THE PROFOUND IMPACT OF COCHLEAR IMPLANTS ON A YOUNG DEAF ADULT`S LIFE & DEAF IDENTITY

LAURA G. GIRARDO

Supervisor`s Name: Rachel da Silva Gorman

Advisor`s Name: Geoffrey Reaume

Supervisor`s Signature: _____

Date Approved: Dec. 18, 2018

Advisor`s Signature: _____

Date Approved: December 18, 2018

A Research Paper submitted to the Graduate Program in Critical Disabilities Studies in partial fulfilment of the requirements for the degree of

Master of Arts
Graduate Program in Critical Disability Studies
York University
Toronto, Ontario M3J 1P3

Date of Submission:
December , 2018

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Abstract

This paper explores my autoethnography about the life experiences of young deaf adults with cochlear implants, and most importantly, researching how we describe and identify ourselves. The generation born in the years 1990 and onwards have been shifting and changing what it means to be "deaf", with new technologies and access to speech and sound. Previously, the term "Deaf" was associated with the Deaf Culture as a linguistic minority. With access to technologies such as the cochlear implants and access to learn sound and speech with auditory verbal therapy, the Deaf culture is declining. However, as someone who has a cochlear implant, the idea of "deaf identity" has become more prevalent as I grow older and continue on my journey in life with a hearing loss- in a community with "hearing" people. My cochlear implant has placed me in the middle- not "deaf enough" for the Deaf culture, and not "hearing enough" for the mainstream, hearing society. The importance of deaf identity defines a place of belonging, and not feeling outcasted. Most importantly, I would like to raise awareness about the significant impact the cochlear implant has on my life, from being able to hear, speak, and integrate into the hearing community.

Keywords: D/deaf, hard of hearing, hearing loss, hearing impaired, deaf identity, cochlear implants

Acknowledgements

This paper is dedicated to the number of people in my life who has helped shaped me into who I am today. Firstly, thank you to my role models- my parents. You have gone through so much to give me the life I have today. From going through extremely tough times, with my two open heart surgeries, to my hearing loss, and even raising three children, makes me proud to be your daughter. You went through a lot of sacrifices and made choices by trusting in blind faith as well as research into making sure my disabilities would not hinder my life. Thank you for giving me the cochlear implant, even though it was hard in the beginning. Thank you for everything. Thank you to my teachers of the deaf who taught me about self-love as a deaf person, and self-advocacy and acceptance in the deaf community. Thank you for educating me on hearing loss, and for all of your amazing assistance and support in my educational career. I wouldn`t be here writing a thesis paper if it wasn`t for your perseverance and persistence in my academics. And lastly, thank you to York University and the Critical Disability Studies Master's program for giving me a platform to share my story. Thank you for making me realize my life`s purpose, which is to educate and advocate for the deaf and hard of hearing community. Thank you to my supervisor Rachel Da Silva Gorman, and to my advisor Geoffrey Reaume for all of your help and support with this paper. Thank you to my other advisors, Connie Mayer and Pam Millett for your support with this paper.

Introduction

As a deaf person, I reflect on my life as an oral speaking, unilateral cochlear implant user, as well as the challenges of the "capital D" Deaf community`s opposition of the cochlear implant. This paper is focused on how introducing the technology of cochlear implants to children of the 1990`s decade has affected their social and cognitive development into becoming independent and contributing citizens of mainstream society as young adults (Chowdry, 2010), and most importantly their deaf identity. The reality is that we live in a majorly hearing society that will not learn sign language. Medical devices and procedures such as cochlear implants and auditory verbal therapy will help deaf people to integrate in a mainstream society with full communication, freedom and independence. The reason why early intervention (although a controversial and ethical situation) is incredibly important, is because of the brain development. Children`s brain developments are still learning and growing, so the earlier the intervention, the easier it is for their brain to naturally coincide and develop sounds from the cochlear implant. Deaf culturists believe that it is abuse that parents are willing to do such an invasive surgery on a young child, to which I am reminded by a comparison my mother has always told me, "If you find out that your child cannot see, wouldn`t you want to help them by giving them glasses? Well, if your child is deaf, why wouldn`t you want to help them by giving them hearing aids?" (or in this case, a cochlear implant?) While I understand and believe that surgery poses some risks and natural fear, and it is not appropriate for many deaf people depending on their level of hearing loss, I also believe that it poses long-term benefits. Also, I want to make a note that a cochlear implant is NOT a cure for hearing

loss. The child will *always* be deaf when they turn off their device. The cochlear implant is a device that aims to amplify sound lost from the hair cells of the cochlea. The sound is then amplified through a magnetic wire that is implanted in the cochlea, which sends signals to the brain. The misconception of cochlear implants being a cure or fixing a hearing loss has become more widely known than the factual benefits of cochlear implants themselves, that it leaves a false hope for parents and candidates who wish to receive one.

