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### A Lot of Noise About Deafness

A deficit conception of deafness medicalizes and defines the condition as “the inability to hear.” For many Deaf individuals, however, deafness is not a loss, but a *gain* – a gain of a unique shared experience and visuospatial language that gives rise to a legitimate Deaf Culture. I argue that culturally Deaf people are a linguistic minority rather than disabled, and the clear majority of disabling factors that the Deaf community currently faces are a result of established institutional inequalities maintained by the hearing community. Deaf people are only disabled to the degree that the hearing majority is unwilling to accommodate them. Cochlear implants act as a lazy proxy for said accommodation. The technology not only assumes that the deaf are better off as hearing, but it attempts to forcibly change the individual’s identity. I argue that even if cochlear implants were a perfectly-functioning “bionic ear,” a parent refusing implantation for their child is neither immoral nor maleficent. But adding in all the complications and risks that the procedure currently carries, choosing *to* implant a child is a major invasion of their autonomy. This is a parental choice that is unfairly thrust into the limelight. I argue that the stakeholders in this choice – parents, children, and to a lesser degree, health care workers – are not provided with adequate information to make a decision that is fully formed, culturally competent, and medically sound. The best solution moving forward consists of proper education of stakeholders and a greater public awareness of Deaf culture.

An astute reader observing the discourse will notice the usage of both the lowercase “deaf” and the capitalized “Deaf.” The former refers to the medicalized definition: someone whose hearing does not allow them to readily use and understand spoken language. The latter refers to a cultural identity. Deafness is unique among conditions that are often classified as disabilities because it alone led to the creation of a new culture. There are many competing definitions of culture and what constitutes a cultural group. Often, it is described as people concentrated together who share their own language, art, music, customs, writing, institutions, and events. More generally, it is a system of meanings and values that shape one’s behavior. The desire to communicate is innate and powerful. When one pathway is blocked, another is sure to be created. In the absence of sound, deaf people created their own manual languages. American Sign Language (ASL) is the manual language that I will be focusing on. No other “disability” necessitated its own language. Braille may come to mind, but it is simply a coded form of existing languages and is not used to communicate person-to-person. It is not a language unto itself. And while paraplegics and the blind may form communities and have unique shared experiences with other community members, those communities still exist under the umbrella of hearing culture. Only deafness, with its own language, is able to exist separately\* (see addendum). This establishes the case for Deafness as a culture, rather than a disability.

It is no question that deafness is definitively a departure from species-typical functioning. The lack of hearing is not a social construct, but a tangible, real fact. Because of this, there seems to be this disconnect when Deaf culturalists advocate for their rights – how can they argue on the one hand that they are a linguistic minority and not disabled, yet at the same time push for legislation like the Americans with Disabilities Act (ADA)? If Deaf people are just as capable as hearing people, what is the need for these supports and accommodations? But this assumes that

the Deaf and hearing start on a level playing field. The truth that reconciles this incongruity is that the ADA ultimately serves to provide these minority populations with rights that have been unjustly withheld. Requiring public businesses to, for example, build a ramp to allow easier access for people in wheelchairs would only act as a “special privilege” if we assume that the standard practice is to have the person get out of their wheelchair and heave their torso up the steps.

But the concept of disability is a social construct that is wholly environment-dependent. In a noisy bar, music blaring, two English speakers may be completely unable to hold a conversation, yet a Deaf couple could comfortably communicate from across the room. A hearing SCUBA diver must drill some rudimentary hand motions into their brain as part of their NAUI certification, yet a deaf family could have a full conversation underwater on their very first tour; sixty feet under, and their ability to communicate is not affected at all. Paraplegic wrestlers often have an advantage over non-“disabled” opponents; focusing all their strength into their arms and upper body makes them incredibly powerful for their weight class. Paraplegics have far more experience wrestling against people with legs than the other way around, and a wide range of techniques like ankle locks and heel hooks are rendered completely useless. Sir Douglas Bader was a fighter pilot for the UK’s Royal Air Force during World War II. He lost both his legs part-way through his career, but he continued his military service. Once again, the loss of his legs gave him an advantage over other pilots. The high G-forces sustained during combat maneuvers draw blood away from the pilot’s brain and into other parts of the body, potentially causing a black out. But without any legs, Bader’s blood had nowhere else to go, allowing him to perform unprecedented feats of airplane maneuverability.

