I, Andrew J McGrath, hereby submit this original work as part of the requirements for the degree of Master of Arts in Anthropology.

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Beyond Plasticity: Cochlear Implants, Family Objects, and Quasi-Neuronal Lives

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Beyond Plasticity:
Cochlear Implants, Family Objects, and Quasi-Neuronal Lives

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ABSTRACT

This thesis examines how pervasive biomedical economies of care have become in the everyday lives of families with children who hear with surgically inserted devices called cochlear implants (CIs). Based on time spent observing the experiences of three such families, including my own, I analyze how contemporary medical epistemologies become entangled both morally and pragmatically in the months and years after diagnosis, surfacing most fluidly at the level of familial relationships. As a way of highlighting the importance of individual family’s worlds for negotiating the experience of biomedical ways of knowing, accompanying the text of my thesis is an experiment in visual collaboration among my research participants and myself. In an attempt to find multiple ways of presenting ethnographic research that traces the affective feeling and resonance of my interlocutors’ worlds, I have worked with them to take photos of objects they use in their everyday lives. I want to think about image making through photography as a seed for each family’s varied resistances to their biotechnological futures. Our acts of collaboration, as experimental and expressive practices, stand as relational proving grounds for cultivating an evolving everyday form of counter-hegemony.
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For M and L
# Table of Contents

Abstract .................................................................................................................................................. i

Acknowledgments ................................................................................................................................... iii

Introduction ........................................................................................................................................... 1

Andrew, Mary & Lottie......................................................................................................................... 15

Christine & James ................................................................................................................................... 34

Ayesha, Bashar & Mena........................................................................................................................ 43

Circulation and Difference ................................................................................................................... 51

Conclusion ............................................................................................................................................. 60

Bibliography ......................................................................................................................................... 67
All digital photographs included in this thesis are the collaborative work of the author and his research participants.
INTRODUCTION

On a winter evening, some hours after she had given birth, Mary and I slept despite the unease at being away from our newborn daughter. I struggled to get comfortable in a hospital room set for two patients that barely fit one. The Catholic hospital in urban Cincinnati functioned as a non-profit that readily accepted Medicaid, and as such, was one of two places in the city where poor folks could have children. The other was the local university hospital, but they were always overburdened and were not taking new patients when our kid was due.

Mary was in considerable discomfort; she had torn significantly giving birth to our daughter Lottie several hours earlier. She stirred and tried to induce in herself any distraction from the offers of pain medicine that multiple nurses had presented to her. Mary had deliberately toiled through a drug-free childbirth. Like many young women, she endured pain as a deliberate rebuke of our parents’ eagerness to embrace the medicalization of childbirth in the latter half of the twentieth century (Martin 1987). Indeed, Mary was more upset by the absence of our baby in the moment, than the hours she spent in delivery. Lottie had been taken by a technician inside her metal bassinet and wheeled down the hallway, out of sight for over an hour. Ultimately it was the anxiety of being apart from the baby that pushed Mary, at some point after midnight, to accept the Percocet from the shift nurse. It was more to quell the tension and panic than the pain.

Around two in the morning, we were roused by the clanging of the bassinet as it bumped into furniture on its way into the overcrowded room. I lumbered and rolled off the makeshift bed; there was no easy way to get off it otherwise. Mary sat up straight from sleep, nearly dislodging the IV inserted in her forearm. She winced as the technician turned on the nauseating
fluorescents overhead. Lottie whimpered and began to cry softly; her lungs were still wet and not at full capacity. I fumbled for my glasses, eager to see my child.

_So, your baby failed the NIHS. You are going to have to follow up with an audiologist soon. It’s probably nothing._

The words of the technician were obtusely blunt. In the diffuse green light of the hospital room, her blank face and lack of eye contact gave her the affective air of a bored teenager. My stomach lurched. Mary’s eyes opened to full orbs rolling between Lottie and me. She began to ball the bed sheets up in her fists. As the technician made gestures to exit without any further explanation, Mary pleaded sharply, a mounting agitation in her voice: _What is that? What test is that? Is there something wrong?_

The technician answered: _I’m sorry this is the NIHS. It’s the Newborn Hearing Screening. We do it to make sure that your baby can hear properly, but failing the test could be because of other things, too, so don't worry. Like, she could have amniotic fluid in her ear canals, which messes up the test. That’s why you got to follow up with an audiologist to do a couple more, better tests that can tell you for sure...._

We both braced ourselves against the closest pieces of furniture to us. It was like an electric skewer had pinned us each in place. Choking on the heat, we failed to muster a response to what had been said. The words were a flash fire carbonizing this event with a thousand unanswered questions. Lottie began to cry loudly. As we turned to her, the technician briskly exited the room as a person might retreat from a bombing. Were it our own health, the

1 Throughout the text, italicized dialogue represents speech I have reconstructed based on my recollection of events as they happened. For dialogue in quotes, I have transcribed those from audio recordings exactly as they were spoken during my fieldwork.
dismissiveness of the technician might have been a source of consolation. Like other first-time parents, we opened ourselves up to biomedical post-natal screening technologies with a certain level of heightened ambivalence. Rationally speaking, we could expect the occasional lack of clarity in the aftermath of tests, scans, and even procedures. But our fragility of mind in the hours after baby’s delivery heightened our senses to the buzzing spaces between the passing and failing of routine markers. Indeed, our questions about inconclusive results on a hearing test ignited the lower rungs of a funnel of fire, searing us away from both our happy futures, and for some time onward, each other.

I picked up Lottie and handed her to Mary who began to shake and cry in undulating syncopation with the baby. Neither of us knew what to say. We could neither make sense of the news, nor how it was given. In the months leading up to Lottie’s birth, we pondered possible issues that could arise. Mary’s obstetrician had offered us amniocentesis to look for genetic markers for congenital conditions such as Down’s Syndrome, but after measuring the risk inherent in the procedure, Mary declined it. If there was a sense of savviness in us as we planned for Lottie’s arrival, or a mutual belief that we had anticipated all possible post-natal futures for our young family, we had hitherto been stripped of our arrogant reproductive cosmopolitanism.

Indeed, what we would come to know as congenital hearing loss was so foreign to us that the words used by the technician pooled around our heads, something smeared and indecipherable. It was an event: a cataclysm so visceral that we could not reach one another in the moment to begin to process what could be for our daughter. Instead, as Mary nursed Lottie, I flipped the overhead lights off and lay back down. All three of us were out within minutes.
The Pains of Diagnosis

That night, Lottie had been whisked away to experience what is required of all newborn babies by law in almost every state in the country. Called the Newborn Infant Hearing Screening (NIHS), it was enacted in Ohio to address the fact that so many children born with severe to profound hearing loss were being diagnosed late, sometimes by up to three years (Carney et al. 1998; Yoshinaga et al. 1998). Deafness, which for more than the past hundred years had been culturally ensconced in the fabric of American disability narratives as an out-group with its own culture and norms, in that moment, had been revealed to me for the first time as a temporal contingency. Something can only be diagnosed “late” if there is something that could be done to change it. Deafness has emerged in the twenty-first century as a biomedical condition to be monitored and mitigated through the confluence of science and its accompanying ideologies.

This thesis examines how biomedical economies of care have become pervasive in the everyday lives of families with children who hear with surgically inserted devices called cochlear implants (CIs). Based on time spent observing the experiences of three such families, including my own, I analyze how contemporary medical epistemologies become entangled both morally and pragmatically in the months and years after diagnosis, surfacing most fluidly at the level of familial relationships. Further, I describe how my interlocutors resist, accommodate, and modify an emerging climate of “neuronal-fitness” that increasingly has become the bar against which parents of Deaf children are measured, if their child is to be an ideal candidate for CI surgery (Mauldin 2016; Rose 2012).

As a way of highlighting the importance of individual family’s worlds for negotiating the experience of biomedical ways of knowing, accompanying the text of my thesis is an experiment in visual collaboration among my research participants and myself. In an attempt to find multiple
ways of presenting ethnographic research that traces the affective feeling and resonance of my interlocutors’ worlds, I have worked with them to take photos of objects they use in their everyday lives. My hope is that such images can embody the subtleties with which each family engages the loneliness and implicit violence of clinical encounters, creating traces that speak to an identifiably human presence, while retaining their anonymity. For this reason the photos are placed without captions. This allows them the space to both align with the ontic nature of the following ethnographic encounters, and to subsequently attach to broader narratives of life and matter in resistance to the specter of sovereign power in the twenty-first century.

More than that, I want to think about image making through photography as a seed for each family’s varied resistances to their biotechnological futures. Our acts of collaboration, as experimental and expressive practices, stand as relational proving grounds for cultivating an evolving everyday form of counter-hegemony. As Susan Sontag writes, images can circulate at both private and public levels. In her book *On Photography*, Sontag frames the familial practice of taking pictures as both a way to memorialize a vanishing past and “take possession of space in which they are insecure” (1977, 9–10). By engaging families unsettled by the diagnoses of their children in photographic curation and creation practices of otherwise banal material objects in their homes, it becomes possible for my interlocutors to both acknowledge a vanishing past and solidify within their intimate worlds a “political otherwise.”

Here, political is not the broad strokes of structure and power, but the civil imagination promised in any act of collaboration that seeks to establish its own agency (Azoulay 2015, 175). Locally, the images document material traces of each family’s world, chosen by them to be included from the convergence of things in their lives both within and without the clinic. They are photos that necessarily document, but do so abstracted from their immediate contexts. Taken
out of a linear trajectory, the objects and their portraits become vital agents in their own right, capable of enmeshing and even countering the assumptions of what life is like for a biomedically marked family.