The next generation of deaf citizens are living in a technologically-advanced world where medical intervention is easy to access, starting from newborn babies. Today, newborn babies can be implanted as early as 12 months whereas back in the 1990`s, this brand new device caused an uproar of controversy and fear of the unknown future. 30 years later, how successful is the cochlear implant? How are the babies born from 1990-2000 and on, coping with their lives as deaf adults? How has the cochlear implant improved on their livelihoods, but most importantly shaped their identity? Do they view themselves as deaf people? How has their upbringing affected this? Does their deafness limit them in their daily lives? Or improve their lives because of the cochlear implant? What have they learned from themselves as cochlear implant recipients? What do they want to advocate for? Have they ever thought about the deaf representation in the media and how they feel about it being always painted as the signing deaf person? Or seeing a cochlear implant misrepresented as a "cure" on television programs like *The Young and the Restless?* As someone who wears a cochlear implant and is an oral speaker, I openly identify as deaf and advocate on behalf of my deafness. However, in my personal

experience, I have come across deaf people who treat their hearing loss the way some people would treat their prescription glasses for eyesight- like an accessory, they don`t identify as “deaf”, and they never had to go through assistance in school such as wearing an FM system and working with teachers of the deaf. This even includes never being bullied for their hearing loss. I have always been in awe of that because of how different my life was compared to theirs. This is why my research is important because I want to explore the relationship between cultural identity and the use of a cochlear implant, including revolving their lives around their hearing loss, having gone through struggles (or not), participation in the deaf community (or not), and becoming advocates. Due to the limited scope of an MRP, I explore these questions in the form of my autoethnography, as well as relying on journals and articles that speak on this subject.

Methodology

Research Paradigm

This paper is a qualitative research from a deaf insider. This paper will rely on collecting data from literature and secondary sources. The focus of this paper will rely on literary review papers with an auto-ethnography component. I identify as a person with a hearing loss, but I do not identify as a member of the Deaf culture because I do not communicate in sign language, and I wear a cochlear implant.

Sample Strategy

This paper is a qualitative, positivist biographical research. Along with my autoethnography, I searched for literature such as journals that discuss young deaf adults who have been implanted from 1990-2003, and were between the ages 0-6 at the time of

the procedure. They must also have severe to profound hearing loss as cited on their audiogram. Being implanted post-lingually (ages 4-6), requires auditory verbal therapy to re-train their brain, post-surgery, with new sounds and speech, which is where I fit into. They usually identify as having an auditory, oral deafness. In doing this research, I hope to find a common ground on young adult`s viewpoints of their deaf identity in relations to how their cochlear implant shaped their livelihoods.

Data Collection

My data was collected in the form of a literary review with an analysis from an auto-ethnography on my background. My data collection also consisted of my own personal experience and stories, which I linked through the experiences of other young, deaf adults. I also had the pleasure of attending the *Canadian Hard of Hearing Association*`s first Youth Forum which was a conference for young, deaf adults aged 18-25, brought together from all over Canada to indulge in workshops discussing self-advocacy, deaf identity, mental health and more. Lastly, my data collection also consists of literatures to assist in legibility and historical context. These literatures such as journal articles and books are found in online databases, and the library catalogue at York University. Through doing my research, I would like to find a correlation to their findings on deaf identity. I also need to use my research to further explain my four subcategories: *Brief History of Cochlear Implantation, Impact of Cochlear Implant Technology, The Deaf Culture and Debates About Cochlear Implant Technology,* and *Changing Nature of Deaf Identify as a Consequence of Cochlear Implant Technology*.

Ethical Considerations

This paper will be considered a controversial paper, especially to the Deaf culture. There are many people who are diagnosed with a hearing loss and identify as deaf, "capital D" Deaf or hard of hearing. The categories are then defined through a community who accept and label themselves as such. The words 'deaf' and 'Deaf' hold two specific meanings, so in this paper I will identify "capital D" Deaf, for those who identify as part of the linguistic minority community, the Deaf Culture, where they predominately speak in sign language. "Small d" deaf and hard of hearing people, are medically diagnosed as deaf, but may not identify as "capital D" Deaf because they choose to communicate orally, and for some, they have chosen to wear a cochlear implant. This results in the lack of acceptance from the Deaf culture. Deaf culturists and advocates are opposed to the idea of "curing" or finding solutions to mainstream children who are deaf. They view this harshly, comparing it to a form of genocide, which will lead to the obliteration of the "Deaf race" (Tucker, 1998).

