be critical. Invocation of the term 'medicalization' alone suggests critique and disapproval. Likewise, as a member of the field of disability studies and the Deaf community, I was also acutely aware of the pressure to do work that unequivocally advanced the critiques that these fields have been making against the medicalization and pathologization of disability for decades. This was definitely a quandary. Would this compromise my research? How could I witness interactions within a healthcare setting when I was already critical of medicine, and especially this specific practice? How should I present myself in a setting where I, as a sociologist, was to respectfully and responsibly represent the reprehensible?[32]

I would need to set a tone. "Conflict is the social process and hostility is the emotional tone that permeates much contemporary medical sociology (Bosk 1985:11)." Some ethnographies of medicine find that there is a conspiracy to prey on vulnerability merely to make a profit, but there are various ways these findings can be presented. I take my lead from Katz again, who warns of over-romanticizing those who are labeled deviant, who tend to be researched by and evoke the sympathy of sociologists (Katz 1997). I proceeded from the assumption that the inverse also held true: I should avoid demonizing the participants in my research, who might be cast as the 'bad guys' before I even started. I wanted to be open to the idea that things were more complicated than I knew, and thus tried to maintain an air of neutral, undecided curiosity. Furthermore, this raised ethical issues. I did not want to portray myself as the happy ethnographer, market my work to the clinicians as neutral and possibly able to benefit

[32] Thank you, Barbara.

the clinic, and then manipulate the participants into sharing their world with me only to turn around and write an expose´.[33]

Anspach and Mizarchi argue that medical ethnographers push the ethical limits of ethnography "as they decide whether to disclose their actual research agendas, whether to ask tough questions or to reveal their concerns, and whether to give advice." (2006:713) Anspach and Mizrachi (2006) make a Bourdieuian argument about the role of the ethnographer in medicine, arguing that medical ethnographers belong to two conflicting fields and are "situated in a second kind of field…the setting s/he studies, the web of relationships in which s/he comes to be embedded, and the obligations and mutual expectations that develop between researcher and researched" (Anspach and Mizrachi 2006:714). Furthermore, the tensions between the academic fields of medicine and sociology are antagonistic, citing that sociologists are "perennial irritants to those we study" (2006:714). They go on to discuss the ethics of this and, referring back to Bosk, they assert that ethnographers in medical settings fail to "disclose the most significant risk: the damage to self-esteem and reputation that ensues when we portray them in an unfavorable light" (2006:714). Thus, "we betray our subjects twice: first, when we manipulate our relationship with subjects to generate data and then again when we retire to our desks to transform experience to text" (Bosk 2001:206). But short of *not* doing the research, I had to decide at every turn, very carefully, how I was going to proceed.

This was difficult. Anspach and Mizrachi go on to describe phenomena similar to what I experienced. For example, I was interested in how people made their way to the clinic and what

[33] As Bosk so aptly tells it, ethnographers must manipulate relationships with their subjects to a certain degree and most of us "justify it with a sleight-of-hand maneuver. It is not particular people that we are interested in, but general types, diffuse social and institutional processes. If people are treated as means to an end, it is not qua people but as social types. We do not betray individual trusts and confidence; instead we generalize them (Bosk 1985:11)."

conditions led them to return. This was picked up on by professionals in the clinic, who conveyed their interest in knowing this for purposes of market research and improvement in how they provided service, particularly as a way to compete with other CI centers in the area. The idea of 'helping' the implant centers made me uneasy. This is a problem: "For fear of damaging field relations, seeming confrontational, or hurting members' feelings, field workers typically err on the side of discretion, avoiding the hard questions and failing to explore the most sensitive issues." (Anspach and Mizrachi 2006: 719) I too did not raise critical issues during the day-to-day routines. I did not start conversations about the controversy over CIs, but rather framed most of my questions as concerned with the parents' experiences and feelings. My reasons for this approach were twofold: I did not want to be a confrontational presence and the issue of the 'controversy' came up on its own amongst participants as well as voluntarily with me. There are a few examples of these moments, which will appear in the following chapters. At best, I can describe them as moments when the 'implicated actor' that I spoke of in the introduction is invoked – that of what has been called the 'Deaf cultist' or a more generalized actor of the Deaf community in general – whose characteristics directly reflected much of my own thoughts on the matter. But, I feared identifying as 'one of them' would stop the conversation, and so I often continued, silent on my own alliance with one side or another.

Perhaps, had I been more willing to explore certain moments more thoroughly, this ethnography would be richer. As Anspach notes, "Such trade-offs between the two fields have significant consequences…in failing to ask critical questions, we censor ourselves from the outset" (2006:720). Nevertheless, many of the moments speak for themselves, and in an effort to maintain a sociological distance and avoid an overly sinister tone, I borrow from Anspach and Mizrachi (2006) and Bosk (1985, 2001) by trying to generalize the feel of moments. My attempt

is to set the interaction up sociologically, to avoid trying to determine who is right, but rather to illustrate how the participants characterized others they were interacting with. But, in the end, I cannot claim to know; I choose some interpretive frames, and as such, I do not choose others. Such delicate negotiations are risky, I hope these struggles raise useful methodological questions rather than compromise my findings.

***Previous ethnographies of scientific controversies***

Despite any carefulness on my part, however, the findings will be politicized, as evidenced by previous research in controversial sites. In STS, scientific controversies are traditionally approached by searching for which side is right, typically resulting in "explaining why the other side persists in its claims" (Scott et al 1990:474). The fieldworker, concerned with the social construction of scientific knowledge, would usually analyze competing truth claims symmetrically whilst being told not to grind an 'evaluative axe' (Scott et al 1990). If the research does take sides, then the researcher is said to have been 'captured', failing to maintain an objective, symmetrical approach (Scott et al 1990). For example, Collins and Pinch (1979) studied views of parapsychologists in conflict with orthodox psychology and the processes of legitimization promoting orthodox psychology. They claimed their study provided insights into the dominance of scientific culture, but were criticized for adopting the parapsychologists' perspectives and terminology. Because "they constructed their analysis from some of their participants' points of view, they were said to have been "captured" by the controversy and not neutral as their work was used by one side of the controversy (the parapsychologists) to support their own claims" (Scott et al 1990).

In his study of the controversy over fluoridation, Martin (in Scott et al 1990) depicted how opponents were disadvantaged against the proponents' objective, scientific claims. He

writes that his "analysis corrected this imbalance by showing the nonscientific, value-laden, and politically motivated basis for the proponents' decision making" (1990: 479). However, because this was interpreted as undermining to the proponents, he was perceived as taking the side of the opponents. He was eventually accused of having "started from a conclusion and then sought evidence to support it" (1990: 479). The question he then raises is: In these situations, does that make one a bad researcher? Or is it part and parcel of the task? As he also notes, even studies that are claimed to be neutral and symmetrical result in side-taking. For example, Richardson (writing in Scott et al 1990) intended to conduct a neutral study, but came to be relied upon by one side over another, despite this effort. Thus, claims of being neutral, in the end results in saying, "I too have been 'captured'" (1990:490). The irony then is that despite intentions of neutrality, that an "epistemologically symmetrical analysis of a controversy is almost always more useful to the side with less scientific credibility or cognitive authority. In other words, epistemological symmetry often leads to social asymmetry or nonneutrality (1990:490)."

Per my training, I proceed from the assumption that all scientific claims are products of ideological systems. Like other studies before this, the medical professionals and educators, I observed, armed with scientific knowledge, referred to opponents' claims for alternative methods of coping with deafness as irrational, unscientific and thus merely "ideological." Like Scott (1990), I did not intend to take sides, but the processes I uncovered do reveal the social and ideological processes that also shape scientific knowledge claims about the CI. In other words, my task then is to point to how all knowledge claims are constructed. But, none of these prior studies provide practical help for an ethnographer to navigate this.

As you will see, I provide an in-depth background of the controversy (in the next chapter) and then focus my analysis on the side that has been largely accepted as rational and scientific. In

some ways, the task is already set before me as a sociologist of scientific knowledge and medicine: to show how scientific and medical knowledge and practices are anything but objective. Still, throughout fieldwork, I constantly asked myself: How do I proceed? What do I owe them? There were no easy answers to these questions, but having answers was less important to me than being honest about having the questions in the first place. Scott et al (1990) determine that:

> It is so easy to be caught in the cross fire that many prefer to don positivist camouflage and seek shelter in the best-fortified trench, rather than adventure out into the no-man's-land (which is even more a no-woman's-land) of sustained symmetry. The combatants have a good deal at stake in the sociologist's interpretation and presentation of news from the war zone (490).

It seems we can never avoid taking a side, but it may be possible to understand the merits of both and 'sustain symmetry.' Becker (1967) writes that it is no secret that sociologists tend to be liberal in their views and take up the case of the underdog. "So we are left with the question of whether taking sides means that some distortion is introduced into our work that makes it useless" (1967:245). Who is to say that I will not be accused of starting with a conclusion and then finding ways to support it? I can only hope that a heavy dose of reflexivity and the eventual unfolding of complicated and conflicting sympathies I describe throughout the rest of this dissertation show my attempts to exist in a space of 'sustained symmetry,' engenders a sense of trust in the reader, and does not result in a perceived misuse of ethnography.

***Gaining access***

Gaining access to a CI clinic took approximately six months. To find a site where I could conduct clinical research, I looked at the Cochlear website (cochlear.com) which lists clinics by area where one can obtain a CI. I then emailed the director of every center listed in the New York City metropolitan area. Two responded quickly, denying my request. Some never got back

to me at all. Another welcomed me to her clinic, but upon visiting, I found it had a number of limitations. Not many of the patients were CI patients, although they utilized hearing aids and other services, and most of them spoke Spanish, which precluded access to direct interactions or interviews. Interestingly, this clinic was situated within a large hospital that served a depressed, lower socioeconomic area and was located next to a guarded, psychological ward. The facilities were modest and the director of that clinic appeared frazzled. She wanted me to conduct my research there, and noted how I could help serve as an interpreter for her. I believe this site would have yielded rich, but different data. I remained in contact with the director in the interest of possibly gathering data at this site for comparative research at a future date, especially with a translator for the predominantly Spanish-speaking families this clinic served.

Shortly after, I was contacted by the director of another clinic, who invited me to present my research proposal. I quickly learned how difficult and awkward the task that I set out to do was going to be, with her opening line: 'So how did you come to do implants? No one wants to touch this unless they have a connection to it.'[34] Because implantation is a controversial and politically charged medical practice, there was immediate alert about my interest. Of the three center directors I spoke with, all of them asked me right away why I was doing this project. My answer was always that I wanted to understand pediatric implantation from the perspective of the professionals and parents engaged in it. However, as soon as this particular director saw my credentials and background, she asked me, 'How do I know you are *really* a graduate student? How do I know you are not here to conduct an expose′ of myself and my staff?' I struggled to explain that this was a sociological project, and deployed claims of neutrality. Eventually she

[34] A note on quotes: When I use double quotes, I am writing from recordings made on a digital voice recorder. When I use single quotes, I am writing from notes I took either during the interaction or immediately after. If there are no quotes, I am paraphrasing from memory when I could not immediately write down what was said.

told me I could not do my research there, although I cannot claim to know the exact reasons why. Even before I formally began my data collection, data were occurring all around me. I had to tread carefully, as I was attempting to do a study in a place where I may not be welcomed at all and where emotions and suspicions ran high. I scribbled in my notebook after the meeting "only here to gather data," "not here to argue," and "only emphasize parent experience."

By the last, and successful, clinical site where I met with the director, I had better honed my presentation to reflect a focus on parents. Taking shelter in my identity as a sociologist, I briefly referred to my background in Deaf studies and Deaf culture as "previous study," which seemed to alleviate reservations about my politics. I was open with the director of the clinic where I conducted my research about my background and fluency in sign language and work as an interpreter. I will say more about this throughout fieldwork, as the subject of my bilingualism came up on more than one occasion during fieldwork. Rather than reeling, she conveyed a sense of respect for that knowledge, though she never asked me directly about it or what my views were on CIs. She simply said, 'One of the reasons I like your project is because you're coming at this from an entirely different perspective.' I cannot be sure, but I assumed she and the chief audiologist perceived my interest in conducting fieldwork in the clinic as tacit approval of its actions. Accordingly, I suspect most participants expected that our views were more aligned than they were, especially since they were willing to have me in the clinic and talk to me. None of this, however, was talked about. I did not raise the issue of controversy over implants other than to say I knew about it, but that was not the focus of my work. When I presented my research project, I centered it around trying understand to the experience of pediatric implantation for parents and professionals, which was and still is true.

The director told me at the end of the meeting that I would be allowed to conduct my research and welcomed me to the center. This was not an indicator that I was trusted or accepted, however. While ethnographers often contend with an outsider status, I possess all the makings of a person that is not to be trusted in the CI world. Despite the fact that I am a sociologist interested in the way implantation is socially organized and emphasized an aim to understand the experiences of parents as they went through the CI process, my motives were not immediately trusted. As I left the center that day, the chief audiologist pulled me aside and said, 'We're proud of what we do here,' and proceeded to tell me she was open to my curiosity. I felt relieved and excited to have found a clinical space that seemed open and comfortable and a staff that was friendly and warm. For the most part, this remained true throughout my research, and I am deeply grateful to the director for championing me, as well as the chief audiologist for continuing to make me feel welcome. Not only this, but the director was the co-investigator on the hospital IRB. I am grateful, for if she had she not been willing to do the extra work for this, this study would not have been approved since it required a hospital employee's sponsorship. Finally, I was never asked to keep the site confidential, though I am doing so because of the controversial nature of the topic. Like Bosk, I also prefer to generalize the actors and their sentiments, and do not wish to emphasize precisely who they are. I believe keeping the site confidential better sets the stage for broader thinking about the issues this study raises.

***Preparation for clinical research***

The following week, I gave a presentation during lunch to the entire staff of the center, which numbered approximately twenty-five. As everyone ate lunch, I spoke casually about my interest in the parent experience. I explained that I was a sociologist and that I would probably be "lurking about," that they should go about their usual professional duties, but feel free to talk to

me or let me know if I was in the way. I also let them know that I might be asking them questions at times, scheduling an interview with them, and/or shadowing them throughout their days. I warned them that although they may think they are doing something uninteresting, not to worry about boring me as I would always be 'gathering data.' I then passed around a consent form, which they all signed.

The following month was spent fulfilling all the prerequisites for clinical access. First I had to be trained in HIPAA regulations and then I had to pass drug tests, undergo a series of immunizations, and attend a hospital volunteer orientation. Once I had done this, I was sent to security for a picture and identification badge like all employees wore. It bore the title "Volunteer" under my name and I was given clearance for my assigned unit, the hearing and speech center. I always dressed professionally and made sure my ID visible. The director provided me with office space, and I was given a desk in the cubicle next to the secretary for the CI surgeon, an otolaryngologist, who saw a variety of patients, not just those who were scheduled for a CI-related appointment. This office was located across the hall from the director's office, giving me easy access to her if needed. Additionally, I was provided a computer, given access to the schedule software the center used to follow daily schedules, access to the patient database and histories (these histories were only accessed after parents signed a consent form allowing me to do so), and permission to sit in on staff meetings and to talk to center staff and be present during daily routines. I was at the clinic twice, sometimes three times a week, for approximately five months.

***The site***

The CI clinic is housed within the third largest hospital system in the nation and is part of a hearing and speech center that treats patients with a variety of audiological conditions. The

participants were those that work specifically in the area of pediatric implantation, including the audiologists, surgeon, speech therapists, and social worker, and the parents that interact with them. The day-to-day operations of the clinic include an array of services, but the focus of my description is on the specific processes of the clinic related to infant CI recipient, such as evaluation, candidacy, surgery, and all aspects of long term follow up care. I also sat in all 'CI team' meetings and some appointments in otolaryngology, a separate department, which was housed within the center. This particular center offered an array of CI-related services and was often referred to by parents and staff as a "one-stop shop". It not only provided audiological testing and diagnoses, hearing aids, and the CI surgery itself, but also speech therapy, educational consulting, parent support groups and a social worker that helped coordinate community services, such as the New York State Early Intervention program. The primary inclusion criteria for parent subjects were that they were parents of a patient who was under six years of age when implanted. The range of time since implantation of the parents in my study varied. Some had a child who was implanted anywhere from thirteen years prior to my interviewing them, whilst others underwent surgery during my time at the clinic. Thus, the amount of time since the child's implantation surgery was highly variable for my parent subjects, ranging from thirteen years to one day. The average age of the child at the time of surgery was more uniform, however, which was two years old.

Implantation is an on-going process that requires long-term medical attention. As such, it is not a 'one-time' event, even though many consider the surgery to insert the CI as 'the moment,' this comes after months of evaluations and it is not a first-line treatment. In other words, parents must try other methods first and once a child has shown inadequate response to previous treatments, such as hearing aids, only then will candidacy for implantation be taken to

the next steps. Candidacy determination, pre-implantation appointments, surgery, surgical follow-ups, and multiple types of long-term care are all undertaken for a period of years. Average implantation time is two years of age, with multiple years of long term care, including speech therapy and specially tailored educational programs. There are no clear guidelines as to when to abort auditory rehabilitation, nor are their clear guidelines for defining success. All of this will be made clearer in the following chapters, but the participants in my research were all at varying points of the implantation and rehabilitation process and constantly moving from one phase to the next.

***Participant-Observation and interviews***

The extent of my participation-observation in the clinic was almost always pure observation. There were rare occasions where I did participate in clinical appointments in a limited way. For example, I would sometimes entertain or play with a child while the audiologist and the mother – and in rare cases father- would talk at the end of the appointment. These extended conversations between parent and audiologist were often impossible with a small child crying and needing attention in the room. So, I would sit with them and play with building blocks or stickers or other toys to give the parent and audiologist the opportunity to delve further into concerns. Sometimes I listened and wrote down snippets that I overheard, other times I could not hold in my mind the attention that the child needed and what was being discussed.

The center's facilities were newly built and comfortable, there were play areas in the waiting room for children, and it was a well-staffed, quiet environment. Though not physically attached to the main building, it is part of a teaching hospital. As such, almost all of the appointment rooms are equipped with one-way mirrors and wired for sound. As a result, I was able to observe appointments without being obtrusive. I tried to blend into the clinical

atmosphere by dressing in office wear, eating or having coffee in the break room with the rest of the staff, 'hanging around' the hallways and listening into conversations and making small talk with audiologists if necessary. When a CI appointment was scheduled, I would wait for the parent in the waiting room and introduce myself. I explained that I was conducing a study on parent experience with implantation, asked permission to observe the appointment and went over the consent form with them if they agreed. Almost all the parents, with some exceptions that will become clear in the following chapters, were eager to share their stories with me and readily agreed to let me be privy their child's appointment. Notably, almost all the parents had gotten their child a CI at least three months prior to speaking to me, and some more than ten years prior. I had little access to those still deciding about the CI; they were reluctant to talk to me and the staff described them as lost and overwhelmed.

Before the appointment, parents signed the consent form and I obtained their contact information for a follow up interview. I explained that I would be observing the appointment and contacting them to set up an interview where I would come to their home or where ever was convenient. I also emphasized that the audiologists or center staff would not have access to the content of the interview. Most of the time, it was the mother who was in with the child, although there were two fathers included in my study that were interviewed. The prevalence of mothers appears by some staff simply referring to parents as "the moms." In general, the interviews with parents were often used to get a 'back story,' to follow up on perceptions of appointments or concepts that were raised in the clinic. I saw it as a useful way to get more than one perspective on an interactional event; often I witnessed the appointment, interviewed the clinician after and then some time later interviewed the parent. Over time, the appointments, issues, and comments

of both parents and clinicians became predictable, patterned, as will be fleshed out in the following chapters.

In the clinic and during interviews, I used a digital voice recorder to record interactions and always had a notebook with me where I wrote down field notes. I conducted in-depth interviews with most of the center staff, but they never occurred when patients were present and were most often casually initiated during their downtime in their offices. All fieldnotes, recordings, and interviews were transcribed and analyzed line-by-line for recurrent themes.

***Sites beyond the clinic***

I conducted multiple interviews each week with the clinic's approximately fifteen regular staff. I interviewed ten parent subjects who were interviewed on average three times over a period of three months. Subjects were obtained through the clinic or by attending community events, creating a snowball effect in data collection. These events were parent support groups, informal parent dinners, and parent 'advocacy trainings' arranged by local hearing loss related organizations. CI corporations often sent representatives into schools to run parent trainings on how to best utilize the device and I attended these.

As I began to interview parents in their homes, we developed a rapport. I would spend time with them and was eventually invited to go to school events with them, parent meetings at school, or even informational meetings that were conducted by CI corporate representatives. As a result, my interview pool expanded, creating a snowball effect. I had a separate consent form that was not affiliated with the clinic for individuals that I met off-site, such as educators. In total, I conducted multiple interviews over a five month period with approximately fifteen parents and twenty professionals.

***Sample skew and limitations***

In terms of decision-making around the CI, this sample is skewed; the subjects I had access to opted for the CI and were considered highly compliant by clinic staff. Those that chose not to obtain a CI were unavailable to me, pointing to a hidden population in clinic-based research. Furthermore, the dataset is small and the interactions described here of only one clinic. Thus, my results may not be indicative of national trends. For example, the extent to which resources are allocated to CI programs depend on a number of factors, such as whether it serves a major metropolitan area, the socioeconomic status of its patients, and proximity to educational programs. This clinic had a particularly rich supply of resources because it was located in one of the largest healthcare systems in New York State and in proximity to a number of deaf schools and programs. The sample was notably homogenous: almost every single participant was white and middle to upper-class.[35] My results are most likely generalizable to clinics in larger cities with resources such as schools and state agencies. However, if compared to other socioeconomic backgrounds, I suspect this study will be useful for documenting disparities in services. Currently, there are no national guidelines that CI clinics must adhere to for implantation practices, although clinics typically follow FDA guidelines and CI manufacturer's recommendations (Bradham et al 2009). This study then may be most valuable as an exploratory study to indicate what factors need to be followed up on with larger datasets.

***Summary***

What follows is a description of this world that does not seek to present moments as clear-cut fodder that supports one theoretical frame over another, although some theoretical

[35] That those receiving CIs are predominantly white and from families with relatively high socioeconomic backgrounds has already been well documented. Allen (2000) and The Gallaudet Research Institute (2003) report that in 1992, 86% of recipients were white and in 2002, 65%. Furthermore, 57% were from families with household incomes above $50,000. Thus, it seems "the Cl remains large1y a phenomenon for children from White, upper middle class families" (Johnson 2006:35), an issue I will address in later chapters.

points become more elucidated over others in the process. I do not wish to tell the stories of these individuals and this community in order to chastise how people are 'indoctrinated' into a medicalized society to make a point about how these subjects do not have agency. That would be both methodologically over-simplified and theoretically unnuanced. Instead, I want to show the people that I studied as complex individuals, at times adhering to what they are told by persons in the position of authority, and at others carving out their own systems of meaning. No matter what they are doing, I found the participants in my study to be struggling to do what they felt was right, though I do not claim this to absolve them of criticism.

It would be easiest here to take up the charge of employing ethnography to 'prove' a theory of medicalization – most often a critique of the medical establishment and adoption of its regimens – but after considerable time in the field, I do not think it right. Even though when I began this fieldwork, I was at times so disturbed by what I saw that I felt physically ill, I learned to suppress my discomfort with what I saw. Over time, as I became used to seeing it (much like practitioners of medicine in general) it was less disturbing. And I was disturbed by this development in my self. And yet I came to respect the experiences of the participants and the claims they were making, reflecting a feminist approach to the matter. As the researcher, I chose to wrestle with the stories of the women, my subjective turmoil as the researcher, and the larger political landscape within which these events were taking place. If I cannot be willing to describe this world as it means to its participants, then what is the use of being an ethnographer in the first place?

I hope that by moving outward from these interactions and showing the conditions shaping these worlds and the participants' experiences of it that I critique systems of meaning rather than the individuals. Along the way, I hope to bring insight in a way that allows differing,

conflicting, and simultaneous frames can be used to see the same event, almost as though shooting a film, rewinding the camera, and re-shooting the moments over again and layered on top of one another – what filmmakers call superimpositions. To that end, I will show how there are often multiple, complicated, and irreconcilable ways of looking at things that if one can be open enough to considering, then the story is only richer, not hindered. Our theoretical concepts should be adequately nuanced to account for this, and in the next chapter I will outline the theoretical traditions that influenced the way I interpreted data.

## Chapter 3: The Making of a Controversy: A Social and Historical Context

In this chapter, I give a brief history of how technological change impacted implantation practices and early intervention protocols. Then I overview the history of sign language in the US and provide the historical context behind the controversy over implants through both the disability and Deaf cultural movements, the development of their respective academic fields, and finally the Deaf critique of implantation.

### *The identification of deafness: technological & institutional change*

In 1988, the Commission on the Education of the Deaf reported that the average age of identification for profoundly deaf children in the US was two and a half years old. Hearing screenings, or tests that showed if a child had a hearing loss, were rarely used. The result? Without knowledge that the child was deaf, s/he was often without access to language for sometimes up to the first two and a half years of their lives. Over the next two years, the Joint Committee on Infant Hearing (JCIH)[36] recommended that children at a higher risk of having hearing loss, such as those who were jaundiced or had needed neo-natal intensive care, be screened before being discharged after birth. In 1990, the Surgeon General then challenged state and federal agencies to devise a plan to have all deaf children identified before the age of twelve months.[37]

During this time, the CI was moving from an experimental innovation to having "clinical feasibility" (Blume 2010). In 1990, the same year that the Surgeon General gave the challenge to

[36] The JCIH (www.jcih.org) was established in 1969 and composed of representatives from audiology, otolaryngology, pediatrics, and nursing, among others.
[37] For a concise history, see http://www.cdc.gov/ncbddd/hearingloss/ehdi-history.html#4

identify all children before twelve months, the Food and Drug Administration (FDA) dropped the minimum age of implantation to twenty-four months. In an astute analysis of the development of medical technologies, Blume shows how the CI emerged out of a particular set of socio-techno-relations resulting from "inter-organizational fields" on the professional level (1992). As the research side of CIs gained ground, the experimental side of CIs needed other fields of science and industry to collaborate. In other words, to test the viability of the CI that had been developed by researchers, clinics were needed to identify candidates and begin implanting them to test these developments and improve upon them. In particular, there needed to be a clinical aspect of implantation that had a public message that resonated with potential CI candidates (Blume 2010). As a wide range of fields came together to design and configure the device, it still needed a market. A variety of efforts were undertaken which aimed to show that the CI was beneficial in real lives. He illustrates this unfolding process through detailing the experiments that were undertaken with deaf persons and the kinds of representations found in media (Blume 2000).

Nevertheless, in the 1970s and 80s, some professionals working in the field of implants thought that it was "improper" or "premature" to make claims that essentially the CI could 'make the deaf hear.' However, Blume writes, it was public opinion that acted as the 'vast force' spurring CIs forward, rather than documented successful outcomes. He contends that the public persona of CIs was dominated by a "passionate desire to see medicine vanquish deafness and all

other 'ills' that the flesh is heir to" (Blume 2010:121). Thus, despite great variability or even predictability in outcomes, the CI became clinically feasible.[38]

In 1993, just three years after the FDA approved a minimum age of twenty-four months, the National Institutes of Health recommended that all newborns be screened before leaving the hospital. The following year, the JCIH wrote, "all infants with hearing loss should be identified before three months of age and receive intervention by six months of age" (JCIH 1994). In 1995, the National Institutes of Health (NIH) convened a consensus meeting of "specialists in auditory anatomy and physiology, otolaryngology, audiology, aural rehabilitation, education, speech-language pathology, bioengineering, and other related disciplines as well as representatives from the public" (NIH 1995). At the time, current data available supported "the importance of early detection of hearing loss and implantation for maximal auditory performance" (NIH 1995). It was 1995, and the earliest age of implantation was still twenty-four months, but they asserted that, "there are reasons to reassess this age limit…younger age of implantation may limit the negative consequences of auditory deprivation and may allow more efficient acquisition of speech and language" (NIH 1995). Thus, the conclusion spawns the research: there is a need for data on implanting earlier, and therefore they begin to implant earlier.

After reading reports, studying data and hearing testimony, the members of the consensus group concluded that the success of implantation was highly variable, and these variations were unexplained. Nonetheless, the data showed a general trend that indicated the shorter the duration of deafness, the better the performance with a CI. In 1998, the age of implantation was lowered

[38] This is not unlike other aspects of science and is a central axis of this dissertation. Heralded as 'objective,' social studies of science have shown over and over again that scientific 'progress' is social and constructed and far from emergent from 'natural' fact.

to eighteen months, and in 2000, the FDA lowered the age to twelve months. However, surgeons may implant earlier at their discretion and criteria for candidates continue to loosen and some children are being implanted as early as six months of age (Sampaio et al 2011). Today, Healthy People 2010, a federal program, aims to increase the number of children identified before three months of age and enrolled in intervention services no later than six months of age, as well as increase the number of children and adults with CIs (US Department of Health and Human Services).

In accordance with the recommendations to screen all children as early as possible for hearing loss, there are now Newborn Hearing Screening programs (NBHS) mandated in every state. The Center for Disease Control (CDC) heads the larger national Early Hearing Detection and Intervention (EHDI) program, under which state programs operate. The EHDI seeks to "promote communication from birth for all children."[39] This is paired with other state programs, such as Early Intervention (EI), a social services program created through legislation. Although originally passed in 1975, the Education for All Handicapped Children Act was eventually amended in 1986 to support "the right to early intervention services of all infants, toddlers, and preschoolers with a disability" (1986). Further amendments lead to the Individuals with Disabilities Education Act (IDEA) of 1990, which intended to enhance the development of infants or toddlers who have been identified with a disability of delay and to minimize its effects, added a mandate that all fifty states provide EI services.

[39] See http://www.cdc.gov/ncbddd/hearingloss/ehdi-goals.html for details of their mission, goals, and methods. Note that they seek to provide 'communication' to children, the type however is not specified, but generally implies speech communication.

The IDEA primarily aims to reduce special educational costs by intervening in childhood, specifically from birth to age three, in order to minimize the needs and/or services of these children upon arrival at school age. In implantation then, the logic is that the more a child undergoes 'auditory training,' the less the child uses sign and the less services s/he will need. Where a deaf child goes to school, or what is called their "educational placement," is crucial in the story of deafness. In the past when a child may have been identified much later and CIs were not available, parents often, though not always, sent their child to residential schools where they learned sign. They also might have sent their child to a local specialized deaf education classroom or program if that was available.

***A brief overview and history of sign language in America***

ASL is a complete language that is entirely different from English in structure and modality. It is signed, not spoken, visual-spatial rather than oral; it has its own grammar, syntax and idioms and an entirely different linguistic and social history from English (Bellugi & Klima 1979, Liddell 2003, Valli & Lucas 2001). Due to their visual-spatial modalities, signed languages across the globe have largely been left out of the history and philosophy of language, and in many respects, cultures that use sign languages are analogous to 'oral cultures' which also have no written system (Bauman 2008a, 2008b, Ong 1982). The formal history of ASL begins when the US educational system became concerned with educating deaf students. Thomas Gallaudet and Laurent Clerc, two educators of the deaf who came to the US from Paris, assisted in establishing deaf education and standardizing a signed language of the deaf in the US. Influenced by these educators, ASL has much more in common linguistically with French sign

language[40] than it does with spoken English. In fact more "signed languages in the Western world today…trace their roots to French sign language (LSF) than to any other" (Lane 1989:175). The first deaf school was founded in Hartford, Connecticut, in 1817. At this time, sign language was considered to be the "natural language" of deaf persons; the residential school was the primary site for cultivating a common language and community (Van Cleve and Crouch 1989, Burch 2002).

Through the mid-nineteenth century in the US, sign language was utilized by deaf educators and romanticized as natural and beautiful (Baynton 1996, Lane 1989). However, as the late nineteenth century arrived, the pendulum swung. In the late nineteenth century, Alexander Graham Bell began to pioneer alternative methods of education that focused on teaching the deaf to hear and speak.[41] It was thought that deaf people could overcome their hearing loss and be made into good workers and citizens by disallowing[42] sign language and enforcing spoken language – a trend broadly called "oralism" (Buchanan 1999, Burch 2002). Deaf persons and their 'natural language' also came to be seen as similar to the massive waves of immigrants entering the country, a notion that linked the projects of colonialism and the marginalization of deaf persons (Wrigley 1997, Lane 1993).[43] The adoption of oralism in the deaf schools will be addressed further below in the Deaf cultural movement, but it illustrates the complexity and centrality of the language-culture feature of the DEAF-WORLD. Today, the project of oralism,

[40] Langue des Signes Française
[41] Mills (2011) does a brilliant job of analyzing how technological changes with regard to audiometry contribute to shifting perceptions on deafness.
[42] In many cases, deaf children were punished for using sign language and use of it outside of the classroom as well at residential schools was banned. For striking memoirs on this, see Cyrus et al (2005), a more historical account Lane (1989), and Longmore's analysis (2003).
[43] Paddy Ladd also written extensively on Deaf culture as a colonized culture. Although his work is more focused on the UK and the Deaf movement there, his broader, global vision for 'Deafhood' is outlined in his book *Understanding Deaf Culture* (2008).

or what is often called auditory-verbal, is quite different than before due to the CI. The history of deafness as an impairment or disability -considered by society to be deviant, inefficient, and undesirable - *and* a characteristic which may render one a member of a linguistic minority group, once again makes it difficult to know where to locate the Deaf community for analysis. To that end, I will now give a brief history of the disability rights movement in order to locate the Deaf cultural movement and explain the relationship between disability and Deaf studies.

***The disability rights movement & disability studies***

The disability rights movement was one of the major social movements of the twentieth century. In the 1970s, the US saw a variety of new social movements – civil rights, women's, gay and lesbian - based on claims that what society considers to be undesirable can be a source of pride or identity and deserves to be protected from discrimination. Likewise, the disability rights movement sought to shift the focus of pathologizing one's bodily capabilities to analysis – that is, the medicalized understanding of the disabled body - to the social systems that surround the disabled body (Shapiro 1993). A number of issues, such as deinstitutionalization, community participation and integration, education, work, transportation, and housing, emerged from the Independent Living Movement, [44] as well as a general demand for less stigmatizing social attitudes (Shapiro 1993).

As a result of this movement, the field of disability studies emerged and focused on the political aspects of disability in the 1970s in both the US and the UK (which also has an active disability rights agenda and movement). Perhaps the most important work that has come out of

[44] See the National Council on Independent Living website at www.ncil.org for a detailed history and philosophy of the movement and its social justice work, especially around deinstitutionalization.

disability studies is the two models put forth for understanding and analyzing disability: the medical model and the social model (Barton, 1996, Corker 1999, Davis, 2010). A medical model of disability sees the body as the site of the problem to be fixed, while the social model distinguishes between 'impairment' (the physical condition of the body) and 'disability' (the social attitudes towards that body). In the social model, social barriers and attitudes produce disability, not the body or its condition. Disability studies shifted the site of analysis for all things disability from the body to the society it is located in. In doing so, disability studies set up a framework for scholars to begin to analyze and critique social and cultural challenges experienced by and imposed upon those with disabilities. This refocusing also reflected the work of the disability rights movement in another way; disability need not be a stigma, but rather a point of pride for one's identity, a link to a broader disability culture, a 'neutral variation' in human experience, and an opportunity for political action (Clare, 1999, Linton, 1998 & 2007, Mairs, 2001, Asch & Parens 2000). As such, projects of medicalization, and attempts to 'fix' disability based on the notion that it is inherently undesirable are vehemently disliked and highly politicized. Today disability studies is an active, interdisciplinary field of inquiry.[45]

***The Deaf cultural movement***

As outlined above in the section on sign language, Deaf people have been adapting to the hearing world's linguistically inaccessible environment for a long time through the social technology of sign language. Accordingly, Deaf persons and their communities also have a history, as well as their own movement. Lane's account is perhaps the most comprehensive (1989) and although Deaf history began long before the US cultural movement in the 1980s, the narrative of the Deaf cultural movement in the US is often situated around the iconic protests of

[45] For a list of programs, publications and all things disability studies related, see the Society for Disability studies website at www.disstudies.org.

Deaf President Now (DPN) in 1988.[46] The protest was held at Gallaudet University, and cemented the university's role in the movement' it is still often referred to as a "Deaf Mecca." Deaf scholar Brenda Bruggeman (1999) asserted that DPN was the starting point of a collective cultural 'coming out' of Deaf culture and equates it to the Stonewall Riots in queer culture. In 1988, the seminal *Deaf in America* (Humphries & Padden) was also published, detailing the culture of those who use sign and identify as Deaf. Over the last few decades a "Deaf Renaissance" has occurred, with an explosion of Deaf artists, Deaf film festivals, conferences, annual meetings, Deaf-related cultural organizations, active online communities and vlogs (blogs in video format), and the emergence of Deaf studies as an academic field. In 2006, a second round of protests occurred at Gallaudet, which the *New York Times* characterized as an outgrowth of oppression, writing that, "all too often [d/Deaf persons] continue to be denied the right to access information and to speak for themselves" (Cohen 2006).