Nothing is intrinsically a disability, regardless of how much it deviates from the norm. Imagine the daily life of this hypothetical deaf teenager; they know ASL and attend their state's school for the deaf; all of their classes are taught in ASL; their friends are deaf and all know ASL; they are on the wrestling team and have a competition against a hearing school. One team learned their techniques in ASL, the other in English, but once they are on the mat talking doesn't matter. At what point in this student's daily life are they "disabled"? Perhaps it's when they go to Starbucks, and the barista has no knowledge of ASL. The student has a complicated order, but doesn't have a pen and paper to write on, so it requires a bit of pantomime to get their drink made. The exaggerated gestures draw the attention of on-lookers, and while a bit embarrassed, the Deaf are no strangers to the staring of hearing people. Regardless, this deaf student only feels the effects of their "disability" when they enter a hearing space. By establishing the relativity of disability, as well as the necessity of place in the concept of disability, it stands to reason that if deaf people are considered disabled, then the majority environment must be intrinsically inhospitable towards Deaf people. Reality reflects this reason: many of the disadvantages faced by people who are deaf turn out to have social and institutional causes and could be rectified by changes in the way society is organized (Sparrow).

I recently attended the Louisiana School for the Deaf's performance of *The Little Mermaid*. The students on stage all signed, but there were interpreters and singers present in consideration of hearing family members and the general public. The singers were atrocious. The interpreters voicing the characters were clearly inexperienced and did not have a script, often giving improper interpretations or simply omitting huge swaths of dialog. There weren't enough microphones for every interpreter, so their voicing would stop as they passed the microphone down the line. Sebastian, a crab with an iconic Jamaican accent, played by an energetic young

black student, was voiced by a 60-year-old white woman who barely spoke into her microphone. I can't even remember all the occasions that disrupted my experience. But absolutely *all* of that went unnoticed by the deaf people present. (But at the same time, from a deaf perspective, the entire play is nonsensical. The central problem is that Ariel loses her voice. To deaf people, what's so tough about that?) Just as a deaf person in a hearing space faces adversity invisible to the majority, a hearing person in a deaf space has their own set of distractions to contend with.

In an environment of true equality, the most significant difference between the hearing and Deaf is the use of spoken language versus manual language. But in the *current* environment that emphasizes speech over signing, what's valued is your ability to communicate with others, not other's ability to communicate with you. This enforces the cultural hegemony of the speaking majority over the signing minority; instead of altering norms to be more inclusive and respectful of Deaf culture, the hearing community asks the deaf *individual* to conform. Cochlear implants have become a destructive proxy for said accommodations.

A cochlear implant (CI) is a medical device intended to create a sense of hearing for a person who is hard-of-hearing or profoundly deaf. CIs bypass the damaged cochlea and directly stimulate the auditory nerve. But this does not let someone hear; it only provides a digital approximation of sounds (Voices, while intelligible, sound robotic and muffled; the beat and rhythm of music is discernable, but it lacks a sense of musicality.). These procedures have received significant negative backlash from the Deaf community. For Deaf individuals who view their deafness as a cultural marker rather than a disability, the pursuit for "a cure for deafness" is a direct threat to their way of life. Deafness is about the shared experience of being deaf in a hearing world. When a child receives a cochlear implant, the Deaf community loses a potential member. For this reason, the advent of CIs has been seen as cultural imperialism imposed by

hearing-normative society that threatens the very existence of Deaf identity (Jones). It has even been likened to a genocide or an ethnocide of Deaf culture (Sparrow). This debate has called into question the morality of choosing to implant a child, and choosing *not* to implant a child.

For a purely argumentative purpose, let's begin by assuming that current cochlear implant technology is a perfect "bionic ear" that assigns an identity at birth. A deaf infant who receives one will grow up as a hearing person, and a deaf infant who does not receive one will grow up as a Deaf person. I will explore two different viewpoints from which to consider the ethical implications of this choice.

The first viewpoint approaches the topic as a conflict between beneficence (the well-being of the child) and parental autonomy. When a doctor recommends for a child to receive a cochlear implant, at the end of the day, it's the parents who are the ones taking the child home. The doctor is not a major stakeholder. As such, decision-making should favor the parents by default. Parenting is a constant weighing of values – it has so many different forms that universal agreement on "wholly-moral parenting" is impossible. It is largely a hands-off process for any legislative bodies, except in cases of abuse. At that point, non-stakeholders can intercede and overrule parental autonomy. For the *doctor* to have the final say on whether or not to implant a child, it must be proven that a) being deaf is a harm, and b) being deaf instead of hearing is abuse.