My Lived Experience

I would like to use this opportunity to explain my journey and where I stand as a deaf person, in order to give a better understanding of my views and biased opinions for this paper. I also want to make a note that no two hearing losses are the same. Every deaf person has their own story, diagnosis and opinions. This is mine. I identify as a female with a severe to profound hearing loss. I identify as a deaf and disabled person in a mainstream, hearing community. I don`t identify as a "hearing" or able-bodied person. I don`t feel connected to the Deaf culture because of their predominant sign-language

community. I am an oral speaker and I do not communicate in sign language. I wear a cochlear implant on my right ear. I was offered to do another surgery on my left ear, but personally declined as I worried about losing my hearing I already had. On my right ear, I am 100% deaf, and on my left ear I can hear low pitched sounds only. When I am not wearing my cochlear implant, I cannot hear sounds like the alarm, fridge, birds or any other high pitched sounds. I look back at my past and see what I went through and the sacrifices my parents went through to give me the life I have today. I was born with a congenital heart condition that resulted in two life-threatening open-heart surgeries under the age of one. After the surgeries, I was diagnosed with a severe to profound hearing loss at the age of two. My family members are all individuals who have normal hearing, so when they found out that I was deaf, they were devastated to find out I had another disability. My parents had no knowledge about the Deaf culture or what being deaf entailed, so after meeting with an Ear, Nose and Throat Specialist, they decided to enroll us (parents included) in a sign language class with a sign language teacher. Growing up in a pre-dominantly hearing family, meant that my parents also had to learn sign language. They thought that enrolling me in a sign language class was what I needed to get in touch with my “deaf roots”, and they also thought it was the “right thing to do”. They even started researching deaf schools for me to attend to, as they felt that that was where I needed to be. Unfortunately, the closest school for the deaf was in Milton, Ontario, which was an hour away from where I lived. This meant isolating myself from my family and friends. After a few unsuccessful sessions, my sign language teacher saw that I was not connecting with sign language. I was verbally expressive. One day, she sat with my parents and told them that while this was going to break her oath as part of the

American Sign Language profession, she saw that I wanted to use my voice. She recommended to my parents that I go see a speech therapist and do auditory-verbal therapy. While I had trouble comprehending the importance of speech as a young child by throwing many tantrums to avoid going to the sessions, I can now say as an adult that this was the beginning of a new chapter in my life that changed for the better. At the age of four, my auditory verbal therapist recommended the cochlear implant to my parents. After learning that it was a surgical procedure, they did not want to go through with it. I had already experienced two traumatic surgeries. Why would they do another invasive surgery that was new, not well known and posed a lot of surgical risks? (Remember, this was in the year 1999) I also wore hearing aids at the time which was troublesome. I did not like the way the ear mold fit, or the way the sounds amplified the high-pitched sounds. I constantly took it off, and misplaced it many times (including a time when it ended up in the laundry machine). Because of my severe to profound diagnosis, I was still not hearing all the sounds, and was missing the majority of them, because of the heavy focus on high pitched sounds. My speech was little to none, even with the help of the speech therapist. It was evident that the hearing aids were not working for me. While researching other "hearing" possibilities, my parents were told to give me a trial with digital hearing aids. Before this, I was wearing analog hearing aids that amplified low sounds but not high sounds. Digital hearing aids were a new device that could be adjusted to electronically highlight sounds I could not hear and lower sounds I could hear, so that my hearing was as equally balanced as possible. This was a theory that was supposed to work, and it didn`t. During the hearing aid trials, my parents included me in the process by talking to hearing specialists, audiologists, surgeons, as well as families who had

children with cochlear implants. A year later and after numerous discussions about whether the cochlear implant was the right fit for me, my parents finally decided to go forth with the surgery. On Thursday, July 11th, 2001, at the age of six I was implanted. My parents told me how my language exploded, and I was introduced to news sounds I didn`t know existed, always asking them what it was. And it was sounds that hearing people take for granted, like alarm, the doorbell, the airplane, the fridge, and so much more. Because of the cochlear implant today, I am able to orally communicate with my friends and family. Being in a majorly hearing community, sign language would not have been beneficial for me. I feel more independent, free and confident. I am able talk on the telephone (sometimes, even though I prefer not to), I can go to a restaurant and order my meal, both in store and in the drive-thru window, I am able to drive a car, and I am able to go to appointments without depending on my parents. I am able to do many things that I personally feel would not have been accessible to me had I signed. However, the implant does not replace or cure my hearing loss. I am still deaf, and I still experience many occasions of not being able to hear everything with the cochlear implant. I still need accommodations like a notetaker and an FM system and closed captioning to make sure I am picking up and understanding every piece of information. On December 18th, 2010, at the age of fifteen, my internal magnet broke and I had to have another surgery to replace it. Going through the second surgery meant another round of rehabilitation of training my brain with sounds once again. I was eligible for a second cochlear implant on my left ear, and was offered to do the surgery while the doctors were fixing my first implant. By then, having bilateral cochlear implants was not uncommon and I knew a few people who had done it. I had heard great results from those who felt like having two

cochlear implants as opposed to one changed their hearing and lifestyle more. I respectfully declined to have bilateral implants because I was scared to lose or ruin what was left of my hearing in my left ear. I was comfortable with it and I felt like it was a "companion" to me when I didn't have my cochlear implant on. I was also scared of the risks that came with implanting my left ear "late", with a developed brain. Once I lose the hair cells in the cochlea, it will never grow back and I would have lost more hearing. I was not six years old anymore, and my brain had matured and developed. But a part of me always wondered "what if I had the second implant?" However, I do not regret my decision at all, and I still have my left ear as my companion. I remember both surgeries, both at six and fifteen years old. Both times, I woke up feeling like a train had hit me or an elephant sat on my head. It was painful and the recovery was long. I felt like I had more trouble the second time around with the post-operative recovery, because the swelling took longer to go away and the mapping and hearing tests were not up to par. It took longer than it needed to, but once we found the right sound, I was back to hearing the world with my cochlear implant.