The Deaf cultural movement has similarities with other identity based new social movements. It is also useful to think about the Deaf community as analogous to other identity-based cultural groups that emerged in the new social movements of the latter twentieth century. For example, one could juxtapose the Deaf community alongside the queer community. There is much historical overlap: the dominance of pathologization, attempts at normalization through medical interventions (hearing aids or CIs for deaf persons/therapy for queer persons), and the development of social movements aimed at demedicalization. Indeed, scholars in both disability and Deaf studies have frequently borrowed from queer studies to support the social model of

[46] DPN was a rally, which lasted approximately one week, on the campus of Gallaudet University to demand that the Board of Trustees select a deaf person as the next president of the school. This event is cherished by those in the community and a symbol of the struggle for Deaf rights and freedom from hearing persons making decisions for deaf people (Ganon 1989, Barnartt & Christiansen 2003).

disability (Bienvenu 2008).[47] The word 'queer,' once derisive, was reclaimed and became a word that represented an ideology of resistance. Similarly, the use of "Deaf" suggests a consciousness of marginalization, entrance into a collective group, and engagement with politics seeking social change and the dismantling of systems of oppression. The systems of oppression most often identified by Deaf culturalists are the social policies that reward attempts at functioning as a hearing person, medical intervention and accompanying speech therapies aimed at acquiring speech and denying access to sign, and educational method decisions made for d/Deaf persons, without the input from the d/Deaf community.

***Disability and Deaf culture: tenuous relations***

Although there are overlaps and similarities between the Deaf cultural movement and the disability rights movement, for the most part the relationship between these two is uneasy. While disability studies and the disability rights movement often include the Deaf movement and 'claims' the d/Deaf community as part of their own constituency, the Deaf community does not reciprocate. In fact, many Deaf persons see the central tenets of the disability rights movement as anathema to Deaf culture. For example, Shapiro writes, "To them [Deaf persons], one of the first great victories of the disability rights movement – the mainstream education law – was a threat. It led to cuts in public funding for segregated deaf schools" (1993:100). The historical role of the residential school in Deaf culture and its role in the formation of community cannot be overstated. Maintenance of such spaces is indeed quite counter to the disability movement's goal of deinstitutionalization. Furthermore, as Lane et al (1996) write, "Deaf people themselves, who surely should know whether they have a disability or not, typically find they do not" (1996:410).

[47] See seminal disability theorists Thomson (1997) and Linton (1998), as well as Swain and Cameron (1999) who write, "the disabled person [who 'comes out'] no longer regards disability as a reason for self-disgust, or as something to be denied or hidden, but rather as an imposed oppressive social category to be challenged and broken down" (Swain and Cameron, 1999:237)

They then go on to suggest that disabilities are often accompanied by ambivalence, but that the "Deaf-World is not ambivalent; its members characteristically think it is a good thing to be Deaf and would like to see more of it" (1996:411). They also write that the Deaf agenda is fundamentally incompatible with the disability rights movement. For example:

> According to the United Nations, people with disabilities seek, above all, better medical care, rehabilitation services, personal assistance services…and independence. However, Deaf people do not attach particular importance to medical care, or place any special value on rehabilitation or personal assistance services; nor do they have any more concern with autonomy and independent living than people in general…Instead, like other language minorities (for example, Hispanic-Americans), Deaf people campaign for acceptance for their language and its broader use in the schools, the workplace, and in public events (1996:411).

Emphasis on language and identity appears to be the foundation of the academic field of Deaf studies, which has emerged from the Deaf cultural movement. However, as I will explore further in the next chapter on theory, there are two problems in the Deaf position: a problematic devaluation of disability and disavowal of the materiality of the body. But because of the central role of language and identity, we will see below that Deaf studies largely relies on an identity politics framework.

***Trends in Deaf studies***

Scholars in Deaf studies have used a number of approaches to theorize the Deaf experience.[48] Although advocacy of a social model of understanding deafness over a medical model is implicit and directly attributable to disability studies, the debates about the role of disability and disability studies in the field of Deaf studies continue.[49] In its short history, multiple lenses have been deployed in Deaf studies, such as collecting the artifacts of Deaf

[48] For a detailed history of the beginnings of Deaf studies and a variety of perspectives, see Bauman's edited collection, *Open Your Eyes: Deaf studies talking* (2008).
[49] The 'exchange' with disability studies or with women's or queer studies is also not without controversy in Deaf studies. Some argue that these exchanges are not productive, while others see the merit. For some of the debate over the 'boundaries' of Deaf studies, see Bechter (2008).

culture (Humphries 2008), attempting to define "Deaf identity," queer takes on and alliances with the Deaf experience (Bienvenu 2008), literary criticism (Krentz 2007, Bauman 2008), and linguistics (Bahan 2008, Reagan 2011). An ethnic model of deafness has also been suggested as an alternative. Lane (200) argues that the DEAF-WORLD meets the criteria set forth by social scientists to constitute an ethnic group. He does state, however, that "there is a significant difference from other ethnic groups: For many Deaf children, socialization into Deaf culture starts late" (2005:294). Furthermore, 'intergenerational continuity' of kinship and values is also impeded because more than ninety percent of deaf children have hearing parents. Because of this, parents have a "different ethnocultural identity that, lacking a shared language, they cannot pass on to their children" (2005:294).

Post-colonialist interpretations have also been utilized. For example, Paddy Ladd's concept of 'Deafhood' asserts that Deaf people are ultimately a colonized people through the conduit of language, or more precisely oralism (Ladd 2003, 2008). He uses the phrase "the oralist holocaust" (2008:54) and hypothesizes that had oralism not been adopted and the use of sign language readily in embraced, there would be more "literate, strong, proud Deaf people, [and] many Deaf superintendents and administrators, teachers and professionals" (2008:43). These are not just theoretical modes of understanding the d/Deaf experience and the social category of being a d/Deaf person, but they are also ultimately appeals to sweeping changes in educational and language policy for deaf children and students.

One of the more important concepts explored is the term 'audism,' which I described in the Chapter One.[50] In line with this, the development of techniques that encourage deaf persons to appear or behave as hearing is essentially "a system of privilege, thus resulting in stigma, bias,

[50] This was also circulated in the form of a film, co-produced in 2005 by Deaf studies scholar Dirksen Bauman, *Audism Unveiled.*

discrimination, and prejudice—in overt or covert ways—against Deaf culture, American Sign Language, and Deaf people of all walks of life" (AFA 2010). Thus, it follows that medical interventions, but particularly the CI, is the symbol of an audist enterprise.

***The Deaf critique of implantation***

Certainly the CI has been controversial and is a familiar topic in Deaf and disability studies. The academic, cultural, and critical work undertaken in the DEAF-WORLD and Deaf studies unfolded over the same time period that the CI was being increasingly adopted in the treatment of deaf children. To the Deaf community, implantation is a threat to the strides made by the Deaf social movement and eliminates diversity. Because deaf people are born into hearing families ninety percent of the time, Deaf culture depends upon discovery of one another, the building of community, as well as the flourishing of a common language. In the DEAF-WORLD the social technology of sign language, like the biotechnology of the CI, has *moral value*. More than this, educational institutions, like the deaf residential school, promotes the acquisition and proliferation of sign through a bringing together of deaf children. This brings the role of deaf education into clear focus: because deaf children are typically born to hearing families, deaf schools and educational programs that use sign language are thus seen as *the* conduits for the discovery of one another and a cornerstone of Deaf culture and history.

The CI is seen as counter to Deaf culture because it is not only embedded with a medicalized view of deafness, but it is also accompanied by actual institutional changes across a variety of arenas that are systematically dismantling the previous conduits available for sign language acquisition and community formation. That is, CIs are understood to be in opposition to and mutually exclusive of sign language, something that Bauman (2008) has referred to as a false dichotomy. Thus, the heated debate over CIs – both as symbolic and material agents of change -

consists of multiple, ethical and moral claims around practices in medicine, as well as moral questions regarding technology and social change. For example, the ethics of implantation are often discussed on two different levels. The first is individual and concerned with the rights of the deaf child to avoid an invasive operation performed without their consent, especially given the argument that deafness is not inherently a 'problem,' and thus should not be a subject of medical intervention. The second is collective: because of the changes occurring alongside increasing usage of CIs, this technology represents the potential destruction of a language and culture because it may render ASL unnecessary and thus a community obsolete. Thus, is implantation unethical?[51]

In the vein of the latter argument, Deaf scholars not only argue that ASL is worthy of existence and continued use, but also argue that Deaf culture and identity is a feature of liberal, democratic and diverse societies that is important to foster (Blume 2010, Crouch 1997, Ladd 2003, Lane 1996, Bahan & Lane 1998, Sparrow 2005). Furthermore, since it has long been linguistically settled that language is not exclusively spoken and that signed languages are equal to spoken languages, the barrier to recommending the adoption of ASL in medical and early intervention must be a result of ideology, and therefore problematic.

***Summary***

A multitude of arguments against CIs have also been made. Both sides of the debate, however, use ethical claims to exert a political position. For example, in a review of arguments over implantation outlined in a report by The Hastings Center, a bioethics think-tank, found that to those in support of implantation, the CI is an invaluable opportunity to correct hearing loss via

[51] The location of CIs in medicine and the moral claims on deafness have resulted in a lot of discussion in bioethical circles. Bioethics, however, has not been an effective platform for Deaf culturalists. I will say more about ethics in a later chapter.

available technological means (Tucker 1998). Furthermore, implantation is construed to be an act of social and parental responsibility. In other words, the individual and collective level critiques leveraged by the Deaf critique are also mirrored by those in favor of them. On the individual level, Tucker implies, parents must adhere to an ethic of care to intervene upon a child with a disability. Not giving a child a CI is constructed as limiting a child's opportunities and depriving them of a basic sensory capability. (Tucker 1998) On the collective level, parents who refuse to intervene and allow their child to be deaf and use sign language are not adhering to their duty to the state. More specifically, deaf persons should later not be allowed to 'depend' on state services that cost the government money when the 'problem' could have been remedied through medical intervention (Tucker 1998). These are indeed highly charged political differences. Going forward, I will now overview the theoretical ideas that informed my entry into the field and then move on to the empirical data about how implantation is accomplished, which yields critiques for both sides of the debate.

## Chapter 4: Towards a sociology of disability

I entered the field with theoretical training from a range of disciplines – disability/Deaf studies, sociology of the body and health/illness, STS, and bioethics - as departure points. In this chapter, I lay out the broader theoretical context informing my research. To begin, I first argue the general notion that disability should be studied as a social category, but with the caveat that any attempt to do so should utilize a version of feminist theory that includes the materiality of the body. I then further contextualize this work at the intersection of studies of medicalization and technology.

### *Disability as a social category*

According to the US Census Bureau (2006), more than fifty million people in the US have a disability and approximately 30% of families have at least one member with a disability. Additionally, as a result of medical interventions, more live with chronic illness or disabilities, and as the number of elderly persons continues to dramatically rise as Baby Boomers age, the prevalence of disability can only be expected to increase. Disability affects a huge swath of the population and there are hundreds of types, from congenital to acquired, mobility to sensory, stable to progressive. This makes it difficult, if not altogether impossible, to speak of 'disability' in general, hence my focus on one (deafness). However, as I have already outlined in the introduction, institutions and legislation from the UN, WHO, to ADA, typically base their definitions of disability on an individual's level of "functioning." For example, the Census considers one disabled if s/he has had, "difficulty performing a specific activity such as seeing, hearing, bathing or doing light housework, or had a specified condition, such as Alzheimer's

disease or autism" (US Census Bureau 2006). This is echoed in the ADA where disability is "a physical or mental impairment that substantially limits one or more major life activities" (1990).

Like race, class, or gender, disability is a social category (Davis 2010). Yet, in all of these definitions, disability is approached as a public health problem and/or quantification of an individual body's capabilities, directly countering the disability and Deaf movements. As noted in the introduction, the struggle to gather accurate data is one of the problems with this approach regarding d/Deaf persons. In summary, despite the fact that the field of disability studies has rapidly grown in the last two decades and there are rapid increases in the number of individuals with disabilities, persons with disabilities remain a largely ignored population for sociologists, who give significantly less attention to this social category than others.

***Sociology and disability***

In the previous chapter, I outlined the basic theoretical approach of disability studies: the differentiation of medical and social models of disability. As noted above, the field of disability studies has focused on social and political aspects of disability. These analyses have the capability to raise a wide range of theoretical and empirical issues in sociology and provide a rich site for understanding "basic normative and ethical issues for society as a whole." (Barnes et al 1999:5). However, sociologists tend to address disability "pre-eminently from within an 'illness' perspective…which distinguishes between the medical concern with disease as an abnormal bio-physical condition, and the sociological focus on 'sickness' and 'illness' as social states" (1999:3). But much of this is actually "guided less by theoretical debates in sociology than it is by practical medical and health service concerns" (1999:3).

While medical sociologists and disability theorists may sometimes start from different viewpoints, they are increasingly aware "that their concerns in some ways overlap and are not

necessarily mutually exclusive. Each group stands to gain from an analysis which draws on both literatures." (Barnes et al 1999:5) Still, Barnes et al state that "a theoretically informed sociology will approach disability as a social state *rather* than as biological difference." (Barnes et al 1999:37, emphasis added) I aimed to utilize and contribute to the two, often opposing, literatures that Barnes et al mention: medical sociology and disability studies. However, not necessarily in the manner Barnes et al might be suggesting at that moment. Like many in disability studies, they participated in a bifurcation between the body, or the physiological, and the social, as well as between what is "medical," and understood to be in opposition to "social." I contend that the medical *is* social and that attending to the [disabled] body as it interacts with forces of medicalization is exactly where disability studies and sociology of disability should go. Furthermore, I do not wish to simply use sociological theory to address issues around disability, but to use empirical data on disability to challenge and re-make sociological theory.

***Rethinking models of disability***

I began my research from the position that disability is a material phenomenon as much as it is a social one. I followed the lead of Shakespeare (2006), a rare sociologist of disability (and one of the authors in Barnes et al) that embraces the body, as well as Siebers (2008). I entered my fieldwork heavily influenced by Shakespeare & Watson's (2002) critique of the social model and Shakespeare's later development of what he calls a 'critical realist' model of disability (Shakespeare 2006). Similarly, Siebers (2008) called his conceptualization 'complex embodiment.' Shakespeare & Watson (2002) argue that the social model was "massively important…it enabled the identification of a political strategy," and secondly, it suddenly allowed people to "understand that they weren't at fault: society was" (2002:12-13).

Nevertheless, they describe a 'strong social model' that focuses on social and political barriers, yet there are contradictions:

> Most activists concede that behind closed doors they talk about aches and pains…even while they deny any relevance of the body. This inconsistency is surely wrong: if the rhetoric says one thing, while everyone behaves privately in a more complex way, then perhaps it is time to re- examine the rhetoric and speak more honestly (2002:14).

They further argue that the success and central role of the social model in the disability rights movement is exactly its weakness. The social model "became a 'sacred cow,' an ideology which could not easily be challenged. Part of its effectiveness arose from its simplicity" (2002:12). Indeed, previous disability studies work that did not maintain a strict adherence to the social model was called 'ideologically doubtful' (Shakespeare & Watson 200214).[52] "This tendency, to evaluate ideas on the basis of their conformity to social model orthodoxy, can be seen regularly in the pages of the international journal *Disability and Society"* (2002:14).[53]

While the social model has been profoundly important, I adopt Shakespeare's critical realist model where, "Impairment is not the end of the world, tragic and pathological. But neither is it irrelevant, or just another difference." (2006:62) As such, I aimed to describe the meanings that deafness and the CI have for parents and professionals, even if it meant acknowledging that they located the problem on the body. Doing so and framing this dissertation within disability studies and medical sociology is apt to ruffle feathers of some in Deaf studies. However, I contend that the disavowal of disability on the part of the Deaf community and Deaf studies

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[52] Oliver (1996) assigned key words to an individual or medical model of disability, including work that grappled with such concepts as 'medicalization' and 'care.'

[53] Bioethicists Cox-White and Boxhall (2009) argue that the social model of disability has "untenable implications;" they claim that the body is the cause of disability *and* that society is morally responsible for not excluding people with disabilities. Likewise Shakespeare & Watson state that, "People are disabled both by social barriers and by their bodies. This is straightforward and uncontroversial" (2002:23).

actually only furthers the very notion that disability is inherently undesirable; the Deaf rejection implies a fundamental disgust with the notion of disability, echoing the larger culture's abelist ideology. Davis (2008) also says this, characterizing the Deaf refutation of disability as abelist.

I am not saying here that medicine *should* be used to alter individual bodies to the exclusion of considering social context, but rather pointing out that there is a difference between situating bodies as *deterministic* and acknowledging bodies as *influential*. Like Shakespeare, I would suggest that, "judgments about how to improve individual situations are complex, and should be based on evidence, not ideology" (2006:62). Unlike social model orthodoxy, my approach allows me to describe how parents discover and respond to their child's deafness as a troublesome bodily state, the intentions and actions of parents and professionals, and, as I will elaborate on further below, the generative aspects of implantation.

My approach to deafness also most closely resembles Lennard Davis' critique of Deaf studies in his essay *Postdeafness* (2008). He points to the limits of claiming identity and ethnicity as primary modes of thought in Deaf studies, and similarly points to the problematic eschewing of disability. He also sees the problems of relying on the body or a bodily state as the prerequisite for identity *and* how identity is an unreliable starting point. Social constructionism and feminist critiques of essentialism expose the body, like identity, for what it is: dynamic, interpretative, and a moving target. Policing the bounds of identity then polices bodies and a Deaf studies intent on digging in its heels and proceeding from identity politics alone will not serve it well.

But thus far, the Deaf community does not claim 'disability' and a similar orthodoxy is seen in this identity-based, social model of deafness largely advocated for in Deaf studies.

Similar to Shakespeare's efforts, Friedner (2010) points out that 'deaf' and 'Deaf' are often conceptualized in opposition to one another, where Deaf is an identity outside of the forces that colonize and deem the body as 'deaf.' But Friedner writes that there is more of a link between deaf and Deaf, and that audiograms[54] are simply performing boundary work (2010). She is suggesting that we reposition Deaf not as *outside* of social forces but rather that 'Deaf' is a product of ongoing relations of power. Accordingly, I focus on the specific processes of medicalization that produce the deaf, as well as the Deaf, body. I am, perhaps alarmingly to some, including medicine here and asking: What happens to the understanding of 'Deaf' if we back up and turn a sociological and ethnographic eye to the medical, to the very practices that are widely viewed as 'evil' and counter to analyses of 'Deaf?'

***Disability politics are body politics***

Arguments in Deaf and disability studies are fundamentally arguments over both medicalization, which I address later in this chapter, and what to do with the body. While the social model attempts to move the site of analysis off the body, the politics of disability cannot be disentangled from the projects of normalizing bodies, especially via medical intervention. Instead of embracing the body and its troubles, Deaf and disability studies decided, among other things, to focus their critique on the larger cultural, normative context within which meanings are made.[55] Yet, a refusal to engage in the realm of the medical for fear of acknowledging the needs of bodies, however, only further 'gives up' disabled bodies to the medical gaze; not only is the

[54]An audiogram is the standard, graphic form used to represent hearing loss.
[55] This is/was not a bad idea: "These politicized conceptions of disability and the increasing consolidation and visibility of the social movement that spawned them have precipitated significant social change, including the deinstitutionalization of thousands of people incarcerated in nursing homes and hospitals world-wide" (Tremain 2005:2).

price a false theoretical divide between the medical (or biological) and social, but it also prohibits critical Deaf and disability studies from shaping the realms of 'the medical.'

There are similar struggles in theorizing the body in both feminism and sociology of health/illness. Feminist theorists pioneered the same shift away from the physical body, originally focusing on representation and social construction to forge epistemological analyses that worked in opposition to biological or ontological understandings of sex/gender and other normative body projects (Butler 1993, Grosz 1994, Turner 1996, Fausto-Sterling 2000, Haraway 1991, Bendelow et al 2003). Ontology was often addressed through narratives of experience and standpoint theory (Collins 2000). Meanwhile the body was also largely a silent actor in the rise of social constructionism emerging from symbolic interactionism, labeling theory, and discursive critique in medical sociology (Goffman 1963a, 1963b, Schur 1971, Foucault 1973). Similarly there was also a shift here to the phenomenological through a focus on 'illness experience' (Frank 1995).

Still, feminist theory tends to be comfortable with the constitutive nature of biology and the social, but often able "to allow this constitutive effect to flow only one way: from the social to the biological" (Wilson 2004:98). It seems we have another "sacred cow:" versions of social constructionism that only allow for one way relationships between the social and biological. Similar critiques are found in sociology of health/illness, where some versions of social constructionism operate in abstract concepts and focus solely on interaction and meaning-making in medicine (Brown 2000). In these situations, discourse and social constructionism, while important, can fail to see the material body and "natural essentialism is displaced by discursive essentialism" (Shilling 2005:71).

But there are possible solutions. In her work on feminist inquiry and neurobiology[56], Elizabeth Wilson (2004) asserts that feminist scholarship, in further parallel with disability studies, "relies on theories of social construction; in defiance of biological models" (2004:13). I contend, like Wilson suggests of feminist theory, that disability and Deaf studies, can be "deeply and happily complicit with biological explanation" (Wilson 2004:14). Accounts of the body, feminist and otherwise, she argues, should be open to neurobiological data in particular, which "need not be at the expense of critical innovation or political efficacy" (Wilson 2004:16). Thus, I set out to attend to neurological discourse, as well as take the bodily materials being referred to – brains, neurons, neural pathways, circuitry – seriously. By doing so, I hoped to take the opportunity to show how social organization may actually flow *from* an understanding of the neurobiological.[57] Understanding how this operates could lead to more productive and empirically grounded critiques of social organization that emerges from bodily and technoscientific[58] knowledge.

My wish to make the body explicit, how we respond to it, and how individuals seek to shape it is not new in social theory (Butler 1993, Grosz 1994, Turner 1996, Fausto-Sterling 2000, Harraway 1999, Bedelow et al 2003, Birke 2003). But I want to do so by locating this research at a theoretical intersection critical of Deaf/disability studies' and social theory's unease with the body. I claim here that mining the very processes held in disdain – those associated with medicalization and specifically here the generation of neurobiological data – may yield important

[56] I focus on neuroscience in this dissertation because, as the data will show, the brain is the main object of discipline over time in implantation.
[57] Gibbon and Novas write that Rabinow's concept of biosociality (1999) is useful for showing how new biotechnologically driven understandings are "reassembling existing cultural, social economic ethical and political practices" (2008:1).
[58] Technoscience is "a blurred site of knowledge production…[and] denotes a dynamic relationship among instruments and people within a cultural context"(Sassower 1997:3).

insights. I wished to set aside the alarm such an idea "would normally elicit in certain critical and political circles, and listen for what kinds of useful critical and political tenets such a juxtaposition may be laying before us" (Wilson 2004:19). As Wilson asserts, neuroscientific interpretations are necessary conceptual frameworks that can provide new and useful modes of interrogation for "feminists and other countercultures of science" (2004:14).[59]

***Medicalization***

A crucial underlying question here is related to determining which bodies' and conditions should be under the purview of medicine, which also mirrors anti-medical model critiques from the social model of disability. Likewise, the central debate over CIs is a difference in opinion over whether or not deafness should be medicalized, underscoring the socially constructed aspects of illness/disability. The contingent and contested nature of illness/disability has been central to analyses of medicalization, since "an entity that is regarded as an illness or disease is not ipso facto a medical problem" (Conrad 2007:5-6). As Conrad sees it, the essence of medicalization is a "definitional issue: defining a problem in medical terms, usually as an illness or disorder, or using a medical intervention to treat it*"* (2005:3).

According to Conrad (2005), medicalization studies have typically had three main concerns: the power and authority of medical professionals and medical knowledge, the activities of health-related social movements, and the professional activities and organizations that

[59] On the one hand, one might critique the use and circulation of scientific discourse by 'countercultures of science.' I recognize the irony, but see no compelling reasons for *not* utilizing the social capital of scientific discourse in say, policy debates. As Sandra Harding wrote, "Science is politics by other means" (Harding 1991:10).

perpetuate medicalization.[60] These analyses have been predominantly critical; from Zola's (1972) critique of the expansion of medical power, Illich's (1976) assertion that medicalization was essentially "rendering individuals and societies less able to deal with these 'natural' processes" (Metzl 2010:10), to later social constructionist studies of medicalization examining knowledge production, consumption, and claims-makers (Freidson 1988, Patton 1990).

Indeed, medicalization should be critiqued for the way it narrows the scope of what bodies are considered acceptable, and applies a logic to bodies that accomplishes the feat of transforming social problems into purely individual pathologies. (This imperialism is especially true of neuroscience, as it colonizes discourse of both mind and body.) But, I would argue that one should study medicalization whilst acknowledging that its 'evils' may not be so clear-cut. Critiquing medicalization initiates important discussions about how we define disability, for example, but as I have said, a sociology of disability cannot let a blanket critique of medicalization lead to a distaste for – and thus absence of – studies of it. There have been "few attempts to encourage dialogue across the disability studies and medical sociology divide" (Thomas 2004). However, as Zola wrote, we must bring the body back in (1991). I too claim we must bring medicine in to the study of disability and situate this study precisely at these boundaries.

***Biomedicalization and the politics of technological artifacts***

While my approach is informed by Conrad's concept of medicalization as a form of collective action between and among medical professionals, interest groups, and patients (2007), I was also influenced by approaches that differ from his. While he would acknowledge that biotechnologies play a role in this process, I took an STS approach and positioned the technology

[60] See, for example, Brown and Zavestoski (2004) on embodied health movements and Epstein (1996) on the AIDS related interest groups and patient activism.

of CIs as *co-productive* of deafness itself, that is, an active part of the definitional process of both a condition and the constitution of the deaf body (not just an 'engine' driving it). This co-production via biotechnology is a phenomenon that may fall under what Clarke et al call biomedicalization, where medical and technical knowledge are interwoven, such that medicalization is fundamentally altered through "dramatic changes in both the organization and practices of contemporary biomedicine, implemented largely through the integration of technoscientific innovations" (2005:161).[61]

Sociologists of knowledge and STS scholars have long said that science and technology are social (Sismondo 2008).[62] Like bodies, technological artifacts are not just material objects, but also embedded in and inscribed with social and political relations (Winner 1980).[63] I approached deafness not as inherently or 'naturally' a neurological problem, but co-constructed as such through the introduction and incorporation of the CI, a neuroprosthetic device, into clinical practice. That is, the body and the technology are bundled; inscribed with social relations together. An example of this is seen in Jain (1999) where prosthesis "defined as that which supplies the deficiency…[also] encodes disability" (Jain 1999:33). Prosthetic devices are "discursive frameworks, as well as material artifacts" (Jain 1999:32) and "the term prosthesis can

[61]Conrad agrees that increases in technology are shifting the 'engines' of medicalization, but he does not agree that it has been replaced by a new phenomenon and critiques this notion for being over-encompassing and 'losing focus' on the definitional aspects of medicalization (2007).
[62]Classic studies in STS have shown how, rather than emerging from an objective or 'natural' truth, science is collectively 'made' through interactions (Callon, Law & Rip 1986, Kuhn 1962, Latour 1987).
[63]STS scholar Ingunn Moser (2006) argues disability studies suffered from theoretical myopia toward cultural analysis to the exclusion of analyzing science, technology, and medicine. As a result, relations between technologies and disabilities have largely not been critically analyzed and need STS informed studies. "Few scholars have actually looked into what norms and divisions become enacted or undone through available technologies." (Moser 2006: 375)

include the creation of deficiency *and* the antidote to the deficient body" (Jain 1999:33, emphasis added). By arguing that prosthesis suggests a process of working toward 'wholeness' of the body, "certain bodies…are often already dubbed as not fully whole" (Jain 1999:32).

Of particular interest here is how Moser and Law's (2006) study of a communication technology called Rolltalk, designed for persons with disabilities who are non-verbal, illustrated how an individual's voice is "constituted or 'articulated' into being within material arrangements which include social, technological and corporeal relations" (2006:3). They write that uncritical approaches to the 'voice' being given to persons with disabilities via a technoscientific object would be risk overlooking "that 'voices' that happen to be non-verbal are simply not recognized, or disqualified" (2006:4). By framing it this way, they show how technologies both *produce* and *preclude*; giving voice also "takes away other possible voices" (2006:8).

Lastly, it seemed to me that Conrad focused on the 'front end' notion of medicalization and suggested that ensuing relations are not explicitly under its purview. I incorporated a view of biomedicalization, where medicalization is not just a product of specific relations and collective action, but also productive itself; out of it comes ongoing, emergent forms of relations that empirically show us what 'medicalized life' looks like. This, along with considering the role of technology, opens up further fields of analysis and provides the opportunity to understand how individuals are socialized into a medicalized way of thinking about deafness *and* how they embody and enact it over time. Incorporating the theory of biomedicalization examines the consequences more deeply; it goes beyond knowledge production and social constructionism and sees medicine as so permeated and transformed by technologies that the effects are multiple and diffuse, redefining health as "a matter of ongoing moral self transformation" (Clarke et al

2005:172). Adopting biomedicalization and its invocation of morality, provides a crucial link between studies of medicalization and analytics of the biopolitical.[64]

***In summary***

I began this research attempting to work between theoretical spaces; I took disability to be a sociopolitical category as much as a physiological reality, framed the neurobiological as a conduit through which to understand the social, resisted using medicalization as a way to easily delineate 'sides' of a debate,[65] and incorporated the role of technological artifacts in ordering social relations. I set out to describe some of the emergent organizational, structural, and social aspects behind implantation that shape the definitional process. But, I was also concerned with the ways technology shaped *how* it happened and in what ways this mattered beyond moments of definition. In doing so, I asked: What are the ongoing consequences for those involved and how does this biomedicalization re-organize social life? How are these lives organized around care and its associated regimens? As patterns unfold in the following chapters, it becomes clear that additional theoretical concepts are needed for understanding the answers to these questions. While these theoretical ideas were useful for framing my initial approach, their limitations were highlighted throughout fieldwork as unpredicted themes emerged from the data.

[64]As the following chapters will illustrate, biopolitical concerns clearly emerge from the data. According to Lemke (2011), biopolitics " stands for a constellation in which modern human and natural sciences and the normative concepts that emerge from them structure political action and determine its goals" (2011:33).

[65]I heeded Parens' (2011) suggestion that we "get over the traditional assumption that medicalization is bad per se, and try to articulate the difference between good and bad forms of it" (2011:2). But, as data will show, making such a judgment is far less important than considering that perhaps it is *both* good *and* bad; as I present my data, I will show how I came to think of this as a form of 'ambivalent medicalization.'

## Chapter 5: Never Say Fail: Identification and Socialization

*Well if I'm lying on the floor having a panic attack, I'm not exactly making a healthy dinner. – Jane, mother of Lucy*

*It is possible to refrain from understanding objects as the central points of focus of different people's perspectives. It is possible to understand them instead as things manipulated in practices. – Annemarie Mol, 2002*

Getting a CI is a long process, a long emotionally draining, socially dynamic, and institutionally embedded process. Some children are identified with a hearing loss at or soon after birth, others become ill in infancy and lose their hearing. But everyone has a point of entry, though they are not always the same, and then they move through similar stages. There are numerous etiologies and a multitude of efforts that are employed to mitigate a child's hearing loss through manipulating embodied, behavioral processes. Some became CI 'candidates' that were later implanted and became CI patients, others do not fit the criteria and were funneled elsewhere. While there are always patients moving through the various stages, the clinic, its protocols and its structures are consistent and facilitate this flow. I decided to call these 'anticipatory structures,' which mirrored other patterns that emerged out of the data, namely professional anticipation of parental grief and anxiety.

### *Anticipatory structures*

Anticipatory structures are 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. The main goal of these is to encourage and maintain compliance. Compliance is defined as "the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice" (Haynes et al 1979:1). Other terminologies have appeared, such as adherence, to incorporate the complexity of

social relations surrounding compliance. Compliance "suggests that patients acquiesce to, yield to, or obey physicians' instructions; it implies conformity to medical or medically defined goals only" (Lutfey & Wishner 1999:635).

Some argue that adherence more accurately "captures the increasing complexity of medical care by characterizing patients as independent, intelligent, and autonomous people who take more active and voluntary roles in defining and pursuing goals for their medical treatment." (Lutfey & Wishner 1999:635) Here, I do not replace compliance with adherence, but rather see them as interrelated. These concepts have a complex relation to each other; there are structures (even manipulative ones) in place enforcing compliance, but there is also agency and relief experienced by the parents who are consuming them and incorporating them into their lives. Increased levels of anxiety and stress for parents of children with disabilities have been well documented. This is especially true with EI services and the professionals that with parents who have a child identified with a hearing loss.[66]

All of this contributes to the concept of 'ambivalent medicalization' that, over the course of the following chapters, emerges. In this chapter I largely focus on the professionals and techniques they employ, but would ask that the reader holds in his/her mind the contradictory qualities of these structures that the parents are subject to. Namely, how parents are drawn into specific modes of compliance, as well as experiencing a range of emotions such as anxiety and relief in the middle of this. This is a dynamic that continues through the dissertation.

Although there is no one CI story, in this chapter, I try to give a chronology that illuminates both the structure and context surrounding implantation, as well as the techniques

[66] Numerous studies have already shown that centers often develop programs that encourage parents' active roles (Ingber et al 2010, Ingber & Dromi, 2010, Moeller, 2000, Sass-Lehrer & Bodner-Johnson 2003).

and constraints framing parents and professionals meaning-making of these experiences. To begin, the CI process consists of five general stages: identification,[67] intervention, candidacy, surgery, and long-term follow up care. In this chapter, I address identification and intervention. However, intervention lasts for years; here I will focus on the structure of interventions, while Chapter Six delves further into the discursive and social aspects of ongoing intervention policies and practices through candidacy and surgery.

While in the clinic, the parent participants in my study were at various points in the implantation process. For a variety of reasons, including the fact that implantation is a multi-year commitment, I could not follow all of them through all five stages. Thus, I weave together a story of the process through different parents at different stages, and how the clinic shapes and organizes experiences of them.

***Identification***

One way that this process begins is through the statewide Newborn Hearing Screening (NBHS) program.[68] As I mentioned previously, this program's goal is to identify all newborns with a significant hearing loss and failing a hearing screening is often the first triggering event. One Thursday morning at the clinic I met up with Margaret, the NBHS coordinator for the CI center. The previous week, we had arranged for me to accompany her on her duties that day. This morning she spoke of being ready to go and "check on her girls," meaning the NBHS

[67] When I first began research, I mistakenly thought there would be a 'moment' that I would witness that constituted diagnosis or a moment that constituted the decision to implant. This was not so. Sometimes diagnosis was a result of cumulative events occurring over a number of appointments, sometimes it was unclear, but most importantly, the meaning attached to having a child with a hearing loss was built and cultivated over time and through the passage of these stages.

[68] This type of screening should be understood in relation to other screening changes in recent years; numerous additional conditions being tested or 'screened' for in newborns besides hearing set in motion new forms of knowledge production (Timmermans & Buchbinder 2011).

technicians. When she talks, it is clear to me that she is passionate about what she does and has been doing it for a very long time.

We leave the CI center and head toward a neighboring department. As we make our way, we go through a variety of back, unmarked doors and corridors with stairs and fire doors. There are no other people around, and then suddenly, we emerge in a maternity ward because nurseries line the long hallway. This is "well babies," meaning, the department where babies are born without other major complications or conditions.

We go through an unmarked door next to one of the nurseries and enter an equipment room where we find Cheryl, the NBHS technician, or "screener." She is gathering her equipment together on a cart with various machines, tools, and stacks of pamphlets on the bottom shelf, along with round, brightly colored "I had a hearing test" stickers.

Margaret explains that there are different kinds of screening devices, the auditory brain stem response (ABR)[69] equipment, as well as the devices testing for otoacoustic emissions (OAE).[70] The OAE screening machine is very small and used most often. It looks like a credit card machine that produces a receipt, except the wire coming out of it is attached to a remote control-sized device that has an ear probe with a rubber tip on the end of it. These portable machines run on batteries since the screener also makes rounds through the neonatal intensive care unit (NICU).[71] The pamphlets on the bottom shelf are separated; one is for if the child passes the screening, the other if the child fails it. But, Margaret tells me emphatically, 'you

[69] ABRs measure the electrical activity in the brain in response to sound stimulation.
[70] For an OAE, an earphone and microphone are placed in the ear. A sound is then presented and if the baby hears normally, an echo is reflected back into the ear canal and measured by the microphone. If there is a hearing loss, there is no echo.
[71] NICU is another testing environment altogether. 'It is for very, very sick babies. You have to know when a baby can tolerate the test and its safe. If a nurse spent an hour trying to feed the baby and you come in and test them and they throw up, that nurse will hate you forever, so you really need to avoid that.'

never say 'fail,' and it does not use the word fail in the pamphlet.' Instead, she goes on, 'It says, we couldn't get a passing result yet.'

