Abstract

When parents learn that their infant or child is severely hearing impaired or deaf, they are faced with life-altering decisions that have to be made fairly rapidly: how to raise a deaf child in a hearing world is a complicated question for most parents. Foremost among these questions are whether to teach their child ASL and raise them as culturally Deaf or utilize hearing aids and cochlear implants and teach their child listening and speaking. In this study, interviews with 33 parents who had decided to implant their deaf children with cochlear implants, revealed that the decision-making process combined both practical and emotional decision-making features. Interactions with powerful groups and individuals such as cochlear implant manufacturers and surgeons, helped influence parents to choose cochlear implants for their child. Considerations involving theories of normality, medicalization, and stigma are addressed.

The Cochlear Implant Decision: How Parents Decide to Implant Their Deaf Children with

Cochlear Implants

> It was a no-brainer for us. We knew we wanted him to speak and listen, no doubt about it. We had no doubts. Very easy to make the decision, it was a no-brainer.
> —Julie, mother of 12-year-old bilaterally implanted boy

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

This article is about how parents make the sometimes— difficult decision to give their child a cochlear implant. It answers the research question: how do contemporary parents' decisions to get a cochlear implant for their children reflect the relationships between social meanings of deafness, deaf technology, and social beliefs about normality?

Underpinning all of the interviews were undercurrents of medicalization, normality, and stigma. The concepts of normality, medicalization, and stigma will be defined, explored, and serve as anchors for this article. Although there are several ways to approach the definition of normality, it is generally considered to be the statistical norm within a society, or as behaving in the way that "nature intended" (Horwitz, 2016). Horwitz and Wakefield (1999; 2009; 2008),

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

In order to explore decision-making processes, I interviewed 33 individual parents or couples between March 2014-December 2014 who had decided to give their deaf children cochlear implants. Cochlear implants are a ripe location for studying decision—making processes because parents typically invoke both logical/rational decision—making narratives and emotional decision—making narratives, as well as invoke conceptions of what it means to be normal. Deafness is in a unique position to explore people's relationship to normality. One reason for this is the fact that, in many people, cochlear implants can partially or completely eliminate the appearance of disability. People can literally choose to belong to a cultural disability community, in this case, the Deaf community, or to the apparently normal community of those without deafness. Few, if any, other disability groups are able to offer their members a choice to appear disabled or to not appear disabled. Based on the evidence presented in my

interviews, I argue that the cochlear implant decision-making process is logical/rational *and* emotional.

NORMALITY

Different social groups construct the meanings of physical difference to fit competing ideologies and interests (Zerubavel, 1999). When a condition or state is identified as abnormal or disabling, corrective procedures and technologies are often offered to the afflicted individual(s) to restore or gain normality. Identifying normality is so important to us because of the outcomes for those labeled abnormal. People categorized as abnormal are, on the one hand, given special accommodations and treatment (such as preferred parking spots), and on the other hand, are stigmatized and outcast. As a society, we vacillate between accommodations and outcasting, and these outcomes seem to depend on the perception of the labeler- and it is the labeler who stigmatizes, or accommodates, so it is a vicious cycle. Because of the biological nature of physical abilities such as hearing, specialists and laypeople alike forget the purely conventional and social nature of disability classifications, and instead attribute a profound natural power to these categories (Harkin, 1994, Lane, 1999). Bodies themselves are a highly contested space, in which competing cultures vie for the right to define and sculpt that body (Harkin, 1994). The concepts of normal/abnormal and disabled/abled exist as social constructs— *people* have to define things as normal/abnormal— they are not "natural" states of being (Horwitz, 2016; Zerubavel, 2020). Defining a body as disabled or abled does not occur in a vacuum, nor is it an automatic classification; instead, it is always in contrast to the *normal* (or abled) that the abnormal (or disabled) is understood.