While all of the families I have engaged with here are often defined by their relationships with the clinic in ways both active and passive, each also hums with alternative narratives of love, resistance, and hopeful self-determination. However, neuronal plasticity in the brains of our children has meant clinicians demand of us the strictest cadence in our adherence to their pedagogical conceits. Medical economies of care have been intervening into the lives of children and their families through technology earlier and earlier. These clinical approaches have evolved partly to mitigate the perceived risk in cost and care the dis/abled individual poses for society as a whole. In the pages that follow, I argue that individual and collective compassion, intimate resistance, and imagining a “political otherwise” can set us on different trajectories that embrace the inherent risk in living. I aim to show that early twenty-first century brain-based epistemologies and the technologies they require can engender both a thorough rendering of the disciplined body and, through the relational attachments they equally facilitate, abled and materially augmented families, who themselves expand the borders of Deafness into more inclusive and intersectional domains of experience, less encumbered by an artificial medical/cultural binary.

**Methods**

Through this thesis, I highlight how the intimacy of everyday life may offer material, affective, and political ways past being subjects of neuronal governance, or bodies as their
neurons alone. I explore how the bonds of partnership, and their potential to disrupt the structurally known and normalized, may, in fact, offer lines out of the inevitability of marginalized differences. I assert that optimism for individual families is not predicated on one particular form of political adherence. Instead, I conclude that it is the relationships among parents, children, and everyday spaces that offer both resistance and accommodation to essentialist understandings of the brain-as-self.

This research is based on twelve weeks of participant observation at the homes of three families with children who use cochlear implants. It is partially auto-ethnographic, in that my data and resulting narratives are shaped by and situated in my own experiences having a child with cochlear implants. In addition to participant observation, I interviewed the parents from these families three to four times each. The interviews were open-ended and captured with a digital recorder, transcribed by me, and coded for themes using NVivo software.

As stated above, my research also included collaborating with my interlocutors on a series of photographic still-life portraits. My hypothesis was that while biopower was certainly pervasive in these families’ worlds, it might lose some of its augmenting effects in the everyday if families could render their lived environments unique from the clinic. I went into the photo experiment with several parameters that would remain the same across each family. First, I constructed a light box using tissue paper, duct tape, poster board, and an old cardboard box. The design for this came directly from a how-to craft channel on YouTube. I decided that any items we would photograph would be situated best outside of the spatial contexts of the home. In several instances, objects needed to be re-photographed at later dates. This was a result of poor initial image quality and the belief that the aesthetics, as much as the structures of the act of creation, are vital to understanding how the end result can circulate beyond the captured moment.
For these photo sessions, parents from each family were given the size parameters of the light box (about one cubic foot) and asked to provide objects from their everyday lives of their choosing.[^2] The items could be banal, but needed to be well used and currently part of any number of things circulating in their household. These objects did not have to be things they would readily attach to themselves—that is, things that were aesthetically representative of their core identities—but I did not dissuade this either. After the objects were collected, we met at their homes to photograph them with my Nikon D3300 DSLR camera and external lighting rig I borrowed from the University of Cincinnati.

After the photographs were shot, we continued collaborating through a virtual editing process. Because I had more experience in Adobe Photoshop than my interlocutors, I did the manual post-production work and circulated the results to each family for notes. While some individual parents were more engaged in this facet of the creative process than others, images became more and more abstracted from any notion of traditional documentation. Instead it began to emerge as material traces of both the current and speculative desires of each family. As I will discuss, however, such desires were not necessarily always independent from the ethics of the clinic. While I unpack the collaborative photographic process in chapter four, the photos themselves are set on pages throughout the text, roughly corresponding to the family at the center of each chapter.

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[^2]: I will elaborate these reasons in more depth in chapter four, “Imaging Difference.” Briefly, I did not want recreate an exercise in *in situ* documentary style photography. Such an approach is historically and readily associated with representations of “real life,” which have become problematic within both visual anthropology and other social sciences that view photographic documentation as an emergent but loaded tool (Edwards 2012; Pinney 2016; Strassler 2010).
As will become apparent, I went into the process making theoretical assumptions that were, on their own, somewhat overreaching. The familial relationships with the clinic were as varied and complex as the families in my research. But these unexpected differences among institutions, ethics, and families opened up a dialogue about the affective nature of biomedical epistemologies and, in the end, drew forth a line of experience from the participants that spoke to the ambiguities of their individual engagements with the clinic.

**Organization**

Chapter one begins “Andrew, Mary, and Lottie.” Pulling on the work of critical science studies scholars and an ethnographic engagement with my own family, this chapter addresses the concept of *plasticity* as employed in brain research and in narratives about dis/abled pediatric developmental trajectories in the early twenty-first century. Starting from previous qualitative research done on the topic of cochlear implantation and families, I explain how plasticity becomes not only a biological imperative, but also a moral one. Rather than focusing solely on the pedagogical mandates of the clinical encounter between parents and professionals, I frame the experiences of my interlocutors instead as existing in states of relational suspension. Here, parents are not simply one complicit party in the bio-medicalization of their children, but rather are entangled in a milieu comprised of both intimate familial dreaming and the reality of clinical-essentialist norms. Ultimately these families coalesce and re-situate themselves in atmospheres where the pragmatic acceptance of some aspects of bio-epistemologies mesh with a critical resistance to the rote objectification of their children’s bodies. This narrative allows for a deeper
exploration of the appropriation of the biopolitical gaze by some Deaf scholars and members of the Deaf community as paradoxically emplaced upon children with cochlear implants.

In Chapter Two, I complicate clearly demarcated political parameters surrounding medical epistemologies and the effects it has on CI families and the broader Deaf community through the experiences of “Christine and James.” Christine is a typically-hearing mother with deaf parents who herself was raised within the Deaf community. Despite her upbringing and direct kin ties to signing Deaf Culture, she has chosen to implant her own profoundly deaf child James. Her embrace of the pedagogical and epistemological mandates from the clinic is tempered by slight but profound acts of linguistic resistance in her clandestine use of American Sign Language during critical stages of developmental neuronal plasticity in her son’s life. While she is mostly attuned to the narratives of normalcy and the mainstream often used by intervention teams to make a moral sale to new parents of deaf babies, Christine still attempts to dissolve the experiential wall between CI families and the Deaf community. Temporarily eschewing this entrenched binary helps me to focus on spaces of ambivalence and isolation that cautiously points to implanted children as inhabiting a new kind of difference, emergent from, but still entangled with, the threads and knots of Deaf Culture. Remediating these political separations and engaging the persistence of biotechnology helps me pose open-ended questions and speculations about possible futures for my interlocutors.

Chapter Three, “Ayesha, Bashar, and Mena,” centers on the experiences of Ayesha, a cardiologist and immigrant from Pakistan, and her family. Ayesha’s extended family embodies a complex web of changing moral epistemologies governing the dis/abled body and the failures of

3 A word on the capitalization of “Deaf”: Using a capital “D” in the word Deaf refers to Deaf Culture and denotes identity and power. A lower case “d” in the word deaf refers to an audiological condition.
biotechnology to mitigate the range of possible risk in human futures. Ayesha’s daughter Mena, in addition to being profoundly deaf and implanted, is moderately cognitively disabled in ways that manifest in intellectual and gross motor delays. In detailing the family’s experiences sending Mena to an oral/speaking school for children with CIs, I explore how such programs rely on an ideal conception of the dis/abled child that works to streamline what kind of pupil the technology is best suited for in concert with a tailored kind of therapeutic education.

Finally, I engage in a meditation on the ways both images and conceptions of the Othered body can circulate at multiple registers and through varied geographies, ultimately catalyzing dissimilar experiences of the world of CIs. As they resonate within different spheres of experience and structures of power, bodies enmeshed with biotechnologies like CIs might inherently be products of risk analysis and mitigation in a Late Capitalist world. But the very access to typically hearing environments granted through CI intervention may also be the spaces through which persistently marginalized groups within normalizing dis/abled narratives can push for, through solidarity with implanted children and their families, an acceptance of risk as a marker of positive inclusivity.

Set against an auto-ethnographic vignette relating my family’s experience being the focus of a short documentary on cochlear implantation, I conclude the thesis with a critique of contorting implanted children and their families into reductive slots of exceptional perseverance. I posit that narratives like the one conveyed in the documentary further isolate implanted children from the broader Deaf community in ways that serve only to disempower both groups. Such bio-epistemological discourse tends to reinforce a secular neuropolitics (Connolly 2002) as the only valid epistemology to accept. In contrast to the story and images of this documentary, I position the act of photography and the resulting photos of my collaboration with the families as
manifestations of a relational intimacy that creates a counterpoint and an embracing of unseen future ontologies of difference.
CHAPTER ONE

ANDREW, MARY & LOTTIE

Lottie was two months old the day representatives from four separate institutions and agencies came to our apartment to meet her and discuss with us a future course of action. A month earlier, our baby was officially diagnosed as having profound bilateral hearing loss. The intervening weeks had been difficult. Our lack of sleep, compounded by the existential anxiety imbedded in our experiences of Lottie’s unexpected diagnosis, had begun to take their toll on our relationship. The stress manifested in a lethargic silence between Mary and me, and a disconcerting lack of discussion about what life with a deaf child would be like. The idealistic plans for our futures as parents, and our new daughter’s emerging life path billowed out of the drafty windows of our cramped and cracked home. In fact, our thoughts hung more on the horror of having professional strangers into our two-room apartment than on what developmental parameters to ascribe to for our kid. The apartment was a wreck and we had no motivation to change that.

We had lived in the apartment for two years by the time Lottie was born. It was small, affordable, and sensible in how it met our needs as we worked bar hours together in a local coffeehouse and tavern. But the walls closed in on us in the months leading to Lottie’s birth. The neighborhood was a blighted, one-time working-class community where extended families, once open to each other, now mostly kept to themselves. The housing stock was old and lacked the charm fostered by upkeep and continuous monetary undergirding. Yards varied in cleanliness; absentee landlords owned most of the property, including the duplex where we lived. When we
mentioned we were expecting, our elderly neighbor warned us of the lead problem that extended across the entire block.

Well-wishers and family piled our two rooms with mountains of gifts for the baby. The crib I constructed seemed to take up a full third of the available space. In the weeks after the birth and diagnosis, Mary and I buried ourselves in trauma and sadness. The things of new babies—the noisemakers, the musical apparatuses—felt like cruel insults, or at best, vestiges of some other couple’s intentions.