***Shadowing the NBHS screener***

Before we begin, Margaret warns me that because it is late morning many of the babies have left the nurseries and have been "farmed out" to the mothers.[72] Time is of the essence; typically they only have a forty-eight hour window to work with, which is the amount of time insurance companies cover for well babies. 'Early morning is the only time to get the babies,' she explains, because they spend overnight in the nursery. After they have been given over to the moms, 'You're dead - you can spend the whole day getting one baby from one mom for testing.' Besides, she says, having a baby is 'a celebratory event and it's busy, it's harder than you think to take the baby off to test them. People are visiting, they're happy and then we come in with bad news, so we have to very careful.' The upside to this, however, is that Early Intervention (EI) 'is really big now and with the NBHS it's possible to get on it right away.'[73]

Early in the morning Cheryl brings the babies to the test room because you need to have a quiet environment and the baby has to be sleeping. 'If they pass, they get a brochure and they're done, they're outta here," Margaret explains. 'But if they fail the test, we retest; we want to make sure they are a *real* fail.' NBHS is mandated by state law and they are required to tell the parents the results. If they fail, 'and again *you never say fail*, you say we couldn't get them to pass it, we go in, sit down and ask if we can talk for a few minutes and explain what we do. We've

[72] Thus, I did not get to observe screenings of well babies, nor did I observe a screening 'failure.' Nevertheless, I did establish the context within which these moments occur and how they are dealt with by the screener and coordinator.

[73] The NY State Department of Health, which administers the EI program (EIP) was awarded a grant from the CDC to enhance the surveillance system for NYS's Newborn Hearing Screening Program to "decrease the number of children who are lost to follow-up in the newborn hearing screening process, which will require linking of NBHS and EIP data" (Annual Performance Report 2010:25).

developed ways to deliver this news without making moms hysterical.[74] We tell them there are many normal and natural reasons why we may not have gotten a pass.'[75] She also tells me that the mothers always have the same questions for her: 'Is my baby deaf? That is always the first one.' Her answer to that, in a soft, reassuring voice, is, 'We're not saying that. Maybe they're too young, so come on back to the center in a month for a re-test. Usually things are fine, but it's best to follow-up.'

But now, as Cheryl readied her cart, it was time to go to the NICU. When I accompanied them to the NICU, there were babies in incubators with one-on-one nursing, some of them very fragile. Many were on respirators and in large, enclosed pods with lots of wiring and tubing. Some of the machines were taller and wider than myself. Because of this, the babies aren't brought into the testing room, hence the technician was coming through with the cart. As we move through the unit, we first rolled the cart down the hall to one of the last rooms, to the babies who were closer to being discharged. These babies are less fragile; there are about ten of them. The technician walked around, checking to see if it was a good time or if the test has already been done. If it had, there would be one of those colored "I've had a hearing test" stickers at the top of the clear plastic the baby was encased in.

We then move into the newer wing of the NICU, which was completely different, with all glass walls, state-of-the-art technology, and computers everywhere. Each of these babies had their own room, or 'pod' and were are all in incubators. Because all the walls were glass, I was

[74] The use of the word 'hysterical' here is indicative of the horror associated with having a child with a disability. Landsman (2009) found that mothers of children with disabilities experienced 'diminished motherhood,' as they were "often treated as if she has no baby to celebrate" (2009:57).

[75] One such reason is left over fluid in the ears from a Caesarean section. But, Margaret warns, 'You don't want to blame the C-section too much or mom will call up their OB/GYN and complain and then you're in trouble with those doctors and you don't want that.'

able to look into all the pods. In one of them, doctors who were performing a surgery as we passed by surrounded the incubator. We rolled the cart from pod to pod, reading charts and seeing if it was a good time. We came upon one that was in NICU as a precaution because the mother had a temperature during childbirth. Cheryl and I move over the incubator. Margaret, Cheryl, and I all peer into the clear plastic little box the baby is in. He is sleeping. Next to him is a nurse sitting at the computer. Cheryl powers on the equipment and takes a wire from the OAE machine that has the ear probe on it and places it in his ear for a few seconds. She then presses a button on the machine and it lights up. A few seconds later it prints what looks like a receipt: it says "passed" in black text at the bottom of the paper. Cheryl places a sticker on the baby's name card that is at the top of the box. She then places a "your baby passed the hearing test" pamphlet in the crib with him. Since the OAE was passed, she did not need to use the portable ABR device.[76]

***"We've got 'em."***

When we are finished, Margaret and I return to the CI center. As we walk, she tells me, 'You put your head down and you do your job. The testing doesn't tell us anything about what kind or what degree of loss. That's not my job. I'm a pass/fail girl.' But there are instances of failure and part of her job is to make sure that the mother brings the child to the CI center for an ABR, usually within three months. To accomplish this, when a well baby fails the screening she promptly shares this information with their pediatrician. She explains that they are more effective at ensuring that they comply with bringing the child back for further evaluation because they have an established relationship. To the clinical staff, forging a relationship with the parent

[76] I ask what happens if a NICU baby fails and Margaret says, 'We tell the neonatologist, not the moms. They have a lot of bad news to deal with and we don't have a relationship with them, but the neonatologist does. Sometimes they don't tell the mom right away.'

is the most important and crucial step in early intervention. Thus, if a child fails the NBHS, Margaret makes sure that the mother has an appointment paper in her hands before she is discharged from the hospital. She also has a team of secretaries devoted to making follow-up phone calls to these mothers. This is all in effort to stay on parents and, she explains, 'We really keep after them and once they get the moms here, we descend on them and we've got them.'

***"Bad news:" Communication techniques for compliance***

In her description of the protocol for carefully communicating with parents and her emphasis on using a 'non-threatening way of communicating to moms about it to not scare them,' we see the first indicator that deafness is undesirable and constitutes 'bad' news. The technique of avoiding use of the word 'fail' and framing a follow-up visit as a way to get the passing result is an important part of the strategy to have the mothers return to the clinic with the child. As Maynard (2003) argues, relaying news is a highly social event that uses a variety of interactional techniques, including word choice and the suppression of facial expressions. But Maynard also argues that "bad and good news have a common core: both are interruptive (even disruptive) of the ordinary, taken-for-granted world" (2003:4). As such, news incites "emotional reactions and necessitate a realignment to and realization of a transfigured social world" (2003:4). Not only is it emotional, but also socially constructed and highly contingent; the badness or goodness of news – or of the fact that a child is deaf - is not inherent.[77] Instead, the individuals engaging in interactions produce " a mutual sense of some event-in-the-world as news and as having a good or bad character" (2003:27).

[77] Highlighting the contingency of disability and 'bad news,' many Deaf persons express being thrilled if/when their child is identified as deaf. In 2002, a deaf lesbian couple was featured in *The Washington Post* who purposefully used a genetically deaf donor to increase their chances of having a deaf child. ""It would be nice to have a deaf child who is the same as us," they state in the story (2002). In the months following, there was an uproar over this, see Bauman (2005).

All of these actions, or social techniques, are constrained by time and centered on anticipation (deliberate stylization of giving 'bad news' and anticipatory emotional work undertaken by the screeners). Anticipating parental grief, their possible denial, and/or refusal to bring the child back for follow-up testing is part of Margaret's task to ensure parent compliance. But the screening may be rectified with a pass at the follow up appointment, or the child may truly have a hearing loss. Regardless of the outcome, it is in the follow up appointment where an ABR is conducted that often the child's hearing loss is confirmed by an audiologist.

***The ABR: Managing information, managing the parent***

ABR tests are typically done when the parent brings the child into the clinic for the initial follow-up after they have failed the NBHS. However, a child with hearing loss may be identified with an ABR later in infancy for number of other reasons: the NBHS is not necessarily the precursor, but it sometimes is. I sat in on a number of ABRs to understand how mothers and audiologists interacted.

Sharon, the center's director came to my desk one morning to get me for my first ABR. This one was a NBHS failure from a nearby hospital that was born through a Caesarean. There was some question as to whether or not it was a true failure. "With this baby," she tells me, "we are starting from scratch. We know nothing about this child; all we know is that they failed the screening…They could be fine, hearing impaired, we don't know."

As she leaves my office, she says "Often the mother will hold the baby, sometimes they do better in the car seat if they are sleeping, so we just leave them in that, or if the mother wants me to hang the baby from the chandelier, I do, whatever they want." The reason for this is that the child has to be in a 'natural sleep state,' which is not always easily attainable in infants, making this test even more emotionally stressful for parents. Meanwhile, audiologists would

sometimes be especially annoyed by ABRs; the time they take can back up appointments and potentially disrupt work flow.

Sharon goes to greet the parents in the waiting room and ask them if it is okay that I observe. She returns a few minutes later with their approval and has me accompany her to the waiting room, where a young married couple in their thirties are sitting with a pink stroller. They look tired. We explain that one of them can come in for the test and that afterwards we will get other parent and bring them back to discuss the results. They confer and decide that the mother should come back with us. The test is exhausting; it can last up to an hour and half, depending upon the baby and how well she does.

The three of us walk the stroller down the long hallway to the last room on the left. This room is electrophysiology; it is a testing room and the door is about eight inches think and has the appearance of a vault. The entire room is soundproofed; the walls, floor, and ceiling are covered with carpet. The first thing Sharon does is explain that nothing she is doing in this test will hurt the child. She then begins putting the electrodes around the baby's head.[78] "I am adding gel for attaching the electrodes and it's cold and that's probably the most uncomfortable part. Other than that, she'll just sleep." When I sat in on other ABRs with three different audiologists, I found they also calmed mothers right away by assuring them that the test did not hurt. As Sharon attaches electrodes, the mom says, "If you sneeze or clap, she'll jump so I believe she can hear, I just don't know how much."

Sharon does not respond and stays focused on the task. "Let's start with the right ear since that's which one initially failed." She asks me to turn the switch that is behind my left

[78] Lisa, one of the audiologists explained, "ABRs are like EEGs or EKGs, they are just measuring electrical energy that moves from the cochlea to the brain stem, that's why it's called an Auditory Brainstem Response test. It's just like when you get one done on your heart and the stickies go on your chest, with the auditory system, the stickies go up around your ears."

shoulder. I reach up, flip the switch, and the lights go out. It is eerily quiet in this soundproof room, which is now only illuminated by a computer screen. Sharon sits down in front of the screen, manipulating information in the form of graphs and spectrograms. As though anticipating questions during the test, Sharon says, "I won't be able to tell you results during the test." In all other ABRs, this was also stated, for example, one audiologist immediately told the mother that she would not be able to tell anything from the results until the very end. As I watch the ABR, no one says a word and the only sound is the clicking of the mouse as Sharon arranges and rearranges the squiggling lines around on the screen. I am sitting just a few inches away from a tiny little girl who is only a few weeks old. She has electrodes on her head and is breathing audibly, sleeping. The mother looks exhausted. Over the course of the test, when the baby cries out a little or moves about, Sharon reaches over and gently rocks the stroller for a few moments and she falls back asleep. The mother peers steadily at the computer screen, as if to try and decipher all the different colored lines. Sharon stays focused, clicking away, tagging point on the graphs and separating the lines.[79]

About thirty minutes later, it is time to switch to the other ear. Sharon removes the miniature earphone from the baby's ear and puts it in the other. This time she connects the computer to the electrode attached to the other side of her head. To do this, she has to turn the child's head, and she very softly rocks the stroller. The mother looks on, letting Sharon do the mothering at the moment. After the second ear is finished, Sharon moves to another machine in

[79] The technological repertoire of visually representing brainstem activity in relation to hearing is significant; it indicates the neurological importance of the 'problem' as well as produces new sets of relations and foci of bodily project. This will be taken up in-depth in Chapter Seven.

the room to conduct tympanometry.[80] The baby cries throughout this part of the testing, and her mother nervously jokes, "Well, we know the lungs work."

When this is over, Sharon says, "Let me unhook her first so dad doesn't have to see her looking like Frankenstein." She goes to get the father and I sit alone with the mother, she smiles at me, says she is exhausted, but that she thinks the baby did really well. Dad comes into the room with Sharon and he sits down. He anxiously asks, how it was. "Good news: the baby hears. I am picking up a mild hearing loss in both ears, just a little shy of where she should be normally." They go on to talk about the possibility of removing the fluid from the ear to solve the problem, and to see Dr. Brown, the ENT doctor (who is also the surgeon) at the clinic as soon as possible. Before they leave, Sharon asks them if there is anyone in their family with a hearing loss. The mom answers, "No. That's why I was like, were did this come from?" The father then asks, "What if it is a permanent thing? What does this mean going forward?" Sharon goes on to explain how they recommend hearing aids, how they need to address it early, but also assures them that "We're ahead of ourselves here." She gives them Dr. Brown's card and says, "No matter the outcome with ENT, come back to see me here." As Sharon steps out and the mother says to me, "We were worried that she's deaf. Oh god." She turns to her husband and says, "She can hear, thank god."

The tests can most easily be summed up as: connecting wires, putting probes in the ear, pressing buttons on the computer, wait, and repeat. But they do not always go smoothly. Often the child wakes up and will not go back to sleep. If a child will not go back to sleep for another hour, I have seen the faces of parents, already exhausted from having a newborn, be worn further and further down. At the same time the audiologist can get increasingly frustrated, as

[80] Tympanometry tests the middle ear, specifically the functioning of the eardrum, or tympanic membrane.

appointments are pushed back and the waiting room gets backed up. ABRs can become rather tense because of the stress already there, plus the competing tensions between the child's needs, parent's needs, and audiologists' desires.

In these cases, the audiologist leaves the room and lets the mom have the space to get the child back to sleep. They might gather in the shared audiologist office while waiting and express frustration. During these break moments, phone calls are made, paper work filed out and insurance issues for other patients is dealt with. These moments can be lively, as the audiologists' offices are nestled in a corner of the center. Sometimes they reschedule older children to have one with sedation and an anesthesiologist will come in as well.[81]

When I accompanied Holly through an ABR, the child was not cooperating and so we left the room to give the mother a chance to get her to sleep. As we walk down the hallway, she says, "Just so you know, when we do the OAE in there, and you see blue that's a good thing. It indicates it's normal. We'll do that first for a heads up. You'll see red, but above that look for the blue." This was one of those odd moments for me as an ethnographer: I was privy to information about patient before the parent was, and felt slightly that I was 'in cahoots' with the audiologist. This made me uncomfortable; how could this be right? A few minutes later Holly decided it was time to check back and see if the baby was sleeping. "Ok let's go," she says. "What's this patient's name?" I ask. "I have no idea."

Once we got back into the ABR 'chamber,' we found that the baby still was not sleeping. The mother was quiet, she had tattoos and a gold necklace on that spelled out her name. Holly did not explain much, except that she was going to go ahead with the OAE. I watch the machine, but do not see any blue, but I am also not quite sure where I should be looking. A few moments

[81] Sedation does pose a risk for the child, but in the interest of convenience for the clinic's daily operations, this is generally not seen as prohibitive.

later, Holly asks me to press the buttons on the machine as she sat across the room with the child, manipulating the earphones. “Ok, I’m going to put you to work, press that button, not yet, OK now” I press the start button on the tympanometer. A few moments later, I do this again for the other ear. Once again, I feel strange; on the one hand I feel pleased that I have some kind of function since I suspect that as the ethnographer I am seen to be taking up space, and possibly annoying, to the staff in the clinic. On the other, I also feel conflicted at the thought of participating in clinical routines.

One morning while observing an ABR with Lisa, the mother was more overtly anxious. She was hovered over the screen and made suggestions as to how to make the baby more comfortable. She offered to hold equipment for the audiologist, suggested how to position the baby, and wondered our loud whether or not they should start with a different kind of test. Lisa did not respond to most of her comments, and once she got the ABR going, the mother kept her eyes fixed on the screen and asked, “Can he hear that?” Despite having told the mother she would not give results during the test, the mother asked anyway, but Lisa did not respond.

Finally, Lisa announces that she can go over the results. ‘I still can’t get him to pass the screening. It’s telling me there is loss in the high frequencies in the left ear, but the right ear is giving me more responses than last time. However, it is still severe to profound. So, we’ll make sure to test some more.’ The mother seems confused. Lisa continues, “Listen, it’s always best to go through life with two normal hearing ears. But the good news is that you only need one normally hearing ear to develop speech and language.” This was tricky; the child was testing severe to profound; although one ear could possibly be less affected. But it was framed as still not being able to get a passing result, suggesting that the ontology of deafness was alterable through further testing at different times. Lisa gave the mother her email address and said she

would speak with the ENT and that she could be in touch with a plan later that afternoon. Then she left the room. I watched as Lisa walked down the hallway and the mother, in a kind of daze, packed up her belongings and readied herself to leave. I was not sure what she was feeling in that moment. Did she feel hopeful since Lisa had said there was good news that one ear was not 'lost'?[82] Did she feel that the passing result would eventually come?

***Carol's account of the ABR***

It is autumn and when I arrive at Carol's apartment in Queens, I find her with a hand full of sewing materials. We go into her kitchen and prepare tea, then move to the living room. She plops down on the couch and picks up a piece of clothing from a pile of baby clothes next to her, and grabs a needle and thread. On her other side is a pile of baby socks. She starts to sew one of the socks into the top of the baby outfit. "The implants have external controllers," she begins to explain. "Your unit has the microphone and that goes on his ear, but because it's a body-worn controller, because babies ears are smaller," she says it sometimes falls off. So, sewing socks into his baby clothes creates a place to keep the external piece, "It just slips right in," she says, quite pleased. "Plus, because it's sewn into his shirt, the sock, then when he does pull off his head, we're not going to lose it. So it just makes like a little bit easier."

Carol then recounts her NBHS and ABR story. At the hospital, a different one from where I did my fieldwork, the screener came to take her son for his hearing screening. And then,

[82] Here is one of those moments that as an ethnographer made it difficult to be clinically present throughout the process from beginning to end. Often my fieldwork consisted of shadowing audiologists in their routine appointments, not necessarily signing on parent participants. I was able in some ways to witness important moments, but not always to speak to parents about it, although later my participants recounted their stories. But, since my study was specifically about parents of children with implants, it was hard to gain access the possible future CI recipients. It would mean that the parent would already have to have knowledge and acceptance of this, which at times simply did not happen, and it left me in an ethnographic 'dead zone.' Thus, most of the parents in my study had already been through the second stage of being socialized into EI.

they came back and said that he had failed the test and she asked them what that meant. "He probably has fluid in his ears. You know, it was a C-section." He was tested three times. "By the time we're leaving, we're like, "Hmm, so he hasn't passed that hearing test." The screener told her, "It's fluid, whatever, just make sure you go back." They go back. He fails again a month later and they tell her she needs to wait a little longer, perhaps there was still fluid. They go back again. He fails again. "So we made another appointment and, honestly, it never occurred to me, even though he kept failing, that – Because you know what I thought they were going to tell us, was 'He has to have some sort of procedure to clean out the fluid,' or something like that." But on the morning of that appointment, which occurred at the same center where I was observing ABRs with Sharon, that morning, Carol says. "It struck me. I thought, Hmm, well, maybe this is something."

Sharon comes into the room, where Jeremy is sleeping on her lap, to do the test. "I'm thinking, "He's not really making so many movements here. I'm wondering [about his hearing], but I don't know." They sit through the ABR and then, " The poor woman, Sharon, says – and I say poor woman, because it's kind of a funny story. She says to me after it's over, 'Jeremy has a severe to profound hearing loss.' Now, understand that I know what that means now, but that didn't mean anything to me, really." In fact, she thought it might be reversible since she thought it was caused by the fluid. "I understand what deaf means, but I don't know what severe to profound hearing loss means, at that moment." Plus, Carol tells me, Sharon is whispering. "I'm thinking, I think that means he's deaf, but it can't mean deaf, because she's whispering. You know, that's what's going through my mind. I'm thinking she's contradicting herself, because I think she's saying that he can't hear anything. But then why would she be whispering?" And then Carol says, "I said, so you mean he's deaf? And she says yes. But [I ask] then why are you

whispering?" Carol goes on to say how she suspected Sharon thought she was some kind of 'wiseass' for making that kind of remark, but that that was truly what was running through her mind. But right after that moment, she says, "I just got this kind of gasp to myself, because one thought went through my mind: Oh my god, other little kids won't want to play with my baby. It's going to be so hard for him."[83]

To combat this fear, she says she thought to herself, "I'll teach him how to play baseball really well, then other kids will play with them…We can teach him how to be a really good athlete or be good at something, and then that problem's solved. So I thought, okay, I'm good." Then Sharon started talking about CIs and that she nodded and said okay and alright to everything she said. Even hearing about implants, however, did not mean anything to her in that moment. "I'm thinking, Okay, I'm going to have to talk to you about this thing you're talking about. I'm going to have to learn sign language. I'm going to have to do these things." Then I think, "Oh my god, I've got to tell my husband, who's sitting in the other room."

At this point, Sharon goes to get her husband and he comes back to the testing room and he becomes very upset. Carol remains calm and tells him to go and make sure his parents, who are also in the waiting room, are also calm. Then, they all go and meet with Sonya, the social worker at the center. "She starts telling us about the CI and that he might be a good candidate, and we have this service and that service." In fact, she felt Sonya to be "incredibly helpful, she was really great, very knowledgeable, very calming. She gave us a lot of information, saying we're here for you, she was very supportive." She also knew that she needed to listen carefully to all the information so she could perform the impending tasks. Carol, however, emphasized to

[83] This vision of the future is pervasive for parents. Similar sentiments were conveyed to me multiple times. The anxiety over a child's future and his/her 'opportunities' will come up repeatedly in the next two chapters.

me how thankful she was that Jeremy was "just deaf." She had concerns that because she was forty when she had Jeremy, there would be something 'wrong' with him. Upon his diagnosis, she tells me that she thought, "You're telling me he's deaf, but there's nothing else that you think that's wrong, so, okay, he'll be deaf. You know, some people are left-handed, that'll just be that. And the cochlear implant thing, I had no idea what she was talking about. I'm thinking sign language."

*

At the end of ABR tests, there is often a definitive answer or at least it seems you are closer to one, that is, closer to pinpointing the frequencies and pitches where there is loss.[84] This is exactly why compliance after the NBHS as soon as possible is of paramount importance to clinicians. The key reason behind this is the importance put on intervention. All professionals agreed that intervention must begin at the earliest age possible. Sometimes there was no clear plan of what would come next, other than the assumption of additional testing and/or additional appointments. Sometimes the plan was projected far months into the future, into the realm of possible implantation. This created an expectation of future appointments, perpetuating the mother's relationship with the clinic (which the social worker at the center later emphasizes to be of utmost importance in 'working with the mothers').

In fifteen parent interviews with those whose child did go on to be implanted, every single one of them described the end of the ABR and the moment their child's hearing loss was first officially communicated to them. The most common characterization of this moment is devastation and grief (although Carol's account may be mitigated by her belief that she was

[84] Landsman (2009) found attempts to quantify a child's disability served to show the mother "precisely how much less of a child she has" (2009:63).

taking a risk by having a child at forty). Even though the meaning of deafness is contingent, it is an ontological state that most parents are absolutely devastated by. For example, when Jane told me about Lucy's diagnosis in an ABR with Sharon she said, "I went to pick up Lucy - and she was sedated - our eyes met and Sharon said, 'She's deaf'." She continues with describing it as "one of those flash moments with me in my life where I just I remember making eye contact with Sharon…I just fell apart. I remember the wave of grief." Becky, another mother, described when an audiologist diagnosed the child as deaf after an ABR, "They said that she was profoundly deaf in both ears, but I really didn't know at the time about CIs. I had no idea." Then she goes on to describe how the audiologists immediately proceeded to explain the process of implantation in full detail at the end of the ABR session:

> "Then, they explained everything…and they told us that the criteria was that Amy had to go through the hearing aid process first - which didn't do anything for her - they told us you have to go through these steps first to see if she qualifies. They gave us the number and the address and stuff for the implant surgeon. They really wanted us to see the surgeon."

***Constructing the future: the next step in the process***

Diagnosis is often a process itself, and not necessarily a one-time event. For some the deafness is established in the moment the ABR is finished, for others there are still tests to be done to confirm the level of hearing loss. In the ABRs, the reveal and the response to the condition are highly managed, and the ongoing and anticipatory emotional work facing the audiologists is complex and they thus involve the social worker, Sonya, for this purpose. Despite all the authority given to audiologists, they cannot make a diagnosis; they can only state that the testing indicates hearing loss. Audiologists are not physicians who can make an official diagnosis, and so leaving the ABR appointment is paired with the act of making a future appointment with Dr. Brown, the ENT doctor and CI surgeon at the clinic, who *can* make the

official diagnosis. Carol's story in particular illustrated that her initial response was the child was deaf, that was acceptable, and she would need to learn sign language. But, over time, the meaning system around deafness, in relation to implantation, was altered.

Explaining to parents that there is a path for them towards implantation, and a series of steps for them to participate in, essentially constructs implantation as a future-oriented, long-term process, as something 'to come.' In that moment, the devastation of the deafness may be mitigated by the idea that it is combat-able through future medical intervention; vanquishing it may be attainable if one proceeded through all the necessary steps. This is both rational and bureaucratic.[85] Temporality, as well as hope, emerges in these social relations; implantation is future-oriented from the start. [86]

***Support groups & Early Intervention***

After a profound hearing loss is identified, various clinical processes are set into motion and a series of actions required of parents. This may include follow up ENT appointments for diagnosis and etiology, follow up ABRs, or other additional audiology appointments. But as Carol's story illustrated, it also means Sonya becomes involved. The long-term commitment of medically managing deafness engages a multi-pronged clinical approach to shaping parent behaviors and tending to their emotional process. To achieve this, a more expansive set of anticipatory structures is utilized. This consists not just of using Sonya, but also of inter-institutional co-operations between the healthcare system, state agencies, local educational

[85] Strong (1979) writes how mothers in these situations are working within what he calls a bureaucratic format that is actually heavily laden with simultaneous character work. He suggests that a moral order is produced out of such bureaucratic relations.

[86] And this notion of time surfaces again and again in this dissertation. As Gentile (2011) writes, "Modernity organizes the culture through the belief that the future will automatically unfold as positive progress. As such, the promise of a future provides meaning for the present. This is a complex process" (2011:41).

institutions, local support groups, parent conferences and workshops provided by the clinic, CI companies, or their partner organizations.

Regardless of the etiology of the hearing loss, families with a child that has a hearing impairment qualify for EI services, which is facilitated by NBHS. In another layer of co-operation and coordination between state interests and the clinic, Sonya is not just the social worker at the clinic, but is also works as an EI 'service coordinator.' Sonya thus straddles both socializing parents into EI as well as the emotionally supporting parents through their grief process. In other words, there are two simultaneous pieces to the intervention phase that facilitate one another: emotional support and the socialization techniques.[87]

***Anticipating emotional needs***

The clinical staff discusses the ongoing need for and issues surrounding parent counseling on a daily basis. They often praised Sonya for her tremendous skills in being able to offer information and comfort to parents. I do not want to downplay the emotional context this research was taking place in; it is an important feature. Some parents in the throes of decision-making, especially those who had been trying a variety of interventions that did not seem to be working, actively did not want to talk to me. Their emotions were running high and they could not cope with speaking to one more person, especially one that was 'new to the scene.'

[87] Ingber et al (2010) found that "mothers who reported higher levels of motivation to be involved in their children's early intervention programs perceived that more informal social support was available to them" (2010:361). Furthermore, although parents of children with disabilities "have higher levels of anxiety about their children's future, perhaps their active involvement in early intervention programs and their support and guidance from professionals may decrease their levels of pessimism about their children's future…(2010:361). In fact, the more sources of informal support mothers reported, the more motivated they were to participate in EI. Furthermore, involvement in EI programs was highly influenced by "parental motivation to obtain training…in the case of children with hearing loss…parents with high motivation have been found to participate in their children's early intervention programs and to cooperate with professionals" (2010:363-4).

For example, one parent became terribly upset after I attempted to speak with her, which clinic staff did not appreciate. This conflict was not predicted; two members of the staff encouraged me to talk with her, thinking she would be open to the study. While she did not become upset in front of me, she later called the clinic to complain. At the same time, often parents that clinic staff thought would be uninterested, were actually the most willing to talk to me. It was difficult to know who would be able to talk about their experiences and who would not. I had to learn through trial and error; nevertheless some parents were simply to stressed out with worry and overwhelmed with following all the recommended steps of the audiologists, and keeping up with appointments. There was sometimes a fine line between collecting my data and respecting their limits.

To address parents' emotional needs, Sonya meets individually with them as soon as possible, as well as refers them to the parent support group at the center, or even elsewhere. Based on the type and degree of hearing loss, she will know whether to refer them to the CI group or the 'regular hearing impaired group.' The CI support group – started and run by Gretchen and Nancy - is important for fostering parent community. According to Sonya, at this stage, support groups are one of the most effective tools for both tending to parents' grief *and* ensuring their compliance regarding enrollment and socialization into EI.

All of the parents I interviewed – and many more whom I observed at support groups outside of the center - talked about how helpful parent support groups and/or organizations with parent resources (namely AGB, but also hearing loss organizations and local school programs) could be. The CI support group at the center was part of what Sonya referred to as their comprehensive approach and acknowledgment that implantation takes a long time. "It's comprehensive. What's happening with the whole person, what's happening emotionally? We've

had people who were depressed. This is not a quick fix." Sonya says. As will be shown below, these support groups have a cultural role:

> I've seen parents come full circle. In group therapy they say that when you're really comfortable and you're training the next newbie a year later, that you've made the full circle, you've come to terms with it because you're helping the next person…you've become enculturated.

***Support groups***

Gretchen, the speech pathologist who runs the support group, describes the parent group as 'heavier' than the others.[88] In the parent group, "people will express their personal feelings and their grief, and all their emotions, and that'll be a much deeper." The parents that come to that group are those that had audiological testing at the center and are at various points in the process. "Some of them are undergoing the core evaluation for early intervention. Some of them are having to make decisions about whether they want home-based or center-based therapy." Sonya speaks to many of them on the phone and will send Gretchen a list of those in need of support and who she should be on the look out for. All of the parents, Gretchen says, want to come to the center, but sometimes there are obstacles. The center staff keeps each other informed of the parents and where they are emotionally. "It's really hard, so some of them drop by the wayside, which is why Sonya always gives me their names." Sonya mentions those cases, those that are facing grief or are in danger of not returning, to everyone in the clinic. "She just gave me a name again this morning, somebody that Sharon just saw and diagnosed…and then recommended the parent group immediately."

[88] The center runs multiple groups. Sonya also speaks of the difference between the parent group and the adults with CIs group. "The parent groups becomes more therapeutic, it's small and they open up." The adult CI group, however, is more informational. "They're still a little cautious. They'll say a little bit here and there but they don't want to come for therapy." In contrast, she says, "The parent group is more therapeutic. People will cry, they'll be sad… I said to Gretchen, maybe we're doing a really good job when people *aren't* showing up to that."

Gretchen and Nancy, who those at the center refer to as the 'old timer', started this parent support group. According to Nancy, who's daughter Anne was implanted more than ten years ago, at the time the center "didn't provide what we needed and that's why we started the group…There was a lack of support. There wasn't enough information going around." In an effort to make it easier on people, Nancy and Gretchen started the group. This was a strategic move. Nancy tells me that Gretchen, as a professional, may not be able to tell parents "certain things." But, the great thing about a parent group is that, "As a parent, I can tell them anything. We'll be gentle about it. But there comes a point when you say look, getting the implant for your child is probably going to be the best thing you ever did and you know what if it doesn't work out, you still tried the best that was available."

Some of the parents in the group are coping with recent diagnosis, and others already at the stage of making the decision for the implant. They have already undergone diagnosis and EI and have moved into the next phase, which is candidacy. When I ask Nancy about this process, she says that parents do struggle, but only because they are "ignorant of the facts." The problem, as she sees it, is that "They assume that if you're deaf you have to sign. We give them the statistics. More people who are hard-of-hearing or deaf are oral[89] than are using sign." The response to this, Nancy says, is often surprise. "That's why I love bringing people to this!" Other parents, however, did not emphasize this part of their experience, telling me that the implant was something they were interested in from the start, although it the surgery was scary, it was not a choice they expressed doubting.

Once at the group, Gretchen tells me, "It also gives them the opportunity to tell their story." Many of the parents I interviewed attended this support group at one point, but they also

[89] That is, use spoken language, not sign language.

utilized other support groups and resources. For example, Carol joined Hear Us Long Island, which was closer to where she lives. "I met mothers there. I talked to them. I needed to go to something where I could meet parents." As for the support group at the center, she went much later, "You should be supportive [of other parents] and show up. So we try and go." Furthermore, the emotional support overlaps with information sharing. One time, Carol recalls, the group started talking about sports. "You find out how to keep that magnet on his head, if he's going to be playing sports." Parents also discuss the complicated educational system they must navigate. While Sonya provides them a lot of information on that as well, all the parents told me how beneficial it was to talk to other parents. Carol tells me, "It really is a kind of networking effect; that's the biggest thing…Me and these two other moms got to be friends. We formed our own little girls night out, which was, basically, you know, we've got to get together and talk about the kids."

*

It is a sunny, September afternoon when I arrive at Jane's while Lucy is at school; it is a good time for us to talk. When I get there she answers the door with pieces of electrical wiring and a light fixture in her hand. She is a little frantic, cleaning up as we walk to the living room. We sit down and I ask her how she is doing with everything; Lucy is supposed to have her implant surgery soon and, in anticipation of this, is transferring school programs. Due to her specific type of hearing loss, she did not qualify for an implant until quite late. In the next chapter, I spend some time on her story as to why. But at the moment, Jane is overwhelmed with everything involved in the process.

She talks about how she has is going to support groups and discusses her emotional pain. "I understand the process of grief," Jane tells me. She's an active support group member, having

made the full circle that Sonya spoke of. She tells me that "there's a shift and you won't even notice it and you'll find yourself being in support of others." I ask her why she or other parents were at the group. She says, "I wanted to know it was gonna be okay. And without me being there [at support groups now] and telling these parents it's gonna be okay….I make them comfortable, I tell them it's gonna be okay."

As we are talking, she begins to cry. "I haven't had this in awhile." She trails off. I ask her what she has not had in a while and she explains to me that the anxiety of Lucy's hearing loss has resulted in her having panic attacks and experiencing numbness in her fingers. I worry that I should find her a tissue and I look around, but she says, "I knew this [interview] was coming and I worked myself up a little bit. I tried to distract myself with the lighting fixtures, but it's necessary if it helps other parents…It's good, it's cathartic." She is sitting on the couch, hands folded in her lap. She looks down for a few moments, quiet. Then, she looks straight up at me, tears in her eyes, and says:

> It's okay, it's okay to say I have anxiety. Maybe if I speak up, maybe I'll give it a voice because you know parents are going through it, you know they are. Then maybe they can say it's okay to talk about it. Then maybe they can heal a little faster and they can be more beneficial to their children.

When I visited Becky at home one afternoon, we were having coffee and sitting in her living room, and she talked about how her daughter, Amy, responded when she got the implant a year or so before. She had been diagnosed at a year and half of age, and implanted at two years old. Becky told me how she would cry and cry and refuse to wear it. Becky felt "a lot of frustration and pain." Plus, there was a great deal of difference between her experience with the CI and what she saw on the company's promotional materials. She talked about the false "Hallmark moment" that circulated; how CI corporations would show the child when the implant is turned on and they turn and look at you at the sound of your voice. These videos are all over

YouTube as well; often marketed as "deaf child hears for the first time." For Becky – and many others – this felt like false representation, even manipulative, and at best woefully oversimplified. In the groups, Becky found out that other parents felt this way too. Other parents did not have that either, they would say, "Oh, I didn't have that and then you know, it's okay. You know."

Amy threw tantrums and had trouble adjusting to the feel of electrical current. This caused Becky to feel terribly guilty, and very much in need of some way to make it work. She went to support groups at the center, as well as at Amy's school. She described them as "absolutely helpful." Parents would say, "It's not just you," assuring her she was not alone; apparently many families dealt with this same situation. "The main thing that I got from other parents is one that we understand, we went through this. Try this, try that, or they'd say this is what we did when my son or daughter didn't want to really wear it." She also speaks of the camaraderie, "Let's help each other out. Let's be there for each other. Emotionally it helped me out a lot." The main reason, she says, was "because I wanted to know what to expect next."[90]

*

It was January and it was cold. This evening, I was going to a parent support group. When I walk in, I find that Nancy, the old timer, is greeting people. There are all kinds of publications sitting out, like Volta Voices published by AGB, and other materials from CI related conferences. When I arrive Nancy gives me a hug and welcomes me. I wait for things to start. As I wait, parents come in and stand around informally in a circle. Some are there alone, others

[90] Parents also spoke of utilizing online groups. One of the most popular listservs, with thousands of members, is the yahoo group called CI Circle. Other websites like mymagicfairy.com and cochlearimplantonline.com are also popular.

with their spouses. They timidly start introducing themselves. They immediately ask what degree of hearing loss their child has, if they are implanted, and where they go to school.