My parents experienced a lot of backlash with the cochlear implant- both from their own family and the "Capital D" Deaf culture. Our family was able to understand the importance of the cochlear implants once they saw how much I had improved verbally, behaviourally and socially, but the Deaf culture called my parents "child abusers" and "criminals" for doing such a thing to a young child. They made them feel like they did the worst thing to a child. My parents sacrificed a lot but never let other people get in the way of their number one priority, their children. They were scared, worried and nervous. What if the implant was not going to work? They knew they made the right decision after

discovering all the sounds I had never heard before, like the house alarm, the microwave, the airplane! They know they made the right decision after seeing how much my language *exploded* and how much better my speech was becoming, thanks to more auditory-verbal speech therapy, which I did up until grade 4. However, I will always feel very insecure about my voice because of my speech impediment, or "deaf accent".

When I hear about claims that the cochlear implant is turning me into a hearing person, I often feel conflicted about this statement because I know that even though I am able to "hear" and "speak" *like* (emphasis on "like") a hearing person, I have never personally identified as a hearing person and will unfortunately never become one, because my disability is a *permanent* disability. I am a deaf person that chooses to communicate orally and integrate in a hearing community. The cochlear implant is just a device that allows me to do this when I turn it on. I am now 23 years old, and looking back into what my life has become, I truly feel like I would`ve suffered tremendously had I communicated with *just* sign language. And I realize that that statement may come across as controversial, but I didn`t live near a large deaf community, and most of the deaf students in my mainstream schools had already been using oral communication. It is because of my upbringing that I identify as "small d" deaf and hard of hearing; because of my status as an oral communicator and cochlear implant user. I see my deafness as an auditory disability. There are times in my life, especially when I was younger where I never liked or accepted my deafness, and I wanted to be a "normal hearing person", as I was always being bullied. But nonetheless, being deaf has also given me a new outlook and perspective in life that I am very grateful for, such as being an advocate for the deaf and hard of hearing community and raising awareness in many platforms.

Medical Model vs. Social Model vs. Cultural Model of Deafness

While cochlear implant recipients have often been told not to learn sign language to focus on oral speech, do young adults feel deprived of not knowing sign language? Does learning and knowing sign language make them feel more at peace and connected with their deaf roots?

> Others worry that learning a sign language will interfere with the extensive and intensive rehabilitation that is necessary to reap the most benefit from a CI or that asking parents to learn a new language to communicate with their child is too onerous. (…) For a child who receives a CI, the timely activation of the device begins a fuller experience with sound. Reliance on sign language over an extended period of time may negatively affect the child's capacity to learn spoken language after cochlear implantation. Prolonged, inadequate auditory input that fails to support spoken language learning at age-appropriate rates is related to gaps in speech and language after cochlear implantation (Mellon et al., 170-171).

I don't feel that I am deprived of sign language, however, I cannot speak for those who have a cochlear implant and have a different opinion than me. This generation of young, deaf adults are seeing oralism and sign language as a unification rather than a division. Many hard of hearing individuals have often said " I wish I knew sign language", and "I'm learning sign language now because I'd like to 'speak it' ". What is the end goal of feeling accomplished to learn sign language? While I do not feel deprived or showed an interest in learning sign language, I do know that I will eventually have to learn it as that is a mandatory pre-requisite to become a Teacher of the Deaf. The Teacher of the Deaf

Program in Ontario is seeing a significant decrease in the ASL stream and a large increase of the Oral stream, thanks to cochlear implants and the technological access to sound and language. I understand the importance of sign language, but it was never something I wanted to learn because I was in the mindset of wanting to perfect the English language, both orally and written.

I have approached those with a cochlear implant and asked how they felt about their deaf identity and I was surprised when one said he identified as "hearing", even though he speaks and signs at the same time, and also wore a cochlear implant. He explained that his oralism is the reason why he identifies as that. I have also heard other hard of hearing people with cochlear implants feeling that because they don`t have a strong deaf accent, they don`t want to say they are "hard of hearing" because if they do, they are often responded with either people not believing that they are deaf, saying, "oh but you speak so well" or, seeing "hard of hearing" the same way as their grandma`s hearing loss. They like to respond that they are "deaf" to make people understand the severity and seriousness of their hearing loss. I learned that each person approaches their deafness and hearing loss differently with how they want to present themselves to the world.