Social scientists and humanities scholars have identified three general ways to understand the competing categories of abnormal and normal. At one end is a pure social constructionist

approach that argues that abnormal and normal are only real in their consequences because they have been socially defined as such (Berger and Luckmann, 1967). At its most basic level, social construction theories contend that all systems of knowledge and ways of understanding are reflections of culturally specific processes (Foucault, 1994; Foucault, 2009). Our world is inseparable from the social processes that allow us to comprehend and organize that world. Social constructionist scholars do not assume that taken-for-granted categories represent any natural reality, but instead they reflect and respond to shifting social forces (Berger & Luckmann, 1967). Normality, therefore, is culturally created and there exists no universal normality in the same way as there exists no universal morality (Benedict, 1934; Hacking, 1986). This article relies on this definition of normality and is social constructivist in its approach.

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

Lastly, on the opposite end of the continuum from social constructionism is a naturalist approach that understands bodies to be a real, "hard" physical reality outside of the realm of the social. This approach argues that the body has natural functions based in evolutionary processes, and that the abnormal can be understood as harmful dysfunction (Horwitz and Wakefield, 2007; Wakefield, 2007).

MEDICALIZATION

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

In one account of medicalization, Richie (2019) writes, "Medicalization occurs when an aspect of embodied humanity is scrutinized by the medical industry, claimed as pathological, and subsumed under medical intervention." Medicalization of deafness first appears in history in the 1790s, when Luigi Galvani experimented with Galvanism to correct deafness (Lane, 1999). In this attempt, Galvani used a medical treatment to address deafness, rather than a social or cultural intervention, and so is considered among the first attempts to medicalize deafness. However, his surgery failed, and so the event is considered an "attempt" at medicalization, but not a successful one. Attempts such as this to medicalize deafness can be seen by those adopting a cultural understanding of deafness as parallel to eugenics or genocide (Cherney, 1999; Baynton, 1996; Lane, 2005).

Mauldin (2016), in her book about the medicalization of deafness writes, "We can now engage in attempts to treat, find relief, look or feel more 'ideal,' or pass on traits of normalcy— which have social value— to our children." In contrast to Mauldin's findings, Pfister (2018), in an article about deaf children of hearing parents in Mexico, comments that the parents in her study eventually came to realize the goal is not to "fix" their children, but rather to adopt communication technologies such as signed language to facilitate communication. In this

manner, Pfister's (2018) subjects rejected the medicalization of deafness, and instead adopted a cultural technology. Hayes and Hanold (2007) argue that medical and allied medical professions contribute to the medicalization of people with disabilities. In the case of deaf children, this would include the audiologist who conducts the first Auditory Brainstem Response (ABR), a definitive test for deafness. In essence, it is this test, and these medical professionals, who first medicalize the deaf child.

Medical technology is used to ameliorate abnormality. Ideas of what is normal- such as the idea that hearing is normal- inform what problems of living are medicalized, and once a problem has been medicalized, medical technology can arise that addresses the newly medicalized problem. Medical technology cannot be used unless a problem has already been made abnormal and medicalized. An example of this is found in the development of the erectile dysfunction medication Viagra. In clinical studies the medication was found to improve older male's sexual performance, but, at that time, "erectile dysfunction" was not medicalized, sexual performance degradation was regarded as a standard process of aging, and so the medical establishment had to "create" the medical problem of "erectile dysfunction" in order to sell medication for it, thereby medicalizing a previously-understood "normal" bodily process (Carpiano, 2010).

When a condition is medicalized, some people adopt the medicalized model of the condition, and other people resist the medicalized label. Deaf culture is one such group that largely rejects the medicalized model of deafness. This culture is notated by a capital "D," (Lane, 1999) whereas deaf people who are verbal and listen using cochlear implants or hearing aids are classified with a lowercase "d." Most of the people who are Deaf use sign language (Lane, 1999). As 90% of deaf children are born to hearing parents, if even 80% of those children are

given cochlear implants, and not taught ASL and welcomed into the Deaf community, the Deaf community fears the death of their community because of the dearth of new members. What Deaf community members are fighting against is the "infirmity" understanding of deafness— the understanding that deafness is a medical and social problem that needs to be fixed through technology.