Once I sit down, I begin to realize there are also a lot of professionals here as well, especially those that identify as teachers of deaf.[91] The meeting goes for about two hours. One woman, referring to a young implanted girl she was working with, talked about when the child *was* deaf. She quickly corrected herself, saying that the child actually *is* deaf, but that she forgets because she functions as a hearing person would. She introduces herself, telling the parents whose child in the room she used to teach and offering to put them in touch, assuring them that the community is really small. "It's like a little universe," one woman says. One woman says how frustrating it is that people have a really good cultural idea of what Deaf culture means because of media coverage. But, she says, people don't know what it means to have a CI.[92]

Everyone asks each other about the degree of the child's hearing loss, if they have hearing aid or an implant. The couple sitting next to me talked at length about the emotional aspects related to dealing with a child with a hearing loss. The father said, "I don't want my child to be alone, that is my biggest fear. I would trade it in today saying I will be alone forever so she doesn't have to." The mother, with tears in her eyes, says, "My daughter is smart, she's interested in learning, she's a good student. And then she asks me why am I not like other people? Why am I not normal?" After the meeting is over, she turns to me and goes on to say that her daughter does not speak well, does everything on the computer, and has a lot of social

[91] Sometimes support groups hold informational nights, or bring in speakers. However, I will go into much greater detail on the educational professionals in Chapter Eight.

[92] This happened a few times in my fieldwork, where Deaf culture would be positioned as the dominant idea of deafness that they were all trying to combat. Many parents and professionals expressed frustration routinely that people would think deaf persons should learn sign language. This is one of the ways I felt Deaf culture was as a sort of implicated actor; it was something to be against, something to defy, something to differentiate from.

relationships though text and email. They both seem worried about the authenticity of such interactions.

But they are most worried about their daughter being alone – a particular type of 'imagination work' that people often engage in around people with disabilities in general - because of her hearing loss, and their emotional pain and fragility about this is clearly visible. Having a child with a hearing loss is hard; they were clearly trying to do the best they could. According to them, many professionals had reiterated over and over to them for years that she did not need sign language. Now they were questioning their choices. I saw how they doubted themselves and seemed lost.[93]

***Early Intervention: The therapeutic mode***

The support groups in the clinic, and other sites, as well as EI programs provided by the state provide a kind of infrastructure or web of support to assist parents in creating and navigating life as "the parent of a CI kid." I have shown how the clinic staff works together and with other parents to encourage parents' participation in support groups. Furthermore, the clinic is also closely connected to state agencies; from NBHS programs run by the state to EI services and both Margaret and Sonya are the conduits of such inter-institutional co-operations. Now I want to return to Sonya's role as EI service coordinator and show how the clinic works to involve parents in the on-going practices of EI. Since the emotional experience is so hard, as many of the parents alluded to above, Sonya emphasized how counseling goes hand-in-hand with the socialization techniques in EI programs:

[93] Here was another awkward ethnographic moment. My heart broke at the thought their daughter could be benefiting from sign language, but not be given that option by the educational professionals. I felt all I could do at that moment was listen. I did not know the details of the child, nor did I know the details of what they had been told; I did not want to assume anything, nor did I want to stake a political position in the middle of the support group. I felt extraordinarily conflicted; this was one of the many difficult moments in my fieldwork.

> We have people that it takes them five years. There's some people I've been phoning for five years and they keep calling me back...so you have to be, as Sharon says, tenacious. You have got to hold on…My theory is start with EI, have this nice therapist come to you house, it's very non-threatening. She's going to play with the baby, but she's really doing [spoken] language stimulation. So we get them in EI.

EI is not only about providing speech or various therapies for the infants enrolled, but it is a "parent-centered program." This includes parent training and the generation of routine parent progress reports. Parent training occurs when speech or occupational therapists go into the home to train the parents how to practice therapeutic tasks on a daily basis with their child. Sonya explains that they are training parents "in everything, in other words, you can't think that if you bring your child an hour a week for therapy that that's going to be the fix." Parents are given a chart with goals and daily exercises, such as testing their response to their name or their ability to localize sound. "So we're saying, you know, we need you to be an involved person. It is important to keep at this, you need to be on it."

EI programs incorporate methods of assessing auditory training done by parents at home by using progress reports. These reports are done quarterly to detail how the training plan is progressing. Specifically, Sonya tells me, the training plans and progress reports were developed as a way to "monitor what was happening in the home" and provide information about the child's progress as well as parent compliance with the plan. This monitoring yields information that is directly available to clinical staff. The social worker notes that because it is so parent-centered, "very often having kids in EI helps people to get the implant because they're in the therapeutic mode. They're connected to us."

According to Sonya, there is a correlation between parental level of involvement with programs like EI and the likelihood of parents staying engaged for the long term in the

implantation process.[94] As we have seen, clinicians cooperate together in socializing parents into their new social role as 'auditory trainers' (which will be discussed at length in the next chapter) and enforcing this 'therapeutic mode.' Sonya, in her dual role as employee of the center and often the EI coordinator explains the significance:

> They trust us. They're in the loop or they're out of the loop. They're in the waiting room, they're thinking about it. They come here for an EI meeting and they're in the waiting room and they see a kid who's implanted. Or they come to a parent [support] group and they weren't going to implant the kid and they see a parent who brings a child and "Oh! Look how good the kid is doing, can I have your phone number?" you know how things work in the world when people are looking for information…and that's exactly what happens in this culture.

***The emotional becomes cultural***

Throughout this process, there is a kind of centralization of the clinic, or what Sharon sometimes refers to as trying to be a 'one stop shop.' It is positioned as a hub of a culture – it is simultaneously therapeutic, and a site of enculturation:

> I think that that's the nature of groups. You can see the new person, but you have to give that person a year, two years. This takes time; this is not quick. This is *not* quick…But I think culture is what happens. I think there is [CI culture]. I've never seen articles with the word. I think it exists, but it hasn't been labeled yet.

Furthermore, as Sonya alluded to, this emotional work is cultural work. While anticipatory structures located in the clinic attempt to soothe parent anxiety, there is also a particular ideology infusing these efforts, which will be more specifically fleshed out in the following chapters. Furthermore, if parents do not participate, they may be labeled 'resistant' and these anticipatory structures are in place to reduce such resistance. As Sonya explains, "for whatever reason, a

[94] The success of implantation is widely thought to be predicated on long-term commitments from the parents. "Assessment of parental emotional and motivational states may assist professionals in better meeting families' concerns and priorities and determining the optimal intervention strategies for children and their families" (Inger et al 2010:353). Furthermore, efficacy of EI "has been of great concern to the medical profession and policy makers due to the advent of universal newborn hearing screening" (Yoshinaga-Itano 2003:252).

parent doesn't want to come back, I'll try to help them. Maybe it's a transportation problem, maybe it's an insurance problem, maybe they're just being resistant."[95]

***Summary***

There have been many studies of parent decision-making regarding implantation (Archbold et al. 2001, Christiansen and Leigh 2002, Bain et al 2004, Okubo, 2008). But what I found is that there is a large, complex system in place for guiding parents through the implantation process, there is not one moment of decision. CI surgery should not be seen as a result of a decision constructed in such a way, but rather of a subtle shift, over time, in parents' on-going behaviors. Sonya termed this the 'therapeutic mode' and, as we shall see in the next chapter, this has the effect of rendering the decision to go ahead with the CI surgery as a completely expected and natural next step for parents. Furthermore, the connections between staff, parents, and community grow into something much larger and sociologically relevant before, and as we shall see, also especially *after* implantation. Thus, the decision-making process had largely been studied in a framework that incorrectly positioned implant surgery as the endpoint. In reality, implant surgery is merely one moment in a larger, more complicated story. It is not at all an end-point, rather a crucial step in a long, emotional and transformative process that provides entry a new biocitizenry.

***Transformed subjects***

Biocitizenship may be a useful way to frame this process of enculturating parents into new ways of understanding their child's condition, which through further description of this

[95] EI services also address broader household needs, such as transportation, access to food, child care, additional medical services, etc. But importantly – and this appears in the next chapter as well – parents who decline services or approaches in EI are perceived as 'resistant,' and I found this judgment also prevalent in audiologists.

socialization in the next chapter, shows how it shapes both the ways they interact with their child and their sense of duty to carry out the activities that may lead to 'CI success.'

In the process, they are transformed subjects fueled by hope. Beginning here with incorporation into the clinical realm, parents begin to generate their own social relations and networks of experience-based knowledge. They embody this knowledge as social actors in a newly formed network of fellow biocitizens. As Rose writes, "we are seeing the emergence of an innovative new ethics of biological citizenship…our somatic, corporeal, neurochemical individuality now becomes a field of choice, prudence, and responsibility." (Rose 2007:40) Furthermore the data demonstrates his assertion that:

> The maintenance and promotion of personal, childhood, and familial health – regimen, personal hygiene, healthy child-rearing, the identification and treatment of illness – are central to forms of self-management that authorities seek to inculcate into citizens and hence appeal to their own hopes, fears, and anxieties. (Rose 22:3)

Parents' hope, visions of the future, and the pressures to cultivate a 'good citizen' (e.g. one that speaks, hears and works) become bound up in the CI's potential of being successful at some point in the future. That is, implant success – often defined as the acquisition of spoken language, though not always – is not instantaneously achieved (it is not a 'quick fix' as Sonya put it), but rather characterized by long-term rehabilitative commitment based on assumption that it will 'pay off'. The possible narrative of "the superstar patient," as the CI surgeon explained to me, looms over parents as a challenge.

What I have begun to show here is how each stage of the implantation process is complex and situated within a larger medical context, namely the institution the center is housed in. This is not unique to implantation, but characteristic of medicine more broadly. While no one parent moves through the stages in exactly the same way, there are generalizable patterns to be found in the clinical interactions, protocols and structures engaged in by staff. Here, I tried to convey this,

as well as attend to the emotional context for parents in which identification happens and intervention begins and will resume that discussion below. But first, there is anticipation work being done by the professionals via social techniques and use of institutional embedded resources confirms that there has been a host of institutional changes as a result of newborn screening.

In their study, Timmermans and Buchbinder (2011) conclude that the expansion of newborn screening (for a variety of conditions) detects *and* creates diseases and conditions. They argue that "Ontological and epistemological changes in diseases may occur gradually or be provoked by technological innovations…or, as we argue here, the introduction of population-based screening programs" (2011). Changes in technology, they argue, are not enough to create 'new realities' for conditions; technological changes producing new disease categories need to be operationalized in clinics in a way that links patients to treatments. They conceptualize this process as 'bridging work,' since clinic staff must adapt to the newly produced disease categories.

> Generally, bridging work refers to the many activities required to reconcile the promise of technologies with the realities of their implementation. The introduction of new technologies affects a workplace at multiple levels, including the incorporation of technology into available health services, the divisions of labor between medical subspecialties and, importantly, the lives of beneficiaries and others affected directed and indirectly by the technology (2011).

They focus on the clinical work done to incorporate the circulation of new knowledge of a condition into clinical routines and regimens. The impact of working to include the "ontological transformation of diseases following the introduction of technologies" (2011) is lessened through strategies of integration for clinical staff. For example, at the onset of a failed or anomalous screening, staff are interested in "buffering unanticipated consequences produced by the

implementation of new technologies" (2011) with new work routines. Furthermore, these efforts become "integrated not only into the clinic's workflow but also into state policy" (2011).

Similar to my findings, the screeners responded to the detection of hearing loss with recommending more precise testing shortly thereafter, with the proceeding events doled out to various professionals with particular roles: the audiologist conducing the ABRs and the social worker providing emotional support and information. "Bridging work, then, consists of continuously working out unexpected results in the clinic, as they emerge in real time" (Timmermans and Buchbinder 2011).

While they are describing similar concerted efforts, I take this description beyond the 'real time' negotiations of clinic staff and workflow, and examine the temporal aspects embedded in the discourse of these efforts. Without certain technologies, deafness is not a condition that one can *see* necessarily in a newborn or infant. In the past, stories abounded of children not being identified for maybe even the first few years of their life. As Lane, Hoffmeister and Bahan (1996) tell it, it was usually the mother's sense that something was amiss that led to the diagnosis, but mothers were not always readily believed by the doctor, nor were they able to 'confirm their suspicions.' Over the first year of a child's life, perhaps, mothers " may successfully and enjoyably play patty-cake with their child, yet notice that the child does not respond when urged to sing along" (1996:32).

There are countless stories of mothers of deaf children who repeatedly asked if something was wrong with their child, but were dismissed or turned away by a doctor, or maybe even mistakenly told their child was developmentally disabled or, in pre-newborn screening times, mentally retarded. Perhaps months passed and "after repeated cycles of suspicion that a problem

exists, rejection of the suspicion, and its re-emergence," (Lane et al 1996:33) then the child is taken for hearing testing.

This story is less common today; newborn screening now both detects and produces infant deafness. In the past, the diagnosis was retroactive, a lens through which parents could make sense of the past, making sense of what had *already been happening*. The technological changes restructuring workflow reconstructs intervention as constantly preventative and an ongoing future-oriented enterprise, hence my decision to label these anticipatory structures. I found this by moving beyond seeing the body as merely 'constructed' as having a disability and examining parents' responses to the ontological fact of their child's deafness opens up analysis to the emotional.

And this is exactly where temporal aspects of intervention most powerfully emerge. Divisions of labor and the workflow in the clinic actively anticipate and respond to the emotions of parents, building upon the important known link between emotional and informational support and the increasing efficacy and involvement in EI (Desjardin 2005). Simultaneously, the future-oriented quality of the rhetoric and discourse is continually reproduced across stages of implantation. All of this creates 'new realities' and in the next chapter, I turn to a description of ongoing intervention efforts and the work required of parents leading up to and through the next two stages: candidacy and surgery.

## Chapter 6: Accepting Reality/Cultivating Compliance: Class and Candidacy

*For middle-class mothers, the boundaries between home and institutions are fluid; mothers cross back and forth, mediating their children's lives. –Annette Lareau*

In this chapter, I describe professionals' experiences, strategies and goals with regard to maintaining parents' compliance in audiological recommendations and EI service plans as they proceed to CI candidacy and surgery. I also examine how parents understood and experienced the tasks before them, and integrated these practices into their lives. I locate this within larger structures, like social class and institutions such as family, social services, and the clinic, and co-operations occuring across them. Recall in the previous chapter, Sonya, the clinic's social worker, described parents' process of being socialized into EI and implantation as entering into a 'therapeutic mode.' As a child moves further along in the initial intervention stage, to candidacy and to surgery, the characteristics of this therapeutic mode emerge, as does a picture of how it operates at an intersection of multiple dynamics. These dynamics include the effects of social class on intervention, the imagination work parents and professionals engage in of predicting what life with a disability looks like, and anxiety about the future.

### *Demographics of CI candidates and recipients*

In the US, there are potentially 72,000 to 145,000 deaf children who were or will be candidates for implants. According to the American Academy of Audiology, it is expected that "25,000 more be implanted by the end of the present decade, with the most rapid growth of the population receiving implants occurring among twelve-month-olds" (Belzner & Seal 2009:312). But, there is "no comprehensive data on the racial breakdown of implanted children" (Belzner & Seal 312). Even during fieldwork when I attempted to aggregate data on implantees, according to

race, class and gender, Sharon, the director of the center, indicated that such data did not exist.[96] In one study of implanted children under the age of eighteen, however, Stern et al (2005) revealed "a higher proportion of White and Asian/Pacific Islander children and a disproportionately low number of Black and Hispanic children receiving implants" (Stern et al 2005). They also reported that white children were implanted at a rate three times higher than Hispanic children and ten times higher than black children. "Very limited attention has been given to race and ethnicity, socioeconomic status, and co-morbid conditions" (Belzner & Seal 2009:313), but rather, there has been "far more attention on the communication modality over the years," namely whether children use sign or speech" (313).[97] The overemphasis on communication outcomes, however, has not resulted better outcomes. So far studies only show that outcomes are mixed and highly variable. Additionally, far less is known of the "influential dynamic of socioeconomic status…but [studies] are suggesting that SES is important in outcomes variability and measures" (Belzner & Seal 2009:311).

Studies of implanted children in the United Kingdom, however, "showed that the higher the SES, the more likely the implanted child used spoken language" (2009:330). Meanwhile in a survey study of audiologists in the US that specialize in pediatric implantation, Kirkham et al (2009) found that audiologists overwhelmingly "perceived an effect of SES on post-implant speech and language outcomes" (2009). In qualitative responses, audiologists "uniformly demonstrated…that lower SES patient populations were more likely to experience reduced speech and language outcomes" (Kirkham et al 2009). They gave two primary reasons to support

[96] In subsequent inquiries to Cochlear Americas, I was also told that this data was not available.
[97] But this data too is not comprehensive and is largely made of up correlates; the younger the child is implanted the more likely they develop speech. But there are no established predictors. According to Belzner & Seal (2009), there are no comprehensive studies on overall language outcomes in every single CI recipient.

their perception: 1) parental "shortcomings," such as parental self-efficacy and adherence to recommended interventions, and 2) other external factors such as a lack of resources or access to therapies (Kirkham et al 2009).[98] But, the patterns emerging from my data indicate that judgments about adherence, especially as it relates to parenting styles, were the most significant predictor of candidacy and contributed to an overall assessment of parents as "accepting reality" or "being in denial."

***Parenting style and compliance***

Based on data available, it may be a fair assumption that white children from higher SES backgrounds who are approximately twelve months of age are most likely being implanted at the highest rate. Conversely, EI demographics (across all disabilities) indicate exactly the opposite. "There is an "overrepresentation of low-income children among EI recipients" (NEILS Report 2007:2-6). I would like to draw attention to the perceived lowered likelihood of implant success – and therefore decreased chances of being deemed a 'candidate' - that audiologists associated with lower SES backgrounds, particularly as it relates to judgments of 'parental shortcoming.' This is no surprise: "Increased knowledge, without increased responsibility on the part of the society, translates to increased knowledge with inevitable responsibility on the part of mothers" (Rothman 1993:xii). And while I cannot present data on what happens to those parents and patients who do not get the CI and maintain ongoing ties to the clinic, I can show what it looks like *when they do.*

While there is a lack of hard data about the impact of SES on implantation, it is well established that participation in EI services is associated with higher rates of implantation and

[98] Kirkham et al, however, conclude that audiologists have identified an SES-related disparity, and suggest "a broad and culturally sensitive effort to both increase access to qualified healthcare professionals and develop approaches that will aid parents in the at-home habilitation process" (2009).

better outcomes (Niparko et al 2009). In my study sample of parents and professionals, the participants were overwhelmingly white and middle-class.[99] Furthermore, more than ninety percent of EI providers are white, female, monolingual (in English), and have an advanced degree (NEILS 2007). All of the parents in my study were recommended to me as participants precisely because the audiologists deemed them as compliant: they were perceived to have consistently integrated recommendations of the clinic and EI therapists as they readied their child for implantation. In short, they practiced particular methods of intervention from outside institutions, namely the clinic and social service agencies, in the home.

***Intervention and concerted cultivation***

One of the most useful tools for understanding this phenomenon may be located outside of medicine in Lareau's (2003) observations of middle-class families showing they were more apt to integrate recommendations form institutions into their parenting style. In her study of the ways parents' social class shapes the life experiences of their children, Lareau found that middle-class parents see themselves as 'developing' their children and engage in what she calls 'concerted cultivation,' while black and working/lower class parents participated in what she termed 'accomplishment of natural growth approach.' Concerted cultivation is a style of parenting where parents "actively fostered and assessed their children's talents, opinions, and skills" (Lareau 2003:238), especially through organized activities. In the accomplishment of natural growth approach, parents "viewed children's development as unfolding spontaneously, as long as they were provided with comfort, food, shelter, and other basic support" (Lareau 2003:238).

[99] The minimum income of families in my study was sixty thousand dollars a year.

Lareau emphasizes how these parenting styles correlated with attitudes towards institutions; in white and/or middle class homes, there was more of a "seamless overlap" between institutions and the home. Yet all families must "interact with central institutions in the society….which firmly and decisively promote strategies of concerted cultivation in child rearing" (Lareau 2003:3). As a result, "families that do not adopt a concerted cultivation approach tend to feel a sense of distance from such institutional experiences" (2003:4). How might this be impacting parents' response to integrating implantation practices? That class and parenting is more than just a measurement of access to resources, but also about value systems, may explain why my sample was overwhelmingly white and middle-class. Seeing it this way offers a more complex sociological picture that sharply contrasts with audiologists' assumptions that those who did not opt for implantation were simply not "accepting reality."

***Home interventions***

Once EI enrollment is initiated, mothers may utilize an assortment of services and therapies available. For example, they may enroll in infant/toddler programs at local schools with specialized education programs, have home-based or center-based therapies, and begin the long process of multiple audiological appointments in order to work through the required steps to CI candidacy and surgery. These steps include two main aspects: 1) implementing EI recommendations at home, and 2) putting hearing aids on the child. As Sonya emphasized, EI services are administered in a parent-centered style, which emphasize parents as a performer of 'auditory training.' Meanwhile, the audiologists recommend hearing aids to facilitate auditory training by providing amplification.

I did not have the opportunity to observe home EI services, nor did I conduct home studies that were nearly as detailed as Lareau's. However, in interviews parents where described

their experiences with EI, they were highly favorable.[100] EI services are founded upon the philosophy that deaf children should receive speech therapy and auditory training. This comes from a particular ontological understanding of deafness as medical, that is, as an auditory processing disorder that can be mitigated through auditory/verbal therapies in combination with hearing aids and/or CIs. The goal is, through a therapist, to train parents to intervene in a therapeutic way on their own. To illustrate, let me take the example of Strivright-The Auditory Oral School of New York. I chose Strivright because they contract with the New York State (NYS) EI Program (EIP), Sonya at times coordinated provision of home services through them, and many of the parents in my study worked with Strivright's therapists in their home.[101]

***Therapy now, opportunity later***

Speech therapy and auditory training regimens are represented in particular ways, namely by addressing the future of the child right away, emphasizing that if parents use these therapies, their children will not be hindered by their deafness in the future. Strivright's philosophy is "aimed at enabling our students to go on to live absolutely unlimited, successful lives with all social opportunities, academic choices, and career options open before them" (oraldeafed.org). Secondly, they devalue sign language. Their philosophy, "focuses on teaching children to speak and hear, not relying upon compensatory skills such as sign language or lip reading" (oraldeafed.org). In other words, 1) they claim the child will be able to speak, hear and use spoken language in the future, and 2) visual methods of communication, like sign language, are

[100] Again, these are parents for whom the CI was 'successful.' Thus favorable recollection is to be expected.

[101] According to their website, they utilize auditory training approaches and therapies and "continue to make miracles happen every day" (oraldeafed.org). I could spend much time analyzing the rhetoric of their representations of EI, but I will focus here mostly on how it preys on highly normative future visions of what it means to be 'successful;' i.e.: speaking, working, 'overcoming' a disability. But conjuring up visions of 'the future' is a strategy also used by the clinics and marketing companies.

'compensatory,' and therefore not in and of themselves whole. If these two tenets are abided by, it is assumed that the child shall have 'all social opportunities" open to him/her.

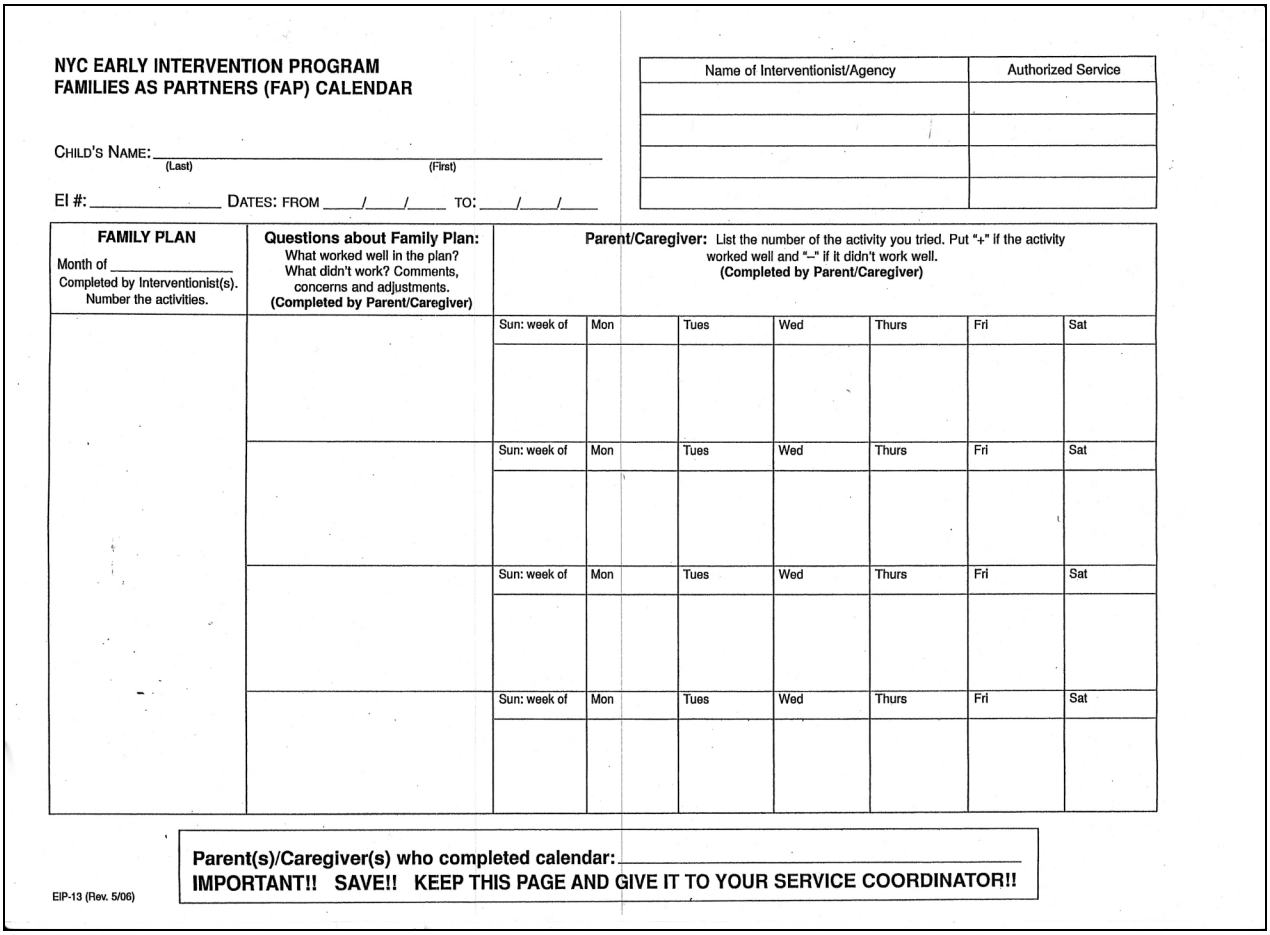
According to the National EI Longitudinal Study (NEILS), in-home speech therapy is the most common form of therapy found in the NYS EIP (2007:2-6). For children with a hearing loss, this means their Individualized Family Service Plan (IFSP) will focus primarily on speech therapy and having parents work with their child to develop auditory skills. The IFSPs that parents fill out and give back to their EI service coordinator, which is often Sonya, provide the clinic with information to monitor the progress being made at home.[102]

It is well known in studies of EI protocols that higher levels of parent-child interaction and participation in EI correlate with greater rates of improvement in expression and comprehension of spoken language with pediatric implant recipients (Niparko et al 2010). And although at this point the child has not been implanted yet, audiologists see parent participation in intervention practices specified in their IFSPs as a predictor of future CI candidacy and success. In addition to showing how parenting style may be an important factor to consider, I want to pay careful attention here to how both the parents and professionals invoke and depend on 'the future,' as well as the budding conceptualization of deafness as a neurological problem.

Every parent I interviewed talked about the role the EI therapist had in the home, as well as how they came to depend upon her as a source of information and comfort. Becky raved about her therapist who worked with Amy at home "for years." "She was phenomenal and she also had worked with a lot of implanted children and she had mentioned [Amy's school]." Ultimately, the EI therapist's recommendation ended up leading to Amy's educational placement once she reached school age. "I gave them a call, I went down there and they were phenomenal. They

[102] IFSP activities may include things like eye tracking behaviors and sound localization, and speech production patterns.

were a wealth of information." This was not unique; all of the other parents relayed a similar story.



**NYC EARLY INTERVENTION PROGRAM**
**FAMILIES AS PARTNERS (FAP) CALENDAR**

| Name of Interventionist/Agency | Authorized Service |
|---|---|
| | |
| | |
| | |
| | |

CHILD'S NAME: _____ (Last) (First)

EI #: _____ DATES: FROM ____/____/____ TO: ____/____/____

| **FAMILY PLAN** Month of _____ Completed by Interventionist(s). Number the activities. | **Questions about Family Plan:** What worked well in the plan? What didn't work? Comments, concerns and adjustments. **(Completed by Parent/Caregiver)** | **Parent/Caregiver:** List the number of the activity you tried. Put "+" if the activity worked well and "–" if it didn't work well. **(Completed by Parent/Caregiver)** | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | Sun: week of | Mon | Tues | Wed | Thurs | Fri | Sat |
| | | | | | | | | |
| | | Sun: week of | Mon | Tues | Wed | Thurs | Fri | Sat |
| | | | | | | | | |
| | | Sun: week of | Mon | Tues | Wed | Thurs | Fri | Sat |
| | | | | | | | | |
| | | Sun: week of | Mon | Tues | Wed | Thurs | Fri | Sat |
| | | | | | | | | |

**Parent(s)/Caregiver(s) who completed calendar:** _____
**IMPORTANT!! SAVE!! KEEP THIS PAGE AND GIVE IT TO YOUR SERVICE COORDINATOR!!**

EIP-13 (Rev. 5/06)

**Figure 2: Sample Early Intervention Individual Family Service Plan**

### *Julia and Paul, and their son Morgan*

I first met Morgan early on in my fieldwork at the clinic. He was implanted at two and a half. When I initially met him at age four, I was struck by how well he 'passed' as a hearing child; if I had not known he had a CI, I would have assumed he was born hearing. In late August, I went to his home and spoke to his parents about his EI services. This was the first and only interview I had where both parents were present. As we take a seat in the living room, Julia

begins by telling me how wonderful their EI therapist was. "She was really good as far as training…Telling us what we needed to do." Paul adds, "Yes, her name was Marianne. I still have her number in my cell phone because there's still so many people in my parish that say my kid is delayed, do you know anybody? I'm like yes! I'll scroll down and, you know, I'll always use her. I'll always recommend her no matter what. Marianne was fantastic, still is fantastic."

Julia nods in agreement while Paul continues. "Marianne came when he was three months old and started working with him. Then we also went to the deaf school at three months old." They both go on to tell me how much work it involved, the high number of phone calls and time spent on doing research. But Marianne was a key source of information for them. "She told us about [deaf school program]. She actually gave us names of other parents who were fine with her giving their names out. We spoke to them," Julia added. And upon her recommendations, Morgan was enrolled in the infant/toddler program. "It all went very quickly."

Julia had also tried to go to support groups, but she found all the parents to be speaking a lot of medical lingo she did not understand yet. "What type of hearing loss it is, and what type of genetics it was. When they were saying Connexin 26[103] and we haven't even done our genetic testing yet. We didn't know what they were talking about. We just felt like between the speech therapist and [the school], they were educating us so let's just stick with this for now."

But they both attended workshops at the center. Paul goes on to explain that, "Before we had the surgery, those different workshops that we went to really helped us to understand." Meanwhile, the center had helped Julia get all of the EI services in place and Marianne, the in-home speech therapist, was coming to the house twice a week "to be with Morgan" and to go

[103] Connexin 26 is the name of the gene associated with hereditary hearing loss.

over all the information. “Then fast forward right to his cochlear implants and he has continued on from three months old right through now at [the deaf school].”

Marianne “worked with him before he could even hear just to build the patterns.” Julia reaches over the couch and picks up a stuffed animal. She starts to squeeze it, making it squeak.

> If I do this [squeezes the animal], I’m looking for you [points to me] to look here [points to the stuffed animal]. I’m showing you a stuffed animal and I’m squeaking it, and even though you can’t hear it, because I want you to [hear] - once you can hear - relate that there’s a sound. I know what that is, it’s like building a total teaching method. And I just thought that was phenomenal how – I don’t know, as a teacher I wonder if I would be able to suspend that ‘well he can’t hear me anyway’ kind of thing. But they worked just as hard with him.

The way that Julia understood it was that they had to ‘build patterns’ of looking. She would often mime being able to hear something. She shows me what Marianne might do, like holding out an object that is making noise, then taking it away. “Then she would be like ‘I hear it’ and he couldn’t hear it, but then she’d bring it back.” I ask her, “So, they are teaching him how to hear when that time comes?” She nods her head, “Right. Like the visual that will eventually go with the oral.”

What Julia is describing raises some interesting ontological and neuroscientific questions. The body is no longer static and immutable, and technologies facilitate our acting upon it. Here, and in the following chapter, it is the brain that is the focused site of malleability. If Morgan is being taught to ‘simulate’ hearing behaviors, would his brain look like and be molded into one that looks like a ‘hearing’ brain? This is more than just a neuroscientific question but, as I will argue in the following chapter, also a feminist one and an ethical one.

Paul leans forward and begins to tell me his routine of accompanying Morgan to the deaf school program on Monday mornings. “I remember going to [the school] at nine in the morning and being there until eleven. Because, see, it’s not just them doing it; it’s also teaching the

parent that this is what you do." And then begins to comment on what these therapy sessions were like as well, but mostly he talks about he was always the only father in the group. "I'm not like a mushy gushy kind of person. When I'm surrounded by women…women acting all mushy, gushy, I have a hard time with that. I openly admit that, I do. I have a hard time…I didn't want to be mushy gushy. I couldn't do it. So after awhile they said 'Oh you have to do this, dad." Julia starts laughing and they talk about how he would come home after these sessions and Julia would ask him how it was. " I said it was so horrible. I had to do this stupid song about the teddy bear."

Paul recounted all of the women's names, marveling at how supportive the in-home as well as center-based EI therapists were of parents. He especially remembered one woman, Kate, was particularly enthusiastic. "She'd run down to the cafeteria and she'd run back. 'Here's coffee with milk. Please drink this. You've got to stay with me. I know you're exhausted.'" In that program, he spent time with both a speech therapist and a 'teacher of the deaf.' Julia pipes in, saying to Paul that all of the professionals were "good at pushing us, like they did with you and the coffee, to push you beyond your comfort level. [Julia turns to me] It's not about your comfort, it's about what he needs."

At this point, they begin to act out the ways in which they were taught to 'work with' Morgan as part of the therapy, which would eventually train him for auditory cues. Julia starts by saying, "Everything was an opportunity - like I hear a knock at the door. Knock, knock, knock! Do you hear it? [She cups her hand behind her ear.] It's all animated, you know? Getting them excited. I hear the phone ringing! Did you hear the phone ring? [Again, her hand goes behind her ear] Let's go see! [She waves her arm] Someone called on the phone! If someone called on the intercom, it was like I hear that! Do you hear that? But it was all really dramatic."

While Julia, Paul, and Morgan were participating in EI and undergoing all of the medical and audiological work ups to prepare for candidacy, Paul also attended an informational workshop held at the CI center. Cochlear Americas also hires "Cochlear Representatives," who make appearances at workshops at clinics. Some of their representatives are implantees who, in their ability to speak and listen and show they are gainfully employed and 'functioning' in the hearing world, provide a glimpse of an idealized future for the parents. Julia and Paul, when attending one of the workshops or informational sessions at the center prior to the surgery met one of them. As Paul tells it, "Both of us met a guy who was 36 years old and he was a Cochlear representative, and he himself had cochlear implant." He was at the workshop and this was also the same day that Julia and Paul met Dr. Brown, who was Morgan's surgeon.

> I said oh, I've got to hear this. This is good. He got up there and he spoke and everything. He was on hundred percent for cochlear. Wow. I spoke to him for a few minutes and then I basically took all my time and gave it to Dr. Brown because I just thought Dr. Brown was very easy to talk to. I was blown away. He's doing just fine and he's talking and he's doing great! His speech was fine. That made me feel really good to see that.

Morgan was implanted two years before our interview. Paul goes on to tell me how he struggled throughout the whole process, but looks back on the time with EI now. "I mean God might look at me and say hey, yeah alright so he was born with no hearing. However, I supplied the right doctor for the job, the right people to help him with his speech, the right people to help him out with this, that, and his schooling." In Paul's eyes, the work of the people involved, and the help of God are what have made his son able to use speech. Julia adds, "We have every reason to believe that he'll be intelligent, independent, and high functioning."

***"It wasn't therapy for him. It was therapy for us."***

"With Sonya, you've got to get all this therapy and everybody has to be approached…social services, EI. Sonya took care of all of that; she would setup every meeting

and she's super organized." According to Carol, Sonya helped make the process of instituting EI smooth, although dealing with the agencies that contract with the NYS EIP, like Strivright, was a little more difficult. She also helped Carol get EI services through Strivright to work with Jeremy. "We looked to Strivright; Sonya said you can get speech therapy in the home or where he goes to daycare, but we looked to get it in the home." They were, however, interested in having his services at a daycare; they wanted Jeremy to be able to receive services while socializing with other children. But, "It was hard because deafness has a lot of other problems. For example, if somebody's bothering him, he can't tell them to go away. So you get some other behavioral problems."[104] Plus, she explained, even though there is a variety of agencies that contract with EI, they do restrict where they will go. She remembers how Strivright "in order to get you as the client, they say, 'we'll go here, we'll go there, we've got people. Yes, do us.'" But, once you do sign on, they told her, "You're signed up as a Strive Right client. Now, let's get you the therapist. No, I'm not going to [daycare]. I can't do Tuesdays. Blah, blah, blah."