The second viewpoint discards the opinion of non-stakeholders and solely weighs between parental autonomy and child autonomy. Children are not yet able to make informed decisions, but they carry a status of potential autonomy. Parents act as their proxy until the child reaches adulthood. To determine if parents are overstepping their bounds as proxy, we must first know where the bounds are. That is to say, we must establish what rights a child has. Joel

Feinberg begins his discussion of children's rights by stratifying rights in general into four categories. There are the rights that adults and children share; there are the "dependency-rights" possessed only by children, due to their dependency on others for basic needs such as food, shelter, and protection; there are the rights shared only by adults; and there are the "rights-in-trust" which are to be "saved for the child until he is an adult" (Davis). Because these rights-in-trust must be protected now so that they can be exercised later, they are what Feinberg calls "the child's right to an open future." Parents violate a child's autonomy, then, when they limit the range of opportunities for their child's future. To know if such a violation occurs, it must be proven that hearing children and deaf children have differing ranges of possible futures, and it must be determined which of the two ranges is widest.

Parenting is a messy affair and attempting to apply strict ethical doctrines like beneficence does little to clear the haze. There are countless parental decisions made every day that, if brought to the public forum for debate, would catch considerable flak. If every parenting decision needed unanimous approval, nothing would get done. Cochlear implantation simply had the misfortune of being pushed into the fore and the ensuing scrutiny. But to consider deafness as a harm is misguided, and to view it as abuse is patently incorrect. Do we look at the disparities in education and income between racial and ethnic groups in America and decide that the solution is to eradicate minorities? I would imagine that many African Americans would say that their life would be easier if they were white, but I would also imagine that few of them express a desire to become white. As a gay man who has experienced my own share of hatred and discrimination because of it: if there's a life after this one, I hope I'm gay again.

Weighing between parental autonomy and child autonomy is a much more congruent dilemma and accepts logical analysis more readily. Ultimately, the main consideration is to ensure that the child grows up in the culture that will provide the widest possible range of opportunities. Depending on how large we judge the difference in opportunities available to Deaf and hearing children, “trapping” a child in a culture with reduced opportunities is morally wrong. But a Deaf person who does not identify with hearing culture may not value the opportunities that exist within it. The assessment for the range of a child’s opportunities almost always comes from a hearing center. It assumes the opportunities at stake are the ability to hear, to speak, and participate in a larger society including the economic and social incentives that come with. But for a Deaf person deciding whether to implant their child, the risks are instead the loss of the opportunity to experience the unique and rich culture of the Deaf, and to pursue all the ways of life that *it* makes possible.

Whether the argument focuses on beneficence versus parental autonomy, or parental autonomy versus child autonomy, each perspective is defensible. But it is important to remember that I specified that my argument above assumes that cochlear implants are a perfect “bionic ear.” This is far from the case. Their flaws are major and myriad. As part of my research, I interviewed Denise Crochet, who has been a working ASL interpreter for over 23 years and is also a professor here at Tulane University. Having lived through the entire lifespan of cochlear implant technology and having observed it with an acute awareness of Deaf culture, her perspective on the controversy is quite tenable.

These are umbrella-like topics that cover a wide range of experiences. There is no one-size-fits-all answer. “Even if it’s just a disclaimer, it’s important for you to say: no one response can speak for an entire group of people... and hit that home often.” But definitively, cochlear



implants are pathological by nature of being medical procedures and have sprung up from a philosophy of “something’s broken, let’s fix it.” She believes they are a wonderful tool for late-deafened individuals. Despite knowing the controversy that surround CIs and being integrated within the Deaf community, “if I’m deafened tomorrow, I’m lining up to get one. Because I was raised as a hearing person; I value my hearing.” But from her experiences, she has yet to see CIs do what they claim to do. She’s met a lot of people with cochlear implants, and while she stresses the anecdotal nature of her statements, she has yet to see CIs “manifest the successes that they claim.”

The successes that they claim – whether or not they are truly present – are always accompanied with bodily risk. When a cochlear implant is installed, the cochlea is destroyed. Any remaining hairs or cilia in the ear are also destroyed. Recipients lose any residual hearing they may have had when the electrode is installed. “It’s not a fit for everyone, even though we are seeing it used as a fit for everyone.” For people who would have previously just been hard-of-hearing, “doctor’s are like ‘oh but the cochlear will do it: put ‘em in.’” And, Denise emphasized, “getting synthetic hearing doesn’t make you hearing.” Despite receiving a simulated sense of hearing, the person’s identity doesn’t change. They are still the same person after the procedure. If someone removes their CIs, they become deafer than they ever were. If there’s any difficulty with the device, or it needs to be improved, “it’s another piece of surgery, it’s another rerouting of the cochlea, it’s another adjustment of the tones that you can hear, it’s another round of speech therapy if that’s what you’re pairing it with.” It takes an incredible commitment to consistent speech/language therapy and tuning of the device to seek the results that, often, aren’t really feasible.