Although the term "deaf eugenics" implies the reduction or elimination of deafness through compulsory exogamous marriage and sterilization or through gene therapy (Lane, 1999; Lane, 2005), the term "genocide" evokes a more active attempt to eliminate a group of people or a culture. The word genocide recalls vast pogroms and systematic killing, however, the slow elimination of a minority group can occur by the destruction of the distinct elements that bind the collectivity, such as language, customs, and art forms (Lane, 2005). Because the medicalized model of deafness aims to, in the words of one speaker at a National Academy of Sciences meeting, "clear out the schools for the deaf" (qtd. in Erickson, 1990), and eliminate the need for ASL, the loss of this language by either outright elimination or dialectizing it (Lane, 1999), could result in the loss of the culture itself. In this way, language death, or glottocide, can lead to the loss of cultural identity (Nicholls, 2005), and may represent the denial of the basic human and civil rights of children to speak their native language (Lane, 2005; Nicholls, 2005). Technology can be a medicalizing force, contributing to the demographic issues in the Deaf community.

The affirmation of the infirmity understanding of deafness leads to the search for new and better technologies to address deafness, including stem cell research (National Institute on Deafness and other Communication Disorders, 2009) and gene transfer therapies that aim to ultimately eliminate the birth of deaf infants (Lane, 2005). These techniques are never neutral and raise important moral and ethical questions (Bosteels et al., 2017). These advanced

techniques, if "successful," will have the effect of regulating and, according to some deaf advocates, eventually eliminating Deaf culture, language, and Deaf people (Lane, 2005).

STIGMA

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

There exists a rich literature on stigma and deafness. Scharp and Barker (2021) explore the meaning of deafness for adults who use hearing aids. Stigma relating to the aids was prominent in their interviews, however, they also discovered a theme of, "this is just my life." (Scharp & Barker, 2021). Other studies have found that deafness impedes social exchange and relationships (Oleszkiewicz, 2021). Self-efficacy can be impacted by stigma, and those deaf

people who experience the most stigma also have lower self-efficacy scores (Crowe, 2021). Deaf

people, like others with disabled bodies, must manage stigma (Lash & Helme, 2020). In one

study, parents of disabled children dismantle stigma by rewriting the narrative of being the

parent of a disabled child (Thomas, 2020).

PARENTS' MEDICAL DECISION-MAKING PROCESS

I will broadly discuss parental medical decision-making scholarship, then will address

parental decision making in the case of cochlear implants which in part is influenced by hearing aid

and cochlear implant technology advertisements and websites.

Madrigal et al. (2012), in a study about parental decision making in a Pediatric Intensive

Care unit found that parents prefer to make medical decisions in combination with the doctor, or

alternatively, prefer significant independence in the decision (Madrigal et al., 2012). Although this

data comes from studies in which children are significantly more ill than deafness, there is no

evidence that suggests that the medical decision-making processes are different between life-

threatening and "lifestyle threatening" conditions. In researching "voluntariness" in a study about

parental decision making for seriously ill children, male gender, non-white status, and lower SES

all contributed to a lower perceived voluntariness of the medical decision (Miller and Nelson,

2012). Voluntariness is perceived to be key in parental decision-making. If one feels forced to make

a decision, they may make the decision with less deliberation and less feeling of choice.

In a study of the parental decision-making process in circumcision, it was found that

parental education had no bearing on the decision-making process (Binner et al, 2002). For the

parental decision about giving their pre-teen daughters the HPV vaccine, trust in the medical

system was key (Allen et al., 2010). In a comprehensive review of parental medical decision

making, Carlton et.al. (2013) identified several factors that parents considered when making

medical decisions for their minor children. Overall, their findings were that recommendations from others were most often identified as influencing decisions, and that pragmatic issues, effectiveness, and research evidence, were also very important in the decision-making process (Carlton et al., 2013).