But, she says, it's complicated. "These are all independent contractors, and I can't blame them." Even though EI had approved therapy in daycare, it never happened. Once they tried to come to the home, she says, she was very unhappy with the scheduling difficulties. Ultimately, in contrast to the other parents in my study, she chose to go to the center and work with Gretchen, the speech pathologist who also ran the support group. Although EI ended up not being at home, she still felt satisfied with the experience. She also maintained strong ties to the center through frequent visits.

[104] Parents' willingness to forego giving deaf children access to immediate language expression through signs (thus possibly eliminating 'behavioral problems') seemed to increase as time goes on and commitment to implantation (which often excludes sign language) is cultivated by professionals. This is highly problematic and will be discussed at length in the following chapter.

> Honestly, the therapy for him when he was a toddler, it wasn't therapy for him. It was therapy for us. We watched them play with Jeremy so we could learn to play. And, in fact, what I wound up doing is my mother would come. My mother would come with me on Fridays to go see Gretchen. And that was one of the best things I ever did, because my in-laws, as much as they love Jeremy, he's just their world…they were devastated by the fact that he was deaf, which, actually, really angered me. But, you know, him being defective really bothered them. They couldn't get over it…They were convinced that he was not going to be able to get job when he grew up…Making them go to [Jeremy's] therapy too was the best thing I ever did, because they drank the Kool-Aid.

Clearly, Carol and her family worried about the future, but experienced relief through the utilization of EI services. Sonya alluded to this process as well; she talked about how through experiencing speech therapy with EI service providers, parents become more accustomed to the 'therapeutic mode' and settled down emotionally. But Carol also seems to see it with a degree of objectivity, understanding it as the "Kool Aid." She also was deeply reflective of her class privilege and cultural capital:

> You know, you have to do your homework and you have to do a certain amount of work...And I'm an academic. I have time to get on the phone and put my phone on hold and wait, wait, wait, wait. I cannot imagine what somebody who doesn't have their own private office, who's working, doesn't have time. I don't know how you do it. … I'm sure if you dealt with any insurance stuff, you know, you've got to get to the point pretty quickly where you know your system better than they know their system. I mean, I got that that point pretty quickly, so I could be on the phone and say, 'No, actually, I don't need pre-approval for that, and this is you've got to give me the MPT code.'

What I found with her, and many of the other parents, was a willingness to have what Lareau called 'seamless overlap' between EI, the clinic, and home. But I also found a degree of discontent with some of the established rules of intervention, especially when it came to strict restrictions on sign.[105] Nevertheless, EI and audiological recommendations are generally overlaid into family life patterns such that the children have activities that may not be, enacted through organized sports or activities like Lareau's middle-class families, but rather *organized therapy.*

[105] Many of the parents in my study actively 'broke the rules' when it came to sign, which I will discuss in the next chapter.

Similarly, I found that even though the efforts associated with intervention and concerted cultivation were difficult and exhausting, it did not seem to lessen its appeal (Lareau 2003).

***Hearing aids***

While parents undergo EI, they are also told to intervene audiologically, specifically by providing and monitoring response to hearing aids. While a child is receiving speech and language therapy, s/he is recommended to be wearing hearing aids. In fact, CIs are not considered a first line treatment for deafness; Dr. Brown, the surgeon, reminded me one day that, "a hearing aid is first line treatment." With all the talk of implantation and often parents being introduced to the idea of CIs on the same day their child is diagnosed, most of the parents in my study regarded the hearing aids as a 'hoop' to jump through for insurance companies in order to qualify for the implant.[106]

The measured benefit from hearing aids is one of the factors used in determining if a child is a CI candidate. Dr. Brown emphasizes that you must first see "if they're getting inadequate benefit from a hearing aid and how you define inadequate benefit really depends on the age of the patient." So, as parents move along in the intervention phase towards candidacy for the implant, the adequacy of hearing aids is being evaluated, along with their performance as auditory trainers and overall participants in the therapeutic mode. Even within the category of pediatric implantation, the age range – from newborn to later in infancy to even five years of age – there will be differences in how to proceed. "If it's an infant, say they aren't making any response to sound…or they're not beginning to verbalize. You look at whether they're babbling.

[106] Parameters for CI candidacy are evolving, but most insurance companies require not just a certain degree and type of hearing loss, but also documentation that hearing aids were insufficient.

If they're a pretty young infant or an older child, are they developing any language skills at all?"[107]

***Transitioning to Candidacy***

Most prior studies of implantation focus on the decision-making around surgery, rather than on the months or years that lead to implantation and the months and years of therapies that follow. Before I began fieldwork, even my goal was to observe *the* decision. I thought that I might witness *the moment.*[108] But this expectation was clearly not based on what implantation turns out to be: a very long process in which the implantation surgery was one mere step in a much larger story, normalizing surgery into just another step in the process. Blume (2010) also found there to be what he called a "blandness" in decision-making about CIs, writing it is "more or less automatic for most parents of deaf children in rich western countries" (2010:171).

The parents I interviewed reported that they were anxious to proceed to candidacy; they wanted the time span between intervention and surgery to be as short as possible. Many parents understand from the moment of diagnosis in the ABR, that getting the implant should be the goal. And the social technologies put into place, as I have shown, often prevent the possibility of making a healthy deaf child outside of the medical gaze (Rothman 1993). As I move into describing candidacy, I want to make two important points. Firstly, time and 'the future' of the child are increasingly invoked, causing parents may become increasingly anxious and raising the extent to which the CI is seen as an artifact of hope. Secondly, while parents are going through

[107] Regardless of the fact that each stage of infancy may have slightly different parameters, all parents and audiologists use *lack* of efficacy of hearing aids and to determine whether or not a child is a CI candidate. The result: candidacy is predicated on a *lack of language*. Essentially, deaf children are watched to see if they can acquire spoken language without being able to hear. I shall take up the ethics and politics of this in the next chapter.

[108] Besides, social science research on decision-making in implantation had already been done through surveys and in-depth interviews (Christiansen & Leigh 2002). Almost all the studies focus on the events leading up to implant surgery, such as referral, access and decision-making.

this, the audiologists and other clinical professionals assess their compliance, which influences their determination of candidacy.

*New notions of time*

Technology and society reciprocate and constitute one another, including recasting the meanings we associate with time. As I noted in the previous chapter, the promises and imaginations of the future cast meaning onto the present (Gentile 2011). One difference in the age of implantation is that in the past parents were "not led to an overview of the life-trajectory that is probable for their [deaf] child…[nor] led to imagine possible futures" (Lane and Bahan 1989:36). Today, parents are led to believe what their child's future is and encouraged to imagine it. Consider Strivright's claim of the unhindered or "absolutely unlimited" future of the child who receives intervention. This future, however, must be created in the present time, which is constructed as pressing as parents are told the earlier the better.

This of course makes the experience of time before implantation fraught for parents. Some parents want the CI as soon as possible and see everything before that as "wasted time" without language. Some, like Jane, even began having panic attacks and experiencing other psychosomatic indicators of anxiety. There are certainly those who do struggle and are more hesitant and worried about commencing with surgery.[109] But generally, time prior to being implanted is wasted and the child's access to the world understood as partial. Consider Jane:

> What worried me the most is Lucy is a late implant[110] and her speech is gonna be…I just keep seeing all these one year olds [with implants] and that was the big deal when I saw

[109] The parents who struggled with the decision were most vocal about *not* wanting to talk to me. The audiologists surmised they were simply to stressed out with worry, the hoops they had to get through in order to follow all the recommended steps of the audiologists, the testing that had to be done, the appointment books to keep, and so on

[110] Lucy, unlike most of the other children of the parents in my study, which averaged less than two years of age, was not implanted until she four years old. There was some difficulty diagnosing Lucy due to the type of hearing loss she had. This prevented approval from the

> Dr. Brown the last time we saw her before surgery. I said, look every time I come into your office my heart breaks. I see these little kids that are barely walking and they're getting CIs. I choked up and said please, please [putting her hands together] let us be next, she's four! And every day that goes by is another day that we sacrificed her language. It's more time that we've lost. It's already late. Shit or get off the pot already.

Carol had also told me she decided instantaneously, once the CI brought up to her and her husband at the time of diagnosis. He turned to her and said, "Well, we've got to get this cochlear implant." Similarly Becky, Nancy, and Jane were ready for the implant from the moment they found out about it. But Jane had a long wait between diagnosis and candidacy; she even had to endure Lucy being deemed a candidate and then not. This was because of her particular kind of hearing loss being caused by Pendred Syndrome.[111] "Pendred is a rollercoaster. You're up, you're down. And I remember Annette saying, "I've heard of this, but I've never seen it".

There were times when Lucy seemed to have her hearing, "I could call her name and she would respond with no hearing aids." And then suddenly, it would be gone. "And I knew when it was gone. At this point, all the doctors at the center knew...They didn't want to touch her. 'Let's watch her for a while"- watch her for a while!?" She throws her hands up in the air in exasperation as she is telling me, "How can Lucy learn language if one day she wakes and I don't know if she's hearing that day?"

Even more frustrating to Jane was that a second ABR confirmed Lucy's hearing loss. Jane was ready. "She had auditory memory,[112] I knew it could be salvaged." And she felt like her case would be heard. She felt that she had a strong relationship with the center. "We were there every week because she ate the [hearing aid] mold, she found ways to destroy it." And so

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insurance company as well as caused some hesitance on the part of the surgeon and audiologists.

[111] Pendred is a genetic and progressive form of hearing loss that usually appears just after birth. The hearing loss often occurs suddenly and in stages.

[112] Parents and audiologists often talk about auditory memory in a way that suggests that a child who once had hearing and processed information auditorially would retain this ability despite hearing loss and be better equipped to 'decode' the signals the CI provides.

she did all the things she was told to do for Lucy, she got EI services at home, she made sure she wore the hearing aids. In fact, she felt she was extremely effective with getting "tons" of EI services, even if she had to be confrontational to do it. "They [EI providers] do know me. I'm the person if you need something it's done. I've always been a good worker….I had to fight for her. I went in, I went in very defensive, I went in ready to start a fight." She had no problems intervening on behalf of her child.[113]

But then Lucy seemed to be responding to sound again, and surgery slipped through her fingers. It had appeared that Lucy was a candidate; but the testing results were conflicting. Jane had gotten everyone together: Annette, the chief audiologist, Monica, the primary pediatric CI audiologist, and Dr. Brown, the surgeon. "We were ready to do surgery, and then they decided not to," she tells me. Here, she recounts that appointment:

> We were picking out the color of the processor, and then they were like, let's not do that and they shut the box….Monica was showing us how it all works and I remember: she shut the box. [She mimes the closing of a box.] The box was wide open, we were going over everything and she said it's based on whatever hearing test we get today, that will be the deciding factor. Dr. Brown had said that if it's the same or better, we're not going to touch her. But if it's worse, we'll do surgery. And they brought Lucy back into the room and Annette said, 'It's the same' and Monica shut the box. We were so close…."

At this point, Jane begins to cry. She was clearly recounting something that she found extraordinarily devastating. "I was mad," she says. She felt desperate to get Lucy's hearing loss treated, and she began to feel increasingly anxious. She emphasized to me what a 'big deal' that appointment was for her and her family by telling me that her husband 'had even taken the day off' to accompany her to that appointment, which is not something that he had done in the past.

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[113] Again, this was similar to Lareau's findings: "Typically, individual outcomes are connected to individual effort and talent, such as being a "type A" personality, being a hard worker, or showing leadership. These cultural beliefs provide a framework for Americans' views of inequality" (Lareau 2003:7). I saw this characteristic in many of the parents in my study, especially Nancy, the old timer, who repeatedly told me her daughter's implantation was a success because of the hard work she put into it.

"We left the appointment and he said, "That was bullshit. I had to show up for that? I was supposed to be signing a release form for her to have surgery. *That's* why I took the day off."[114]

Jane continued to fight for Lucy, she tells me. "I had a couple of phone calls with Monica…I finally got my wits about me and I said, you need to figure out what is going on, we need to make a decision. Shit or get off the pot. It's been a year." This time, she also threatened to go to a different center. "If I come in one more time, I'm taking my paperwork and going home." At this point, she says, she became aggressive and when she came into the center and sat down with Monica. The next time Lucy was tested, it was a go. And just three months after this interview, I sat with Jane and her husband all day at the hospital while Lucy received a second implant.[115]

*The CI as hope*

Parents often have high expectations that are misaligned with the actual expected outcomes (Hyde et al 2010). When I asked the surgeon why parents often assume that the CI will always "be successful," Dr. Brown answers:

> The myth is, honestly, is human hope. That if you can read about it, you can be in that best possible category and you'll achieve it. The other thing is honestly, the marketing and literature for the CIs from the companies.[116] They are such that they really lead you to believe that everyone can perform you know, fabulously with this, that there aren't grades of performance.

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[114] This gendered pattern of care was so prominent that it felt unremarkable that fathers were not there. Their absence was so pervasive that when they were involved, like Paul and Julia's seemingly equal participation in care, it was surprising. The clinic staff seemed socialized to this norm; I never heard them critiquing fathers' [lack of] participation, but, for example with Paul, he was said to be 'one of the good ones' for taking so much initiative in Morgan's care. Here, Jane's husband seemingly fits this pattern, illustrating the role that fathers typically played in the clinic.

[115] Receiving implants in both ears is called bilateral implantation, and this practice is becoming increasingly common.

[116] The marketing materials for CIs are available to parents and usually printed on glossy magazine paper, and also include a promotional DVD titled "An Absolute Miracle!"

Sometimes parents want their child to be a candidate and they are not. "There are inappropriate implant candidates," Dr. Brown tells me. Those are the "really hard evaluations" for Dr. Brown because it takes much more time to tell someone that they are not an implant candidate when perhaps, on paper, they might look like they are. In other words, they might meet the requirements for type and degree of hearing loss. But, according to Dr. Brown, this does not take into account the fact that one must be deemed a candidate audiologically, there are many other factors to consider as well. Dr. Brown illustrates the extreme level of hope that parents associate with CI through this disturbing story:

> For instance there was a child that we saw…that by audiological criteria they clearly met criteria to get an implant. And when I had done the imaging on her, she had a normally formed cochlea and yet the internal auditory canal that carries the hearing nerve from the cochlea to the brain had no auditory nerve running in it…She has a cochlea. You can theoretically, surgically put the wire in, but you're not going to have any central connection. So, I advised against implantation. It was a hard thing to say, but…. as we all, as parents, care about our kids and we'll do anything for our child… [They] got an implant for this child [at another clinic]. And to this day, this kid has no response to the implant, is not getting anything, is nonverbal and has no functional results of the implant…The kid isn't really signing, isn't really communicating, has no oral language skills at all and they've had an implant for a number of years.

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***Determining Candidacy***

A child's implant candidacy is not only audiologically determined, but there are also medical and social criteria. The audiological and medical criteria are what Dr. Brown refers to as hard criteria. Audiological tests that determine the type and degree of hearing loss and amount of functional gain provided by hearing aids are one measure. Medical criteria include a full work of the child's overall health and physiology, to make sure the child is 'intact,' for example, that they have a cochlea, and there are no other precluding conditions. All of this is

part of the standard process toward implantation candidacy, and requires parents to schedule testing and imaging appointments, such as MRIs.

While parents are undergoing the transition into candidacy and preparing for surgery, clinic staff have been long monitoring where they are emotionally, as well as how compliant they are. The center had monthly "CI Team Meetings" to have a variety of perspectives evaluating these soft criteria.

For audiologists and other clinical staff, it is socially unacceptable to choose against the implant. The 'CI team" will consider the commitment, compliance, and understanding of the parents regarding the long-term requirements when recommending a child for implantation. But they also talk about the EI service placement as well as educational placement if the child is older. All of these structures and clinical staff then work together to determine how well parents are being socialized into effective "parents of CI kids."

***CI team meetings***

One morning before the CI meeting as we were gathering the folders on the children who were being discussed that day in the CI meeting, I asked Sharon if parents knew that all of the clinic staff talked to each other about their cases. Often these meetings end up showcasing the different relations that parents have with audiologists, as compared to the speech therapist, the social worker, or Dr. Brown. In fact, Sharon says, "We get together and we discuss things and sometimes Dr. Brown is blown away by what we say that the parents, say and vice versa."

Although the staff all talked to each other about the patients, formal CI team meetings were new at the center, and I sat in on the first one. I was surprised by how many people were in attendance. It was held in the conference room on the lower level of the center, at a large table where about ten of the clinic's staff were sitting, eating their lunches and going over a printed list

of pediatric CI candidates and patients that had been passed out. The staff in attendance included Annette, Monica, Sharon, Gretchen, and Sonya. People began to complain about the meeting starting late. Besides, Dr. Brown was late, apparently still in appointments. Sharon sighs audibly, "I don't know why anyone thought this would work! What was it that we wanted to discuss?"

She starts going down the list of patients, and for each one they all discussed a surprisingly wide range of issues that each child's family was dealing with. For example, when discussing whether or not a patient should be implanted, I began to see that there was much more being considered than just their audiological and medical work ups. It was sitting in on these meetings where I learned that a lot of complex dynamics were considered when determining candidacy.

In each of the cases, the discussions included what institutions the family was working with, which services they were receiving, whether or not parents understood how to advocate for their children and form connections with institutions, and how well they were navigating social services systems. In other words, they were deciding whether or not parents were in engaged in concerted cultivation. Dr. Brown arrives while they are discussing the first patient. The discussions switches momentarily over to briefing the rest of the staff on the etiology of the child's hearing loss, their possible surgery and initial stimulation dates,[117] history of hearing aid usage, patterns of hearing loss and functional gain. But after this, the audiologists began to talk about how the child's home environment and his parents. 'Spanish speaking, so that's a double whammy,' Monica says. Later, when I follow up with Annette on this comment, she explains that exposure to spoken language with the CI is crucial, but it must be consistent. It seems to me that English at school, home and in all environments is implied, and Spanish or any other non-

[117] This is the date, about four weeks after surgery, that the implant is turned on for the first time.

English spoken language is perceived to muddy that process.[118] They decide, like in many cases, to "wait and see" on this patient.

They move to the next case where the big question is whether or not if the child is implanted that the parents will be 'consistent' with it. Because of the child's educational placement, they are confident that during school hours the use of the CI at all times would be enforced, but they worry about at home. 'How do we know if the CI will be on during the weekends?' Dr Brown asks. 'We need the consistency.' Monica adds that they will also have to make sure someone is checking the equipment regularly to ensure it is programmed correctly. But Gretchen says she feels the child should be implanted and saying, "I showed the kid the audiogram to show functional gain with a CI compared to a hearing aid and he understands what good hearing meant. He understood he would have more benefit with the CI.'Dr. Brown decides that there needs to be a 'big meeting with the family. I have lot of questions and I'm uncomfortable moving forward with the CI."

As I am sitting there and listening to the center staff go through each child's file and discuss in depth their home, school, and EI services, I can see how much is involved. The center staff all strike me as deeply motivated; and I get the feeling that they see themselves as really trying to figure out how to help people. They seem to feel good about it, feel it is not only necessary, but also *right* to intervene in these ways. This is important to them. As the Annette told me on the very first day that I began my fieldwork at the clinic months earlier, 'We are very proud of what we do here.'

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[118] The "double whammy" strikes me; it is not just sign they seem to have a problem with, but any other language that is not English as well.

***Assessing emotions and compliance: "Accepting reality"***

During all of their encounters with parents, audiologists look for a process they often called "accepting the reality" of a child's hearing loss. Time and again, I heard audiologists at the center talking about the absolute necessity of parents accepting their child's hearing loss. Landsman (1998) writes, "Mothers of disabled children make their way within a society that devalues their children and in which their motherhood has 'failed' to follow the culturally appropriate trajectory" (1998:77). In the multiple studies of maternal 'adjustment' to a child's diagnosis of disability she reviewed, she found similar patterns. Most of the studies showed how medical and social service providers described mothers processes in the same terms I found here: denial, compliance, and acceptance of reality. Like Landsman, I want to show here how 'accepting reality' "may not be a matter of becoming resigned to one's misfortune" (2009:11). Rather, I situate this within normative ideas about being a 'good parent' (such as concerted cultivation), as well as the specific ways – and to what extent - we should rely on science, medicine, and technology.

While Landsman found that acceptance of reality often referred to professionals desire to make parents aware of and understand the 'worst case scenario,' I found that 'acceptance of reality' for audiologists to mean something different. However, parents 'proved' their acceptance in the same ways: by participating in the culturally accepted and "socially approved project of 'overcoming' disability" (2009:180). But the acceptance audiologists speak of is not akin to acceptance of biology. As Rose writes "in advanced liberal democracies, where individuals are enjoined to think of themselves as actively sharing their life course through acts of choice in the name of a better future, "biology" will not easily be accepted as fate or responded to with impotence" (Rose 2007:26). While Rose is speaking about individuals

compelled to intervene upon their own bodies, here it intersects with expectations of parenthood and devaluation of disability. What audiologists call 'acceptance of reality' is code for whether or not parents appropriately emotionally process their child's diagnosis and accept their recommendations on intervening audiologically to mitigate, alter, or circumvent the biological reality. It is the parental failure to move through emotions and participate in biotechnological intervention – or implantation in this case- that constitutes a failure to "accept reality."

Annette, the chief audiologist at the center, explained that, "So you have those families where there's no question about it; how could you think I wouldn't do this? …I can say it tends to be routine with normal hearing parents with deaf children." 'Normal' parents decide to implant. And this decision is foreshadowed and implied in the decision to participate in the interventions that lead up to official candidacy evaluation. And this participation, Annette says, is "acceptance, really believing it." She also says that in these families where there is not compliance, "denial is the big common denominator...We've all had these families. It's probably a handful, but some stand out more than others." Denial is often blamed as the cause when parents reject the idea of hearing aids, refuse to put them on their child, or do not actively participate in EI. Annette becomes exasperated as she tells me, "The fact that he's not talking, would you rather people think he's just stupid or mentally retarded? That's better?" Over and over again she says she just does not understand. "At what point can you keep this a secret? I don't get that…I don't understand the thought process down the road when they do that. I tell them, you should put the hearing aid on him, but I can't go home with them and say do this. But at what point can you still keep this a secret?"

This kind of ongoing denial, she says, is rare. But it does happen. Sometimes it takes years, but she and Sonya 'stay on' the families and eventually they may come around. She

postulates as to some of the reasons why, suspecting that perhaps it is the stigma associated with hearing aids. "I think that's huge. That's huge! 'They're going to make fun of him.' What do you think is going through a parents head when you tell them their kid is hearing impaired?" Similar to what many of the parents told me, she said what she imagined they were thinking: "They're going to pick on him at school. And they're first thought is: will my child be able to speak? Will I be able to communicate with him? And when he goes to school he's going to be tortured."

Other times, Annette tells me, parents have to become desperate in order to get "on board." For example, she described one family to me whom she was excited had finally made an implant evaluation appointment. "He [patient] is starting to sign and they can't communicate with him and so if they get a CI - well now they're ready to get a CI like yesterday! They want to know how fast he'll start talking." From this statement, it is implied that: 1) it is okay for parents to not communicate with their child in sign language, even if that is the language the child uses, 2) the child's use of sign is a fact that constitutes a sense of urgent intervention to reverse, 3) if the child is implanted he will learn to use spoken language, and 4) by wanting the implant they are 'normal' and this is celebrated as a success for finally seeing compliance or "acceptance of reality" in the parents.

***"Difficult moms"***

During a discussion with Monica about one of her 'difficult mom' cases, she tells me about a child that is almost five years old. The mother had a "very difficult time just even accepting the hearing loss. It took her a long time before she would get to the point where she would allow us to fit her child with hearing aids because she was still going through acceptance." I tried to clarify what Monica meant by that, and she tells me, "She couldn't really understand why sometimes she would hear a sound and be able to turn, but she wasn't talking. That was

probably because she did have some residual hearing and so she could hear louder sounds. But, she didn't have enough hearing to understand speech. That took an awful lot of parent education from not just myself, actually, from a lot of people, the social worker, other audiologists, Dr. Brown. It took a lot to get her to the point where she would accept the hearing aids." When I pressed further and asked her what she thinks that is, she surmises it is a mixture of denial, and being unable to emotionally handle the situation. "She was actually evaluated for an implant three separate times. We've been wanting to implant that particular child for years already." The child was finally fitted with hearing aids and "placed in an appropriate school program, getting a lot of services." But, Monica and the rest of the staff felt that she had reached a 'plateau.' "There's a plateau that you reach in terms of the clarity of the speech because she didn't have access to as much hearing as an implant could provide her with."

The problem, as Monica saw it, was that the mother did not understand that while the hearing aids were good, the implant was better. "She's coming along, but she we knew she would do better with an implant. But it took again, like I said, we went through three [official implant evaluation appointments], before the mom would sign the [paper]." These evaluation appointments, which consist of a large battery of hearing tests and discussions with the parents, took place over the course of a year and a half. "It took mom a long time. The school was pushing, trying to get her to take the implant."

When I asked her what she thought took this mom so long, or what made her so 'difficult' she said she thought it was partly the idea of surgery. "Sometimes that end of it is more of a difficult hump for people to get over because they are afraid of the surgery, afraid of the anesthesia…But mom is coming through, she's definitely making progress with the implant. She just had a tough time, but she's coming around." This is frustrating to Monica because she

and so many other professionals that work with the child have been saying, "go go go" from the beginning. "But everybody is different. It depends on what their frame of mind is when they start the process; if they've accepted the hearing loss or if they haven't." But other parents "would be on our doorstep every day if we let them, so there's a huge, huge range."

Monica stresses that it is not just the audiologists who push for CIs. "Everybody on that child's team does the same thing and the parents learn over time. School plays a very big role in that because the child is there at school the majority of the time and they offer a lot of parent education and working with the speech pathologist. The school is one issue, we on the other hand, we have a whole parent education meeting here actually…The support group is run by Gretchen and it's role – well it comes back to parents accepting the hearing loss."

***Identifying the difficult ones***

For Annette, difficult moms were those that were "hard to get on board," but she emphasizes to me that this is a 'cultural' issue. Often, she could predict which families would present difficulties. "Most of the families that don't implant are parents who are deaf themselves…I can say if you're interested we can talk about the CIs, but those are the families where [they say] "If my child wants to get implanted, when they're old enough to ask for it, then we'll consider it." She does not expect them to engage in social services, audiological intervention and implantation. "Culture is big, but you know that already because you know the Deaf culture."

But she finds the Deaf families are not the only ones she experiences as 'difficult.' While most 'normal parents' do implant, "the outliers are the ones who tend to not to be American…they tend to be foreign born parents who have more cultural issues that start to come into play." She recalls a family she recently was trying to work with from Russia, surmising that

"having an impaired child or putting something on them, having to put a hearing or a CI is so obvious." Plus, once she had identified the baby as deaf, "They didn't even want to talk to me and they left me a message and telling me to leave them alone…I have another Israeli family…they picked up and literally I swear to you they moved to Israel to get away from me." But, she tells me the story ended well because the parents moved back, and after a long time of deliberation finally decided to get a CI for their daughter and "She's talking now, so everything's fine." In her experience "culture is big" and those that do not implant tend to "be parents who are not native [English] speakers and parents who are not born here."

***Concerted cultivation and language***

There may be a connection here between the experiences of immigrant families, as well as Deaf families, as it relates to concerted cultivation. "Our society places a premium on assertive, individualized actions executed by persons who command skills in reasoning and negotiation" (Lareau 2003:133) and this is primarily done through the conduit of language. Without necessarily situating her work within the context of parenting a child with a hearing loss or even deaf education, Lareau's findings turn out to be quite relevant; she found that language was an axis of differentiation across social classes; the use of speech was variable between middle-class and working-class or poor families. Middle-class families had a *relationship* with language; "they enjoy words for their own sake, ascribing an intrinsic pleasure to them…parents use language as the key mechanism of discipline" (Lareau 2003:107). In contrast, poor or working-class families used language "in a more functional fashion" (Lareau 2003:107). She concedes that there is an "unequal educational benefit for children from the different approaches to language in the home," (Lareau 2003:107) as poor and working-class children may harness less of the skills that might be helpful in the future as the encounter and negotiate institutions.

But what happens to these kinds of relationships to language and patterns of usage when they are disrupted by hearing loss? While I am not sure of the answer to this, I did find that these very patterns and relationships with language found in middle-class families to perfectly frame the medicalization of deafness and ethos of implantation. "One of the benefits of middle-class status appears to be the transmission of exceptional verbal skills" (Lareau 2003:111); these skills are ultimately meant to enable children to negotiate institutions, persons, and 'customized advantages.' These important language skills are seen as part and parcel of middle-class life; that is, using language to your advantage, along with skills in negotiations, "is an important class-based advantage" (Lareau 2003:111). Though sign language is linguistically equal, its status as a minority language is misaligned with broader patterns of language use in middle class homes.

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***Preparing for surgery***

It is summer; prime time for children to get their CI. If they are school aged, implanting them in the summer allows time for the surgery without disrupting school attendance, but also lets the month of healing before initial activation of the implant – or turning it on- and acclimating to the flow of electrical current and the frequency settings, a process I will describe in much more detail later, before school begins. No matter what their age, the summer months are better for surgeries as there are fewer ear infections.

On this day, there is a pediatric implant evaluation appointment (PIE) on the schedule. These are long appointments; today a four year old is coming in and Lisa and Monica and I

discuss the case before he arrives. "We did a sedated ABR a year ago and indicated that the loss was appropriate for hearing aids, but now may recommend a CI, something must've changed." Monica nods her head in agreement, "Right, we aren't sure if he's even a candidate for CI, so will do aided tests today and get a history from the mom. This appointment is PIE and we won't know until we get the test results if he is [audiologically] a candidate for CI.

The first thing Lisa and Monica do is ask the patient's mother if she had read all of the materials on the CI they had given her and watched the DVD from the CI company. She had. I ordered my own copy from my contact at Cochlear. The main menu of the DVD, *An Absolute Miracle!*, consists three section: "Real Life Stories," "Learn about Cochlear Nucleus 5," and "See What the Experts Say." There are four patient stories, two pediatric and two adults. All of the families and/or patients featured are white and show in middle-class, suburban areas.

The pediatric stories show one girl, who at seven lost her hearing and was bilaterally implanted. She is interviewed talking and listening, 'passing' for hearing. It also included the 'Hallmark moment' of initial stimulation, as well as interviews with teachers talking about how they no longer have to accommodate her in any way. The second was the story of an infant, aged twenty months who had been implanted five months prior. This story focuses on the parents' experiences, telling the story of 'not passing' the NBHS and following up with an ABR and being told she was profoundly deaf. But, they were relieved and assured that it would be okay because of the availability of the CI.

The surgeon was also interviewed, saying that the parents need to make the decision for their child right away, with reassurance that the child will perform well. She adds that if they wait until the child is older, "They've lost the battle." They described the surgery, how it went well and there were no complications. After the CI was turned on, she responded to

environmental sounds, playing with toys and looking around at sounds. They do home speech therapy twice a week and continue this after surgery, with the mother featured in the story emphasizing how crucial this is. This is the information parents have typically consumed before implant surgery.

Lisa and Monica then talk to the patient's mother about how often she uses the hearing aids with her son, what brands and settings she is using, and if she has had all the imaging done. They had been, and the CAT scans and MRIs did not show anything that would preclude surgery. Lisa and Monica go on to talk about his current educational placement and overall history. He was set to transition into regular school in the fall, since his hearing loss was not congenital, and for some time he had seemingly had residual hearing and auditory memory. He was also receiving speech/language therapy.

In PIE appointments, candidacy is determined by seeing how much benefit aids are providing. So, Lisa and I go into the booth while Monica sits with the patient on the other side of the window. Lisa proceeds to present tones at varying frequencies and decibels, while Monica determines his response. They measure the difference that the hearing aids make in both ears, determining the "functional gain." Meanwhile, the patient's mother is filling out a questionnaire with questions about how he functions with the aids, the behaviors she notices. The answers are scaled, and along with functional gain testing and the speech/language development reports from Gretchen, audiological criteria for implantation are assessed.

During a break in the testing, Monica comes back to the booth to look at some of the results with Lisa. I ask Monica if she thinks that he should get an implant. "Yes, based on the amount of benefit he's getting from aids." We then move from the testing booths into one of the appointment rooms with observational mirrors. I go behind the mirror and watch as Monica sits

down and says, “Let’s go over things. If we can raise the level of amplification, which is maxed out right now with hearing aids, we can give him more access. He’ll do better with a CI. It will also help with his behavior; he has to work really hard to hear and with a CI he won’t have to work so hard.” But, Monica emphasizes that they only have partial information right now, she’ll need to bring him back in for additional speech perception testing. But she assures her that, “Yes, I think he can benefit from the CI, but it’s not just my decision.”

Monica proceeds to describe the CI, showing her a CI that they keep on hand as an example. She explains how the electrode is snaked into cochlea, and it that it is the cochlea that is damaged, “So, information isn’t getting sent to brain.” She goes on to say that one month after surgery, he will come back in. They will turn on the “sophisticated computer” that is now implanted in him, explaining that it holds different programs called ‘maps.’

> See, the computer inside changes these programs to code, which is then sent through the [magnetic] coil, which communicates with the internal piece. This fires and sends information to the auditory nerve. There are twenty-two electrodes. We will stimulate all of them on first day, but they will not be turned all the way up. We will send you home with four maps so that you gradually turn it up more and more. Then periodically you come in to change the programs; we’ll put four more in…You have to get used to the electrical stimulation, he may not be able to hear speech in beginning. He will have a lot of appointments at first, as we bring up the CI. But we do it a lot; it will be fine.

*“Audiologically, this patient is a CI candidate.”*

After this appointment, I went back to my desk to look through some of the medical records of CI patients that were part of my study. As I did so, I saw the phrase “Audiologically, this patient is a CI candidate.” Although I had had begun to understand there was more to being a candidate than just audiological evaluation, for example I also knew that medical clearance had to be determined through MRIs and other imaging techniques like CAT scans, I still wanted to know more about the social criteria that had come up during the CI team meetings.

I walked down the hall, through the waiting room and into the front corner of the center where the audiologists' offices were. Shelly, another audiologist at the center who shared an office with Monica, was sitting at her desk. I sat down and asked if she had a few minutes to explain candidacy to me. "You qualify audiologically if you have the audiogram for an implant, the horrible speech, and you're medically intact to have an implant. But if you don't have the support system at home, or you don't keep hearing aids on, then you won't succeed with it. Then that's where it gets to: Are you a candidate or are you not?"

She explain further, saying that there are social factors to consider. Unlike the "double whammy" comment I had heard in the CI team meeting, however, Shelley told me this story:

> In New York, we have so many cultures. I remember being in CI class in my online program for my doctorate. I had to do a group project and I was placed with people from Kansas, Wyoming, everywhere but NY. We were given cases and we had to pick who was a candidate for an implant. There was a little Korean family and the mother only speak Korean and the father was in denial about the implant. Dad is in denial. Mom is ready to go forward with the implant. I said yes. I got yelled at by everyone in my group. 'They don't speak English!' I said, 'You're from Kansas. No one speaks English when you come to NY, you learn that's how it is. They wouldn't listen to me. We get the project back. We got that question wrong. I was right, he was a candidate. The teacher said just because he doesn't speak English doesn't mean he can't get an implant. And what happened with this case was, she said, he got an implant, mom took classes and learned English and dad got like therapy to realize his kid had a HL.

Family context clearly plays a role in decision-making about candidacy, but it is not always clear-cut and, from Shelly's story it is not uniform or agreed upon. "It's a whole big battery of pieces if you think about it," she tells me.

As I looked further into this, I found that there are currently no agreed upon, national guidelines for determining candidacy. Even as CIs proliferate, there are no uniform national standards of practice. "With the lack of evidence based-standard of care, patients are seen as needed by the audiologists and the schools or early intervention systems are responsible for

developing and implementing the aural (re)habilitation program" (Bradham et al 2009:32).[119] Thus, CI candidacy assessment varies from center to center, but FDA guidelines and minimal tests needed "are audiological testing at two points in time to demonstrate degree of hearing loss and (lack of) auditory development" (Bradham et al 2009:35), as well as medical evaluation. But the American Speech-Language-Hearing Association (ASHA) recommends asking the following: Do the necessary supports exist in the individual's psychological, family, educational, and rehabilitative situation to keep a cochlear implant working and integrate it into the patient's life? If not, can they be developed?" The particular center where I worked was clearly operating under this question and took social factors quite seriously in their determination.

***The pre-op appointment***

One morning in July, I meet a couple named Jim and Tina in the waiting room. They have brought in their daughter, Amanda. She is twelve months old. This is the final appointment with Dr. Brown before Amanda's surgery. Jim and Tina are a white couple, in their thirties. When they are called by the ENT receptionist, I help them gather their things and the we all squeeze into Dr. Brown's small exam room.