Lottie herself was cherished, affectionate, but docile in the way all newborns tend to be in their first couple of months. Mary, despite her devastation at Lottie’s deafness, was disciplined at breastfeeding. Mother and baby became quite inseparable in that way, while I attempted to organize the slate of appointments and evaluations Lottie would need. This visit to our apartment was one of the big team meetings that had to happen for services to be effective, or so it was presented to us. Despite this, the event did not feel like a team meeting. As two social workers, a deaf education specialist, and a care coordinator from a local child services non-profit crammed into our little mess of a world, I now remember it as an evaluation of us.

In her book *Made to Hear*, sociologist Laura Mauldin describes what she calls “anticipatory structures,” or the infrastructural roles played by professionals and the tests they administer to ensure deaf newborns are placed into the proper care pipeline (2016, 37–49). As Mauldin points out, evaluation for services indicates that certain children will end up getting qualitatively different care than other children. While some of this is related to the etiology of the hearing loss and specific biological factors that point to one intervention trajectory being preferred over another, the evaluation process raises questions about how socioeconomic differences are stratified through anticipatory structures of care. Mauldin, however, makes clear
that it is the *parents* of children marked for cochlear implantation that become the focus of an epistemological intervention in the early days of the diagnostic process.

This dynamic was not lost on me. On the day of the meeting, I found myself overcompensating with diction and tone to offset the reality of our poverty: the mildew, the clutter, the un-mopped floor. The more I self-edited and tried to seem intelligent, or frame my family as temporary victims of financial circumstances, the more confused our guests appeared. None of it felt right. It was certainly not supportive or therapeutic. The particulars of our situation made us feel guilty of some form of child-neglect. Our financial, familial, and aesthetic wounds were so apparent around our beleaguered apartment. They became for us shameful marks of our unfitness: judgements projected into the eyes of the professionals cramped onto our tiny couch. Despite this class self-consciousness we imposed on ourselves, after telling them we had Medicaid, talk quickly turned to cochlear implantation.

Access to CIs as therapeutic tools are contingent on a confluence of social and economic capital. There are perspectival trade-offs. Wealthier families are the best primed for having children who will be successful CI candidates. On the whole, they have the financial resources, but also the attunement to the prevailing moral infrastructure that undergirds a secular ethics now normalized for those who can turn to medical professionals without fear of ruin (Christiansen & Leigh 2002). But possessing Medicaid, as we had since the second trimester of Mary’s pregnancy, was a boon for all parties in the CI process, since they could bill for services rendered.

Indeed, there was a palpable shift in the mood in our living room when we revealed that we had coverage through Medicaid. We were well spoken, if nervous. In our one bedroom apartment in a dodgy neighborhood, this meeting felt like an odd performance for the benefit of
our guests, as though we kept secrets that could explain our place in the world. But no matter, with Medicaid there would be no reason to speculate on access to cochlear implants and no pertinence to wonder what we could leverage to get the procedure paid for. What really mattered was our ability to be trained in the nuances of neuropolitics (Connolly 2002).

This topic was broached and led by Natalie, a deaf educator who specialized in children following an oral/speaking route of education. She looked around our apartment as she talked, unpacking information on childhood neuronal development, slowly working through each aspect of the specific timing inculcated in certain milestones for children’s cognitive growth. Her eyes stopped on the kicked over piles of records and CDs next to our frameless mattress on the ground near to where we all sat. Taking her cue from what she could gather from our material environment, especially the festooning clutter throughout the apartment, Natalie integrated the oral/speaking script and the benefits of cochlear implantation into a narrative tailored to her speculation of how we might envision Lottie as a toddler:

*Imagine Lottie being able to dance and sing to music! I suspect you guys are into music, so I’ll bet her hearing loss has you worried about the possibility she might not ever get to enjoy your favorite band. Well, with the proper training and honing of the brain, Lottie will be able to pop in her favorite Wiggles album and enjoy it! Now, CIs won’t give her the same experience you and I would have of music, but the earlier and more intensive the conditioning of the neuronal circuits, the more profound music will be for her.*

While the professionals there that day were courteous and bore no ill intent, in hindsight it became clear that the meeting, as well as multiple others with surgeons and audiologists over succeeding months, was a subtle evaluation of our receptiveness to a very particular narrative about the brain. From the beginning of the clinical intervention into the lives of families experiencing a child born with profound hearing loss, the story of *plasticity* takes center stage. All of the structures put into place are there to facilitate harnessing a baby’s potential for aural
neuronal-plasticity in the developing brain. By proxy then, it is the parents’ acute acceptance of this idea that makes or breaks their child’s potential candidacy for CI surgery.

Having a child for the first time is an experience that is relatable. It often connects people across vast social and economic divides in the United States, if not everywhere. But unexpected disabilities in newborns elicit both very personal reactions from parents and increasingly public structural responses rising from safety nets bureaucracies, institutions, and care providers have put into place to anticipate such births (Rapp & Ginsburg 2001). These responses are directly attached to the possibilities of science in general, and cognitive intervention in particular. In the latter half of the twentieth century the vehicle for this was primarily pharmaceuticals, but the new century has seen the emergence of biotechnological implantation procedures, viable catalysts for the enmeshing of people and circuitry to mitigate disease.

**Biopower and CIs**

In his lectures *Society Must be Defended*, Michel Foucault describes biopower as the control of human bodies through epistemologies of reason, which are used by institutions as ideologies to fetishize their ordering effects on all people (2003, 240). The end result is a stratification of life along a moral spectrum, but which in practice, creates binaries of worthiness and unworthiness. A prerequisite to this sort of biopolitics is the ideological and epistemological control over life itself. Here, the dis/abled body becomes a risk for society because it requires accommodations and cannot fit the structural, epistemic, and competitive norms of late neoliberal capitalism.
Deaf Studies scholar Harlan Lane’s 1992 book *The Mask of Benevolence* paints a stark opposition between the medicalized world of cochlear implantation and Deaf culture. Using biopower as a frame, he asserts that the body of the deaf child is objectified through medical intervention and thus devalued by society through an isolating individuation (Lane 1992, 81). Further, Lane points to the cochlear implant intervention as the ultimate ceremony of cultural suppression and indoctrination of the deaf child’s body. By intervening with biotechnology from the very beginning of the child’s life, language, culture, and community are being repressed through the isolating and devaluing practice of the CI economy of care (Lane 1992, 84).

Similarly, Paddy Ladd writing a decade later argued the clinic had reached a point where such interventionist practices had become refined among state, medical, and private infrastructures. Calling it a clarification of biopower, Ladd asserts that Deaf culture had now fallen on one side of the bio-politically informed abnormal/normal binary (2003, 123). According to Ladd, within this dichotomy, there is little ambiguity about the cause mobilizing the clinical methodology. The implanted child is a victimized body, wrangled into solidified structures of the essentialist gaze of medicine. Thus, for Ladd and Lane, biotechnological intervention is a process that strips children of their subjective experiences of Deafness. Moreover, their parents are complicit.

Pushing back on this, anthropologist Michele Friedner writes that while Ladd and Lane aptly describe the classification, individualization, and medicalization of deaf children through parameters of biopower, they fail to see how power itself created the conditions through which the Deaf community was politically possible in the first place (2010, 336–347). Arguing against the notion that Deaf culture is solely a site of resistance to biopower and normalizing epistemologies, Friedner highlights the ambiguities experienced in lived practice for individuated
deaf bodies (2010, 337–340). While the Deaf community has been considered a safe space for people with congenital hearing loss, possessing in itself a varied and rich culture and history as plural in scope and practice as there are countries in the world, it is unique as a subaltern body. For deaf parents living within Deaf epistemological norms, there is no guarantee that their children will be born deaf themselves. Regardless of individual familial desires about the statuses of newborn children, the broader Deaf community is consistently faced with the realities of integrating the needs of mixed deaf/typically hearing intergenerational relations into their broader identity (Buchino 1993).

Following the logic set forth by Friedner, if Deaf culture is entangled with biopower in productive ways where bodies are simultaneously objectified and empowered, then the same may also hold true for deaf children who are born and then undergo cochlear implantation. That is, though Ladd and Lane frame cochlear implantation as borderline genocidal for the Deaf community, the reality is that the majority of children with cochlear implants have been born to typically hearing parents (Papsin and Gordon 2007, 2380–2387). Such parents, like myself, not only lack experiential connections to the lived phenomenology of life in the Deaf community, but proximal connections as well. What does it mean to be given an epistemological map from a community that is exterior to oneself with instructions for how to raise one’s children?

While, on the one hand, this is an argument that can be made against clinical knowing and the biomedicalization of parenting, it is equally possible to use Ladd and Lane’s logic to turn their argument back on themselves. If cochlear implantation is the embodiment of the clinical gaze for some Deaf scholars, it could also be argued that imploring parents to conform to the norms of the Deaf community can equally be seen as an instance of corporeal hegemony. While the burden of structural violence is unequal between the clinic and the Deaf community, internal
policing of the borders of the linguistic and social practices within Deaf spaces by Deaf communities and activists could be experienced as a biopolitical divide by the child and her parents. This is particularly true in situations where typically hearing parents are raising a deaf child. But, as I will relate in chapter two, such closure also marks hearing children of deaf parents as well. Despite the reproduction of essentialist norms of value and worth that make Lane and Ladd’s assertions problematic, their assessment of biopower’s effects on the body of the Deaf child are useful ways to consider how state, medical, and private institutions ideologically and pragmatically engage the dis/abled child and her family. As with multiple disciplines engaging Science and Technology studies (STS), Disability Studies has turned to notions of the plastic brain to highlight the need to de-normalize what counts as healthy versus pathological (Friedner 2010, 346).

**CIs and Plasticity**

Cochlear implants are a technology used to treat severe to profound hearing loss. Because they are not able to come close to mimicking the abilities of human hearing, they are not a cure for deafness. They are biomedical devices, surgically implanted, that function as a proxy for the damaged hair cells of the cochlea in the human inner ear. They work best for children who receive them prelingually.