The opposing views of the medical model, social model and cultural model of deafness has an impact of the perspectives of deaf identities. I do not agree that the cochlear implant should be understood as being a part of the medical model perspective because as a recipient myself, I find that it is certainly a *solution* that alleviates a few barriers in my life. *The Canadian Hearing Society*, a non-profit organization for Deaf and

hard of hearing individuals provided a detailed definition outlining the differences between the medical model and the social model of deafness.

> *Medical model* – Focuses on the medical/pathological condition of the individual – a functional loss, handicap or impairment that needs medical intervention and rehabilitation to increase one's quality of life. Common terms used in the past to describe the deaf or hard of hearing individual or their physical state using this model include "disabled," "hearing impaired," and "deafness."
>
> *Social model* – Focuses on humanistic/social condition – the abilities and unique function that are needed to gain equal access to satisfy quality of life. Common terms used to describe the deaf or hard of hearing individual or their physical state using this model include deaf, deafened, hard of hearing, and people with hearing loss.
>
> *Cultural model* – Focuses on a shared language and/or cultural condition – a desire to celebrate Deaf culture and life. Newer terms used to describe the deaf or hard of hearing individual or their physical state using this model include Deafhood and Deaf-gain (as opposed to "hearing loss") (*Canadian Hearing Society*, "Models of deafness").

The medical model sees that the disabled person is the problem, whereas the social model sees that "the problem is the disabling world, with oppression and exclusion of people with impairments face that is caused by the way society is run and organized" (*Inclusion London*, "The Social Model of Disability"). The cultural model "explains the position of

the sign language community, focusing on the shared experiences, histories and (…) the central role that sign language plays within the Deaf community" (*Inclusion London*, "The Cultural Model of Deafness"). Deaf Culturalists see the medical model as an invasive, negative and aggressive perspective that aims to only fix and find a cure for hearing loss. While I don`t believe in the prospect that "I AM THE PROBLEM" because of my deafness, I do agree with other parts of the medical model of deafness, because of my awareness that my lack of hearing IS INDEED a loss, a disability and an impairment (whereas the social model sees it as a "difference").

> Deafness can be regarded both as an audiological disability and as a social and cultural construct. Regarded as an audiological disability, the focus lies on the ability to perceive sound and linguistically coded information mediated through speech. When this ability is reduced or lost, it will affect the person's life conditions, and different types of compensatory measures can be implemented (e.g. hearing aid, speech therapy, special needs education, etc.) (Ohna, 20).

By seeing my deafness as an audiological disability, it is recognizing that through my loss, I am different than my "hearing" peers, and recognizing how to individually adapt myself though accommodations and advocacy. I am deaf, but not dumb.

> Generally, people holding this viewpoint consider the hearing condition the optimal model and use the auditory methods to obtain the goals of using residual hearing, speechreading and speech. An individual is deemed successful if he/she gains good oral skills. The use of assistive devices such as hearing aids and cochlear implants is considered appropriate. A person who has this viewpoint is

called ‘deaf’ (*Diversity in the Deaf Community*, “Medical Model of Deafness vs Cultural Model of Deafness”, 2015).

The social model of deafness looks not at what is wrong with the person`s hearing but what the person needs to be able to live in a barrier-filled world. When I read the social model`s definition of creating a barrier-free world, I don`t understand why the cochlear implant isn`t a part of this category? While it is not “fixing” or “curing” my deafness as some people would like to believe, the main goal and primary focus of the cochlear implant is assisting in giving me the access of sound that I lack to be able to integrate, adapt and correlate in the hearing world. For example, Ladner expresses the relationship between assistive technology and the models of disabilities through the following,

> *Medical Model*- People with disabilities are patients who need treatment and cure or partial cure. Generally, treatment is very expensive and may require continual monitoring over a lifetime. Some assistive technologies can be prescribed by doctors or other medical professionals. In such cases, the technologies may be paid for by medical insurance.
>
> *Social Model*- People with disabilities are part of the diversity of life, not necessarily in need of treatment, cure, or special assistance. They do need access – often through technology – to partake in many activities of life, but they do not need to be taken care of or have decisions made for them by others. Technology developed in the social model is typically paid for by the individual with the disability or is free, if mandated by law (Ladner, 26-27).

I believe that placing the cochlear implant in this category can generate a better response and acceptance as a device that temporarily helps a barrier-free life. It is almost like comparing the need for a ramp outside buildings and stores so those who are in a wheelchair can enter the building. The solution to an inaccessible building is the ramp, just as the solution to solving the barrier of my hearing loss is my cochlear implant. I don`t know if people, especially the Deaf culture, understand the powerful impact that a cochlear implant brings, which is why I become upset when people want to dismiss it so quickly. A cochlear implant has allowed me to do many things that I know I would not be able to do without it. I tried sign language and I tried hearing aids. For me, they gave me more barriers than alleviated it. A cochlear implant has allowed me to speak, listen, drive, watch, hear, advocate, and educate myself (and others) on my deafness. My cochlear implant tells me what barriers I need to tackle (i.e. being in a social environment, advocating for accommodations), while simultaneously tackling barriers for me as well (i.e. amplifying sounds I cannot hear). With or without my hearing loss, I still need to be a self-advocate, I still need to be extra cautious and aware of my surroundings, and still I need to do extra work to make sure that I can "catch up" to the hearing world, through my education, career and social life.