Dr. Brown greets them as she comes in and says that this is it, the last time they'll see each other before the surgery. They had pushed the surgery back one month to wait for the newest version of Cochlear America's Nucleus Freedom, which is sitting there in a box. It is white, includes upgraded software and a remote control. It looks like an Ipod.

> The difference between a new internal, and the reason it's significant in someone her age, is do you see the height of the two implants? [She holds out the previous model, the internal piece that is implanted.] This one [the newest one] is a lot flatter. One of the

[119] This lack of evidence-based or outcomes data-based practice should clearly be questioned and critiqued. Part of the work here then is to show what practices are being undertaken, how they are being undertaken, and to what extent claims are made even in the context of 'highly variable' and unknown outcomes.

> problems with the Freedom used to be that it used to stick up a fair amount from the scalp. This has a much lower profile. What happens is it lies much closer to the skull and it doesn't protrude as much, okay.

Dr. Brown holds out the new internal piece to Jim and Tina. "If you want to feel the two, there's a big difference because in an infant, you actually have to drill all the way through the skull down to the dura, which is the linings of the brain. [Pauses] Okay? In all cases." But the difference here, is that the previous design "actually presses into it, because of the profile [being larger], where this one, what's protruding from underneath is a lot less…Before this used to stick up a fair amount."

Tina asks her if that is the only difference between the two models. "There's no real upgrade in terms of the electronics themselves?" From a surgical standpoint, Dr. Brown tells them, there is not a significant difference. "Drilling a well is drilling a well, and I'm just going to change its shape a little." Furthermore, the rest of the surgery's procedure is identical. " It's the same in terms of the mastoidectomy, going over the facial nerve into the middle ear opening, the inner ear, that's all the same. Opening the cochlea and putting the implant in is the same; all of that is unchanged."

Jim and Tina are nodding, looking at each other, watching Dr. Brown intently. They are calm, but inquisitive. Dr. Brown asks Jim and Tina if Amanda has had any recent ear infections. She has not and Dr. Brown lifts Amanda up onto the examination table. "Oh, you're a wiggly worm and a half!" Amanda starts crying. Her hearing aids are on, but Dr. Brown wants to look in her ears. "Oh! I'm sorry," Tina says. "I'll take your hearing aids out. How can we look in there, if those hearing aids are in?" Dr. Brown looks into her ears and asks if they have made their appointment for the initial stimulation. They have and Dr. Brown says to Amanda in a high voice, "You're so good!"

When Dr. Brown is done, Tina puts Amanda on the floor to play and Jim and Tina continue to go over the surgery details. "Basically, the incision is pretty much the same. It goes from here to about here. Dr Brown runs a finger behind the ear, motioning from the top to bottom. "She'll wakeup with a head wrap dressing on her head. If she feels great, she could go home the same day. If not, certainly, most people I keep twenty-four hours. Parents that want to go home the same day, that's fine." Dr. Brown goes on to explain that for three days the incision can get wet, but no scrubbing. "It's critical to keep her fingernails as short as possible. You don't want her scratching at that wound. If she scratches that, she could introduce a local infection. That's one of the biggest issues in young kids." Jim and Tina nod.

Jim says that they had watched some videos on YouTube, "which was really great." There are a lot of videos of surgeries and activations on line. In fact, the moments after surgery and initial stimulation appointments are some of the most popular and most frequently associated images related to implantation. In marketing materials, these moments are often used as emotional "Hallmark moments" as Amy's mother Becky had put it when talking to me about it. During the surgery the implant is tested to make sure it is working. "Intraoperatively," Dr. Brown says, the CI is tested to make sure it is sending a signal as well as examined by x-ray. The x-ray tells me the position, that I like it, that's in the cochlea, that I don't have concerns about where it is."

Then, Dr. Brown goes over all the risks associated with the surgery. There are risks; there are the standard risks with anesthesia, the possibility of facial nerve damage, and a higher rate of contracting meningitis. Parents do worry about anesthesia, but none of the parents I interviewed particularly emphasized this fear. The risks are well known, but managed via standard techniques (Loudon et al 2010). They include infection, facial paralysis, and

meningitis. Complications are rare; sixteen patients out of sixty thousand contracted meningitis, and this has been responded to preemptively by vaccinating children before surgery. Similarly, facial nerve damage, which if occurred would cause Amanda's face to be paralyzed on one side, is avoided by using a monitor during surgery. "I will use a monitor. It tells me where the nerve is and how to work around it safely. I've never injured a facial nerve," Dr. Brown assures them. Jim and Tina nod and say okay.

Jim, who was playing with Amanda, stands up. He looks at Dr. Brown and asks, "So what's the failure rate?" But there is a miscommunication here. 'Failure' of the implant is understood only in terms of functionality of the device itself, and considered largely avoidable. Dr. Brown responded by asking, "You're talking about immediate failure versus later on failure?" The father clarifies that he is asking about both. The surgeon answers his question in this way:

> So immediate failures, there really isn't, okay, because if you put in the implant and we're not getting responses off the electrodes and we're not getting the – you know, the x-ray doesn't look right, I'm going to put in my backup implant. I always have more than one around [in the operating room] for the instant, you know, maybe if it's an off the shelf failure. Maybe that implant didn't work. That's why we test. That's why we want to know before we close up [the surgical site] and say, you know what, this implant is a good implant. That's the whole point of doing the NRT.[120]

Whether or not the implant 'works' is not a question of long-term results (these are framed as questions of the brain, not the CI), but rather a question of if the device is operational. And this shift from defining the efficacy of implantation from the device to the discipline of the recipient will be most evident in the following chapter.

*Scheduling surgery*

[120] NRT refers to "Neural Response Telemetry," which is a method of testing that electrical signals are reaching the auditory nerve.

After the pre-op appointment, I head downstairs to Jeans office, which is in the corner past the break room, and past Margaret's NBHS offices. There is a lot of talk upstairs amongst the audiologists about a missing CI candidate file, and I go to her office to ask if she knows where it is, but also to follow up on what her role is in the process. All the CI candidate files are red, which stand out against the bland, standard light colored folders that fill the hallway. The CI files are intended to 'stick out.' As I round the corner, Jean is sitting at her desk, talking on the phone. She hangs up and goes on to tell me how she is the one who schedules the surgeries, and is the liaison between the center and the operating room (OR). "I schedule surgeries and pre-tests, that means scheduling with the OR, making sure it's available. I give the parents instructions for [insurance] pre-certification and make sure all the necessary testing and bloodwork is done before the surgery happens."

I bring up the missing chart. She confirms it is missing, but she does not know where it is, despite, she says, sneaking into Dr. Brown's office, which is filled with stacks with multiple piles of papers and folders. "We've got to find that chart!" she says, and at this point she can't ask Dr. Brown for it or she might be annoyed. She gives me a list of some of the upcoming CI surgeries. I ask her if she has ever dealt with a deaf family getting one. "No. I think it's a generational thing. Older [deaf] people seem less accepting and I guess deaf people in general." She turns to me, "I guess they have all kinds of feelings about that?" She looks puzzled and I am not sure if she is asking me a question or making a statement. "Besides, I've noticed a problem with older deaf patients when I email with them. They don't get it, they don't understand, I guess there aren't as literate, yeah that's a good word. On of the audiologists once told me that they don't comprehend stuff as well because of their hearing impairment." She seems baffled by this information.

In her spare time, Jean does fundraising to gather funds that pay for CIs for those patients with any out of pocket costs. We do this so "we can give them the gift of hearing." In fact, she started as a fundraiser, but when CIs became more common and "technology increased and they needed someone to do the scheduling, Dr. Brown needed help with surgical coordination." But she only talks to the parents just before surgery, not after. She calls to give them instructions not to give the child food or drink after midnight the night before, and tells them what time to arrive for the surgery. Most of the time "the moms" are not nervous, but sometimes they are. "One of the moms said something about Valium and I said, "No, he can't have it." She said, "No not for him, for me." Jean lets out a big laugh at this. The phone starts ringing; it is Dr. Brown who, Jean says, is overwhelmed with surgeries.

***Surgery day***

One morning in August, I met Jane and her husband at the hospital around seven in the morning. It is Lucy's surgery day. We had talked the day before when I had seen what time her surgery was in the computer and called her. An hour later, she said, Jean called her to give the instructions. Everyone in the center was talking about Lucy's upcoming surgery; it had been such a long time coming. In the waiting room that morning, I met her after they had already taken Lucy back to the OR. "They are drilling a hole. They are touching the brain stem. It is minor brain surgery. It is *scary.* I know Dr. Brown has never done this, but her face could be paralyzed. What if we did this and it wasn't the best thing to do? What if the electrodes don't take?"

She sunk down on the couch, a TV blared out CNN. I had brought some snacks and offered to get coffee while we waited. "We got here at 5:45 this morning!" She looked extraordinarily tired. "At least you know how my anxiety manifests." She touches her fingers. I

said, “I know,” and I ask her if she has eaten anything, but she has not. Her husband had forgotten her BLT that she had wanted. Nothing else sounded good to her. “I love my husband, but I think he was born with a defect when it comes to emotional support.” Meanwhile her teenage son was at home with the other two young children and she paced. “My head is there [at home], but my head is here too.”

While we wait, Jane tells me how Dr. Brown had to call Cochlear Americas that morning because Lucy was having the Nucleus 5 internal implanted, but “I ordered the old external, nothing internal has changed but there is no FDA approval on the new battery.” I was puzzled. Why did that matter? “If you get that one, you are spending zillions of dollars on batteries…The CI uses three batteries. They have to approve every part of it, the coil, every piece. If you buy a package of batteries for $195, it will only last a few weeks. That’s why I went with the old unit that has FDA approval on rechargeable batteries, they’re much cheaper and have a one year warranty.” She was already beholden. A couple of hours later we were called back; Lucy is out of surgery.

***Summary***

In this chapter I have described the transition from initial intervention to implant surgery, showing the subtle details of the steps involved as the ‘therapeutic mode’ emerges. This mode is characterized primarily by the adoption of practices that align with what Lareau identified as a concerted cultivation parenting style. Various aspects of concerted cultivation fit into processes and demands characteristic of medicalization, especially as healthcare and social service institutions come to share interventional goals.

But the encroachment of medicine or morality into parental obligation is also not new (Rothman 1993, Landsman 2009). Implantation is merely one example that, if analyzed, shows the ways in which a child – and how a mother responds - embodies various cultural values. Studying clinical interactions helps to show the ways new medical technologies and their implementation then contribute to the "subtle restructuring of patients' or professionals' identities" (Timmermans and Berg 2003:104). And I did see how professionals believed in their roles, were wholeheartedly committed to 'helping' families, a narrative often accepted as safely benevolent.

But it is in this benevolence that these appeals to parents' ethical obligations to their child's future occur, forming "the milieu within which novel forms of authority are taking shape" (Rose 2007:27). It is within this context that "a moral economy of hope in which ignorance, resignation, and hopelessness in the face of the future is deprecated" (Rose 2007:27). I characterize this ongoing nature of intervention as ethopolitical; that is, actively shaped by appeals to ethics and obligations (Rose 2007). Parents are compelled to intervene *now* for the good of the future, and the faith in the CI and the accompanying emotional work that undertaken by the clinic and EI staff provides hope for and socialization into this mode.

In recent decades middle-class children in the US face the possibility of 'declining fortunes.' "Worried about how their children will get ahead, middle-class parents are increasingly determined to make sure that their children are not excluded from any opportunity that might eventually contribute to their advancement" (Lareau 2003:5). These middle-class values, already laden with beliefs about language and intervention, are easily transposed onto the perceived duties of being the parent of a deaf child. The 'crisis of fortunes' for middle-class kids,

the general cultural distaste for disability, and a high level of anxiety about the future, all intersect with a technology that is held out as 'the answer.'

The compulsion to engage in ongoing 'moral self transformation' has already been associated with biomedicalization (Clarke et al 2005). The moral character of health intersects powerfully here with a culture that devalues disability and measures mothers' worth by the social worth of their children (McMahon 1995). It is in this context that parents are monitored for how much they (ironically) 'accept' that their child had a hearing loss – an acceptance measured by how much they sought to eradicate it. They were implored to intervene, to "drink the Kool Aid," as Carol put it. And even more than all of this, these practices are structured around the larger cultural patterns, *not* outcomes of implantation. In the next chapter, I turn to how, in the face of this, compliance is sustained and community fostered post-implantation.

## Chapter 7: The New Meaning of Sound: The Neural Project

*Neurons that fire together wire together. – Hebb's Law*

*I don't know that there are many children that the CI did not work for, and often it's the case that the implant works fine, but it's the parents who don't do what's needed – Nancy*

As we left off, Jane was headed back to the recovery room to see Lucy after surgery. As I showed in the previous chapter, there is nothing shocking about surgery or the decision to get a CI when parents have been groomed and prepared along the way. Although surgery is emotional for parents because of its invasiveness and anesthesia, it represents one small period of time within a larger progression of treatment. As Jane once told me when I asked her about life after Lucy's surgery, "This is where the rubber meets the road."

I deliberately do not emphasize surgery in this dissertation. This is not because it is unimportant, but because it has been given an exorbitant amount of attention in the literature and media. Documentaries like *Sound and Fury* include following parents through the day of surgery, and there are also thousands of YouTube videos of the surgery and the CI's activation. After surgery, the child is typically sent home the same day or at the most the following day, and then the incision is left to heal for about four weeks. At this point, the parents bring the child back to the clinic for the activation or 'initial stimulation' appointment. This is often called the "initial stim" date. At the initial stim appointment, the external components of the CI (the behind-the-ear or BTE unit) are connected to the internal parts via the magnet that acts as a radio transmitter, which is attached by a wire to the BTE.

Cochlear Americas' promotional materials especially emphasize this moment of activation for marketing purposes. Over and over again in promotional videos or on YouTube, children are portrayed as "hearing for the first time," that emotionally manipulative moment Kim and other parents referred to before. This gravely oversimplifies implantation. It is far more

important to stress the context in which surgery occurs, not just socially and institutionally, but also across time. Clinical studies of implantation have also mainly focused on parent decision about surgery, positioning implantation as a stand-alone surgical event rather than a piece of a larger socialization process. It also marks surgery as some kind of endpoint, instead of a beginning (Archbold et al. 2001, Christiansen and Leigh 2002, Bain et al 2004, Okubo, 2008).

In implantation, coordination of long-term habilitation therapies that coalesce around the CI after surgery is emphasized (Bradham et al 2009). Yet, there is little post-implantation research. What research there is typically focuses on purely functional measures like speech perception tests (Lin et al 2008), early post-CI results as they relate to parental expectations (Hyde et al 2010), 'quality of life' indices (Loy et al 2010, Huber 2005), and, as I pointed out in the previous chapter, attempts at measuring communication modes (Belzner & Seal 2009). Still, as we saw before, there is no comprehensive understanding of exactly what these communication outcomes are.

In one important study, Chang (2010) examined disparities in access to implantation for those who are publicly insured versus privately. There were no significant differences; Chang concludes that because of the wide insurance coverage of implants and routine use of them in audiology, most have access to the device itself. In other words, getting the child to the implantation surgery was the easier the part. However, there are "important differences between groups post-implantation that influence outcomes, namely decreased follow-up compliance" (2010:657) and Chang is unique in calling for such studies. Furthermore, "the parents' perspective, which may more closely reflect the functional outcomes of children in everyday situations…were underrepresented in the literature." (Hyde et al 2010) Chang's study, however, did note that in post-implantation follow-up disparities, there are significant and multiple

unknown factors that influence long-term compliance. This "indicates that centers should further investigate opportunities to minimize these downstream disparities" (2010:657).

In pediatric implantation especially, prognosis "has not yet attained the sophistication, clinical acceptability, and credibility for CI teams to predict outcomes with certainty" (Black et al 2011). As I noted previously, correlates have been established like the relationship between age of implantation and parent education and prediction of speech skills. But, "research to date has not yet comprehensively identified specific pre-implant factors that reliably predict 'success' with a CI" (Black et al 2011). The lack of post-implantation studies is troubling:

> Much of the current literature results from studies written by the surgeons involved in the CI process, and yet the surgeon's exposure to the case is relatively limited compared to the subsequent evaluation and habilitation process required for each case. The majority of the clinical first-hand experience will therefore come from professionals involved in these latter areas, where the current literature is somewhat lacking in volume and quality…the audiological and habilitation areas have a considerable range of assessment tools used to evaluate case progress. These include audiological and cognitive assessments plus intrinsic factors such as family structure and support and expectations and extrinsic factors, including the learning style of the child and educational environment (Nikolopoulos et al 2004). These aspects are assessed by many different approaches. They are often poorly adaptable to quantitative measurements (Black et al 2011).

In this chapter, I aim to push the surgical procedure to the background and foreground the ongoing practices that surround the CI, the child, and the family post-implantation. This is purposefully and exclusively a qualitative approach focused on understanding the social features of post-surgery parental compliance with integrating the CI (or what is known as 'habilitation').

***From a sensory problem to a neurological problem***

The most distinctive feature of post-implantation follow-up care is the centrality of the brain. Through the marketing and routinization of the CI, a neuroprosthetic device, the ontological understanding of deafness has shifted from being a sensory problem to a neurological one. That is, the shift in the treatment of deafness with a neuroprosthesis has resulted in a

redefinition of the social and audiological understanding of the condition of deafness itself. Even on the promotional video from Cochlear Americas, the audiologist featured in one of the child's stories says, "She had all the wiring in place" and she just needed the CI to utilize it. Her mother follows up by saying that her brain learned how to hear once the implants were turned on. Although the neurological aspect of implantation has thus far been implicit, I turn now to how the brain explicitly organized the social relations I observed.

***From the beginning: accessing the brain***

In one of the first ENT meetings I sat in on, a well-known implant surgeon who was visiting was listening to residents as they presented tough cases. During this meeting, the surgeon explained to Dr. Brown and other attendees from the ENT department that there was more to implantation than the equipment. He told them that some synchrony has to happen "up north." The crowd seemed amused at the way he put it.

After the meeting, I went upstairs and found Annette, the chief audiologist, to ask her about this statement. She proceeded to explain how the device itself is not the treatment, but rather the training of the brain. To train a brain, it must be in good working order; the circuitry or "the wiring" should be in place and functional.

Recall that diagnosis typically occurs through ABR testing. This was the test that Lisa, one of the audiologists, described as measuring electrical energy moving from the cochlea to the brain stem. MRIs and CAT scans are required before implant surgery to make sure all the wiring and necessary 'equipment', to make sure no other organic, neurological impediments would contraindicate CI candidacy. The ABR test serves as a neurological point of entry for infant patients who start down the trajectory toward implantation. We begin with measuring neural

functioning and the CI lays in wait as the interface that corrects the missing frequencies; it is a neural programming "patch" of sorts.

***How the CI works***

When the implant is turned on at the initial stim appointment, the child does not 'become hearing,' as the videos or marketing materials may imply. Rather sound waves that travel through space arrive at and are processed by the BTE's microprocessor. It does the job of taking this information and translating it into a digitized signal made up of ones and zeros. This information then travels through the magnet, which is also a radio transmitter, and into the electrodes snaking through the inner ear. This digital signal is then 'fired' up from the electrodes and sent to the auditory cortex of the brain. Depending upon the model of the CI, the number of electrodes varies, although today CIs typically have twenty-four. The electrodes take the place of the damaged hair cells that fill the cochlea. In a normally hearing person, the hair cells, which number in the tens of thousands, communicate electrical signals to the brain. In contrast, an implanted person gets information from, at the most, twenty-four channels. The 'sound' that arrives at the brain does not arrive as a discernable signal. To the brain that has not had access to sound before, it is foreign input, data without a codebook. In a moment, I will talk more about the ways this signal travels through the brain, but how the signal is configured bears mentioning here.

***Mapping***

The configurations of this digital information are determined by program settings in the microprocessor. These program settings are called "maps" and CIs hold four different possible programs, often referred to as P1, P2, P3, and P4. Different programs may be used in different settings, such as one for loud environments, one for one-on-one conversations, and so on.

Mapping appointments are those where configuration settings of the device are tailored to the child for optimal usage.

Making sure that the device is properly mapped is one important aspect of implantation. It is also one of the ways that parents are judged in terms of how "on top of things" they are. All patients must have a certain level of hearing loss unaided to be considered severe or profoundly deaf, but each child's loss is different. Decibel levels and frequency thresholds are unique to the individual. The CI, if configured properly, should be tailored to mitigate the difference between a 'normal' audiogram and an atypical one, and no one child may have the same audiogram or comfort levels as another.

Mapping involves setting thresholds, known as T levels, which are the softest sound a person can hear. Adjusting the T levels helps them to 'hear better,' but C-levels must also be considered. C-levels are comfort levels, which help to avoid over-stimulation or even discomfort. Mapping is the most important aspect of maintaining optimal CI functionality, but children typically cannot provide the user information needed due to the complex nature of the concepts, and infants in particular may not have any means of communication (Mertes and Chinicci 2006). Thus, the pediatric population requires a bit of guesswork. However, adult patients' subjective descriptions of T and C levels have helped audiologists to develop methods of programming maps for children. But it is still process of trial and error that can takes months and years, and requires constant tinkering.

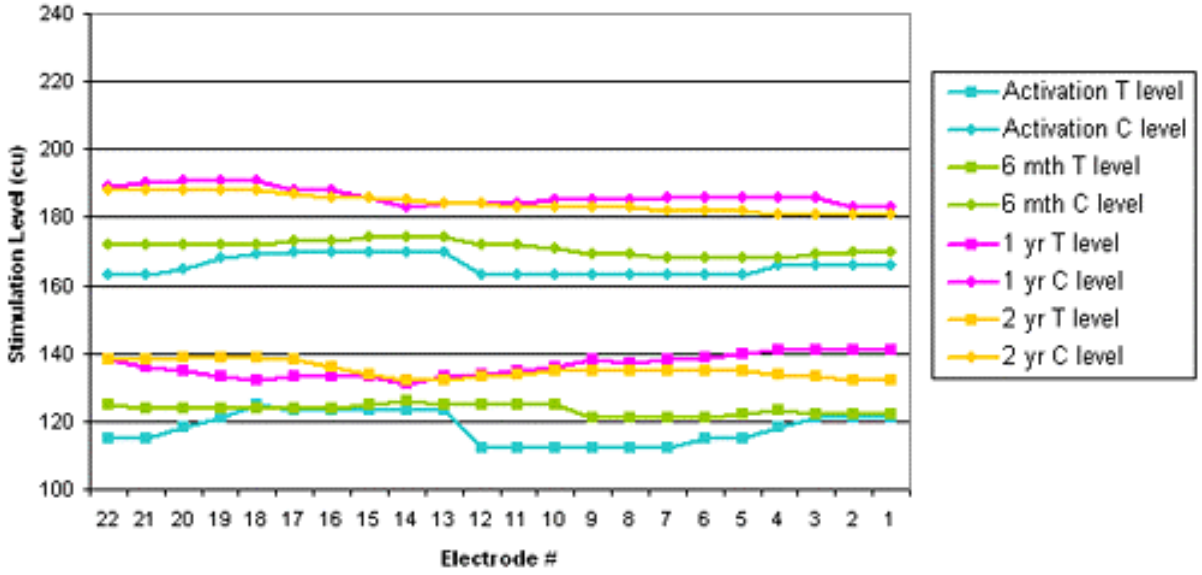


**Figure 3: Sample CI Mapping Chart (Mertes and Chinicci 2006)**

While maps must be carefully calibrated or configured in the audiologist's office, it is parents who must follow the prescribed mapping plans as well as help determine if they are working or accurate, which can be quite difficult. At the initial stim appointment, the process of mapping begins, but with a series of initial, low-level signals designed to slowly acclimate the child to auditory information and electrical stimulation. These initial mapping sessions are close together. One afternoon while at Jane's, she opened up her weekly planner for me. She flung it down on the kitchen counter while we talked about Lucy's acclimation to the implant. She had recently emerged from the thick of the initial mapping sessions. When I looked down, each day was covered in letters and numbers; she had used different colored pens to differentiate the numbers scrawled on each day.

"Mapping is a lot less now than it was in the beginning," Jane says. In fact when Lucy was first "turned on," they were at the audiologist about once a week. "Oh god, she was flying through the programs!" Each time they went, the program changed and Jane had to write it down, track her response, and know when to 'bump' to the next one, gradually increasing Lucy's levels of stimulation. "You have to write the programs down every time you bump her up. See?

[She points at list of numbers.] P3, P1 yeah I had to write it down." She lets out a heavy sigh. She had been carrying around the calendar with her for weeks, and brought it with her every time she had an appointment.

> I have to bring in all this [paperwork, calendar]. In the beginning I had to know because the appointments were so close together. So like okay toady is P1, tomorrow is P2, she already moved through all programs! There are 4, P1, P2, P3 and P4. You have to be through to P4 before you come back for the next mapping. And [she starts talking faster, not quite catching her breath] we moved through it and I haven't had to write anything down because she's been on P4 and we go for a mapping on the 15th at 10am.

While audiologists focus on getting the map technically right, parents have to constantly manage the programs and determine if they are effective and comfortable for the child. This is stressful and anxiety producing, as well as usually dependent upon intimate knowledge and observations in the home or other daily environments. For example, perhaps the child prefers P2 in certain contexts, while seeming to do better with P3 in others. Each child's level of tolerance is not uniform; tolerance is usually the word used by audiologists and parents as they describe moments when they realize the CI is too 'high' – or the C-level needs to be adjusted - they wince or cry.

Depending on the age and school placement of the child, there are always new situations or spaces that must be reconfigured.[121] For example, if there is an FM system at the child's school, the map will need to be adjusted for the frequency variation in this kind of input. Jacks can be inserted into the BTE unit that wirelessly send FM system signals directly to a child's CI. Every space is potentially a new map reconfiguration; every space is a potential source of anxiety.

[121] Interestingly here, the CI does not only hold maps, but it in a sense it also spatially maps the contexts the users enter into. A square room will bounce frequencies in certain ways, a round room another. It is a dynamic between the body, prosthesis and space.

Reading and interpreting the child's reactions over time, often through means that are much harder to delineate, is how parents learn the child's preferences or needs. Usually, parents told me, problems will manifest in other behaviors. Perhaps the programs are changed and they start struggling with bedwetting, have problems toileting during the day, have tantrums, showing a lack of attention, or cry. This is a frustrating guessing game, and they often told me concerns about such behaviors. Since the CI is a one-way device, it cannot respond to the brain's modulations or needs: it can only fire a pre-programmed signal (Chorost 2011).

This one-way feature of data presentation is in stark contrast to the rest of the body's systems. So, the need for mapping changes is often picked up on by mothers in a variety of other ways, most commonly in assessing their children's behaviors and emotions. A few months later, after Lucy had been in her new auditory/oral school program for about a month, Jane told me she was concerned. "Lucy is almost five years old and she just started shitting her pants. That's something psychological." During support groups or on online forums, parents often swapped stories of what worked for their child or patterns of behavior they noticed and how to tweak the device's settings. Jane was beside herself; although the level of anxiety had subsided so that her fingers were not longer tingling as she talked about it, she was worried. But other days Jane was exuberant; in between these behavioral issues, Lucy impressed her teachers with her speech articulation. Meanwhile, Jane was still frequenting parent support groups and online forums, which often focused on tips for managing or configuring the device, as well as dealing with other behaviors.[122]

***Shifting responsibility***

[122] They also often get creative in getting around some of the CI's limitations, namely that it cannot get wet. For example, there are popular YouTube videos that many of the parents mentioned that taught them how to use vacuum sealers meant for food storage as a means of encasing the CI in airtight plastic so that a child could wear it while s/he swims.

At the same time that the CI is positioned as the treatment for types of deafness, it is also downplayed as merely access equipment. The shift from ear to brain corresponds with a shift in responsibility from the treatment or device to the mother. Additionally, because the CI is framed as merely an access device, the notion of failure is transformed. Failure of the implant is understood only in terms of functionality of the device itself, and is thought to be largely avoidable. Consider Jim and Tina, with their daughter Amy, whom I described in the previous chapter as they had their final clinical appointment with the CI surgeon before surgery. In that appointment, Jim asked, "So what's the failure rate?" Dr. Brown responded by asking, "You're talking about immediate failure versus later on failure?" Jim clarifies that he is asking about both. The surgeon answers:

> So immediate failures, there really isn't. Because if you put in the implant and we're not getting responses off the electrodes and we're not getting the – you know, the x-ray doesn't look right, I'm going to put in my backup implant. I always have more than one around [in the operating room] for the instance. Maybe if it's an off the shelf failure. Maybe that implant didn't work. That's why we test it. That's why we want to know before we close up [the surgical site] and say, you know what, this implant is a good implant. That's the whole point of doing the NRT.[123]

Whether or not the implant 'works' is a question of whether or not the device is operational; if it is operational, failure is often attributed to a lack of parental consistency.[124] The first support group I attended where I met Nancy, the 'old timer,' she put it quite succinctly: "I don't know that there are many children that the CI did not work for, and often it's the case that the implant

[123] NRT refers to "Neural Response Telemetry," which is a method of testing that electrical signals are reaching the auditory nerve. It can be done remotely; I once sat in Sharon's office while she conducted an NRT intra-operatively from her office, a building a way from where the surgery was taking place.

[124] There are certain conditions that may emerge later as impediments to success, such as auditory neuropathy/auditory dyssynchrony (AN/AD). This is a relatively newly diagnosed, not condition where the conduit to the auditory nerve is damaged or there are problems with neural abilities to process sound. In recent years, the condition has been gaining recognition, although its features are still debatable.

works fine, but it's the parents who don't do what's needed." So, the CI is constructed as only a conduit to the brain that provides an auditory signal through technical specifications. It delivers a simulation of sound; it makes one technically able to hear. The rest of the work lies at the other end of the electrodes' signals: the brain.

***From the neurobiological to the social***

The brain is composed of billions of neurons. The neuron's job, with its many branches that reach out and touch other neurons, "is to accept spikes of electricity – called action potentials – from its dendrites. Depending on that input, it 'decides' whether to send an action potential of its own to other neurons…A neuron is basically a tiny deciding machine" (Chorost 2011:75). The goal of implantation is to send a signal to the neurons in the auditory nerve, and then (through long term auditory training) to manage and control the decisions that these neurons make. That is, the goal is to intervene so that neurons make 'good decisions' to cultivate certain connections between certain neurons:

> [Neurons] constantly send out new projections that touch other neurons. This happens most promiscuously in the infant brain, but it happens in brains of all ages. At the initial contact, the connection – the synapse – is quite weak; the dendrite can easily detach and hunt for another neuron. But if signals pass through the synapse, the connection becomes a little bit stronger. Pass signals through many times, and the connection becomes very strong and ultimately permanent (Chorost 2011:40).

Biological factors affect what neurons do and the extent to which they do it, such as the strength and shape of the synaptic connections between them. However, the training of neurons' decisions is purposeful and social. For anyone familiar with neuroscience, this is not novel. For anyone familiar with implantation, this is also why auditory training, which works upon these synaptic connections, is of crucial importance.

The CI delivers a signal to the brain that, up until implantation, is unknown. 'Hearing' this information and understanding it are two very different things. "Neuroscientists generally

agree that the brain is an active co-creator of perception, not merely its recipient" (Chorost 2011:43). In this case, an implanted child's neurons must be trained to perceive and decode the signal not just as sound, but meaningful information. Audiologists and educators often referred to the process of creating these meaningful synaptic connections as creating the 'right neural pathways for language.' I will come back to the aspect of language, but first it is important to understand that neurons are not to be trusted to figure it out on their own. They may receive a signal, but it is what they *do* with that signal that is important.

This is precisely the moment for neural intervention; some neural pathways are more acceptable than others. For example, if neural functions were technologically *un*mediated in a deaf child, this would likely result in a sign language user. If neurons were left to their own devices, they would most likely opt for sign language since it is a stimulus that is presented naturally (unmediated by a neural interface), already socially embedded as language, and readymade for uptake. Often, the use of sign was seen as 'the easy way out' or what I would call a neuronal crutch; it was also indicative of a parent's *or* a child's abilities and/or a lack of commitment to auditory training.

***Waiting for the signal: EI as neural anticipation***

Before I turn to the auditory training that occurs post-implantation, I want to point out how pre-implantation interactions are structured by an anticipation of the arrival of an auditory signal. Chorost, an adult CI recipient, writes that, "Training makes an *enormous* difference. Research in neurobiology is showing that the right kind of training has directly measurable effects on people's brains" (2005:173, original emphasis). The brain learns and creates meaning by connecting neurons together.

This is what Julia, from the previous chapter, was doing with Morgan when she focused on providing "the visual that will eventually go with the oral." By engaging in the prescribed EI activities, Julia was making neural connections in Morgan's brain between an abstract, as-yet-known to him stimulus (the sound of the door or the squeaking bear) and responding and attending to it. She anticipated the CI signal; she laid the neural groundwork that would later be paired with auditory information once Morgan was implanted. She was creating neural possibilities by presenting a 'ghost stimulus' and laying the tracks for future neural pathways.

As Julia was doing this work, she was addressing a crucial piece of the relationship between learning and input. "We know that brains can make sense of completely new kinds of input, as long as it can be matched to known correlates in worldly experience" (Chorost 2011:24). If the activities that parents are asked to perform in their IFSPs for EI in are recast in neurobiological light, it can be seen as concerted relations formed in anticipation of neural restructuring. Julia was providing Morgan with traces of an experience; she altered and tailored social relations and micro-interactions to model what experiencing sound *looked like.* And in this way, she was teaching him how to eventually uptake a signal, even without the presence of sound in that moment. The idea was to provide that 'worldly experience' that he would eventually draw from to make meaning out of auditory information. Through creating such perceptive dramas, she was anticipating neural connections to come. Or was she actually creating them? This raises a host of ontological questions: what does it mean to have a hearing brain? A deaf brain? Would Morgan's brain read as a 'hearing brain' at that point?

In preparing parents for implantation, audiologists also made sure to differentiate between the CI and the brain. For example, when preparing one mother for her son's surgery, Monica explained:

> He has damage, so information isn't getting sent to brain…But the CI is a sophisticated computer that holds four programs or 'maps.' The computer changes these programs to code, which is then sent through the coil, which communicates with the internal piece and this fires and sends information to the nerve… we send you home with four maps so that you gradually turn it up more and more. You have to get used to the electrical stimulation, so you may not be able to hear speech in beginning. He will have a lot of appointments at first, as we bring up the CI. We do it a lot; it will be fine.

***Auditory training as neural discipline***

Once a child is implanted, the signal must be mastered through continued auditory training. "It's possible to reshape the brain's neural writing with carefully designed exercises. Developing such training in conjunction with neural technologies will be indispensable" (Chorost 2005:176). [125] Since it is generally accepted that without the creation and maintenance of certain neural connections the CI does not have a solid neurological foundation, ensuring the development and permanence of auditory neural pathways is a complex and long-term project. "The development of new skills takes hours, days, even years. Scientifically speaking, the idea of instant learning is a 'lie'" (Chorost 2011:19). In this case the "instant learning" or the idea that an implanted child simply "becomes hearing," as hearing is typically understood, is the lie.

"Learning a complex skill can't be done on a plug-in basis. It entails physically changing untold numbers of neurons in one's brain" (Chorost 2011:40). The brain is quite democratic. "It so happens that if a part of the body changes, so does the area of the brain that controls it. The brain is not static; it constantly reallocates its available resources to match what is going on in the body" (2005:87). And the creation and dissipation of synaptic connections is not only a neurobiological process, but it is also an equal opportunity one. Neurobiology, social relations

[125] Describing his own experience of implantation as an adult, Chorost writes, "Over weeks and months my auditory cortex obediently refined its topography, making physical division and auditory distinctions where none had existed before. The implant was literally reprogramming me" (2005:88). This raises a host of other issues I cannot address here, from the relationship between the brain and neural interfaces to ontological riddles and the nature of perception.

and life experiences all powerfully affect, and thus are co-constitutive of, the creation and dissipation of synaptic connections (Chorost 2011). And it only follows that if the ideal neural pathways are actively shaped, affected, and achieved through social relations, then these relations and interactions must be managed and surveilled.

I will turn now to how parents are socialized into regimens that reflect these understandings of the brain and encourage specific forms of social interaction said to ensure specific neural habits. Once again, the emphasis is on how the implant merely provides the stimulus – or what audiologists call 'access to sound' – while the rest of the 'work' is up to the user and the user's brain. The most important strategy audiologists, therapists, and educators used to convey this was distinguishing between 'hearing' and 'listening.'

***Hearing versus listening***

In every single clinical appointment I observed, audiologists used the phrase "good listening." I began to suspect they were referring to something beyond simply detecting an auditory event. I soon came to find that hearing is passive, whereas listening is purposeful, active, and *work.* During a lull in appointments one afternoon, Monica and I sat down in her office to talk. Earlier that day, I had watched an appointment where she tested a recently implanted child for her response specific tones and frequencies and asked her mother about her responses at home to what audiologists call 'environmental sounds.' These are sounds that occur around us all the time, a doorbell, a telephone, the hiss of a radiator, someone calling your name.