The earliest commercially available implants were implanted in children and adults in the 1980s. Those who received them varied in age, and it was this diversity that clued researchers in to the problem of a temporally contingent plasticity in the neuronal structures of the brain, and its effect for the CI process. As clinicians longitudinally tracked the quality of the implanted devices across the early years of the availability of the procedure, they observed that those people...
implanted later in age received little benefit from the CIs. They were crude instruments by today’s standards, but, more importantly, it was clear that one facet of successful cochlear implantation relied on very early access to sound in the brain itself.

Ideally, the CI is surgically implanted by the time a child is one year of age. This is the earliest clearance given by the FDA and follows the guidelines of the extensive structures of intervention set up to anticipate the experiences of unexpected deafness. However, clinical and biomedical advocates for CIs—ranging from doctors to medical device manufacturers—have lobbied for earlier implantation. This is grounded in a fundamental argument of neuroplasticity, which has become a mantra used in brain research to describe the brain’s contingent structural formation (and reformation), and advocate for harnessing the most out of the evolutionarily supplied neuronal pathways before they are lost to other brain structures vying for real estate in the temporal lobe where sound is processed. STS scholars Andrew Pickering and Nikolas Rose have used the emergence of brain sciences, specifically tropes surrounding neuroplasticity, to highlight how socio-political power embodied in clinics and governments are tying neuroscience to deeper moral imperatives (Pickering 2010; Rose 2006).

CIs work by taking in sound from the environment through a tiny microphone that sits on an earpiece, a loop of hardware that resembles a hearing aid. That raw sound is funneled along an outer cable to a series of coils, one magnetized on the outside of the person’s skull, the other on the inside of it. In between the inner and outer coils, the sound is digitized and turned into electrical data that is carried down a fibrous wire into the damaged cochlea of the person’s inner ear. Here the electrical data is metered out as impulses that take the place of the hair cells of the cochlea, thus stimulating the auditory nerve into hearing those impulses as sound (Young and Kirk 2016, 128–131).
This is not an automatic process. For the data to be perceived as sound, the person using CIs must engage in very intensive aural habilitation. This enables them to do the training in their brains that typically hearing people do as early as three months in the womb (Young and Kirk 2016, 44). Clinicians, audiologists, and ear, nose, and throat specialists form the core of an economy of care that has made intervening in this process key to the success of CIs. Together with social workers and Deaf educators, they form teams of interventionists whose function is to usher vetted families into the pipeline of cochlear implantation surgery. For them, this begins with the willingness of the Deaf child’s parents to accept the dogma of neuroscience.

Because brain science has become a commoditized discipline in the academy as well as in western bureaucratic initiatives and budgetary plans, CIs are an example of a kind of synthesis of a reductive point of view, based in the clinic but provided to everyday people as consumers of healthcare (Pickering 2010; Rose and Abi-Rached 2013). Again, Rose points to a moral infiltration concerning the practical adoption of neuroscience as an epistemological norm in the minding of bodily care (2013, 134–135). It lends itself to being attached to an undergirding set of imperatives designed to include those who can adhere to the principles of use while excluding those who opt-out, or more likely, who lack the capital to navigate these emergent ethics-based health mandates.

In recent analyses, philosophers of science have taken the consumer-driven model of neuroscience as part of a more diffuse late capitalist ideology embodied by neoliberal structures of care (Mauldin 2016, 127–128; Reese 2016; Rose 2009). Patients are not only assessed as medical problems. In order for biomedical technologies like implants to work within the milieu of the private home and body, social support structures surrounding any potential patient must be responsive and pedagogically malleable. Neuronal plasticity, or the ability for the neurons in the
brain to be changed through therapeutic conditioning, is not simply a good model of cellular development. It is equally a moral model of transformation, where human worth is quantified by one’s ability to move towards preferred, less risky incarnations of oneself.

Foundational to this change is a fostering of bio-essentialist ethical beliefs in everyday non-scientists. Faith in the brain as a site of human identity and the belief that it can be molded and contingently remade, is a pillar of an emergent secular worship rising from our latter day neuropolitics (Connolly 2002; Rose and Abi Rached 2013, 6–9). This fetishization of the brain in western popular discourse is anchored to the view that our executive organ is the black-box of self and other, and the true home of what is real. Essentialist understandings of the brain compartmentalize everything into the neural networks, collapsing experience into sensation and thought into chemicals. Indeed, for cognitive neuroscientists, the spaces between us, and the matter of the universe that exists outside of ourselves is now understood as so much noise, or figments of an evolved anthropocentric perception.

Plasticity has emerged as the promise for greater malleability and control over the human brain. Through our biological understanding and pedagogical training of the developing brain, the bundles of neurons, unfettered by theoretical notions of extended selves or intersectionality, stand to become each one of our avatars, encased for biomedical and cultural regulation and biopolitical control. Philosopher of science Victoria Pitts-Taylor has pointed out how the actual biological and anatomical processes that govern plasticity are mirrored in the social expectations placed upon patients by the clinic, but more importantly, by patients on themselves (2010, 644; 2016, 134). From the point of view of CIs, the ideal compliance to plasticity, be it cellular or epistemological, does not begin with the actions of the child. Rather, it lies with the parents’ willingness to adhere to the regimen of neuronal fitness necessary to allow their child to have the
most opportunities in the future: to effectively avoid the risks of being a body outside of the
purview of a neuroscientific morality (Mauldin 2009; Rose and Abi-Rached 2013).

Sociologist Laura Mauldin (2016) showed how thoroughly entangled the clinical,
pedagogical, and intra-familial pressures can be on families in the processes surrounding
cochlear implantation. Based on two years of ethnographic research among upper-middle class
families in New York City, her work framed parents, mothers in particular, as victims of the
pedagogical mandates of the cochlear implantation economy. While her insight into the
biomedicalization of childhood development and the normalization of neuronal epistemology has
been key to my own research, I believe she was unable to see how struggle and difference
catalyzed by such intrusions can foster resilience and accommodation in the lives of families
within the CI economy of care. Particularly limiting for her study was the lack of socio-economic
diversity among her interlocutors. All of the families in her book could afford to live on New
York’s Upper West Side and were perhaps already normalized to much of the pedagogical
practices instituted by clinicians and care providers after their children were born deaf. Despite
this, her conclusion that women bore the brunt of the parenting, and thus the neuronal fitness
regimens enacted by clinicians, does point to the intersectional problems of experience that
manifest in the day-to-day for families enmeshed in the clinical environment of pediatric
cochlear implantation (Mauldin 2016, 135–150).

**Neuronal fitness**

The contemporary marginalization of the Deaf body comes at a time when science in
genral, and medicine in particular, has become a proxy for religious understandings of the moral
convictions that have been the historical modes for framing individual value in western society.
While the roots of this arrangement lie in the Enlightenment, and are beyond the scope of this thesis, it is important to note that, according to some Foucauldian scholars, control of the human body by governments and private institutions is rooted in the molding of moral epistemologies by those in power (Foucault and Rabinow 1984, 123–130; Rose and Abi Rached 2013). By delineating the ethical parameters within which citizens move, structural inequities that favor that power can become entrenched and self-sustaining. Thus, as doctors and scientists have come to better understand the workings of human biology and the processes of genetics and natural selection, their powerful benefactors have shifted the domain of moral certainty away from religious doctrine alone, to the liberalization of scientific practice (Foucault and Rabinow 1984).

Yet, does this reading of biopower hold true for the everyday lives of my interlocutors? Anthropologist Elizabeth Povinelli argues this reading of Foucault is flawed, writing that one only needs to look to the United States’ Late Liberal legal and penal landscapes to see sovereign, disciplinary, and biopolitical powers co-existing in the management of human lives and deaths (2017, 49–64). She goes on to problematize the divisions of bios (life) and thanatos (death), which are normative to traditional engagements with biopower as a theoretical tool. Noting the work of material feminists who understand the body as a porous and unbounded ecology, Povinelli questions how biopower can hold against emergent theoretical diversions that insist we rethink the reality of vitalism itself (Coole and Frost 2010).

For my family, the decision to have Lottie implanted was grounded in an extreme ambivalence towards the benevolence of institutions of care, running into a nagging fear of a daughter one day marginalized from both typically hearing society and from us. On the one hand, we saw (and continue to see) Lottie as an extension of ourselves not only in some biological sense of posterity, but also in a lived out relational webbing of experience, love, and
potential loss. Before her birth, the space between Mary and me did not include attachments to the facets of Deaf culture that would have been the next alternative if we decided not to implant. On the other hand, implantation was preemptively defining for Lottie an extended relationship with the clinic. While we can mediate that connection for her for many years, eventually it will be her own to make with as she can.

The argument that cochlear implantation is an example of a now normalizing neuronal-governance, and part of a broader trend of the twenty-first century social bio-medicalization of parenting in the largely secular western world, dovetails with theorists and ethnographers across disciplines who take a critical approach to the use of technology as unproblematic therapeutic mechanisms (Blume 2007; Casper & Morrison 2007; Connolly 2002; Conrad 2007; Friedner 2010; Martin 2011; Mauldin 2016; Pickering 2010; Rose 2006; Rose and Abi-Rached 2013). But simply seeing the human body as inscribable landscape for biotechnological hybridization falls short of understanding how relational space can counter claims of corporeal and subjective discipline leveled at the facts of cochlear implantation.

Returning to Laura Mauldin’s ethnographic accounts of families and cochlear implantation in an affluent New York City community, we get a qualitative understanding of the clinical molding of parents to become the social types best suited for CI intervention (Mauldin 2016). Based on her time with clinicians and families, she surmised that class and access to insurance became key components influencing a child’s placement into the cochlear implantation pipeline. However, her fieldwork occurred before the multi-state expansion of Medicaid following the Affordable Care Act (ACA). As most Medicaid providers have fully covered CI surgery since 2011, the class dynamics regarding access to implantation surgery has shifted in the intervening years. Yet, the precarity of politics surrounding health insurance leaves open the
possibility for a re-stratification of access to care, particularly when it concerns expensive biotechnology like CIs.