The cultural model of deafness is a model that is inspired by the Deaf Cultural viewpoints as a linguistic minority. They contrast with the medical model`s point of view by embracing their deafness as a positive experience, rather than seeing it as a tragedy.

> The cultural model "rejects the 'medical definition of deafness' as either a loss or impairment. This is comparable with the social model of disability and Disabled

> people`s rejection of the medical model. Where the Deaf community sometimes depart from the social model is around the term 'impairment'. What makes the (…) Deaf community unique has been its campaign to be recognised a linguistic minority. For the (…) Deaf community, the capital "D" is used in apolitical sense to demonstrate their campaign for cultural and linguistic recognition" (*Inclusion London*, "The Cultural Model of Deafness").

The cultural model`s viewpoints have been branded as a political stance on the oppression of the Deaf culture. "In a cultural-linguistic model of deafness an emphasis on impairment is supplanted by an emphasis on language use and cultural identity. That is to say, the key distinguishing feature of Deaf people is not that they cannot hear, but that they have their own fully grammatical, natural language (Brennan, 1992)" (Young, 159). The cultural model creates a cultural identity of deafness (Oliver, 1990), that "goes beyond the social model`s argument that disability is a socially produced phenomenon. Rather it is a claim to citizenship rights that locates Deaf people`s social exclusion in the denial of legitimate cultural identity" (Young, 159).

The different models of deafness offer opposing and contrasting views on the definition of deafness and hearing loss, as well as deaf identity. What is right and wrong in terms of how a deaf person explains their deafness? Is it a loss, or a gain? And does each model portray a risk? My own opinions are conflicted with each model that is presented because of the way that they define deafness. From my point of view, my deafness is a hearing loss and a disability, is why I agree with the medical model point of view. However, I disagree with their standpoint of seeing the disabled person as a

"problem", because a hearing loss and a disability is not created on purpose, it is a "being" in us that we cannot control, but rather use it to understand how we can adjust with the world, as well as how the world can adjust with us, like in the social model`s point of view. The social model`s point of view sees deafness as a difference, and campaigns for a barrier-free world. Through my works on this paper, and my experiences, I feel a close resemblance to the social model of deafness as an advocate for cochlear implants as well as an advocate for the deaf and hard of hearing community in the mainstream society. I have the most conflict with the cultural model of deafness, because of their lack of ability to see deafness as a disability. While I can certainly appreciate the unity of community and living a life full of positivity, I cannot understand a deaf person`s denial of seeing their deafness as a disability.

Background and Review of the Literature

Brief History of Cochlear Implantation

Dr. William House, a medical researcher from Oregon was known to be the developer of the first cochlear implant in the late 1950`s. His first surgery experienced a negative rejection from the surgery and failed. After much trials, criticisms and resistance from the medical community and Deaf community, he successfully implanted a patient in 1984, which became approved from the Food and Drug Administration (FDA) in the US, "calling it the first device to replace a human sense organ" (Woo, 2012). Another notable developer of the cochlear implant is Dr. Graeme Clark from Melbourne, Australia. In 1967, he began his research for an "electronic implantable hearing device" (Cochlear, *History of Innovation*) after witnessing the struggles of hearing loss from his deaf father.

He was noted for creating the first cochlear implant with a multi-channel stimulation in 1978. *Nucleus* was interested in his company *Cochlear,* and they formed together to create a worldwide company in North America and Asia. In 1985, the FDA approved the first *Nucleus* implant for deaf adults 18 years old and older and in 1990, the US FDA approves the *Nucleus Cochlear* implant for children ages 2-17. Over the years since then, *Cochlear* continues to strive by adapting the times with technology and creating state of the art devices. From a bulky device with a wire attached to the ear, to now wireless and connected with the latest smartphone apps, *Cochlear* continues to strive and update with its customer service.

A cochlear implant is an electronic device designed for a person who has a hearing loss severity from severe to profound. The implant consists of an external portion that sits behind the ear and a second portion that is surgically placed under the skin on the head.

> An implant has the following parts: a microphone, which picks up sound from the environment, a speech processor, which selects and arranges sounds picked up by the microphone, a transmitter and receiver/stimulator, which receive signals from the speech processor and convert them into electric impulses, an electrode array, which is a group of electrodes that collects the impulses from the stimulator and sends them to different regions of the auditory nerve (*National Institute on Deafness and Other Communication Disorders, 2017*).