"You can hear a whole bunch of things but you're not going to understand what you are listening to until you start to attach meaning to a sound," Monica says. But I was not quite clear. I gave her a scenario, suppose the doorbell rang, I said.

> Right and they go like this [looks around] and [the child] heard it, but it doesn't mean anything. We try to educate parents and say if you see a behavioral response to a sound,

> figure out what that sound is and then show your child what that is. Those are the very beginning tasks to kind of get them you know, acclimated to listening and identifying.

This sounded like what I had seen Julia do for me when I went to visit her at home. But I was still confused, how could one 'hear' something and it not mean anything? She uses me, a normally hearing person, as an example. "There's a difference between hearing and listening," she says, "because your ear truly is just a receptacle to pick up sound. It's your brain that allows you to understand what your ear is feeding it. It's really your brain that allows you to understand what's being said."

Hearing, it seems, was the idea that sound waves came across space and time and entered my body. For me, it entered through my ear, which did the job of communicating the signal to my brain. For an implanted child, a simulated version of sound would be communicated to his/her auditory nerve via electrodes that bypassed the ear. Either way, we would both technically be 'hearing' something. The only requirement of 'hearing' was the presence of electrical energy traveling across neurons. It did not have to *mean* anything to the person; it is passively absorbing a signal just by virtue of being there. But meaning? That takes attention; that takes conscious, neural *work.*

"If you think about it, you have to give your brain a chance to listen before it figures out what things mean or what speech is being said. It's the same thing with listening. You could hear a lot, but if you just tune it out, you're not listening to it." The missing component here seemed to be some kind of active attention or concentration. When I ask her if it was related to attention, she says, "Yes. When you first get an implant you may have a lot of access to sound. But you may hear something, but it doesn't mean anything to you, so you just don't pay attention to it." This is where the intervention has to happen, auditory training is the means by which the act of hearing is transformed into listening and one moves beyond merely having *access* to sound.

Mapping sessions focus on configuring each of the four programs. When a child positively responded to environmental sounds or tones mapping sessions, the audiologists would cheer and say, "Yay! Good listening!" But I also observed how the language of "good listening" also subtly masked an undercurrent of willful inattention. For example, if a child did not respond, it was routine for audiologists to say, "It doesn't mean she's not hearing, it's just a matter of getting her to listen." Or, "Oh she just isn't going to tell me today." Thus, if a child does not actively listen, perhaps that is just a result of simply being uncooperative. This judgment of uncooperativeness may also be transposed onto the parents.

Auditory training and good listening are intimately linked. Furthermore, distinguishing between hearing and listening was how audiologists shifted responsibility from the device to the brain (and in pediatric implantation, from the device to the parent). "With a lot of parents, we're trying to teach them to start identifying if a child hears something, then start to identify what the sound is and attach meaning to that." Right, this was exactly what Julia had acted out for me, and exactly what other parents like Carol and Jane had told me.

And I had seen it before. Good listening had also shown up in the EI parent training discourse. When I visited Jeremy's mother Carol one day at home, she had EI materials taped to the refrigerator. It was a paper with instructions for parents to always to put their hands by their sides so that there is no signing or gesturing. It read, "Glue your hands to your sides" and "Make your child accountable for listening." As I observed appointments, I found that 'good listening' referred not just to the process of attending to sound and attaching meaning to it, but doing so without relying on any visual or gestural cues. And this was a crucial second piece.

***Neural vigilance***

There are two pieces that converge in good listening and the discourse on neural pathways here: 1) continuous, consistent auditory training creates auditory pathways for spoken language, and 2) sign language is 'risky' because it impedes the formation of these pathways, and parents are subsequently encouraged to avoid 'exposure' to it. Managing these neural pathways requires vigilance, as visual stimulus is the 'easiest' input for deaf children. Graeme Clark, who was one of the developers of the CI, wrote in his treatise on implantation, "It is important for a child to develop an auditory-oral language with a cochlear implant first, because neural connectivity demands early exposure" (2003:695). Furthermore, "this exposure will be impaired if there are opportunities to focus predominantly on visual language" (2003:696).

Thus, a basic tenet of implantation is integrating the CI's neuroprosthetic functions in a sustained, continuous way. The goal: to train the child to successfully be able to use spoken language. In order to achieve this, professionals across institutions (audiologists, teachers, speech therapists) not only maintain that auditory training should occur as much as possible to create these synaptic connections, but that exposure to sign would impair these synaptic connections.

***"I'd love to be able to communicate with him"***

It is a Tuesday morning and it is summer. Everyone is busy this morning, running from appointment to appointment. The corner of the hallway where the audiologists' offices are is hopping. Monica and Lisa are chatting about the morning appointments. Nathan, who is approximately three and a half years old, is coming in shortly. He was implanted about a year and a half prior, at age two. I find Annette to ask about him. She nods and tells me that his mom, Kelly, would be a great participant for my study. As their appointment time nears, I go and sit in

the waiting room. It is a busy morning at the center. A few minutes later, Kelly and Nathan enter and he is full of energy. Kelly stops him and looks at him square in the face and says, "No running, ok?" He clearly wants to run, but it seems he understands her and heads over to the play area of the waiting room. He is loud, vocalizing a lot, but nothing is particularly discernable. Kelly, in between checking in with the receptionist and checking her phone, attempts to shush him.

A couple of audiologists, en route from one appointment to the next, walk through the waiting room. When they see Kelly, they greet her, but she is on the phone and just waves. From what I can tell, she is trying to contact her son's pediatrician. I am sitting patiently in a chair across the waiting room, just watching. When Monica comes in looking ready to take the appointment, we make eye contact and I know it is time for us to do our routine. Monica brings me over to Kelly and introduces me as a researcher. She has just hung up the phone, is quite friendly, but does not seem to care at all that I am there. I explain that I would like to observe and talk to her in a follow-up interview. As I carefully explain, she easily waves her hand that it is great that I'm doing the study and signs the consent form. We all go back to the appointment room, but I slip into the observation side behind the two-way mirror. Kelly stays out in the hall for a moment, taking another call, while Monica and Annette test him to assess the maps. In the room, they hook up his CI to the computer sitting on the desk with a variety of different colored wires. Annette sits with Nathan at a table as they 'play' with building blocks, but really, he is trained to move the blocks into the bucket one by one as he hears tones at different frequencies through the CI. "We're going to do good listening now," Annette says. This is how audiologists assess the child's access to various frequencies and levels. While Annette sits with Nathan,

Monica's back is to them, looking at frequencies on the screen and clicking on different settings to adjust it.

As they go through their mapping routine, Monica notes out loud that he is getting services at a deaf school nearby with a CI program. "He sounds great," she says. Kelly comes back in and sits down. Monica tells Kelly, "His speech is great!" "That's what they say," Kelly says. Monica continues to click on the screen. Nathan moves the blocks. I observed Monica and Annette in mapping appointments many times. Because they had worked together for so long, they were able to communicate with each other with just a look. They often conducted these appointments in sync, like clockwork.

Kelly sits down and cautiously says, "So, his school is against signing for him." Monica nods her head. "Yeah, he's oral, I understand why they're saying no. They don't want him to regress." Kelly leans forward and says, "But when his implant is off, like in the morning before it's on, I'd love to be able to communicate with him, to tell him he's going to school or something." Annette keeps playing with Nathan at the table, entertaining him so Kelly and Monica can talk. "You could just do the sign for school with him," Monica says. She then proceeds to show Kelly (although it is wrong and actually the sign for learn). Kelly attempts to mimic it, and then Monica adds quickly (referring to me), "Laura will know. How's his balance?" Kelly says it is definitely better. "Any other concerns?" Kelly says no, and she is happy with how well he is doing.

As if on cue, Nathan turns around and clearly says "Mommy?" After a pause, Kelly turns to Monica and says, "Wait, there's nothing you can do about the beach though, right?" They talk about how frustrating it is that the CI cannot get wet. It is summer and this is a conversation I have observed at least four times. While they talk about the beach, Nathan starts saying, very

clearly, “I want my implant on.” Had I not known he had a CI, I would not have of guessed that this child is profoundly deaf without it on. Kelly tells him he has to wait, that first, “She’s got to do something to help you.” Monica and Annette finish configuring frequencies and making changes through the computer software. Soon, Nathan can be unhooked from the wires snaking across the room.

Later during an interview in her home, Kelly told me that she had asked about signing with him because in the morning before putting on his implant, her son asks her questions. She had a two-story house, and when she went upstairs to wake him, the CI would still be charging overnight down in the kitchen. “I want to answer him and tell him he is going to school,” she says, but he cannot understand her without it. “That was the only reason why I thought maybe sign would come in handy,” she says. But, she also understands that signing involves different neural pathways and the oral program he is in at school is against signing because “they feel like he can hear, so they want everything to be just oral... So, maybe when he gets a little older and he can…[trails off] I don’t want to bombard him too much right now.”

In other appointments, parents also raised concerns about communication. Usually they noticed frustration on the child’s part in being unable to communicate, but they cited the strictness auditory/oral educational programs. Once when I was with Jane during an appointment with Lucy, she said to the audiologist, “I’m not ready to see any type of [behavioral] regression go further because somebody decided to draw the line between signing and auditory/oral only.” Regardless of how the parents responded about signing, in these situations, Monica and Annette typically did not directly address the concerns. They would, like Monica did above, stick to their own ‘department’ and emphasize the importance of ‘getting the maps right.’

***Deploying neuroplasticity***

A curious phenomenon is occurring. When Kelly inquired about using sign, the response was that the child was auditory/oral and that it signing might cause a regression in this development. This is a contradictory version of neuroplasticity. On the one hand, neuroplasticity is the foundation of implantation and auditory training. The very principle that synaptic connections can be built, with the aid of prosthesis, is exactly what allows parents to have faith in being able to create auditory pathways in their child's brain despite the fact that s/he is deaf. Neuroplasticity is actually the means by which deafness is attempting to be transcended.

But on the other hand, it is a precarious plasticity, even a vulnerable one. These auditory neural pathways, it seems, are subject to assault, open to attack. The 'wrong' stimulus (visual language) could derail these synaptic connections, and thus parents must not use sign for fear that they would cause their child future harm. However, there is no evidence that learning sign actually impedes spoken language development (Baker 2011), in fact bilingualism is well regarded as neurologically advantageous.

This contradictory version of neuroplasticity is the most significant characterization of pediatric implantation. The way that professionals in implantation use neuroplasticity points to the cultural work it is doing. Meanwhile, arguments against implantation often invoke culture explicitly, such as the Deaf culturalist critiques about the role of language and culture, the threat to Deaf culture that CIs pose, and emphasis on identity and community. These arguments are dismissed as being ideological, whilst neuroscientific knowledge, and neuroplasticity specifically, is actively deployed to accomplish socialization and enculturation processes.

As I show below, the neurological divide between these neural pathways directly maps onto the linguistic divide that structures social relations and institutions serving implanted

children. In a strange turn *away* from plasticity, auditory language pathways and visual language pathways are pitted against one another, rather than seen as able to coexist. Audiologists and educational professionals often give parents the same message: if you expose the child to sign language you impeded their ability to form auditory neural pathways and thus, spoken language acquisition.

"***No sign, no sign, no sign!"***

During an interview with Carol, Jeremy's mother, she talked about how there are "a lot of speech therapists and people out there that really feel that if they don't make it strict auditory/oral only that the child won't learn [speech]." But she lamented the divide in the professional world of implantation. Even though "the majority of parents want their kids to talk," parents are told this desire cannot coexist with learning sign as well.

Looking back, she thinks that might be "the one thing where we made a mistake when you decide to go this [auditory/oral] route." After implantation, she enrolled Jeremy in an infant/toddler program at the deaf school tailored for CIs. She had her EI signage up in the house saying "Glue your hands to your sides!" She was vigilant like she had been told to be. "I'm sure you know by now, there's a whole political auditory/oral thing," she tells me. I ask her what this looks like and she describes it as "No signing, cover your mouth, no reading lips." Good listening means learning to hear and listen without visual information, including lip reading. "So they said don't sign, don't sign." She asked repeatedly if she should learn sign and every time the response was: "No, don't sign." She says she figured that the professionals knew what they were talking about. But now, "I think that was a mistake." Jeremy, she explains, was suffering because he was so frustrated around age two, after he had been implanted about two months:

> He's two, which means he has the desires, the cognitive abilities, the wishes, the motivations, and the goals of a two year old. Other two year olds say me, mine, mommy, milk, go, no, yes. My baby could say nothing, and he doesn't even know how to form the words let alone even think about getting them out. But, you know, I was told no, no, no, no! No sign, no sign, no sign!

Carol was suspicious of the claim that learning to speak must necessarily exclude sign language. She described how she thought long and hard about it, and came to the conclusion that excluding sign was wrong. "I think this is all garbage. This whole political divide between the talkers and the non-talkers - I'm not having any part of it." She did not give explicit neurological reasons for this belief, but did emphasize the importance of communication for safety. "I'm going to teach him sign for the words I need to teach him. So when he's in the bath, he knows sit down. I can't have him standing in the tub. He knows [signs] 'careful.' He knows [signs] 'stop.'"

When her and Jeremy were attending the infant/toddler program at one of the local deaf schools, she described how her and some of the other mothers would deal with the therapists or educators.

> Everybody spouts the same party line, but some people clearly believed it more than others…Some people are belligerent about it, though. There's a woman, actually, [name], who's a consultant at [child's school]. She's very good and she really knows what she's talking about. And she's incredibly well respected. But, I have to say, she's not parent-friendly at all. The first couple times I met her, I thought, you know, I've got no use for you. I don't need you pointing your finger at me.

She found allies in other mothers who felt the same way she did. They banded together and a few of them together decided that they "weren't crazy about her" and thought of ways to appease her while she was watching. This was how they developed techniques for "dealing with her." Carol added that it was all because the educator would tell them, "You're harming your child" if you sign with them. I interrupt Carol to ask her to clarify why she used the word 'harmful' to describe exposure to sign. "Because they're not going to be able to communicate [with spoken language] as well as they possibly can and they're going to suffer from that." While Carol

understood where this woman was coming from, she says, "I have to live with that child every day."

When I had spoken to Kim, Amy's mother, about this experience, she told me something similar. She too described how she struggled to get information across to Amy early in the implantation process. Amy had now been implanted for a number of years and was, by all accounts, doing well in her speech development. However, Kim had also turned to sign when Amy was frustrated and unable to communicate. "Once we started learning sign, that was a blessing because then she started to be able to communicate with us." She goes on to say that Amy did really well with sign and picked it up very easily.

> And I loved it because to me, I was able to communicate with my daughter. I didn't care how I was able to do it, as long as I was able to do it. We finally understood each other. Our frustrations went away. She just was so happy, and I was so happy – and I loved it!

This is not to say that Amy uses sign language now as her primary mode of communication. She does not. As she underwent the process of implantation, she began to develop speech. But Kim's major concern was that so many parents "were against sign and even against lip reading! They didn't want their child to- they'll do this when they talk [covers her mouth with her hand] - they don't want their child to read lips either. I don't care if Amy reads lips!"

***"We're okay with grey"***

The pervasiveness of anti-sign language rhetoric in professional circles does not dictate parent behaviors entirely. In the intimacy of their homes, parents commonly expressed a lack of total allegiance to one side or the other. After a couple of months of being implanted, Lucy was doing quite well at school. In fact, when I went with Jane to a school meeting one afternoon to listen to a Cochlear Americas representative explain how to 'get the most out of the CI,' Jane was gleefully telling other parents and teachers that we ran into how well Lucy was producing

her 'Ling 6.'[126] But this does not mean she was against sign language. Earlier that day at her house, Jane had told me matter-of-factly where she fits on the language divide:

> I'm the parent that says: 'We're okay with grey. We're alright with that.' But, there are a lot of speech therapists and people out there that really feel that if they don't make it *strict* auditory/oral only that the child won't learn quickly. And I kept saying 'Look, if you're going to learn French as a second language, I don't' tell you to stop speaking English, just because you're learning French so you'll learn it faster.' It doesn't make sense to me. So that's where we are right now. We're stuck in this - I want to be grey and they want to black or white.

Jane's version of plasticity was one that was capable of bilingualism; she believed in the ability to shape Lucy's auditory pathways, and she believed this could occur even in the presence of sign. But Jane knew this was not acceptable to the audiologists, therapists and educators. but she had a strategy. As I had observed her in audiology appointments with Lucy, she would tell Monica that she used sign with Lucy and why. She also told me that she decided to be very up front with her child's educational team. Despite her child being implanted and in an auditory/oral program she explains to me that, "I tell them that I'm doing this [signing at home] and have them work with me on that aspect, as opposed to lying to them…You know what? Yes, we do use sign, that's how we handle our situation." Jane was the only parent I saw directly confront a professional about how to 'work with' Lucy.

Still, the overall culture of implantation is characterized by parents who "don't want their children to learn sign language," Jane says. "Why do you think there's only three kids in that [signing] class? It's the same three that were there last year. Parents of deaf kids don't ever learn sign language." But, she tells me she thinks this is problematic. She begins to tell me a story. One day she was at the store and saw a little boy that she recognized from Lucy's school. He

[126] The Ling-6 sounds "represent various different speech sounds from low to high pitch (frequency). They help to test your child's hearing and check they have access to the full range of speech sounds necessary for learning language" (cochlear.com).

was with his father, who Jane says does not speak English, and Jane had all three children with her.

> This is what kills me. The little boy was crying, hysterical. He was signing something about needing to go the bathroom. I walk over and I'm like "Is that Eric?" and the brother spoke English and said yes. I said "Can I just take him for a minute?" The father had no hearing aids on him, he had him out in public, no equipment on and not using sign. What psychological damage are you doing to this kid? He's got the equipment to hear. You don't want to learn sign. But you're gonna talk to him without anything to amplify because you don't want anyone to look at you weird?

Even though some parents may want to deviate from the strict auditory/oral approach that focuses on good listening, there is not formal infrastructure to do so. For example, Jane tells me that Lucy's school is supposed to offer weekly sign language classes for parents. "But nobody takes the sign language classes. So the sign language classes got cut down to…I think I had three classes at the school [in a year]." She said she went to the principle and criticized them for not following through. The compromise was that she got 'extra hours' of home-based services. "Apparently they'll be giving me some extra hours this year [for sign language instruction]. Five hours a year, so that's five sessions. It doesn't seem like a lot does it?"

***"I'm gonna make this thing work"***

Despite these stories of parents not necessarily following professional advice to consistently and only use good listening to develop spoken language, there are many who do. Nancy is a prime example of that, and the way she frames the experience is one of sacrificing clear communication in the immediate moment for better spoken communication in the future. I had just met Anne, her daughter, that morning when we visited her school. Anne had been implanted for over ten years. I asked her what it had been like when Anne was a child.

"Anne was such a stubborn kid," she says. She was clearly proud of her and when I met Anne, I found her speech to be exceptionally good. She moved, talked, and interacted much like

a hearing person would. Nancy had strictly adhered to auditory training recommendations, even if it was difficult, she said.

> I didn't doubt [the success of the CI], but my husband doubted it. We were in a store, I remember this, and Anne wanted something. We were going through the aisles in the store and she just kept pointing and pointing. I said Anne that's it, we're going, we're getting out of here. She was screaming. My husband said See? She needs some kind of sign language, she can't communicate! I said no. I said, it has absolutely nothing to do with her communication. She's just stubborn.

There are tensions here, in all of these mothers' stories. There is tension between the commitment to neural discipline and auditory training that is asked of mothers, despite the immediate communication frustrations that could be 'solved' via sign language. This is solved in a variety of ways. There is a faith in the technology and the method, as well as adherence to the creation of malleable synapses, but a belief that this process can be impeded by visual stimuli. Below I will address the cultural work the neuroscientific understandings of the brain is doing here, but first it is important that audiologists and professionals are not *always* against sign.

***When it does not work***

Audiologists acquiesce that the implant does not always 'work' and those that it did not work for should be given access to sign. This may happen if appropriate neural processing is not occurring. For example, this may occur if there is suspicion that the neurological processes of the auditory cortex are not intact. If the auditory neural pathways simply cannot be won, then there are no linguistic battles to be fought.

I asked Annette, the chief audiologist, about how you know if the implant is *not* working for a child. I carefully phrased the question about the long-term results of implantation, as to not have the question be a question about the functionality of the device itself. "If your criteria for 'it worked' is that they are oral communicators, then [refers to a patient seen earlier] it didn't

work…and we want them to be oral communicators obviously." Since after implantation one of the first things audiologists test is whether or not the child recognizes environmental sounds or responds to say, the sound of their name. Some, she says, are implanted and have never been able to do this. "But we put them in the [testing] booth and we can document that they have access to sound. But it's like their brain doesn't know what to do with this information," she tells me. "So we can get what we call functional gain testing at each specific frequency…just tones…but they don't seem to be doing anything with that information."

The children the CI does not work for are those who seem to have no 'concept' of sound. Their neurons may be receiving a signal, but no neural connections are occurring that attach meaning to that auditory information. The brain is not 'decoding' it. This is where the problem is pinned on auditory processing, which is *not* considered a hearing impairment, but a neurological one. Auditory processing disorders often occur in children with normal hearing abilities and is may have a variety of causes. With the patients the CI does not seem to work for, "We don't know if there's auditory processing. We know the information is getting to their brain, but what is their brain is doing with that information - that's the big question mark."[127]

I specifically asked Annette about the group of patients the CI did not work for because I did not have access to them. "What do we call them? Are they failures? Did the implant fail?" But she was hesitant to use the word 'fail.' "We do have a group that it's not working for," she says. "Monica and I have talked a little bit about this, because it's hard to put our finger on it."

She goes on to remind me that CIs are only access devices to mitigate hearing loss. "When you implant your child, say at twelve months of age, you can't predict that autism won't

[127] The latest topics in CI trainings have to do with the role of 'executive function' in cognitive processing for spoken language acquisition in children who use CIs. (See Pisoni, et al 2010)

be identified until eighteen months, or twenty-four months."[128] In these situations where there are additional diagnoses or auditory processing problems, audiologists have no qualms about recommending sign language.

***Implantation as a neural project***

Unlike in the past, deafness is now predominantly articulated in neurological terms, mediated by a specific understanding of how the brain works, and framed in relation to the CI, a neuroprosthetic device. These neurological conceptualizations can be agilely threaded into the same kind of ethos as body projects where, there "is a tendency for the body to be seen as an entity which is in the process of becoming; a *project* which should be worked at and accomplished" (Shilling 2003:4, original emphasis). Good listening is *work.*

Neural projects are body projects on the most minute of scales. In implantation, pathology is being directly attributed to a kind of somatic encoding on the neural level, and managing these encoding patterns is the project. This is an explicit attempt to both locate the brain in the context of body studies, as well as interpret the social relations surrounding implantation through a neurological lens. As Pitts (2012) notes, this may be suspicious work. "Not only does this proposal open up the self to an array of bio-ontological claims, but it also biologizes social ties between selves and communities that most feminists believe to be culturally constructed."

But I am inclined to go there. "Attention to neurological detail and a tolerance for reductive formulations will enable feminist research to move past its dependency on social constructionism and generate more vibrant, biologically attuned accounts of the body" (Wilson

[128] She is pointing out a larger trend in pediatric implantation literature about the problems that earlier implantation encounters when children develop other cognitive issues. This is one of the main topics being currently being debated in CI practices.

2004:13-14). If it is taken further in the context of implantation, this may open to the door to looking at the neurobiological aspects of language, cognition and the development of subjectivity in deaf children. While this would not be novel to the scientific literature, these have typically not been topics of critical cultural approaches to the issue.

And yet the centrality of the neurological is evident in the ways that professionals teach and encourage parents to discipline their child's brain. This is not unique to implantation; Landsman (2009) found narratives of mothers who had children with developmental disabilities who talked about "overcoming" the disability were routinely basing this on the concept of neuroplasticity (along with the child's willingness, and the mother's 'hard work). One mother even referred to herself as a "synapse-builder" (2009:139). Furthermore, mothers are considered responsible for regulating experiences of children. "There is a moral component to developmental progress not only for the child, but also for the mother" (2009:139). Highly regulated synapses, highly regulated mothers.

***Drawing on neurobiological understandings***

The neuroscientific concepts relied upon in implantation provide a topography not just of the contours of synaptic patterns, but also the social relations they come to create and mirror. I found here that going directly to the neurological, although antithetical to anti-determinist axioms, was actually productive. "Neurological obligation, then, is one way of understanding…there is a mutuality of influence, a mutuality that is interminable and constitutive" (Wilson 2004:22).

Connolly (2002) writes that cultural theorists, in an attempt to "escape the curse of reductive biology," unfortunately "reduce body-politics to studies of how the body is represented in cultural politics." (xii) Here, I worked from the other direction, from the neurobiological to the

social. I described how detailed neurobiological phenomena are used, in conjunction with technology, to shape subjectivites and social relations.

And I think it is fruitful. What I have shown is how control over language exposure is control over the neural pathways, and that 'good listening' excludes visual language. But looking at this allows me to see that parents are socialized into the culture of implantation on contradictory principles of neuroplasticity. The brain is decidedly plastic, but only to a certain extent. On the one hand, motivation (or cooperativeness) on the part of the child, vigilance on the part of parents, and integration of neuroprosthesis through sustained auditory training *can* mold the brain. At the same time, other modes of stimulus are said to undo or impede this process. Plasticity does not hold, rather than creating optional pathways that a plastic brain knows how to navigate and use as needed, the brain it seems is only capable of one language at a time.

This is in direct contradiction to much of the neurolinguistic research on bilingualism and in fact, much neuroscientific research on using both sign and speech actually shows they facilitate one another.[129] Thus, the neuroscience that is deployed in implantation reflects normative values about language, not the actual functional limitations of the brain. The concept of neuroplasticity is used to justify prosthesis, yet it is simultaneously rejected in order to justify suppressing a visual language. As is common in medicine, this is evidence of cultural work being executed in the name of science. Ironically, professionals working in implantation diminish Deaf arguments against CIs as cultural and thus dismissable as 'merely ideological." But, the arguments for implantation are *equally cultural.*

I do not intend to reduce the politics of neural or cyborg technologies to neural firings, but rather to show how particular understandings of neural firings and neural pathways parallel

[129] See Baker 2011 for a literature review and summary of a wide array of neurolinguistic and educational outcomes studies.

deeply embedded social relations. In the next chapter, I give a brief look at how these neural divides also materialize in the institutionalization of linguistic divides in deaf education practices.

## Chapter 8: Education: The Classroom-Clinic

It was a Monday morning in the fall when I arrived at Nancy's home. Her daughter Anne was at school. Nancy was a white woman in her early fifties. Anne had been implanted fourteen years ago, which was partly what earned her the moniker of 'old timer.' Nancy told me stories of the changes in implantation. When she got Anne her implant, it was the nineties and CIs were not as routine. "Oh it's not like it is today!" For six months Anne had to wear an FM system, where her hearing aid was linked to a microphone and transmitter. "There was a whole protocol you had to follow," Nancy says. "That's no longer?" I ask. "Nope. Then, you had to exhaust all possibilities. Parents had to go through psychological testing because they said on the street somebody might come up to you and say you maimed your child, what would you say to that?" I had not heard of psychological testing of the parents being required, although clearly they were informally assessed in the process today for compliance. "The Deaf community at the time was dead set against it." In fact, she says, if a Deaf person saw you with your implanted child, "They would actually accost you, and say you maimed your child, how could you do that?"

But Nancy also had status in the community because of her unwavering commitment to auditory training, her relationships with professionals at various CI clinics, schools, and organizations. She had energy, and she effectively advocated for support services for deaf children in oral educational programs as well as their parents. She was somewhat of a guru to other parents. When I met her at a parent support group one night, she held court. She was clearly knowledgeable, she was passionate, and she was generous with her time and her resources. She was there was there to provide guidance and advice to the 'newbies,' parents with newly diagnosed or implanted children. And on any given day, she was strategizing ways to make implantation better, to make the community better organized, to make educational

programs stronger. On this morning, she was escorting me to a CI-tailored auditory/oral educational program. It was one of the strongest and pioneering programs for the oral education of deaf students in the nation.

***Community networks***

Her home was nestled in a middle-class residential, suburban area of New York City. The phone immediately started ringing as she ushered me inside. On the phone was one of her colleagues at the Alexander Graham Bell Association[130] (AGB). They were collaborating with her on a CI-related conference that parents and professionals could attend. She discussed the information for the brochure, hung up, and then the phone promptly rang again. She discussed more details with another colleague and then proceeded to tell me about her AGB community listserv and contacts in various undergraduate programs for audiologists and speech-language pathologists in the region. She sometimes visits these programs to present on how important oral education of the deaf is and that all deaf children do not need sign language, as many seem to think. I ask her how she knows so many people and has so many contacts. "When you've been in it this long, you know everyone."

I probe further, wanting to understand how these interconnections happen. She tells me "It depends. Sometimes Sonya will call me and say can you speak to this person? A lot of them meet me at the support group. From the school here, Linda [the principal] will tell parents to call me." She goes on to explain how the school is also a site for AGB-sponsored dinners for parents. "We have AGB meetings at the school because most hearing impaired kids will get services from these schools," she tells me. "But I'm at the dinners that we do, I'm at the

[130] As I mentioned in Chapter Three, AGB is a national organization for people interested in the oral education of the deaf. AGB has numerous local chapters in each state, providing built-in and heavily-resourced communities and social networks. See www.agbell.org

meetings, I'm at the open houses, you know, so…and even some of the teachers here have called saying they have a family that has some questions, would you mind speaking to them." She also works as a fundraiser for other schools that provide oral education methods. We continue our conversation as head over to meet Linda, and as we arrive at the school, she says, "It's a pretty small community."

The school looks like any other elementary school, there are colored pieces of paper on the walls with drawings and I can hear the teachers' voices spill out into the hallway as they conduct their classes. There are eighty children at this elementary school, more than half of whom have a CI. The Department of Education is trying to prepare for the continually rising numbers of students whose parents want these kinds of services, and this is one of the programs they have been paying attention to in developing ways to cope. At the back of the corridor is the principal's office. Nancy leads me over to her door and the two of them greet each other warmly; they have an easy rapport. Nancy introduces me to the principal, Linda, and the three of us walk through the hall, peering into rooms as they both explain the set up to me.

There are an increasing number of children with a CI on one ear and a hearing aid on the other and the incidence of bilateral implantation is also rising (Brown et al 2007). All of the children had hearing aids and/or CIs and were using spoken language. In the first classroom we come to, the teacher has a variety of empty plastic film canisters filled with different items. The task at hand was to shake the canister and based on the sound it makes, determine what is inside. I watched as one implanted child guessed correctly: pennies. I also immediately notice that the teacher is wearing a microphone and that there are speakers mounted at various points in the room. In the nineties, oral programs depended solely upon sound field systems, which consists of a microphone, a 'base station' and multiple speakers. The teacher wears the microphone,

which takes the acoustic signal and sends it to the base station, which then transmits this to the speakers located throughout the room. This ensures that the auditory information is being distributed equally to all areas of the room and that all children are immersed in the sound field.

Linda explains that "About five years ago, they switched over to personal FMs…Now a personal FM is one where the teacher is wearing the mic and the children have their own FMs in their implant." These personal FMs, which operate through radio waves, can also be used with hearing aids or CIs. The signal can be transmitted directly into the child's CI microprocessor through a special jack that is mounted on the CI. Linda explains, "So you're seeing both – you're hearing through the sound field. But the children also have direct input." This individualization of technology results in using classroom equipment to meet each student's particular audiological needs, which are defined by medical professionals. "So it's very tailored…that's going to depend on the type of hearing loss they have and the audiological recommendations." Linda goes on to say, "I was happy we were individualizing, and that we had the sound field, and each child had his own system."

***CI center and school partnerships***

The implant center plays an integral role in classrooms of this CI program. The recommendations for classroom adaptations come directly from the clinic; this makes the school yet another arm of the clinic and extension of medical practice. Hence, the classroom is a *prescribed* environment. Some implant centers will "send their people here to do mappings for the kids." This is one of the pioneering collaborative efforts in this program that has caused many in the oral education of deaf students to take notice. "So you can choose to – if you were implanted at [center], you can choose to go there to have it done. Or you can make the arrangements when the person comes here, to do that." The audiological services at this school

are sophisticated. “These are the actual audiologists from the implant centers. They schedule time to come here, and they do the mappings onsite…It’s a partnership.”

This partnership between the implant center audiologists and the school is not the only staff crossover. In the CI team meetings I sat in on, there were also educational consultants in the meetings. These were consultants, often termed “educational consultants in a medical model,” work for the implant center and know each child’s case. For school-aged children who are candidates for CIs, they will visit the child’s current educational placement to assess the accommodations. This is part of the rubric used in determining CI candidacy and ongoing efficacy of the implant. For example, in a CI team meeting, as they go down the list, each chld’s school placement is discussed in depth. They will talk about the least restrictive environment (LRE) that is mandated in special education law, and discuss the politics of each placement. That is, they have to follow the law and ‘get a good placement’ for a child. Each school institution is different, has its own system, individuals within them with their own motives and politics. It can get quite complicated.

As we turn the corner, we arrive at the audiologist’s office, which is a couple of doors down from the classrooms. There is an entire wall full of tiny plastic clear drawers. In these are cables, coils, jacks, spare parts, electro-chords, electro-magnets, and batteries. The audiologist has to be able to replace any part of any child’s hearing aid or CI at any given moment. The principal continues: “It used to be everybody had one [hearing aid] ear and you just made the molds and that was education of the deaf…That was the old style of deaf ed.” But, she explains, that when she took over this program the first thing she instituted was a full time audiologist so that every child can have his/her personal system, which “is a prescription from the center audiologist.” She wanted it to be much more precise and much more tailored to the students, so

that their educational/communication method reflected their medical prescription. "Obviously it meant a huge paradigm shift, from a generic application system to customizing the FM or sound field or systems to the hearing aids or the cochlear implants…. And the whole idea is that you want it to be customized as precisely as possible."

CIs and hearing aids are not separate cases anymore, although the audiologist explained to me that, " We definitely have more kids with implants than hearing aids, at this point. It's swung. In the past couple of years, it's definitely made a turn." Furthermore, there are a large number of students who wear amplification on both ears, whether it is a combination and CI and hearing aid or two CIs or two hearing aids. There has definitely been "a swing toward bilateral as well."

As the children come up through the program, they are eventually integrated into the 'regular classrooms' of the elementary school that this program shares a building with. This kind of classroom is a 'collaborative classroom.' It is "a mixed classroom with both a teacher of the deaf and a regular education teacher."

***Teachers of the deaf***

The notion of a "teacher of the deaf" is an entry point to illustrate how the context of implantation is not just a form of mediated communication, but also a force that is generating a new meaning of this role. During my time at the school, Nancy and Linda continually referred to their teachers of the deaf. I had to inquire about what teachers of the deaf offer in the classroom as it was not apparent to me. I indeed saw two teachers in the room, but I saw nothing particularly 'deaf.' There was no sign language and all of the children appeared to use spoken language, as did both of the teachers. The principal explained to me that, "they are sharing and supplementing and modifying and accommodating and doing all the things to make this a

successful placement." I was not sure what this translated into, as I associated the term teacher of the deaf with sign language. Furthermore, when I observed a collaborative classroom in action, the children with CIs and the hearing children were indistinguishable, and the regular education teachers and the teachers of the deaf were barely distinguishable. Linda even noted that "Many times, when I'll point them out, I'll ask, "Who do you think is the teacher of the deaf?...Ninety-nine percent of the time they don't know." This is because the CI provides the access to the spoken language world, but the educational infrastructure supporting here it is intended to enrich and constantly reinforce this language. To illustrate the subtlety, Nancy tells me this story:

> One time I brought someone here, when [her daughter] was in second grade. And the teacher of the deaf was explaining something…as she explained it, she said, "Okay. Now we're going to look at this door. And I'll just give an example. The door is open. What's another word for 'open?' 'Ajar.'"…They just pull out much more vocabulary, much – they make the connection with language, so that – in reading, in math, whatever they do – it's really language enriched….The teacher of the deaf also makes sure that when a certain concept is being taught – maybe she'll have visual supports, like charts and pictures and things…and add more to the multi-sensory feel of the classroom.

The formal training for the kind of educational method seen here is auditory-verbal therapy (AVT) or auditory-verbal education (AVed). According to the principal, speech therapists typically are certified in the former, while teachers of the deaf are certified in the latter.

AGB provides the training programs and certifications, yet another link between CI companies, CI industries and the non-for-profit. These teacher certifications are specializations that individuals attain to work in these kinds of programs that are tailored to CI-related educational methods. But, AGB regularly partners with CI companies for various programs and events, emphasizing the interdependence within the technology, the industry, healthcare, and education. According to their website, "The AG Bell Academy for Listening and Spoken Language is the global leader in certification of listening and spoken language professionals." As an organization that has continually proliferated, especially as CIs have become more

common, it has a powerful stake in creating and maintaining professions that grow directly out of implantation.