For her analysis, Mauldin pulled on sociologist Nikolas Rose’s interpretation of biopower to assert that mothers had become the focus of control by the clinic (Mauldin 2016; Rose 2009). Far from simply imploring mothers to learn techniques for facilitating communication with their pre-lingual child, in the CI milieu, the clinic develops moral imperatives to which they push and cajole mothers to adhere. By pedagogically situating learning outcomes and projected social expectations between signing and CI children, proponents of biotechnological intervention are aptly framing the differences as moral decisions to be made by parents within a narrow time frame for best results. Rose, citing Foucault, shows how the ethical ramifications of bio-political control are passed in the family from parent to child. This is particularly true for mothers, whose moral worth has been tied historically to the viability of their children. As such, the neuronal-fitness directive becomes an existential crisis with enormous stakes.

But how does this play out in everyday life? Under Mauldin’s framing of the experiences of her interlocutors’ engagements with clinical and pedagogical structures, the mother of the deaf child is subordinated to the will of neuroscience, a plural agent asserting as a clinical body that defines brain functionality (2016, 50–52). While some parents were curious about the workings of Deaf Culture, clinical professionals used research on the brain as a tool to counter individual parental agency (Fjord 1999, 3-4). Following this, Mauldin was able to show how any failure of CIs for individual children was detached from the technology itself and instead framed as a shortcoming of parenting, particularly of mothering (2016, 55).
Minding the Connections

The culture of the intervention revolved around discouraging deviation from the science of plasticity. For my family, pre-existing social differences between us and the suburban clinic and school involved in Lottie’s intervention fostered an ambivalence in both Mary and me about the day-to-day of taking our child to appointments and education sessions. Whereas many families had relocated to the area for the CI intervention and pedagogical training, we already lived near enough to not have to do so. If we had not been in such close proximity, it is questionable whether any of the intervention would have been possible. Conversely, the families that did relocate were, by default, of considerable means. This difference between us would be subtly reinforced through both a real feeling of interpersonal alienation, and through our own lagging sense of self-worth in the face of such a socioeconomic gulf. Looking back on the first year of Lottie’s life as a time of intense intervention, Mary explained:

I felt really out of place with all the people we had to see in getting Lottie ready for surgery. Like everybody was nice, but their was always an, I don’t know, a kind of condescension taken by them towards me. Like they were suspicious of my ability to do the language practices with Lottie. We were such weirdoes compared to the other parents at OOS [Ohio Oral Speaking] and it was hard going there by myself, cause you were working. It was really lonely.

Ohio Oral Speaking (OOS) is a private school for Deaf children who use hearing aids and cochlear implants. It follows the Betsy Moog methodology, an oral/speaking educational pathway that is specifically structured to get deaf children “mainstreamed” into typical schools by the second grade. The program is rigorous for both children and parents. Training begins in earnest in the eight months before implantation where parents and their babies work with deaf-
educators to make sure the family is primed to make the best use of CIs after surgery. For us, that time was little more than a reinforcement of Lottie’s total and profound deafness.

To get Medicaid to approve CIs, children must go through a trial of using hearing aids. Lottie detested them and it became an incredible struggle to get them to stay on her ears, especially knowing that they served no purpose as far as auditory input. But to clinicians, this tedium served a larger purpose. This was an extension of the fitness training championed by the intervention team as a way to mold parents into attentive agents, minders who would be almost obsessively concerned with the whereabouts of the child’s audiological hardware. Mary recalls:

I mean Lottie is easy to love, but the damn hearing aids made me fucking crazy. They would constantly feedback because they would never fit appropriately or stay on. But [the Deaf-educator] would just be like, “That’s a good thing. At least you can hear them when you lose them…” Yeah, whatever, bitch, you come over and keep the hearing aids on a baby’s ears.

As time progressed it became important for Mary and me to find a new way to reconnect for the sake of our partnership, but in a way detached from the notion of fitness propagated by those who had so adamantly indoctrinated us into a neurobiological-based ontology of family. Our marriage had suffered under the mutual self-doubt fostered in the dynamics of a tense moral-biological community mindset. Eventually, progress together meant challenging the authority of clinical specialists and instead embracing the intuition of Lottie herself.

Neuroscientific discourse on plasticity describes a process that is contingent on timely access and early manipulation. Plasticity as a theory insists on itself in both the brain and in the social worlds of families. The temporal risk involved in implantation catalyzes a deep set of moral imperatives in the economy surrounding brain training and the family (Lock and Nyugen 2010). Anthropologist Margaret Lock has written extensively on how biomedical procedures and
diagnoses become entangled with broader moral economies of care, the ramifications of which are most acute for mothers normalized into being culpable for the success of her children. Because medicine as a practice is highly specialized and cordoned off into various forms of expertise, parents are asked to accept moral epistemologies like plasticity on the grounds of a broadening secular form of faith (Lock 1997, 267-292). For us, that way of living was counterintuitive and manifested as a disingenuous way to raise our daughter. If she was to love her body for all of its differences, we had to accept the alternative to implantation as something other than amoral parenting. We had to acknowledge that the biopolitical left its traces in us even as we resisted being defined by it. Additionally, we had to accept the decisions we made for Lottie in enmeshing her flesh with technology, even as we began to allow her to make choices for herself.
CHAPTER TWO
CHRISTINE & JAMES

While data show that most children born with hearing loss have typically hearing parents, it is not uncommon for many grandparents of those children to be deaf as well (Papsin and Gordon 2007, 2387). This is a result of the multiple recessive genes that are known to contribute to being born without functioning cochleae. In particular, GJB2, also known as Connexin 26, is responsible for around half of all instances of congenital genetic deafness. The ubiquity of the gene’s presence as a causal factor has made it a common part of many family’s personal narratives on deafness. In this way, Connexin 26 and other genes have been moralized into the workings of everyday life for families of children with cochlear implants. The presence of these genes marks parents as both carriers of risk and as acolytes of neuroscience.

When children are born with congenital issues, many parents struggle to understand why, looking for an agent of responsibility in their own biological makeup or in their perinatal behavior. When there is no discernible etiology to provide answers, such internalizing can consume them emotionally. Though Connexin 26 accounts for many of the instances of congenital deafness, there are untold combinations of other gene locations that may contribute to hearing loss, but for which there is not enough yet known for systematic diagnoses. Additionally, because there can be non-genetic factors at work in the presentation of hearing loss, mothers are often left pondering every instance of illness they experienced during pregnancy and internalizing responsibility. In trying to understand how Lottie came to be deaf, and because it was part of the process of CI intervention, Mary and I were asked to attend genetic counseling.
Using Lottie’s DNA to run diagnostics before the appointment allowed them to rule out the usual suspects in the etiology of her deafness. Without Connexin 26, or other genes to inculcate, the genetic counselor is left to guide parents through a conversation of possible risks for having more kids. And while some parents are probably intimidated by the haziness of intractable congenital deafness, still others double down on the mitigating technologies available to them. Cochlear implants are marketed as a miracle, yes, but also as a normalizing agent. They are intended to dissolve notions of difference, not simply for the child, but for the entire family.

Christine is a mother of two children in her mid-thirties. Her youngest is five-year-old James, a slight but precocious child born with profound bilateral deafness. Christine’s husband works long hours and did not wish to be interviewed for this thesis, and so I would meet Christine and James at their home down the road from Ohio Oral Speaking during the day while her husband worked at a global consumer goods corporation. Christine, in addition to being the primary caregiver for the kids, is also an outreach worker for the Regional Infant Hearing Program (RIHP) of Southwest Ohio. Her job is to make first contact with newly diagnosed children and their parents, traveling across multiple counties to individual homes to facilitate the coordination of services.

Unofficially, her job is meant to lend objective moral support to new parents still in the throes of shock following the mostly unexpected diagnoses of hearing loss. I know from my own relationship with another such outreach worker that Christine’s work is delicate. It requires a subtle and unobtrusive ability to read parental body language. She relates:

Some parents are happy to have you in their home, but most of the time there’s a lot of tension in the air. People are weird about strangers in their home talking about their kids. But I try and make them feel better, you know, put their minds at ease…. Usually, the thing that gets them to open up is when I tell ‘em about James. I let them know, it’s all going to be ok. You know, we have the technology now. It will be ok.
I noted that she introduced the idea of cochlear implants so quickly in the outreach process, and asked her if there was something she looked for in her clients to gauge when to breach the topic of implantation. Was she certain that her personal narrative was going to be a source of comfort?

Well, I can honestly say that I haven’t had any parents who weren’t receptive to CIs so I’m personally comfortable bringing it up pretty much from the beginning. I mean, technically I am supposed to be objective and not favor one over the other [sign language versus implants], but I also know hearing loss from both sides … and frankly pretty much everybody gets excited about implants.

Christine does know Deafness from both sides. Not only is her son a recipient of cochlear implants, both of her parents are profoundly deaf. As a typically hearing person, Christine had the rare experience of growing up in a household that was actively situated within the signing Deaf Community. However, this fact made for a difficult childhood, fraught with obstacles that would elucidate her current approaches to work and her broader convictions surrounding what it could and should mean to be Deaf:

I was a very, very lonely child. I was known as the kid with Deaf parents and so I walked around with really low self-esteem. I will tell you, I didn’t learn to speak until I was almost five. It’s true. I mean, I signed with mom and dad, but because I was always with them, I never had the chance to learn to talk. Our house was so quiet, and I just felt really lonely. I mean, I finally learned to speak properly in kindergarten. Thank god…. Anyway, so I know what its like to miss out on language, and I wasn’t even deaf! When James was born, I was like uh-uh, we got cochlear implants now, and this boy is going to know the sound of my voice.

Christine’s parents both passed away before James was born, and her relationship with them deteriorated long before that. It was clear that she suffered trauma growing up in an
environment closed off from her peers. I asked her about her interactions with other Deaf families as a child.