By wearing a cochlear implant, the user understands the following: that they will always be deaf and their cochlear implant does not “cure” their hearing, but only amplifies sound

that they do not have without it. A cochlear implant does not prevent a user from learning sign language, but for those who have chosen not to communicate in sign language have their own reasons, such as family and environmental factors.

I want to make a note here that, while I am writing a paper campaigning for the cochlear implant on a biased opinion, I understand that not everyone is eligible, as we will learn later in the paper, and that in some cases sign language may be the only option for some people. I want to use this section to help one understand what a cochlear implant is and how it changes a lifestyle that aims for integration, independence and intellectuality.

The cochlear implant is a surgical procedure that is recommended for young children and infants because of their brain and language development. The following is a quote that describes exactly what the cochlear implant does.

> "The cochlea, located in the inner ear, is a very small, fluid-filled, snail-shaped tube (…) that contains thousands of microscopic hair cells. When these hair cells are unable to stimulate the adjacent auditory nerve fibers, the auditory nerve, which connects the cochlea to the cortex of the brain, is unable to transmit sounds to the brain. This results in a sensorineural hearing loss. A cochlear implant is designed to do the job of the hair cells and stimulate the auditory nerve fibers. A cochlear implant consists of external and surgically implanted internal parts. The external components consist of a battery, a small microphone, a microcomputer, and a headpiece that magnetically connects to an internal receiver. The internal

components consist of the receiver and a wire-like electrode array that runs from the receiver into the cochlea" (Burch, 192).

The internal and external devices are connected magnetically and when turned on, will proceed to provide sounds in the environment, picked up by a microphone in the external hearing device, and are "changed into an electrical signal that is sent to the processor via thin cables. The electrical representation of the original acoustic signal is manipulated or processed" (Estabrooks, 15).

The evaluation of a potential candidate for the cochlear implant involves rigorous stages and testing developed by a team. The team consists of professionals with expertise in the area such as otolaryngologists, audiologists, speech-language pathologists, educational, and psychologists, including the child`s parents (Chute et al., 17, Estabrooks, 20). Table 1 summarizes the pediatric selection criteria (Estabrooks, 20-21).

Table 1: Preoperative Selection Criteria for Children

1. Profound bilateral sensorineural hearing loss
2. 2 years of age or older
3. intact auditory nerve
4. little or no benefit from hearing aids. For children whose hearing aids have not been previously or appropriately amplified, a minimum 6-month trial with hearing aids or other sensory devices is recommended. In conjunction with appropriate intensive auditory therapy
5. No medical contraindications to undergoing surgery
6. No active middle-ear disease
7. An educational setting that emphasizes auditory therapy and communication
8. The family, and if possible, the candidate should be highly motivated and have realistic expectations

Once the decision to implant has been made, the next stage of receiving the cochlear implant is the surgery. This stage is often the most stressful stage because of potential risks that come. These risks include, anesthesia issues, facial nerve damage, postoperative

infection and meningitis. The child will be placed under general anesthesia and the length of the surgery differs from 2.5 to 5 hours long. After surgery, the child will be bandaged up heavy on their head to protect the incisions and stitches from the surgery. When they wake up they will feel pain and dizziness from the surgery. Speaking from experience, I felt as if a train had run over my head. It was heavy and painful. I also experienced inner-ear imbalances as I found it hard to walk at times, which is normal because of the result of the anesthesia, as well as the result of the impact of the surgery on the ear.

The post-operative stage, known as the "activation" stage is when the child visits the audiologist for the first time since before their surgery and is ready to have their sound processor turned on. This is usually done a month after the surgery. This stage is a very emotional time for parents, as all of their hard work into researching and going through the cochlear implantation process will be worth it when they see the child`s first reaction to sound once they are turned on.

A cochlear implant is turned on by the computer that the audiologist sets up. The external device that is magnetically connected to the head, is attached by a cable connected to the computer, where the audiologist controls the frequencies that the child will hear. They will start at a very low current and work their way higher until the child is comfortable. In order to assess the response of the child with the cochlear implant, the audiologist looks for searching of sound source, a facial reaction, such as a twitch or any other reaction depending on the age of the child.

Impact of the Cochlear Implant Technology

Depending on the age of when a child gets their cochlear implant, they will be required training to develop their speech articulation skills and learn how to listen to sound. Because of the advancements in technology today, children with hearing impairments have access to sounds and language through listening, therapy and cognitive learning.

> Simply providing hearing devices does not mean the sound will be perceived or interpreted. The child needs to learn to listen and understand through these devices. They need to learn that sound has meaning and is related to all that is going on around them. It is important to remember that access to sound does not automatically mean that speech and language will develop (Chowdry, 2009).

The advances and benefits of a cochlear implant is helpful in the long term of a child`s life. Commitment and time is required to develop and learn the process of speech and language. It is not an easy process, but it is a very important key factor that will help one to able to integrate in a hearing society.