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

Kluwin and Stewart (2000), in their study of parental motivations for seeking a cochlear implant for their child, found that parents relied heavily on information from medical professionals. If they sought help from medical professionals, they were much less likely to seek information from other sources (Kluwin and Stewart 2000). However, other research has found that parents do research on the Internet to make the cochlear implant decision, and that this information was an important adjunct to information from doctors and professionals (Porter and Edirippulige, 2007). Most parents found the decision process difficult and stressful, but some found it easy because they perceived there was no other option for their child (Hyde et al., 2010). Parents are often influenced in their decision-making process by their personal beliefs, attitudes and values, at least as much as they are influenced by the data available to them (Li et al., 2004). Kluwin and Stewart (2000; Christiansen and Leigh, 2002) also found that the most important deciding factor in giving their child an implant was allowing their child to hear and speak like a

hearing person. This speaks to parents' desire for their child to be normal. Normal speech was especially important for these parents (Hyde et al., 2010; Kluwin and Stewart, 2000). Most of the parents in their study did not consider any other alternatives to the cochlear implants (Kluwin and Stewart, 2000). Not all parents see the cochlear implant as positive, though. Andrew Solomon, in his book about children who are profoundly different from their parents, writes about one parent who said, "[we] decided to respect Emma for who she was rather than to fix her." (Solomon, 2012).

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

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

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

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

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

Current literature has explored why parents decide to get a cochlear implant for their deaf child and has examined some of the factors parents consider when making this decision. What is lacking, however, is a discussion about normality and how thoughts about normality inform this decision. In this article I am going to address this gap and explore specifically how thoughts of normality affect the parental decision.

INTERVIEWS

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

I used several different methods to recruit these families. First, I contacted the Alexander Graham Bell association, which is the leading oral and cochlear implant non-profit group in the

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

Originally when I began my research, I planned to not only interview parents who had chosen cochlear implants for their child, but to also interview parents who had chosen ASL or another signed or manual language (such as Signed Exact English— SEE, or Cued Speech) for their children. I wanted to understand how Deaf and hearing parents who chose ASL for their children understood normality and the meaning of deaf technology. To recruit subjects whose children used ASL, I posted a recruitment ad on Facebook groups for parents of Deaf children. Concurrently, I sent letters, and made follow up phone calls, to all 34 of the US ASL schools, using the same process I used when contacting the cochlear implant/oral schools. However, the response I received from the ASL schools and Facebook groups was profoundly different than the response received by oral schools. By and large, the oral schools were happy to participate, and went out of their way to advertise the study to parents. However, in the ASL group, not a single school responded to my request. It was the same situation with the Facebook ads— not a single parent responded to the ads. This one-sided sample was discouraging, and I think it limits

the generalizability of the findings to only families of deaf children, and not Deaf families. Understanding how Deaf families understand the concepts of normality, medicalization, and stigma would shed light on how a distinctly "abnormal" group (by a statistical conception of normal)- ASL-using Deaf people- explain normality in the face of using a non-typical communication method. One can learn a lot by studying the *absence* of a phenomena, in this case, not implanting children with cochlear implants. It is possible that the existential threat felt by some Deaf people, specifically the demographic problem presented by cochlear implants, led Deaf educators or parents to resist being the subject of research. Research conducted by people already imbedded in Deaf culture— either by virtue of identifying as Deaf, or close friends, family members, or interpreters (Mauldin 2016) of Deaf people will probably have a greater chance of conducting research with Deaf families. However, even with the lack of ASL-using families, my interviews with hearing parents of children who use cochlear implants provide insight into how some people understand normality, medicalization, and stigma as it relates to deafness and technology.

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

research. When asked to report their social class, 24 participants responded, "middle class," three defined themselves as "lower middle class," and six defined themselves as "upper middle class." I used the respondents' own language to define their social class and did not probe any further about their characterization. All names are pseudonyms.

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

DECISION MAKING

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

Normality

Parents often cited the fact that the Deaf world is totally different from the hearing community, and if they had made the decision to teach their child ASL and send their child to Deaf residential schools, their child would be in different community than the rest of the family. Being an active part of a family and the community was important to parents. Dana said "We're all hearing. I wouldn't want a child who could only speak and understand Chinese, and that's

what ASL is like. Chinese." "We wanted listening and speaking, and we would do anything to get her there," Julie explained. She went on to say, "We only knew hearing people, and we understood how hearing people go about their daily lives. We had no idea how a deaf person would make a life for themselves in a hearing world." As Dani, the mother of a 1-year old son with a unilateral CI said, "I'm hearing. My entire family is hearing. Why would I want to have a child that is living in a different culture that I do?"