There really weren’t any. Mom and Dad kinda lived in their own world, even apart from me. Like, if you’re asking if we went and did things with other Deaf people, I would say no, maybe once in a while. But I know I’m not the only person who grew up like that! Maybe mine was just hard, you know?

A couple of times, I met Christine at Ohio Oral Speaking in the school’s parental resource room. Often, she would be at the school in the capacity of her job, meeting children and parents who were enrolled in the infant program. Because implantation could not happen until children were one year old, many of her clients at the school were pre-implantees. Her son, like my daughter, had been coming to the school since he was four months old and it was in this early period that much of the teaching was focused on the parents as proxy for the pre-implanted child.

Working in tandem with staff educators at the private school, Christine was extremely knowledgeable and enthusiastic about the neuroscience of hearing loss. We discussed the dynamics of her working at OOS versus working in client’s homes. She said,

I love being at OOS. I mean, if you are working with parents there, you got everything to make your case right there at your fingertips. It’s true that at that point, I mean if they’re already with their baby at the school, it’s kind already a done deal, but still, I think this place is pretty impressive. Don’t you? Total miracles!

Christine’s experiences and positions regarding CIs and Deafness point to more than the epistemological power and discipline inherent to biotechnological engagements with the human body. Her attachment to the CI intervention, even becoming an active professional in the identification and engagement of children born deaf, points to a need to attune to the porous moral parameters that crop up when one’s deepest relationships, like mother to son, become
vehicles for social critique. On the one hand, her present-day narrative is informed by a self-professed lonely childhood with compounding sets of negative experiences informing how she has chosen to engage her own son’s deafness. Moreover, her son’s continued developmental mainstreaming into peer groups she herself longed for growing up, even as a typically hearing child, raises the possibility that her actions as a parent are an answer to her relationships to her deceased parents, and a form of resistance to the marginalization she felt from the Deaf community in proximity to which her parents brought her.

On the other hand, she is professional who engages other families who do no have her personal history with the Deaf community. Indeed, most have no relationship with Deaf Culture at all. It is likely and understandable that the broader Deaf community would be unhappy with the way Christine approaches new clients in her capacity as an outreach worker for RIHP. They would accuse her of bias on the optics of the advice she herself professes to give families making profound decisions about the trajectory of their children’s lives. But it is clear from my time with Christine that she is not intentionally trying to sabotage new parents who wish to seek out sign-language and that would like to engage with the broader Deaf community. She noted,

Signing is something I am grateful for. I was my parent’s interpreter many times as a kid. I feel like signing was like being bilingual, you know? I get sad when the kid’s audiologists tell us not to sign to our kids until they learn to speak. I get the science, but... I signed with James a whole bunch, even after he got his implant.

I ask her if she subscribes to the neuroscience often used by oral/speaking practitioners to dissuade using ASL with implanted children. I specifically question her about the notion of plasticity and the cross-colonization of speech pathways by motor neurons in the brain, potentially hijacking oral/speaking skill development. She sits with my question for a minute and then slowly begins to answer:
Part of me...believes that. But part of me thinks it’s hard to know. I didn’t talk till I was five. I signed with my parents. I had a hard time at school because I couldn’t talk like other kids...but maybe if I had learned to talk at the same time, it wouldn’t have been a problem, you know? Part of me was afraid with James that I shouldn’t sign, but I wanted to be able to talk to him.

Christine’s formative experiences appeared to motivate her to rearrange the social capital available to her own children, whether deaf or not. Such desires are pretty common to any parents, but when James was born deaf, Christine was faced with reconciling her formative years against the needs of her baby son. As my interviews with Christine progressed over several weeks, and as is clear in the dialogue above, Christine’s adherence to neuropolitical dogma was not absolute but contingent and informed by sometimes divergent personal experiences regarding what is best when a child and her family engage what it is to be Deaf.

Where the oral/speaking pedagogical approach has consistently dissuaded the use of ASL by parents considering CIs, Christine embodies a resistance to the unquestioned knowing of biomedical science. Even as the act of signing is attached to memories of a lonely and isolated childhood, Christine felt the need to engage James with sign language anyway. What’s more, she did it for the intimacy of communicating with her deaf child, embracing, rather than deflecting, the risk manifest in such acts of resistance.
CHAPTER THREE

AYESHA, BASHAR & MENA

Ayesha spoke quickly, frankly narrating to me her experiences of her daughter’s birth and diagnosis as profoundly deaf. As she did, she tracked between the cavernous rooms of her suburban Cincinnati home, looking for objects she felt would best suit the kinds of photographs we were about to take. She pulled out a wooden box that was black and covered with pearl inlays, about the size of an everyday family Quran case. She laid it on the dining room table where I had taken up residence for our interview and subsequent photo session. The box was empty, but had a soft and felted red interior both in the bed of the base and inside of the hinged lid. She paused, half-smiling, seeming to look past me in thought.

This box was where we kept all the things from the hospital when Mena was born. Her tags and umbilical cord, you know the things that accumulate when you have a baby at a hospital. [Now resuming her search between rooms.] We also had pictures from that day printed out and I kept them there, but I’ve put everything in a book now, an album. Oh, I should pull that out!

Ayesha’s husband Bashar sat across from me at the table, present for the interview and photo project session but otherwise attuned to his phone. His eyes were dark rings that drooped over his cheeks from an exhaustion I recognized from my time being a father of three. He occasionally interjected into Ayesha’s narrative with his opinions of the hospital staff present during his daughter’s first hours, commiserating with me over our shared impatience with the logistics of hospital accommodations. His body slouched into his dining room chair with a weariness that was augmented by the pajama-like semblance of his baby-blue work scrubs. All
of this contrasted with the beauty of the room we inhabited. Fresh flowers adorned the table in a crystal vase.

Ayesha and Bashar are medical doctors in their late thirties. Mena is the first of their two children. She is five years old; her younger brother Ahmed is one. Bashar’s immediate and extended family lives in Houston, where he was raised, the son of Pakistani immigrants. Ayesha grew up in Lahore, Pakistan, and met Bashar in medical school at Cornell University. Ayesha became pregnant with Mena after Bashar solidified his podiatry practice in Ithaca, New York.

The family moved to Ohio specifically so that Mena could have access to Ohio Oral Speaking and receive care through its partner institution at Cincinnati Children’s Hospital. Ayesha’s skill as a cardiologist made her professionally attractive to many healthcare networks in the Greater Cincinnati region. Similarly, Bashar’s surgical podiatry specialization is so rare that he transitioned to his current position with welcoming fanfare from the local medical community.

In many ways, the story of the intervention process surrounding Mena’s deafness is similar to many other families whose children have been implanted. Mena failed the Newborn Infant Hearing Screening at the outset. As was similar in my own family’s experience, Ayesha and Bashar were told not to worry about a probable false positive, but to follow up with an audiologist two weeks later. Once there, Mena was diagnosed as profoundly deaf and eventually recommended for cochlear implantation. Ayesha and Bashar began the arduous task of scheduling the many evaluations required to both ascertain an etiology for their daughter’s congenital disease and to begin assembling a framework for ongoing care.

As physicians trained in the scientific method, as well as being intensive problem solvers, they related their story to me in a language that enmeshed both the intimacy of parenthood and
the pragmatism inherent in the cadence of those who have had a medical training in anatomy.

Ayesha began:

It was like, if you don’t get her implanted, she probably will not speak. And it’s true! The brain is malleable, but only up to a certain point. That has to do with age and, I’m sure you know, plasticity, right? So I was stressed out and I was reading text after text on hearing loss, the neuroscience of hearing, all these different things … and I was talking to otolaryngologists that I know and they were telling me how amazing cochlear implants are if you get your baby the right team … the most intuitive surgeon, and quickly, right?

Bashar continued:

But Ithaca doesn’t have a Moog School, and we wanted to make sure Mena had the doctor that was best at CIs in children under 18 months. Really, moving to Cincinnati was easy, a total no-brainer. That was before we knew Mena was actually having genetic issues that really made her different than, well different from a lot of kids at OOS.

Mena shuffled into the dining room and crawled under my feet just beneath the oak dinner table. With her dollies in tow, she precociously wrangled my boots as a platform for her toys. I greeted her in the diction of doting parenthood and as she beamed up at me I noticed the shock of platinum hair running up the left side of her bangs. Ayesha caught on as I fixed on Mena’s equally strikingly vivid blue eyes, all set against her olive complexion and black hair. She explained, “Mena was born with Waardenburg’s Syndrome. That’s why her hair is white like that. And her eyes so beautiful, no?”

Waardenburg’s Syndrome is actually a group of genetic disorders that can phenotypically present on a spectrum ranging from pigmentation differences in the hair and eyes to profound hearing loss, extremity malformations, and gastrointestinal blockages (Cullen et al. 2006, 1273-1275). Mena’s Waardenburg’s Syndrome was undoubtedly the cause of her profound hearing loss and the source of her hair and eye color differences. While there are multiple autosomal
recessive genes associated with the syndrome, Mena’s was an extremely rare case of spontaneous mutation. Neither Ayesha nor Bashar were carriers of the most commonly screened for genes in relation to the disease.

Because Mena’s deafness was one symptom of a broader assemblage of disabilities, her relationship to the anticipatory structures of care set in place to mitigate hearing loss coalesced in a much more circumscribed way. Nonetheless, the biomedical models were employed and enacted from birth by Mena’s parents. As physicians, they required little convincing to get them excited about the benefits of a technological intervention. But the narratives used to prime parents like myself for considering the possibilities for typical social successes for our children would eventually falter for Ayesha and Bashar. In Mena’s case, the prognosticating ability of attending a school like Ohio Oral Speaking would eventually wobble in the face of cognitive delays that were not apparent in the early months of her life. Despite this eventual turn of events, Ayesha recalled the hope the school instilled in her on the day of her first visit with Mena, who was a still an infant at that time:

After feeling so bad about everything for three months, OOS made me feel so excited and hopeful. It didn’t look like a Deaf school, right? It was full of kids talking and Joan [the school’s director] was so encouraging, like you knew she cared about the success of her students. Bashar and I had went to St. Suzanne’s [a local ASL based school for the Deaf] to see what they had to offer, and I can tell you, we weren’t impressed. When you go into a place like that and don’t sign, it’s hard to feel welcome, I think anyway.