As far as ethics go, Denise doesn't believe that denying a child a cochlear implant will limit their choices later in life. For one, the medical field does not accurately value the opportunities to be found within the Deaf community. Additionally, the choice to perform major, non-life-saving surgery on a child is an enormous invasion of their rights. In fact, the operation itself may limit the child's future choices. They will be unable to play contact sports, as the electrode may cause irreparable brain damage if jostled too hard. There is a depth limitation that prevents serious SCUBA diving. And many other medical procedures, such as MRIs, cannot be performed on someone with a CI. But what the cochlear debate really comes down to the issue of early language intervention. "Implant your child if you think that's what you need to do. But don't deprive them of any form of language." There's more at stake than just which community, Deaf or hearing, the child will belong to. They are missing an incredibly important time in language development, and there's a whole process of brain mapping that doesn't occur in the silence. Whether it's a spoken or manual language, the child needs *something* to develop properly. Educational outcomes for deaf children are already grim enough. "Early cochlear implant intervention, for a very long time... required that parents who implant their children *not* sign. That was a stipulation in the surgery's early days." So there has always been a form of audism implicit in the CI since its inception. Whether it's AG Bell, 100 years ago, saying "signing's gotta go," this debate has never really stopped. "And cochlear implants really just added more fuel to the fire."

The scientific literature supports her experiences. Acquisition of language skills occurs at an incredibly accelerated pace for infants and toddlers, with a precipitous drop as the child approaches pubescence. Pre-lingually deaf children need early implementation – as early as 18 months – to have similar outcomes as their hearing peers (Vincenti et. al.). There is a significant

decrease of treatment efficacy as the patient ages. The chances that the body can adapt and the implant will take is low. Even if the hearing can be restored, speech difficulties are a major concern depending on the patient's history of deafness. For a pre-lingually deaf child even as young as 10, there is no guarantee that the procedure will work, and even if it does, their speech skills could be rudimentary at best (Gratacap et. al., 2015). The importance of early implementation places enormous pressure on the parents of deaf children considering the procedure.

When hearing parents have a deaf child, many of the problems the child experiences are the result of being born to unprepared hearing parents. It will take time to diagnose the child as deaf, and then the parents must deal with that shock, and then must sort through all the conflicting advice on properly raising a child, and must choose the best option for educating their child, and so on – all the while, the child is devoid of language in the most irreplaceable and crucial time for language development. The outcomes for children who experience this are not stellar, to say the least. And approximately 90% of deaf children are born to hearing parents, and 90% of *those* parents never learn even basic levels of ASL (Weaver and Starner). This is an unfortunate lived experience that scores of deaf children silently suffer through.

When Deaf parents have a deaf child, they may want to share with them the culture that they are so proud of. Or they will know the hardships of the shared Deaf experience and may want something different for their child. But the latter comes at great cost. Other members of the Deaf community may treat the parent's decision as turning their backs towards their own culture. Deaf parents choosing to implant their child and hearing parents choosing *not* to implant their own child, despite being mirror image situations, will experience very similar pains and woes. Their child would not share the same first language. Their child would live in a completely

different world, without their help in navigating it. To choose for their child to receive a cochlear implant, in hopes of giving them more opportunities, or to choose *not* for their child to receive a cochlear implant, in hopes of placing them into a more embracing community, the parents must risk a departure from their own culture, diminished ability to be a guiding hand, alienation from their community, and estrangement from their own child (Byrd et al.).

The beauty of American Sign Language is apparent, and I understand the richness of Deaf culture, but I am also aware of the everyday hardships that are an unfortunate reality for those of us who hold a minority status. I believe in the importance of preserving a child's eventual autonomy and their right to an open future, but I also believe in the validity of choosing a Deaf identity and the opportunities it holds. These ideas are not unreconcilable with each other; there is a synthesis in these dialectics, in this seemingly-diametric opposition. To properly respect the dignity of both sides, science must continue to make advancements in cochlear technology to minimize or eliminate the current risks. Additionally, health care providers, parents, and everyone else involved in the formative years of this child's life needs to be aware of the medical, practical, ethical, and legal issues surrounding Deafness and cochlear implants.

Because of the insular nature of the Deaf community (which is in no small part due to the oppression and alienation they face from hearing society), most hearing parents of deaf children have no knowledge of ASL and probably haven't even met a deaf person before. Positive exposure of Deaf culture in the hearing community would help with these issues immensely. I conjecture that the Deaf community may do well to be aware of the history of the LGBTQ+ community. Both statuses, queer and Deaf, are horizontal identities: an inherent trait that is not shared with parents and must therefore be acquired from a peer group. The queer community was also isolated even until very recently, but in the past decade has seized enormous strides in

public awareness, acceptance, and support. I believe there could be a kinship between the two communities. Unfortunately, the Deaf community has a language barrier that the queer community does not – a barrier that probably cannot be overcome until ASL courses are a staple of educational systems across all grade levels and across all of America.