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

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

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

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

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

Being a good parent

In this study, all but two of the respondents were mothers, and mothers demonstrated intensive mothering (Hayes 1996). For example, Mirena, the mother who drove two hours each way with her hearing 2-year-old son to take her deaf daughter to a well—known oral school, demonstrated intensive parenting, in that all of her daily effort went towards her daughter's schooling. Other mothers mentioned having to go out of state several hours away to cochlear implant centers and audiologist appointments. Louise said, "I need a secretary just to keep track of all of Benji's appointments! And a chauffeur would be nice!" In most of the families in my study, mothers had an unequal burden in managing their deaf child's appointments and other

needs. Veronica quit her job as an advertising executive in order to manage the needs of her deaf daughter, and soon found herself volunteering in deaf organizations.

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

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

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

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

The emotional-centered decision-making approaches focus in part on "being a good parent." These parents perceive that pursuing normalizing technologies for their children will set

their children up for a good future, and that as good parents, they are obliged to do anything in their power to help give their child a good future. Of note is that most parents who used rational decision-making approaches to make the decision cited how they would feel if their child was functionally deaf— e.g., was not able to communicate with the family. Alternatively, those who relied more heavily on emotional centered approaches imagined their child in the future going to college, getting married, having children of their own. Marge, the mother of a 3-year-old bilaterally implanted daughter, used an emotional decision-making strategy and said, "I just imagined her being in high school and not having any friends and only have two college choices to go to. I wanted her to have all the choices in the world, not only two."

Parents want to have rewarding relationships with their child, and while, on one level, that is a practical concern, it's also a very deep emotional concern. The parents in my study, such as Julie and Mary who made the cochlear implant decision while driving home from the audiologist's office after getting the diagnosis, made the decision to go oral from a gut, emotional place. They knew instinctively that they wanted their child to speak and listen. These were not rational, practical choices— these were decisions made from the heart, not the head. I conceptualize rational decision-making as one that relies on a risk/benefit analysis (which is explored in the below section) and is borne out of logical reasoning. I understand emotional decision-making as one that is based on intuition, feelings, and emotions, and does not focus entirely on rational thought. Of course, the cochlear implant decision, for most parents, is a combination of rational and emotional decision making. As an example of emotional decision making, Mary said, "After I called the surgeon, we were still 30 minutes from home, I cradled Joseph in my arms and cooed to him. You will soon hear my voice my precious baby, I said."

Risk Analysis

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

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

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

Parents talked of their children having "dark futures" if they didn't have cochlear implants, and they talked about the loss to the family if the deaf member could not communicate with the rest of the family. When the topic at hand involves cutting into the skull of an infant or young child, and when the alternative is believed to be a sad and lonely future, emotions are

running high. Certainly, rationality plays a part, but I interviewed no family members for whom I think the decision was entirely rational. Mary said, "This was not logical. Cutting into my daughter's head was not logical. But at the same time, it was the only decision that made sense."

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

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

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

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

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

CONCLUSION

In this article I discuss factors of the decision-making process for parents deciding to implant their deaf child with a cochlear implant. There are several powerful groups that influence parents to choose cochlear implants for their children, and these groups have disproportionate

power as opposed to the factors that could influence a parent to choose ASL for their child. Parents rely on social norms and the authority of experts to make this decision. Based on my analysis of my interview data, four main themes emerged: normality, the concept of being a "good parent," risk analysis, and communication.

Normality

Parents utilized conceptions of normality in their discussion about how they made the decision to give their deaf child a cochlear implant. By and large, these discussions were couched using the language of the Harmful Dysfunction model of normality (Wakefield, 2007). In this model, every body part has a function, and if that body part is not working properly, then it may be considered a "harmful dysfunction." However, this model is not entirely biological in nature, there is also a social component, which makes it ideal for studying physical phenomena that are also social in nature. In this case, the ears are "dysfunctional," but the social component is what makes it "harmful." If families are not able to operate in a typical way, if students aren't able to go to school in a typical way, if relationships to others and to the world around the deaf child are impacted, then this would be considered a "harmful dysfunction." In the interviews, parents utilized all the conceptions of normality. For example, some parents focused on other people— "other people" do not use sign language, therefore, their child, if signing, would be isolated. This is an example of the social construction paradigm of deafness. Other parents talked about the fact that their children's ears were "not working properly" and a cochlear implant was the solution to this dilemma. This construction falls in line with the Harmful Dysfunction model of normality. No parent utilized the interactive approach to normality, which would have paired physical realities with social norms— parents used the Harmful Dysfunction model instead, which is similar because it includes both the medical and the social.