Despite these initial impressions, Ayesha struggled with how to conceive of fostering an empowered sense of identity for Mena as a Deaf child, and more hazily as a Deaf woman, in a political environment that was often black and white, and vitriolic. Ayesha actively sought out people and aspects of the Deaf community in an effort to take a more intersectional approach towards raising her daughter. While she was ambivalent about signing, she was not opposed to
learning how to do it, if it benefitted her daughter. However, with Mena in tow and implanted, access to members of the Deaf community was often blocked by varying degrees of closure. This centered on contempt towards Ayesha’s decision to implant her child. Moreover, OOS was not in a position to help mediate for a mother curious about any potential hybridity in child rearing her Deaf daughter.

Until recently, schools like OOS heavily discouraged ASL being used anywhere on campus, and frowned upon parents taking the initiative to use sign language with their implanted children at home. This stance was primarily based on open debates in the neuroscience literature about how many different linguistic modalities a young child could manage in specific developmental phases of brain growth (Young and Kirk 2016, 45). More recent work has shown that any cross-dampening effect between sign language use and oral-speaking linguistic approaches was objectively groundless (Young & Kirk 2016, 47). However, the suspicion and demonization coming from both sides of the debate, Deaf Culture versus Oral-speaking, left Ayesha alienated from her own hopes for Mena’s future. The situation worsened as Mena grew into toddlerhood and was diagnosed with both cognitive and gross-motor delays related to her Waardenburg’s Syndrome. As Ayesha explained,

When Mena got older, things changed at OOS. I don’t know if I should say this part...[I encourage her to continue.] First let me say that we took Mena to OOS thinking it was a place that worked miracles. But it is not a place of miracles. It is a school for a very particular kind of child. Your child, Lottie, she is like a poster child for OOS. My Mena … well it is like Joan and all of the staff were so supportive at the beginning, but after it was clear that Mena was developing multiple issues, multiple delays, we experienced like a coldness. It was like Mena was no longer an individual, but more of a negative asset, a statistical aberration on their good books. With her issues, Mena will never “mainstream” like Lottie has, and we feel like that became a mark against us in the eyes of OOS.
Her large family in Pakistan also made motherhood bittersweet for Ayesha. In the first two years after Mena’s birth, her parents seldom visited, in contrast to their many journeys to see their daughter as a medical student, years earlier. Likewise, Bashar noted that his family, while more present in Mena’s life, was unable to address Mena’s disabilities in any meaningful way. Both chalked these reactions up to culturally relativistic behavior. Bashar explained, “You know surgery for anyone is a big deal. When Mena had her implant surgery, no one called. Not my family, and not hers. I mean, that’s fucking weird, right? But it’s a cultural thing.” Ayesha continued:

In Pakistan, people with disabilities are treated differently than in the United States. Families are viewed as victims, you know? Like, “Oh this poor family, they must be such divine people. Look how they suffer with their disabled child.” My family, at first, they were not comfortable with that, or at least they didn’t understand how to be the family of a Deaf baby. So, I think they avoided us because it was unfathomable to them.

Ayesha and Bashar have thus experienced marginalization from multiple communities, even while appearing to embrace biomedical epistemologies surrounding pediatric cochlear implantation. From the time of Mena’s diagnosis, Ayesha made a concerted effort to take, at the least, an inclusive stance on Deafness as it is related to child rearing. She reached out to ASL-based education programs and attended events centered on building cohesion amongst members of the broader Deaf community. This included making cold introductions to people in public she saw signing, or families spotted with children wearing hearing aids. Invariably these ended awkwardly when the topic of her daughter’s impending implantation came up. Reactions ranged from polite termination of the conversation with Ayesha to outright hostility and accusations of child abuse. Because of these stressors externally stunting progressive interpersonal social
networking regarding child rearing, Ayesha and Bashar have reticently adopted a defiant new tier of difference in relation to their daughter’s identification as a Deaf child.
CHAPTER FOUR
CIRCULATION AND DIFFERENCE

The connection between pediatric cochlear implantation and still life photographic portraiture is not obvious. In conceiving of how trajectories and experiences of physical–material differences might be experienced for families that include deaf children, I turned to the notion of circulation as a rubric to understand how families might engage dis/ability at different phenomenological thresholds. Photographs possess the capability to circulate at alternating and diverging lines of flight, moving among local, global, and intermediate geographies. Personal photos in an album can possess both an affective, intimate corporeal agency and a status as a representation or icon of a person, place, or thing (Campbell 2014; Ragone and Twine 2000; Strassler 2010). Yet, they also can circulate as objects possessing emergent power, contingently extending tethers back to the political moment that created it, even if divorced from their specific representations and affective intentions (Azoulay 2015, 56).

In this way, photographs created through my collaboration with the families are less about the potential for documenting individual histories of engagements with biomedical epistemologies (Fjord 1999, 121), or for representing some intersection of class or habitus. Rather, they are iterations of subjunctive dreaming: political spaces for material transcendence that are at once intimate to individual agencies and detached from the banal provenance of the everyday uses of the objects depicted in-frame. These images are part of each family’s lived material narrative. As artifacts, they reveal a stratum of material assemblages that are useful for understanding how relationships between family members are also comprised of non-human
actors in traces. Such traces are part of an ongoing attempt in engagements with photography that move beyond the quotidian documentary format (Levin 2003, Mackinnon 2017).

In her book Civil Imagination: A Political Ontology of Photography (2015), culture and media scholar Ariella Azoulay examines the event of photography as a porous site of political possibility. While considering the photographic process as both performance and a canvas of textual discourse, she frames it as politically relational, consisting of multiple agents both seen and unseen. For her, photographs can possess qualities of excess and lack of inscription-based evidence. That is, photos are necessarily beholden to all possible trajectories of agentive circulation. For Azoulay this means that the wills of the individual, institution, and all scrums of invested creators and observers in between, can be inscribed on a photo and that its qualities cannot be reduced to one intended representation (2015, 85–87). Because of this, the political event of photographic creation is open-ended, and the artifact, or image, can thus circulate endlessly when decontextualized from historical constraints. Crucial for Azoulay, the political is not to be mistaken for power in the institutional sense (Pinney 2016, 73–78). It is the possibility for unheralded civil collaboration between agents in the spaces of the photographic event.

I engaged in this collaborative curation with the knowledge that there are historical problems of representation when anthropologists employ photography in ethnographic research. By removing the objects from contexts that imply one structural conceit or another, my intent is to allow them to perform from spots of affective and material vibrancy. Here, I am drawing from political theorist Jane Bennett, who argues that materials like everyday objects and photographs can be understood to have a “vital force” (2010, 17–21). For her, this vitality resonates with an inhuman form of affect, creating through agentive praxis that which has hitherto been reserved
for human description and action. Her work has led to others further examining subject–object ontologies while attempting to dissolve the binaries between nature and culture.

By de-territorializing the inscribed linkages between object and world, the emotional, mobile, and what feminist philosopher Stacy Alaimo has called the “trans-corporeal” nature of material objects, we can point to new contingencies for what those things are and where they might go (Alaimo & Hekman 2008). Alaimo uses trans-corporeality to explain how subjects and objects are permeable at their most fundamental level. As such, their engagements with one another leave traces that persist beyond the event of contact. She contends this arrangement is predicated on a “viscous porosity,” where objects are open to, but stick with, other subjects and objects in ways that can be material, ethical, and political (Alaimo 2012, 15–17).

This material vibrancy (Bennett 2010, 15–25) has been key for me to understand how aesthetics and artifices in photography can circulate past the point of exposure. With photographs, the matter is agentive at the level of the photo, the objects in frame, and the manner and methods through which the picture was taken (Azoulay 2015, 34–49). As such, the many entanglements of the photographic act can create spaces for all interlocutors to consider ways of being, knowing, and feeling beyond the confines of one political reality or isolated ontology. The “subjunctive” in the creation of an image (Azoulay 2016, 38), or the contingency of how things seeded in the intimacy of collaboration might circulate beyond the current state of the matter, finds parallel in the everyday acts of resistance, cooperation, and accommodation that embody the experiences of my interlocutors engaging with often overwhelming biomedical epistemologies. By attending to the unique ways that their relationships fluctuate among subsumption, emergence, and the sluggish banality of institutionalization, it is possible to
understand each family differing from the other through unique attunements to class, morals, privilege, and proximity to the bare other-ing historically attached to Deaf bodies.

As both researcher and auto-ethnographic subject, I scale the material, political, and affective incarnations of the clinical-familial nexus at stake in this research. Because of this, I had to understand all of my research as collaboration, not bounded objective declarations. To acknowledge my intrinsic experiential bias forced me, joyfully, to engage my interlocutors as creative forces. Doing so has had practical implications, primarily in that it is an answer to the recent call for a multi-modal approach in both engaging and relaying ethnographic research (Collins et al. 2017).

In an attempt at reflexive multi-modality (Collins et al. 2017) (Dicks et al. 2006, 77-95), my intent was to take the photographic event as both a vehicle for reimagining ethnographic exposition, and as a space for relational play for families as they connect their material lives to geographies outside of biomedical inscription. Together, we constructed light boxes to serve as portrait platforms for the photo shoots. Though the logistics of using such a tool necessarily delimited the spatial range of where to shoot, its homogenizing white field of vision conversely opened the photographed objects up themselves to expansive interpretation and a multitude of affective circulations. Indeed, in this way, the images cannot be understood as documents of families grappling with biomedical hegemony alone. Unattached to the text of this thesis, and intentionally uncaptioned, the photos can do infinite work, resonating in and across growing, but often intractable, aesthetic boundaries.