Preparation is the name of the game. Ideally, informed parents will make informed decisions. If parents are aware of all the options they can provide for their child, then their child will be able to truly blossom and explore a wider scope of options, better equipped to choose their own richest future.

## Addendum

*Note: the information in this addendum is not necessary for understanding the paper, but is offered for the additional enrichment of the reader and the enjoyment of the writer.*

Above I claimed that Deafness is the only condition normally classified as a disability that has its own culture and language. In the very near future, this may no longer be true. We are currently experiencing the creation of a Deafblind culture that is distinct from both hearing and Deaf culture. The pro-tactile (PT) movement arising from the deafblind community in Seattle is a major shift in thinking that serves to empower the deafblind community.

The Seattle deafblind community was established in the late 1980s. The combination of Seattle's mild weather, good bus system, skilled interpreters, and opportunity for work at the Seattle Lighthouse for the Blind provided a more welcoming metropolitan setting than most of America. Washington State Deaf-Blind Citizens (WSDBC) was established in the late 1980s to organize community activities and focus on self-advocacy for the deafblind on a group basis, rather than an individual one. The WSDBC won the bid for the 1984 national convention of The American Association of the Deaf-Blind (AADB), and the ensuing successful convention drew even more deafblind people into the already-growing community. Today Seattle is regarded as one of the most livable cities among deafblind people.

The pro-tactile movement was a social movement that began sometime in the late 2000s. It started as a critical view of the prevalence of sighted people in deafblind spaces. A significant amount of energy and education is expended by deafblind people to compensate for vision loss. But what if deafblind people could create a space that didn't require compensation? A space by deafblind people, for deafblind people. Pro-tactile practices are guided by the following axiom:

“Legitimate knowledge can be produced from a tactile perspective without first passing through visuality” (Edwards). In other words, our reality can be wholly and adequately interpreted by a perspective that is tactile alone. This seedling of an idea was what blossomed into the pro-tactile movement. So “pro-tactile” is not a new language, but a philosophy of a tactile world shaped for tactile people that will inevitably change existing manual languages to fit the tactile needs of the Deafblind community rather than the visuospatial needs of the Deaf community.

But what makes a space inviting for the deafblind? How would a group of deafblind people communicate without sighted people as intermediates? The issues to tackle were quite broad, so the movement is quite broad. One particular event that helped the burgeoning movement took place in 2010. Deafblind leaders organized a series of 20 pro-tactile workshops – no interpreters were provided, and no sighted people were present except for a research crew. The success of these workshops spawned more discussion and showed that deafblind people could determine their own communication practices.

Leaders of the movement have sought a greater shift in the way the deafblind orient themselves to their environment, language, bodies, and social roles (Edwards).

“In order for these changes to take place, boundaries around what counted as appropriate and inappropriate touching, had to be revised, and the norms that felt intuitive to sighted people had to be left behind. Once this was accomplished, tactile alternatives to headnodding, attention-getting, and turn-taking could be established. Tactile communication in groups could be worked out. DeafBlind people could learn to discern qualities such as politeness, impatience, and attractiveness by evaluating tactile cues against new frames of social value” (Edwards).

The movement is still in its nascence, but these changes will inevitably lead to the emergence of a new language, and from there a new culture.

These developments are particularly interesting for those of us living in Louisiana because we house one of the largest deafblind populations in the world. To understand why requires some historical context. During the French and Indian War from 1755-1764, the British forcibly removed the Acadian population from Acadia (a region of modern-day Canada). Many Acadians followed the Mississippi River south and began settling in the Louisiana region in 1764. Some of these settlers carried a recessive gene for Type 1 Usher Syndrome. The founder effect led to a significant population of people with Usher Syndrome within the Cajun region. This remains true to this day. For this type of Usher syndrome, the person is usually born deaf and has increasingly diminished vision until puberty, by which point they have lost almost all of their sight. While mainly concentrated around Lafayette (where much of the Cajun population lives) and Baton Rouge (where the Louisiana School for the Deaf is located), Louisiana as a whole is a hub of deafblindness. However, to quote my professor Denise Crochet once again, “the country deafblind folk down here aren’t as ‘savvy’ as those hip deafblind people in Seattle.” As such, it may take quite a while for the philosophy of PT to migrate down to Louisiana.



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