Medicalization

I treat medicalization in a novel way in this article, because not only do I discuss technologies that treat deafness, which is not a unique contribution (Mauldin, 2016), but I also focus on concepts of morality, especially in the context of what it means to be a "good parent," and how morality is intertwined with technology to create a form of moralized technology to treat deafness. This morality is now medicalized— one must do the right, "moral" thing for deaf children, and that means medicalizing their disorder and treating it medically. In this way, medicalization becomes a moralizing force. For example, the parents in my study who said they "had no choice" are using the language of morality. In this example, morality, and the concept of being a "good parent" are medicalized concepts— the only right, moral way to be a good parent is to give your child a cochlear implant.

Stigma

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

both of these examples, medical science took normally occurring bodily and emotional experiences (decrease in sexual ability as one ages, and postpartum depression), and turned them into medicalized problems.

Parents in my study were very specific about the fact that they believed cochlear implants would lead to academic, professional, and personal success. They weaved narratives of normality, medicalization, and stigma through their stories. Normality is an important lens from which to see stories about disability and ability, as well as medical correction. As medical science continues to advance, more and more conditions will become medicalized, leading to more and more people taking advanced medical treatments to address problems that were previously considered "problems with living" that are now considered "medical problems" that can be treated with advanced science.

REFERENCES

Allen, Jennifer D., Megan K.D. Othus, and Rachel C. Shelton. 2010. "Parental Decision Making
about the HPV Virus." *Cancer Epidemiology and Biomarkers and Prevention,* 19(9):
2187—2198

Barmaki, Reza. 2021. "Erving Goffman's View of 'Deviance': 'Self' and 'Society' as the
Sources of Deviancy and Conformity. *Deviant Behavior*. 42(2):147—161

Baynton, Douglas C. 1996. *Forbidden Signs: American Culture and the Campaign Against Sign
Language*. University of Chicago Press.

Berger, Peter and Thomas Luckmann. 1967. *The social construction of reality.* New York:
Anchor.

Binner, Sharon L., Joan M. Mastrobattista, Mary—Clare Day, Laurie S. Swaim, and Manju
Monga. 2002. "Effect of Parental Education on Decision Making About Neonatal
Circumcision" *Southern Medical Journal* 95(4): 457 DOI: 10.1097/00007611-
200204000-00016

Bosteels, Sigrid, Michel Vandenbroeck, and Geert Van Hove. 2017. "Saving Deaf Children?
Screening for Hearing loss as a Public—interest Case." *Bioethical Inquiry*, 14 :109–121

Carpiano, Richard M. 2010. "Passive Medicalization: The Case of Viagra and Erectile
Dysfunction." Sociological Spectrum. 21(3)

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

Christiansen, J.B., and I.W. Leigh. 2002. *Cochlear Implants in Children: Ethics and Choices.*
Washington, DC: Gallaudet University Press.

Conrad, Peter and Valerie Leiter. 2008 "From Lydia Pinkham to Queen Levitra: Advertising and Medicalisation. *Sociology of Health & Illness*. 30(6): 825—838.

Crowe, Teresa V. 2021. "Factors Associated with Help—Seeking and Self—Efficacy among a Sample of Deaf Adults." *Journal of Developmental & Physical Disabilities*. 33(1): 51—63.

Dubriwny, Tasha N. 2010. "Television News Coverage of Postpartum Disorders and the Politics of Medicalization." *Feminist Media Studies*. 10(3):285—303.