As illustrated by her critical analyses of the discipline’s colonial, complicit, and persistent racializing visual practices, anthropologist Deborah Poole has shown that anthropology has had, and continues to have, an infelicitous relationship with visual technologies and methods (2005,
Historically situated as a tool of colonial appropriation and exploitation, photography in contemporary ethnographic research has evolved in parallel to the discipline’s textual crisis of representation, a turn which has critically called into question the researcher’s power in relation to her interlocutors (Clifford & Marcus 2010, Edwards 2012, Pinney 2016). Moving past this crisis to examine the uses of the image by interlocutors themselves, media anthropologists have highlighted the material worlds of photography as local and global instantiations of resistance and counter-institutional affective narratives embodied in disparate forms, from family archives to identification cards (Lydon 2005; Pinney 1997, 2004, 2008; Strassler 2010).

The troubled history and conflicted present of visual methods in Anthropology must be reconciled even as new technologies and platforms make the possibility for the use and circulation of images more salient for both anthropologists and those we research. Multi-modal approaches are, at their best, an attempt to address the past and present, while also acknowledging the expansiveness and promise of media for future works and negotiations of power relationships. The pictures in this thesis are digital artifacts disentangled from easy representations, yet they remain politically inscribed from the very act of their creation. Equally, they are meant to be affectively antagonistic, prone to changing with the contexts of future circulations.

My aim in incorporating the pictures here is to foster an attendance to material and affective relational practices, both within the worlds of my interlocutors and in the space between them and me as a researcher. Rather than using photography to document their lives in situ, I am attempting to pull on both Azoulay’s ideas surrounding subjunctive civilities (2016, 186–87) and resistant practices occurring in banal but subversive curatorial practices found in the emerging circulation of archives (Campbell 2012; Pinney 2008; Strassler 2010). Still life
portraiture in the manner of my included photos functions at the nexus of local familial curation, where my interlocutors contribute material items of everyday significance, as well as in the possibilities emergent in the act of creation itself. By de-coupling these items, and the photos that depict them, from their fields of habit and assumed purpose they can begin to compound their ability to emerge, over and again along more speculative terrain, opening each family and myself up to what Azoulay calls other “civil ontologies” (2015, 24-27).
CONCLUSION

This thesis has examined how prevailing biomedical epistemologies become entangled with and enacted by families of children with cochlear implants. By noting the structural and relational differences emergent in individual families navigating care economies, I have tried to show how the pedagogical practices of clinicians and educators are subject to intra-familial mediation, manipulation, adoption, and varying forms of resistance. There is no one way for biotechnologies like cochlear implants to materialize within everyday lifeworlds. But as technology continues to change intersectional notions of dis/ability as identity, I believe it is critical to turn to localized narratives of interaction among people, technologies, and families to get a more situated picture of the embodiment of difference in all of its extensions.

As it turns out, my daughter Lottie excelled at Ohio Oral Speaking. She was so successful at adapting to cochlear implants as tools with which to develop listening and speaking skills that the school’s administration chose Lottie, and by extension my wife and me, as the subjects of a short documentary to be submitted to the Reel Abilities Film Festival. The festival is a yearly local incarnation of an international series of film festivals put on by Dis/ability advocates. Their aim is to highlight the broad experiences and contributions of those of diverse ability to our cultural worlds. The film we were asked to participate in utilized our own family photo and video archives, as well as multiple open-ended interviews chosen from sessions with the film’s director and us. Additionally, the director interviewed Lottie’s former and current teachers, both at OOS and her current Montessori school.

The photos and videos we released to the director for his discretionary use in the film were pulled from the previous five years of Lottie’s and our lives together. They were personal
documents in the sense that they were of us, in our home, engaging with each other as young families do. The quality was unselfconsciously mediocre, but not as if to say that we never intended others to see them. For instance, one digital video was of Lottie and me playing our guitars and singing to one another when she was three years old. It was a ninety-second clip that would end up becoming an emotional centerpiece of the documentary. There it was used to encapsulate Lottie’s transformation from “deaf child” to a typically charming and engaged three year old. What’s more, Lottie and my co-presence in the clip emphasized the narrative of parental investment in the normalcy of the moment, and all that is implied for what is abnormal in our earlier selves left out of frame, or not shared (Rangone & Winddance 2000).

In watching this bit of digital media, it became difficult for me to consider the moment of its creation as existing outside of the emotional anchor it had become as part of the film. Whatever I felt about that time Lottie and I sang together, and whatever was actually going on in our lives at that moment, are now partly distorted for me in the director’s use of our likenesses, our bodies, to promote a political intention. As a narrative, it tracked many of the similar moments discussed in this thesis, but ultimately took a non-critical approach to the care economy surrounding CIs. In fact, the director chose to not mention the tensions between Deaf Culture and oral/speaking education practices used in Moog Schools at all. Rather, Lottie was framed in the “miracle” context mentioned by Ayesha in chapter three.

By only articulating Lottie as a success story for a family of a Deaf child who had relinquished themselves to medical and therapeutic professionals both pedagogically and morally, the film felt disempowering for Mary and me. Indeed, this short documentary left us feeling as though we were portrayed as ones who considered no future for Lottie in a world without cochlear implants. By projecting CIs as miraculous and their facilitation through
professionals as the mitigation of difference, but only within a narrow shoot of pre-determined and idealized bodies, the film unfortunately used our family as advertisements for the contained and acceptable dis/abled family unit.

I have come to think about the photos my interlocutors and I made for this thesis as examples of a more speculative form of documentation. That is, rather than assembling tidy narratives around cochlear implantation and the “neuronal labor” (Mauldin 2016) best possessed by families going through the intervention process as depicted in the film, the photos we enacted reflect the porosity of the familial body when engaging economies of care through the tactile habits of their daily lives. As New Materialist theorist Stacy Alaimo notes in developing her concept of “trans-corporeality,” traces of mutually engaged bodies are left within one another and both human and inhuman matter is permeable in this sense (2016, 15–18). As such, the objects in our photos, and the photos themselves, are replete with varying traces of the everyday lives of the people who created the event in which they were captured. In a counterintuitive fashion, when compared to the selection of personal McGrath family photos and videos used in the documentary, these still-life portraiture of everyday material items resonate with greater intimacy, despite being unattached to human bodies. My hope is that the intimate thinginess of the images will allow them further circulation, whether attached to these families’ stories, or not.

I have attempted a productive dissolution of binaries historically attached to dis/abled identity work. That is, relinquishing the notion that there is one way of being Deaf rooted in biomedical technology and therapeutics. Equally unhelpful are accusations directed at parents of implanted children of child abuse or being complicit in a cultural genocide by some within the broader Deaf Community. Both of these points of view represent forms of essentialist thinking that ultimately serve to further marginalize Deaf children from typically abled structures of
living. More importantly, implanted and non-implanted children are isolated from one another through the reinforcement of this binary. For the professionals on both sides of the debate, high vitriol has engendered persistent bad blood.

But my fieldwork has shown that the tension over such epistemic essentialism ebbs somewhat at the familial level. Unfortunately, intra-familial methods of coping, thriving, and embracing a diagnosis of Deafness are mostly being closed out of the professional discourses in the name of risk mediation. From the perspective of neuroscience, infants need to be screened and, if necessary, implanted within the window of plasticity. Concurrently, parents must be enveloped by very particular pedagogical practices to facilitate their child’s successful adaptation to listening and speaking with implants. Anything different is considered risky. Because it is framed as a moral imperative, few parents are willing to contest the rhetoric.

Each of these families had different experiences with the CI economy of care. Indeed, each family attended to learning to communicate with their children with their own varied expectations, rooted in the context of their own preexisting habitual worlds. While it might be intuitive for me to critique Christine’s normalizing attitude to biomedical epistemologies through both her professional and personal worlds, what would a world outside of biomedical normalization look like across varied lines of socioeconomic experience? While there are definite inequalities concerning access to the surgery, would they only increase in a world where the technology was not being fast-tracked?

From my brief but powerful engagements with families of children who have received cochlear implants, I have found that their individual experiences with biomedical epistemologies can foster multiple forms of pragmatic adjustment. They are folks who must be attuned to biomedicine and technology, since their children’s therapeutics mean they will always be
entangled with such institutions. But I saw no evidence of any complete subsumption by notions of discipline and biopower. Rather, through my time with the families, including my own, I have observed acts of both subsistence and resistance to being institutionally-defined.

In this instance, I use the legal definition of subsistence, which means to stay with, or persist within. Each of these families subsists in the reality of biopolitical discipline even as they each enact ways to resist disappearing into brain-based pedagogical scripts. For Ayesha and Bashar it has meant embracing the totality of multiple diagnoses for their daughter. Doing so has allowed them distance themselves from the unattainable and marginalizing ideals of the cochlear implantation economy and how it shapes a preferred CI oral/speaking learner.

Mary and I continue to navigate the precarious structures of biomedicine in seeking paths for maintaining Lottie’s access to care. There has been some catharsis in examining the experiences of other families who have gone through the CI world and understanding the structures and motivations undergirding the specific ways caregivers enact care with us. Unfortunately, the inequity built into healthcare in the United States points to tiered access to cutting-edge biotechnologies, with the paradoxical effect that the poor will have access to technologies but will be circumscribed as moral failures in the eyes of the clinic. Subscription to the right neuropolitics is a position of privilege. Such a position will make care providers ambivalent about following up with marginalized groups and therapeutics like CIs will become less useful for those so marked.

Regardless, as each of these three families move forward, they will have to continually re-negotiate their relationships with technologies and systems of care that are themselves exponentially evolving. Improvements in cochlear implant quality for providing access to typical-like soundscapes, and which implanted children shall be privileged enough to receive
such upgrades will continue to shape relationships between care providers and patients, families and families, and contribute to parent’s and children’s conceptions of self-worth. Sometimes their need for a resistance to clear biomedical identifications will conflict with a desire for belonging or the fear of isolation. Coping, resisting, or thriving for implanted children and their families will arise in the ambiguous spaces between the clinic and the countless civil imaginaries circulating out from the core of everyday life. Like the digital images we created here, intentionally porous but left viscous enough to reattach and perform otherwise, each family will engage Deafness as alternating parts caustic political binary, biomedical biography, and wide-open canvas of world-making
References