From the above, it is clear that it is not just intended to provide children with the access and ability to understand and use speech, but to take it further with the goal of providing nuances. Thus, the students are immersed in an "integrated environment" and benefit from a smaller student-teacher ratio. Not only are there two teachers in each classroom but, "the curriculum is the standard state curriculum, with just whatever legal mandates are available for the hearing impaired and deaf, within the classroom – extra time on tests." Nancy speaks up here with a point that she stresses is extremely important to her, "They do not dumb down the curriculum for these kids. My daughter takes the regular, standard state test…They're not, "Oh poor deaf kid." You know?" Linda adds that, "In the old days, they were so segregated, and there are still programs – like [local deaf school that uses sign language]…When you go into a classroom, the teachers of the deaf have no idea what the general ed expectations are for the children at that grade level. Because they're not immersed in it; it's not their fault."

**"Completely separate"**

The end of my tour occurred at a building across a field a short walk away. As we walked over, Linda explained that we were going to the part of the school that did not employ these technologies or methods. This was the Total Communication (TC) side of the school. Speaking about their separation from one another, she says that when she started the program, "I was doing in-service with staff for the auditory/oral, the TC staff kind of felt like they were left out. I would provide in-service for the TC staff, and the auditory/oral teachers would feel left out. So I recognized that you really cannot have both modalities in one program." There are about half as many students in these programs that she supervises, but it does continue to grow.

Knowing that the rate of implantation is ever-increasing, I asked how it could be that pedagogical methods employing sign language would still be growing. The reason, she explained, is directly related to the access to implant technology, as well as predicted success:

> We have so many families coming in from other countries…. And the children are seven and eight years old…they've never learned auditory/speaking…They have missed the auditory development stage, which is 0 to 6. That's the critical stage for learning to listen through the auditory channel. If you miss any portion of that, it's very difficult to catch up….it's very difficult to expect a child of seven and eight to catch up auditorially. So we give them sign language.

At this particular site, these programs, TC and auditory/oral, are professionally, geographically, and ideologically separated. As Linda follows up, "They are completely separate."

***Separate pathways, separate programs***

Education is an outgrowth of the clinical patterns that I have described in the previous chapters. As an extension of the clinic, "Cochlear implants and neonatal screening have catapulted the deaf child into the auditory-verbal camp" in education (Luterman 2004). Blume (2010) also found that in implantation and education, the professional consensus was that auditory/oral and TC methods had to be mutually exclusive. This is unsurprising, especially given the neurological component of implantation; once again, the neurological divide maps onto the linguistic and educational method divide.

While this separation (and hostility) is not new, what is new is how it is being rationalized systematically in relation to implant technology. And the rate at which educational programs are growing directly mirrors the rapid increase in implantation. "Some states have documented that parents are choosing the listening and spoken language outcome as high as nine out of ten cases" (Murphy 2009:22). In 1997, Murphy (2009) notes that a mere sixteen percent of elementary and secondary students with hearing loss were aiming for spoken language acquisition. But this was before implantation became a common clinical practice. "Today

seventy-three percent of elementary and sixty-eight percent of secondary students are learning through spoken language. That's a dramatic shift to occur over just one generation" (Murphy 2009:22).

***Supply and demand***

When Nancy and I went to lunch after visiting Anne's school, we talked about the controversy over which language to use when educating implanted children. She had recently gone to a panel discussion with various professionals and educators on the topic of CIs and sign language. "Why would you get an implant and still sign?" she asks. "My child is gonna learn to deal with the –what we call the real world – because you can't have an interpreter next to you all the time and you can't live in that little community all the time. You have to get out."

I thought it interesting that her view of a deaf person was someone who was isolated and needed an interpreter twenty-four hours a day. I will come back to this in a moment, but this shows how the bodily capability to hear is transformed into social currency; hearing and listening are cultural values that bind the CI community. "This is a case of supply and demand," Nancy says. "Parents are demanding this and you're going to have to supply it." Going back to the recent panel discussion she attended, she was baffled. "I could see all the professionals down in the bottom row who were still supporting sign," but she had no idea what use sign would be if one had an implant. "They said, sign is the natural language of the deaf." She tells me that Linda, the principal of the school, her friend, and a CI user, looked over at Nancy and angrily told her that English was her natural language, not sign. "Cultures evolve and with technology it evolves faster," Nancy adds. "So yes, you have a culture, but why not integrate everything into that culture if it's something that can make the culture better. It's not making the culture worse,

it's making the culture better…Don't they understand their numbers are going down?" Nancy asks.

CIs and spoken language are seen as evolutionary progress from unmediated forms of deafness characterized by sign language. Sign is analog, outdated, and for those who are not committed to auditory training. The claim that it is 'natural' does not hold up in communities where hearing and listening are valued. Biology can be transcended through a CI and a 'neural project.' Committing to this is a moral act; it is an act of being in the 'real world,' as Nancy "The way that the CI school program is run, the philosophy, what they do with the kids, how they move them along, no hand-holding, no coddling. This is the real world." And I had heard this echoed throughout my parent interviews. Carol, like all the other parents in my study, spoke of this 'real world' element, but usually talked about it in relation to opportunities. "The language of our world right now is spoken. I want him to have opportunities, I want to him to have that spoken language." Carol and Jane both talked to me about the explosion of enrollment in auditory/oral programs. "It is going up, up, up. The enrollment for the total communication K-8 is going down, down, down," Carol said.

But while Carol and Jane expressed sympathy towards the Deaf community because of this, a strong view of ineptitude of deaf persons was present in other parent interviews when we talked about CIs and education. For example, Morgan's father Paul had expressed a similar sentiment the day I interviewed him and Julia. He told me a story about a woman telling him that getting a cochlear implant for his son was 'wrong,' that it shows he did not accept him 'as God made him.' Paul was clearly angry recounting this. He sat up straight in his seat and told me, "I'm not a very aggressive person but you back me up against the wall and I can be. You're not his parent. I am." After a pause, he looked up at me and said:

> Let me ask you a question. Suppose he's out with his friends and he tries to hail a cab in the city. Could he do it? No. Could he tell the guy 44th and Broadway? No. Could he hear what the guy is saying back and forth? No, he can't. He would need to hear in this world, just like you do, you can hear in both ears. Get a CI and you have hearing.

The general ethos that I found during my fieldwork in the CI community is that sign language is an un-mediated form of communication that, if adopted, renders people unable to be 'independent' in the world or able to succeed in an auditory/oral setting. Not only did these children need CIs, but it absolutely had to be paired with a strict auditory/oral educational method. Often, audiologists would lament that if a parent put the child in a TC program, the game was over.

***It will be 'their gift'***

Parents, audiologists, and educators are displayed one commonality: a fierce commitment to doing what they thought was best for deaf children. Linda explains:

> In life, as an adult, when it comes time to get employed, that is going to be their gift. The fact that their speech and language and their ability to converse is one of their strongest areas – that could have been taken away, if they had not had that option to learn spoken language.

The goal in implantation and its accompanying education programs is not to socialize a deaf child, but rather disintegration and/or redefinition of the 'deaf' or 'hearing impaired' qualifier entirely. That is, through technologies like the CI it is hoped that this characteristic is so mediated as to become no longer able to be perceived by others. "We think that deafness is going to be a thing of the past someday in the future," Linda says.

## Chapter 9: Conclusion: Implications and Future Research

This study of the structure and culture of cochlear implantation allows for a more complete understanding of the social and cultural lives of parents and professionals involved. Through ethnographic methods, I describe the day-to-day world of the clinic and argue that implantation, as a specific example of medicalization, technology, and management, has multi-dimensional characteristics. My research demonstrates how the introduction of CI technology has changed how individuals interact and respond to deafness, which generates new cultural practices.

From the moment of diagnosis there is a carefully crafted communication strategy as well as a series of inter-institutional co-operations between the clinic, the state, educators, professional rehabilitation therapists, informal parent support group, and social workers. A CI team – made up of the surgeon, clinical director, social worker, audiologists, and educational consultant – meets regularly to discuss each case, its progress, and strategize about how to best work with the parents.

Audiologists speak to the absolute necessity of parents accepting "the reality" of their child's hearing loss—and this is defined in starkly biomedical terms with an emphasis on acting in the present to maximize the child's future. During interviews, parents repeatedly stressed the "opportunities" they sought to provide their child through biotechnological means. Every imagination of their future was in terms of their child's ability to hear: their ability to be educated, successful, independent and happy. Because this all depended upon the ability to hear, the child's future hinged on implantation and the task of successfully acquiring spoken language.

All of these structures work together to socialize parents as effective "parents of CI users." For several years after surgery, consistent speech therapy and auditory training are

required for the child to acquire speech, although it does not guarantee it. Special education programs and other social services must also be interwoven into families' lives. The ongoing nature of implantation also produces sustained relationships with the clinic, school, and other support programs. As a result, both local and online CI communities flourish as parents meet to share experiences. A significant sociological feature of implantation is that it produces a new community based on shared, continuous experiences. Furthermore, this community shares a politics of deafness that sees it not as an identity, but a condition to be overcome and ideally rendered irrelevant through the CI.

These research provides a more nuanced understanding of how the CI clinic works, the ways professionals in the clinic communicate with and relate to families, manage workflow, and partner with state agencies. It also gives insight into mothers' experiences when obtaining a CI for their child, and the ensuing social relations that emerge out of this technological practice. There are a number of broader implications of this, from theoretical reconsiderations in the sociology of health/illness, body studies, and disability studies to practical issues of health policy and reflections upon the efficacy of Deaf cultural opposition to CIs.

But first, I want to emphasize how this study differs from most studies of implantation. Much of the discussion prior to this research focused on the controversy over CIs and stopped at the moment of surgery. But I have shown the richness of data and information that results when one moves beyond discussion of the controversy and toward gaining a deeper understanding of CI-related practices as they begin and carry on over time. It is especially important to rethink these practices as a collective act, a regimen that takes place before and after surgery, creating ongoing labor imperatives for 'overcoming' deafness. Important sociological data are gleaned. For example, practices are dependent upon and appeal to middle-class parenting styles,

stratifying implantation along class lines. It also depends upon a distinctly neurological justification; the version of neuroplasticity used in implantation directly maps onto and contributes to structuring and maintaining divisions across institutions and communities. These processes have not been a focus of previous research, giving us a new lens with which to view these medical practices as cultural work.

I have located this research at a point of convergence between a number of fields, such as sociology of health/illness, especially studies of medicalization, body studies, disability studies, and STS. I would like to address audiences in all of these, and thus I want to start with a discussion of how this research speaks to these fields in a variety of ways, both broad and specific. I take this kind of integrative, interdisciplinary approach because this investigation was fundamentally driven by the belief that disability is political. Analysis of disability and critical thinking about bodies is useful for fields outside of disability studies. Furthermore, making disability studies known across disciplines accomplishes political and social justice work.

Classic debates in sociology concern the relationship between individual and society (structure-agency), modes of social control, how technology mediates these relationships, and the role(s) institutions play in society. Disability effectively exposes the sociological concept of 'agent' as vulnerable, embodied, and varied. And from these varied, even defiantly different, bodies, what can we learn? In what unique ways do disabled bodies illustrate how subjects in general are compelled to adhere to social norms and codes?

In proceeding with an investigation informed by a political understanding of disability, I focused on one of the primary conduits of social control in society today: medicalization. I took one condition (deafness), one controversial biotechnology (CIs), and the multiplicity of ways deaf children's bodies are acted upon. The medicalization of deafness is structurally

accomplished via complex inter-institutional cooperation and convergence. It is discursively accomplished through redefining the deaf child as a vessel carrying a ripe-for-molding, nascent hearing brain. And it is the parents' expected quest (an ongoing commitment to a 'medicalized life') to develop the child's hearing capacities from which all social relations flow. These expectations were communicated through appeals to parents' obligation to cultivate particular kinds of speaking-listening citizens through technoscientific endeavors, deferment of the present (i.e.: emphasis on the future), and bodily (specifically neurological) intervention. Medicalization here was a particular expression of power, one that is, "an action upon an action, on possible or actual future or present actions" (Foucault 1981:340). So what are the implications of this research for future studies of medicalization? Is medicalization more than just a unidirectional infliction of power?

***Medicalization in disability studies***

I want to pause a moment and make my first appeal to those in disability studies: studying medicalization is important. A lot of work has been done to critique the normalization and exclusion that occurs as a result of medicalization. The primary strategy has been to focus on the social meanings of disability, specifically exposing and working to counter the view that life with a disability is undesirable and therefore should not be medicalized in the first place. Through much of this there has been a perhaps necessary shift to the *ideas* that people have about disability. We have learned to focus our analysis on the ways we think about and represent bodies, carefully positioning the social meanings of bodies as more powerful than the fleshly bodies themselves.

As I outlined in Chapter Four, emphasizing this particular version of the social model of disability and socially constructionism resulted in a turning away from the 'medical' aspects of

disability. The medical model of disability placed medicine as a cordoned off zone where disability is an individual pathology, bracketing off investigation of the causes and effects of bodily conditions from disability studies. I agree with Siebers: "How many books and essays have been written in the last ten years, whose authors are content with the conclusion that x, y, or z is socially constructed, as if the conclusion itself were a victory over oppression?" (Siebers 2008:32). I too am not content with purely constructionist descriptions because they do not reflect what is real to many people, despite how progressive Deaf or disability studies scholars may feel about it. The fleshly bodies themselves and the specific ways they are configured and acted upon in medicine are important. The grief that these bodies cause to parents or others who are obligated to care for them is important. These two things are also intimately connected.

And this is why I described how medical knowledge about deafness is produced and circulated, how parents feel and why they absorbed this knowledge, and what they did with it. I included the process of diagnosis, the despair that parents experienced, the ongoing anxiety they felt about 'fixing' it, and the structure and culture of professionals in theses medical and 'therapeutic' sites. I did not turn away from learning *how* medicalization works, but rather delved further into it to understand why it is works, upon whom it works, and some of the motivations that spur it forward.

***Qualities of medicalization***

We know that as the power and capabilities of medicine and medical technologies expand, and health becomes increasingly laden with moral value, medicalization will continue to be especially important to study. The classic question of sociology is posed: do we change society or change individuals? Who decides? How does this affect individuals and communities?

And so I return to the larger implications of this study for understanding some of the contradictory qualities of medicalization. Is it a 'neutral' descriptor? Is it an inherently oppressive process? A benevolent source of alleviation from physical and existential 'conditions?' These are important questions to tease out. To those unfamiliar with the critique of medicalization (or critiques of implantation and a cultural view of Deafness specifically, say) seeking medical intervention seems perfectly legitimate and helpful. Yet to those in sociology and critical fields like disability or body studies, medicalization is often easily cast as oppressive.

Broadly, if sociologists are to understand medicalization and effect social change within the realm of medicine, there must be some room here for an ambivalent, even irreconcilable notion of it. It can have soothing and ameliorative qualities (for a sick person, for a parent of a deaf child, and so on), even as it causes a different kind of suffering (the work adherence demands, social displacement, failed 'treatments'), performs the bidding of companies looking for markets to sell their products to, of creating or responding to socially embedded subjects that feel they need to be 'fixed,' of perpetuating projects of normalization and stigmatization. It is an ambivalent process, a strange, hard to digest mix.

At first glance, this study may seem a cut and dry argument of oppressive medicalization. And I think this research shows that critiques of medicalization are certainly warranted, especially given the Deaf cultural side of the debate over CIs, disability studies' critiques of the 'medical model,' and previous sociological studies of medicalization in relation to motherhood. I showed how clinics deliberately socialize mothers into a particular, pathological view of deafness through various anticipatory structures. I showed how mothers are appealed to in ways that appeal to their moral obligation to provide 'good' care and future opportunities for their child. But I hope the ambivalence of the medicalization process also comes through here. Many

of these parents were struggling, worried, and anxious and many found hope in the CI. I don't think this feeling of hope should be criticized. Both sides of the experience coexist; framing deafness in relation to implantation was both helpful and painful.

In Chapters Five, Six and Seven, I detail the everyday life of the clinic and the struggles of parents. Through interviews and observations, I revealed how many of the mothers in this study were grappling with their emotional process and sense of agency amidst the struggle. They were urged and socialized into compliance, at the same time trying to figure out ways of communicating with their children the best way they knew how, even if it was counter to what they were told by professionals. I also detailed how professionals actively seek to "get 'em" into the clinic and capture parents' attention and commitment. Chapter Six showed mothers' and families' relationships to institutions, especially as it relates to class. By showing how implantation is especially popular amongst middle-class white parents, I show how implantation does not resolve the 'problem' of deafness. Rather, through its own unique 'institutional expression,' it generates new social organization and social patterns in relation to it. It also produces a different kind of work; rather than working to learn sign and adapt to deafness, they must learn to train the synapses. It is on these economically stratified relations, systems of meaning, and institutions that I focus my critique, not the individuals involved. But like all institutions, they seek to preserve themselves. Here, they do so through largely through emotional work around parents' grief process, the production of a neurological understanding of deafness, and the coordination of anticipatory structures.

Blanket critique of medicalization is too blunt of a tool. I was interested in critiquing the process of medicalizing deafness and pediatric implantation, but I also found that I had to be

curious enough to peer into the emotional, social, and psychological abyss from which parents' emotions emerge from in the first place. For parents (and even professionals too), it came from a place of perceived care, of thinking that this was the best choice for the child's future (I discuss this rhetoric of 'deferment' below). But disability studies scholar Siebers (2010) suggests that when others 'care for' or enact regimens of care upon those with disabilities, it may not be a straightforward act of oppression. I think Siebers is suggesting that embracing the possibility that 'care' may be both good and bad and that seriously studying aspects of care is warranted.

But medicalization should be critiqued, especially in relation to disabilities like deafness that are stable and unrelated to one's 'health.' You call it health and suddenly it is subject to medicalization and a moral choice. This is dependent upon an 'ideology of ability' (Siebers 2008) that is already there.[131] It propels acts of intervention, demands faith in medical technology, is dependent upon a presumed malleability of the body (or here neuroplasticity) and is the scaffolding upon which the medicalization of deafness commences. It "stands ready to attack any desire to know and to accept the disabled body in its current state." (Siebers 2008:26). Critiques of medicalization at the intersection of disability are particularly important; the cultural value of disability, the social justice work of disability studies lends a useful hand in the questioning of the goals of medicine and science to "give everyone a perfect body" (Siebers 2008:7). Defying the ideology of ability means acceptance of difference, a radical act that is terribly counter to so much of our thinking.

[131] Siebers defined the ideology of ability as: "at its simplest it is a preference for able-bodiedness. At its most radical, it defines the baseline by which humanness is determined, setting the measure of the body and mind that gives or denies human status to individual persons" (2008:8).

***[Failed] Deaf cultural arguments***

This study of implantation also allows for reflection upon the Deaf critique and its failures. For all the study of disability and its social meanings and the cultural literacy, advocacy, and critical theoretical work the fields of Deaf and disability studies have accomplished, the rise of implantation exemplifies a failed battle against medicalization and biotechnological intervention. Presenting deafness as a socially constructed phenomenon and producer of Deaf culture and identity did not resonate as meaningful. Quite simply: "Appeals to experience have failed to persuade" (Blume 2010:183).

Expert, scientific knowledge trumped that of experience. Blume states that this in part because d/Deaf communities often lack institutional structures and ties to the implant world. This is true: the divisions between the communities are strictly maintained. But I found that this also occurs because of the neurological discourse specifically. Not only does the version of neuroplasticity map onto a linguistic divide, it works (in conjunction with a culture of the brain, faith in technology, and a constant emphasis on the child's 'future opportunities') to actually encourage controversy and maintain these divisions.

The bioethical arguments I outlined in Chapter Three detailing the Deaf critique also failed. Arguments that depended on the rights of linguistic diversity and a distinct Deaf culture, identity, and community failed because "bioethics had already been shaped by professional interests and by a broader philosophy of liberal individualism" (Blume 2010:183-4). The entire field of bioethics will need transform itself into one that can incorporate a broader lens of cultural concerns for such arguments to work. The American culture of individualism and tradition of parental rights would also have to be reconfigured. And this research showed that none of the professionals in implantation are literate in Deaf culture. In fact, the one time a deaf

man came into the CI clinic and I had a conversation with him, staff stopped and stared. As we stood across from each other in the hallway, people stopped awkwardly, and did not know they could walk between us and continue on their way (when signing with another person it is perfectly fine for someone to walk through). There is little to no discussion of deaf persons as a community. Only one audiologist ever voluntarily brought up the idea of Deaf culture. Upon learning I had interviewed the hospital's staff sign language interpreter, she nervously tried to assure me that they was 'sensitive' to Deaf culture.

One of Blume's suggestions echoed Rapp and Ginsburg's (2001) concept of 'rewriting kinship,' to encourage families to imagine new linguistic communities. Responding to this, Mills (2012) states, "some of this work could occur through changed counseling practices in otolaryngology clinics" (Mills 2012:326). But based on my research here, however, the culture of implantation is not one that is currently receptive to such suggestions. While language is at the epicenter of all things Deaf-related, I think important areas of future research may first need to focus more biopolitical inquiries.

According to Lemke (2011), biopolitical perspectives focus on three main sites: 1) new conceptualization of the body, that the body is less this thing we act upon than it is of a thing that is transformable, malleable through actions upon it, 2) the collective actors, knowledge production, and identity/community formation associated with such an understanding of the body, and 3) the economies and state regulation involved. Future research that focuses on these areas would be especially useful. For example, studies that analyze and use neuroplasticity and other aspects of neuroscientific knowledge to challenge practices may well be better positioned to affect the implementation of CIs. There is also much to be gained by future disability and Deaf studies-informed health policy research that works towards developing methods of studying

CI efficacy. This means demanding outcomes data upon which to base medical practice (as opposed to ideological positions).

***Science, medicine & the body in Deaf/disability studies***

In line with the above and the social world I described in this research, I think more effective critiques of implantation and a more socially just application of them will stem from a fundamental shift in incorporating the body, care, and medical practice into theoretical and empirical accounts. This means entering the realm of 'the medical' and actively considering the ways the body is constituted in such a space, the actors involved, and the culture it produces. This may seem too reminiscent of a medical model of disability. However, Siebers writes: "If the field is to advance, disability studies needs to account for both the negative and positive valences of disability, to resist the negative by advocating the positive and to resist the positive by acknowledging the negative (2008:5). Embracing the positive and negative aspects of disability means incorporating the reality fo the body and parents' responses to the body into our analyses. This is parallel to incorporating ambivalence into studies of medicalization. It requires a more nuanced and difficult theoretical terrain; it means acknowledging the irreconcilability that we must learn to work within.

Why should we turn our eye towards the medical, the bodily when so much has been done to strip away the medical from the political considerations of disability? The answer is that we have more nuanced work to do in sociological investigations of medicalization, more nuanced work to do in disability studies by incorporating the body and care. If we do not understand the intricacies involved, how can they be adequately critiqued? We must look at how much the body's physical condition shapes people's actions upon themselves and their children. This may allow us to meet parents where they are, accept the usage of CIs as inevitable, and

engage in the technoscientific discourse of the day to affect how they are used and implemented. I am talking about bracketing the critique of CIs, and shifting the focus to the *practices* surrounding them. In what ways might this be accomplished?

***Politics by other means***

In implantation, the brain is inserted as the site on the body to work upon. Our current neuroculture means that we are increasingly more willing to restructure our brains than our ideas. Indeed, this research showed that rethinking language, deafness and disability seems to be far more difficult than vigilant management of neural paths and synaptic connections. And there isn't even a guarantee that it will work. Injecting new notions of neuroplasticity, exposing science as a cultural enterprise, as well as engaging in rigorous scientific debate may be the most pragmatic way to affect the implementation of CIs. Thus, I suggest that disability studies and Deaf studies begin to take up the task of both using and critiquing neurological discourse.

In Chapter Seven, I showed how CI-related institutions are united through selective use of neuroscience, namely contradictory deployment of neuroplasticity as it relates to language. This version of neurological understanding is jumping across institutions, shaping our entire deaf educational system. In Chapter Eight, I showed how educational institutions are now the site of emergent relations stemming from shifts in clinical practice. These same neurological divisions and appeals to a child's future structure educational choices and reflect the ever-expanding role of neuroscience into society. As extensions of the clinic, educational systems maintain divisions, and these divisions benefit some programs (namely those that participate in all the related biotech markets surrounding the CI) while it isolates others (those that do not participate in these markets).

This discourse on the brain and language is untenable. Not only does this deny language in its most accessible format – visually – on the claim that they are providing children with spoken language, but it sets up the task of a deaf child's spoken language acquisition as a test of mothers' ability and commitment to their child's care, as well as the child's will and ability. This labor imperative shifts responsibility to mothers and CI users on yet another contradictory ground: the CI is simultaneously constructed as a technological artifact of hope, but also a device that is able to avoid being a 'failure' since it merely provides a signal. Despite these pressures, an orientation toward the future maintains parents' faith in the CI, commitment to spoken language, and shields the CI's efficacy from critique. "Promises, like notions of development, are based on deferments" (Wrigley 1997:210). And this ethic of deferring, Wrigley writes, is based on "the need to sacrifice immediate needs for the possibilities held out for the greater good" (Wrigley 1997:210).

But linguistic studies have proven that sign is linguistically equivalent to spoken language and that the brain actually *benefits* from neuroplasticity (Baker 2011). The deployment of neuroscience here serves to circulate binding ideological and technoscientific discourse that creates a common goal. It is based on values about language (spoken is inherently better than sign), disability (being deaf is undesirable), and our current cultural affinity for reducing social complexities to the firing of neurons  It also effectively maintains divisions and antagonism between communities. This shows that science, by mapping onto and embodying the linguistic divide, *is also cultural*.

And yet at the same time, many implantation professionals dismiss Deaf cultural opposition as purely ideological, or just a 'cultural' argument. The cultural and ideological work that is accomplished through neurological discourse does so in the guise of being 'objective.'

Scientific knowledge, performing cultural work and creating cultural boundaries, is used to dismiss criticisms of CIs, even as it derides these criticisms as pure 'Deaf culture ideology.' Some even refer to the claims of those opposed to CIs as efforts to 'indoctrinate' children into Deaf culture. As one parent who was committed to the CI told me, "This Audism group [Audism Free America] is older [Deaf] people who are trying to indoctrinate young people." The Deaf discontent here is reframed as purely 'cultural' (as opposed to scientific) and, given her use of the word indoctrination, even insidious and harmful.

Exposing the contradictory notions of neuroplasticity as cultural work in the form of scientific discourse stands to be a crucial point upon which to build more effective critiques. Furthermore, this version of neuroplasticity contributes to the divisions between language choice and communities, while it maintains controversy and generates new markets. This should not just be exposed as ideological, but also seen as an entry point to possibly breaking down some of the divisions between the d/Deaf and CI communities.

***Future research in health policy***

I want to go back to Blume's (2010) idea that this study proceeded from at the outset: much time and energy has been focused on making decisions about technologies, and so little time focused on how we subsequently live with them. As Blume showed in his study, and akin to what I found, "neither caveats nor areas of ignorance were allowed to override the conviction that because the implant had been shown to benefit hearing, it merited the confidence of professionals and of parents" (2010:176). The 'conviction' that emerges from the ideological work performed in constructing deafness as a neurological problem in relation to the CI does not just compel parents to adhere to recommended implantation protocols. There is more at stake here.

Throughout all of this, I saw that professionals and parents all had the best for the child in mind. They wholeheartedly believed –they had a conviction – that this was the best way to provide a child with a 'normal' life, with opportunities, with access to the world. No one seems to want to pry further into the particular consequences on a child's overall development that a CI might have. There might be both positive and negative effects, but either way, it remains to be seen how it affects their "sense of identity, personal relationships, schooling, linguistic competence…Linguists, psychologists, and sociologists, not surgeons and audiologists, are expert in these areas" (Blume 2010:176). While audiologists and implant professionals have acknowledged this from time to time, it is not seen as significant enough to reflect upon current practices. Unsurprisingly to sociologists of medicalization and knowledge, "any challenge to professional status and jurisdictional authority, the relevance of other knowledge and experience (whether of members of the Deaf community, linguists, educators, or psychologists – all those who might otherwise have usurped or complicated the evaluation of a medical practices) was marginalized" (Blume 2010:180).

Despite the absence of outcomes data or criteria for measuring CI success, implantation rates have dramatically risen and a CI-related health movement has emerged and fostered alliances between clinics, schools, and parent groups. I advocated earlier for integrating the body, medicine, and science into theoretical work on disability. Changes in technological capabilities, such as neuroprosthetics, will continue to demand investigation. Serious consideration of health policy related to implantation is needed in the form of interdisciplinary collaboration. Arguments for what should be considered evidence of CI success – more than just measuring a brain's access to a signal - are in dire need of crafting. As I also said above,

studying outcomes data or CI efficacy may seem counter-intuitive, but a critical voice in the medical realm is needed.

Based on the research findings here, we need to use a combination of sociological and scientific theories in order to engage with institutions and actors actively involved in the medicalization of deafness. Furthermore, comprehensive studies that examine how mothers actually integrate CI technology into daily life would reveal aspects that are currently not included in the medical literature. Leaving out what mothers are actually doing will continue to produce incomplete patient outcomes and stories of implantation. We must attend to the minutia of ongoing parenting care and interventions, the actual lives of these mothers, the ebb and flow of 'progress', and the frustrations and other emotions associated with. Finally, we also need longitudinal studies on these children. These are the moments of empirical evidence that will not only provide a more authentic account of implantation specifically, but also flesh out how medicine produces new subjectivities.

So, how do we create critical alliances that serve the interests of the children *and* the Deaf community? Parents have largely been identified as key oppressors and obstacles to the disability rights movement, but important studies are reviewing and questioning this construction (Kittay 2011, Landsman 2009, Ong-Dean 2005, Ryan & Runswick-Cole 2008). We should create a space where parents and families can be honest about experiences of impairment and the difficult terrains they must navigate. There is no reason why incorporating the realities of bodies and aspects of care *and* critiques of social structures cannot coexist. And from the social relations I described here, there are disaffected parents who work in the 'grey areas.' Might there be some kind of alliance there?

***Prosthesis, bodies, and disability***

Technology and the body are clearly co-constructed here. Deafness is not inherently or 'naturally' a neurological problem, but co-constructed as such through the CI. Prostheses in particular are most often seen as an expression of power of technology. They are generally thought to free one from bodily limits, illustrate our plasticity, and our adaptability (Ott, Serlin & Mihm 2002). But they are more than just objects of functionality, they require a body with which to work in tandem. Jain (1999) articulated how prosthesis inherently is "defined as that which supplies the deficiency…[thus it also] encodes disability" (Jain 1999:33).

I want to focus here on the particularity of the CI as a type of prosthetic, a neuroprosthetic. This study showed not only how a technology mediates one's experience of the world, but also how one's *sensory* experience of the world is managed, coded, and computed. It works upon and within the brain, a malleable organ of the body that holds the very site where consciousness conceives of oneself and one's identity. Neuroprosthetics present a particular site for body studies, especially with the CI's connection to language, the medium through which we come to *be.* There is so much more room for further study of this, especially if one considers the literature on affect theory (Clough 2007).

This study of CIs also implicates other neuroprosthetics. While neuroprosthetics like CIs are new, "There's an infatuation with them that hasn't yet been tempered by reality and experience" (Chorost 2006:174). Based on this research, I believe users of any kind of neuroprosthetic will be compelled to work in ways that other prosthesis users are not. Users must be committed not just to 'adjusting' or incorporating the device into their body and experience, but they will require specific synaptic realignment, or repeated habit that builds into and becomes a set of synaptic connections. Neuroprosthetics will not translate into freedom from

whatever frailty or variance its user has been deemed to have, but rather it will produce new forms of neural work through rote behavior. Compliance will be redefined. No matter the type of neuroprosthetic, I think it is the new forms of neural work that will emerge, especially in children, that demand more attention from social scientists.

***Summary***

I hope to have shown how disability is a fruitful way to engage in classic sociological debates, but also how empirical research, sociological methodology, and theory can be as potential avenues for further developing critical work in disability studies. I also hope I have shown how the ideology of ability ultimately hurts everyone. I showed how normative interests clearly under-gird medical regimens and compel mothers to take on the work of implantation. In general, I think denying the validity of certain bodies renders us easily coerced into the markets of biotech companies, often at the price of diverse, collective communities of care. It subjects us to the often corporate-sponsored recommendations of the state, to regimens of neural training, and the knowing glances of "bad mothering." When parents cannot and are not encouraged "to conceive of disability as other than a lifetime of pain and suffering," (Siebers 2008:196) that hurts everyone: parents, people with disabilities, and all of us as we move silently and effortlessly toward the future failure of our own bodies.

In turning an ethnographic eye to the medical, I have shown how, despite the fact that the pro-implantation side of the debate is articulated through neurological discourse and couched within the objectivity of science, it is nonetheless just as 'cultural' as the Deaf side of the argument. By embracing and being curious about parents' experiences of their child's body, I have shown how they struggled and specifically how they are socialized into and must navigate a world where the CI itself is a form of care. I have shown how the promise of CI technology is

tethered to the possibility of 'overcoming' a child's deafness. This links parents' desire for CI success with finding relief of their angst, and it is upon these feelings that their choice to use the CI everyday and in every interaction rests. The discourse circulated by medical professionals builds on this angst; the neural and even moral imperatives to commit to it an anti-sign language stance are evident.

The hierarchy between professional and lay knowledge is also highlighted. However, despite the techniques utilized by professionals in implantation to promote adherence to spoken language only, parents of children with CIs do sometimes create their own 'gray areas' and reject the strict divide between the two approaches to deafness. The way that parents merge approaches shows powerful differences in the stakes that professionals have compared to parents. I have shown a light on this point of instability; it is a possibly useful gap between the 'official' discourse around CIs and what is happening on the ground. Doing this kind of empirical work in the realm of the medical breaks down the hierarchies of cultural versus scientific, subjective versus objective, etc. and exposes the medical as cultural. The available, bifurcated models of disability here have collapsed; perhaps this is exactly the departure point from which disability studies can best proceed.

I also hope to have brought a useful sociological lens to Deaf and disability studies, fields that have been typically aligned with the humanities and other disciplines that take up the realm of the representational. However, I researched implantation from a sociological perspective that was concerned with the social relations that stem from bodily conditions as they are understood in the clinic and the 'care' work done in relation to them. That is, I incorporated a disability studies view into the sociology of the body/care/medicine/technoscience nexus. This nexus may be less familiar to Deaf/disability studies, especially because I did not blatantly take up the issue

of identity. Although I hope that by showing the constraints put upon parents and children implicates how some identities are prevented (Deaf), while others (deaf/hearing impaired/CI user) are fostered. There is much room (and need) for more work on the effects of implantation on d/Deaf identities, but I did not do that here.

While this dissertation focused on one condition and one medical technology, I hope this provides an opportunity to think more broadly about theorizing disability. I hope to have shown how looking at the medical and using feminist theories of the body that incorporate the neurobiological actually contributes to critical work in disability studies. Perhaps literacy in the neurological provides a useful discourse for both Deaf and disability studies to engage in critiquing the social qualities of scientific knowledge, and thus the policies in place for implementing it. It is time to look at the shifting theoretical boundaries and gray areas between the medical and the social, the embodied and the discursive. In light of the data I presented, I suggest that we may need a different approach, one that faces the often multiple, complicated, and irreconcilable ways of looking at things. If one can be open enough to considering these irreconcilabilities, then the analysis is only richer, not hindered.

When I was describing my research, someone once pointed out to me that my orientation toward speech therapy and auditory training was one that categorized it as 'suffering.' When confronted by this, I was taken aback. I have critiqued people for the same thing, i.e.: the imagination work that people without disabilities often do when imagining what life with disability or being deaf is like. People often assume it is a life of 'suffering' because disability is presumed to be something one inherently 'suffers' from. But Deaf persons wholeheartedly reject any notion that they suffer because they are deaf. In fact, the suffering they most identify with and emphasize is the suffering they experienced precisely because of being denied visual

language, denied access to other deaf children, and being 'forced' to learn speech. In other words, it was the medicalization of their deafness that caused them the greatest suffering, not the condition itself. This was the cultural knowledge that I brought with me to my research. I had to work hard not to project this onto my participants and onto the implanted children from the start.

Certainly, some readers will project whatever cultural beliefs or stance toward implantation, deafness, parenting or disability that they have onto this. I know that readers will try to see if or how data 'fits' into their own views on the matter. To this end, I struggled with how blatantly I wanted to critique the organized activities of the participants of my study. I also struggled with how much to only describe and leave up to the reader to decide. Thus are the limits of being a human while doing social scientific research.

Given this, what claims can I ultimately make about how oppressive the medicalization of deafness is? On the suffering of mothers or their children? Short of future research that focuses on the parents and of asking these children how they feel about their experiences, we cannot know. But shouldn't the goals here include reducing suffering – *any* kind of suffering, even the kind that results from medicalization? I hope that future critical, disability studies-informed research will take seriously the realm of the medical in an effort to understand these children's experiences as they see them. No matter the claims of professional, parents and institutions, we will need their voices. In the coming decade, as these individuals grow into adolescents and adults, this will be one of the most important tasks we face in understanding the relationships between neuroscience, technology, medicine, and disability.

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