Eisenberg, Laurie S. 2019. "The Impact of Hearing Loss on Childhood Development and Family Constellation." *Volta Review*. 119(1): 56—69. DOI: 10.17955/tvr.119.1.symp

Erickson, Deborah. 1990. "Electronic Earful." *Scientific American* 263 : 132—133.

Fleck, Ludwik. 1979. *Genesis and Development of a Scientific Fact*. Chicago: University of Chicago Press.

Foucault, Michel. 1994. *The Birth of the Clinic: An Archaeology of Medical Perception* New York: Vintage.

Foucault, Michel. 2009. *The History of Madness* London: Routledge.

Goffman, Erving. 1963. *Stigma. Notes on the Management of Spoiled Identity* Prentice—Hall: Englewood Cliffs, NJ.

Gould, Jay. 1996. *The Mismeasure of Man.* W. W. Norton & Company.

Hacking, Ian. 1986. Making Up People. In *Beyond the Body Proper: Reading the Anthropology of Material Life* Ed: Lock, M. and J. Farquhar. Durham, NC: Duke University Press.

Hacking, Ian. 1999. *The Social Construction of What*. Boston, MA: Harvard University Press

Harkin, Michael. 1994. "Contested Bodies: Affliction and Power in Heiltsuk Culture and History" *American Ethnologist* 21(3): 586—605.

Hays, S. 1996. *The Cultural Contraindications of Motherhood.* New Haven, CT: Yale
    University Press

Hayes, Jeanne and Elizabeth M. Hannold. 2007. "The Road to Empowerment: A Historical
    Perspective on the Medicalization of Disability." *Journal of Health and Human Services*
    Administration. Vol. 30, No. 3, : 352—377.

Horwitz, Allan. 2016. "*What's Normal: Reconciling Biology and Culture*. Oxford University
    Press, New York.

Horwitz, Allan V. and Jerome C. Wakefield. 2007. *The Loss of Sadness: How Psychiatry*
    Transformed Normal Sorrow into Depressive Disorder. New York: Oxford University
    Press.

Horwitz, A.V. 2002. *Creating Mental Illness*. Chicago: University of Chicago Press.

Horwitz, Allan. 2007. "Transforming Normality into Pathology: DSM and the outcomes of
    Stressful Social Arrangements". *Journal of Health and Social Behavior*. Volume 48,
    Issue 3, p 211—222

Incesulu, Armagan, M. Vural, and U. Urkam. 2003. "Children with Cochlear Implants: Parental
    Perspective" *Otology and Neurotology* 24(4): 605—611.

Kluwin, Thomas N. and David A. Stewart. 2000. "Cochlear Implants for Younger Children: A
    Preliminary Description of the Parental Decision Process and Outcomes." *American*
    Annals of the Deaf. 145(1): 26—32. DOI: 10.1353/aad.2012.0247

Lane, Harlan. 2005. "Ethnicity, Ethics, and the Deaf—World." Journal of Deaf Studies and Deaf
    Education. 10 : 291—310.

Lane, Harlan. 1999. *The Mask of Benevolence*. San Diego: DawnSignPress.

Lash, Brittany N. and Donald W. Helme. 2020. "Managing Hearing Loss Stigma: Experiences of
and Responses to Stigmatizing Attitudes & Behaviors." *Southern Communication
Journal.* 85(5): 302—315

Li, Yuellin, Lisa Bain, and Annie G. Steinberg. 2004. "Parental Decision Making in Considering
Cochlear Implant Technology for a Deaf Child." *International Journal of Pediatric
Otorhinolaryngology* 68(8): 1027—1038. DOI: 10.1016/j.ijporl.2004.03.010

Madrigal, V.N., K.W. Carroll, K.R. Hexem, J.A Faeber, W.E. Morrison, C. Feudtner. 2012.
"Parental Decision-Making Preferences in the Pediatric Intensive Care Unit." *Critical
Care Medicine.* 40(10): 2876-2882. DOI: 10.1097/ccm.0b013e31825b9151

Mauldin, Laura. 2016. *Made to Hear*. University Of Minnesota Press: Minneapolis.

Miller, Victoria A.and Robert M. Nelson. 2012. "Factors Relating to Voluntary Parental
Decision Making in Pediatric Oncology." *Pediatrics*, 129(5): 5. DOI: 10.1542/peds.2011-
3056

Miyamoto, Richard T., Bethany Colson, Shirley Henning, and David Pisoni. 02017. "Cochlear
implantation in infants below 12 months of age." *World Journal of Otorhinolaryngology
Head and Neck Surgery*. 3(4): 214-218.

National Institute on Deafness and Other Communication Disorders. 2009. www.nidcd.nih.gov
Accessed May 14, 2009.

Nicastri, Maria, Ilaria Giallini, Giovanni Ruoppolo, Luca Prosperini, Marco de Vincentiis, Maria
Lauriello, Monica Rea, Gabriella Traisci & Patrizia Mancini. 2020. "Parent Training and
Communication Empowerment of Children with Cochlear Implants." *Journal of Early
Intervention*. 43(2): 117—134. DOI: 10.1177/1053815120922908

Nicholls, Christine. 2005. "Death by a Thousand Cuts: Indigenous Language Bilingual

Education Programmes in the Northern Territory of Australia, 1972—1998." *The International Journal of Bilingual Education and Bilingualism* 8(2): 160—177.

Oleszkiewicz, Anna. 2021. "Blindness Enhances Interpersonal Trust but Deafness Impedes Social Exchange Balance." *Personality and Individual Differences*. 170.

Pfister, Anne E. 2019. "Predicament and Pilgrimage: Hearing Families of Deaf Children in Mexico City." *Medical Anthropology: Cross—Cultural Studies in Health and Illness*, 38(3).

Porter, Ann and Sisira Ediriulige. 2007. "Parents of Deaf Children Seeking Hearing Loss Information on the Internet: the Australian Experience" *Journal of Deaf Studies and Deaf Education* 12(4): 518—524.

Ruusuvuori, Johanna Elisabeth, Tarja Aaltonen, Inka Koskela, Juha Ranta, Eila Lonka, Inkeri Salmenlinna, and Minna Laakso. 2021. "Studies on stigma regarding hearing impairment and hearing aid use among adults of working age: a scoping review." *Disability & Rehabilitation*. 43(3): 436—446.

Scharp, Kristina M., and Brittan Barker. 2021. "I have to Social Norm This: Making Meaning of Hearing Loss from the Perspective of Adults Who Use Hearing Aids." *Health Communication*. 36(6): 774—781.

Shim, Sungkeun; Kang, Danbee; Bae, Ka Ryeong; Lee, Woo Yong; Nam, Seok Jin; Sohn, Tae Sung; Jeong, Byong Chang; Sinn, Dong Hyun; Kweon, Sun Seog; Shim, Young Mog; Cho, Juhee. 2021 "Association between cancer stigma and job loss among cancer survivors" *Psycho—Oncology*.

Solomon, Andrew. 2012. *Far from the Tree*. New York: Scribner.

Strauss, A., & Corbin J. 1998. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Thousand Oaks, CA: Sage

Sukhera, J., Kulkarni, C. & Taylor, T. 2021. "Structural distress: experiences of moral distress related to structural stigma during the COVID—19 pandemic." Perspect Med Educ

Szasz, T., 1960. "The Myth of Mental Illness" *American Psychologist,* 15 :. 113—118Wakefield, Jerome C. 2007. 'The Concept of Mental Disorder: Diagnostic Implications of the Harmful Dysfunction Analysis.' *World Psychiatry*, 6 : 149—156.

Thomas, Gareth M. 2020. "Dis—mantling Stigma: Parenting disabled children in an age of 'neoliberal—ableism.'" *Sociological Review*. 69(2): 451—467

Winefield, Richard. 1987. *Never the Twain Shall Meet: The Communications Debate*. Washington DC: Gallaudet University Press.

Zerubavel, Eviatar. 1999. *Social Mindscapes: An Invitation to Cognitive Sociology*. Boston: Harvard University Press

Zerubavel, Eviatar. 2020. *Taken for Granted: The Remarkable Power of the Unremarkable*. New Jersey: Princeton University Press.