> …studies examining the vocabulary growth of children with normal hearing sensitivity: early language opportunities seem to affect the trajectory of vocabulary growth, which may have implications for children's overall language development (Hart & Risley, 1995; Huttenlocher, Haight, Bryk, et al., 1991; Huttenlocher, Vasilyeva, Cymerman, et al., 2002; Locke, 1997). This suggests that programs and policies ensuring children's access to rich linguistic environments early in life (…), access to cochlear implants and other appropriate types of hearing aids, and continuing to expand newborn and ongoing hearing

> screenings may enhance children's speech and language development (Hart & Risley, 1995; Huttenlocher, Haight, Bryk, et al., 1991; Huttenlocher, Vasilyeva, Cymerman, et al., 2002; Locke, 1997) and later success in school between early brain development and the linguistic environments in which children develop speech and language, we can develop stronger and more useful theories of language development (Goldin-Meadow, 1).

With the cochlear implant, studies have shown that it has provided a significant impact on the child`s education, speech, language development and academic outcomes. For example, Marschark et al. conducted a study in which they have found that "children with implants frequently read better than deaf peers who utilize hearing aids, even if they lag behind hearing age- mates" (Marschek et al., 2007). Cochlear implants allow deaf children to attend mainstream school, and learn alongside their hearing peers. They may still have some difficulty hearing and following auditory processing, however, there are many accommodations that can help them achieve this, such as assistive devices like an FM system, a note taker or teacher of the deaf in the classroom, and a reduced course load. Archbold et al. conducted a research study for children with cochlear implants` language and literacy developments. Historically, deaf children often experienced poor levels of reading and writing, and were falling behind academically than their hearing peers. With profoundly deaf children developing spoken language and literacy skills with the cochlear implant, Archbold et al. found that combining the research in three categories, vocabulary, reading, writing can help break down the new success of educational studies.

> In terms of vocabulary, 75% of the sample showed scores commensurate to hearing peers (average) on receptive vocabulary. In terms of reading comprehension, 88% of the participants scored within hearing norms with 75% of the sample showing scores on a par with their hearing peers (average), and 13% considerably higher than the average scores of hearing peers (above average). Outcomes in writing were not as strong as those in reading, with only 44% writing at or above grade level. Factors which influenced progress were: age at implantation, the use of two cochlear implants and age at testing. Those who were better readers tended to be better writers, and poorer performance in expressive vocabulary seemed to be linked to poorer outcomes in writing (Archbold et al., 2014).

The results of the study showed that profoundly deaf children were able to successfully attend mainstream schools, as they have shown a high vocabulary and reading skills, but needed to work on their writing skills. The outcomes of this study varied on many different factors of the participant, which includes age of implantation, environmental factors (i.e. attending a mainstream school or a deaf school), and their cognitive understanding when it comes to reading, writing, and language. “For profoundly deaf children who regularly use a cochlear implant, feelings about life overall are no better or worse than their hearing peers. These findings indicate that cochlear implantation has a positive effect on certain psycho-social domains” (*American Academy of Otolaryngology -Head and Neck Surgery*, 2010).

In my personal experience, I grew up going to a mainstream school that had a hearing centre. A hearing centre is a program that is run by a teacher of the deaf that

provides academic support, as well as mental support and equipment support. A hearing centre is usually it`s own classroom that provides a space for students to do their homework with a teacher of the deaf to provide assistance and clarification on the homework, an equipment station full of laptops for students to complete their homework on, and an FM system charging station so that the students can wear their FM systems in the classroom. Depending on the student, the teacher of the deaf also provides advocacy skills, notetaking duties and emotional support for students who are bullied or not doing well in school. Growing up with a hearing centre provided to be the best decision for my academic career because not only did it help me to boost my self-esteem and self-acceptance as a deaf person, but my teachers taught me about self-advocacy, as well as became my support system for academic success. By having a hearing centre, I was still able to succeed in a mainstream school system. My learning style may have been different than that of a "normal, hearing" student, but it didn't mean that I didn't work twice as hard as them. I used my accommodations, such as extra time on tests and assignments, a quiet room to do work, and more to make sure that I was producing my best work. And sometimes, I struggled with subjects including math and science, as well as English for the literacy component. There was a reason I made the decision to commute 45 minutes a day to a high school far away, because I knew I would be reaping the benefits in the future, which to date of this paper five years later, I can strongly say that I am.

> The recognition that we can choose, that we can make choices, is a central point. Another aspect is the fact that it is the individual who makes choices and that this is

> an existential fact from which the person can never be free. However the choices are anchored in one's own situation, not in the norms of the hearing world or the deaf world (Ohna, 2004, 32).

Today, statistics show that there are about 600,000 people in the world that are implant users (*The Ear Foundation*, "Cochlear Implant Sheet", 2016). "In the United States, more than 41,000 adults and nearly 26,000 children have one" (*NIDCD*, "Cochlear Implants"). The number will continue to grow as cochlear implants continue to strive with state-of-the-art technology, most recently with Bluetooth compatibility on smartphones. Bilateral implants are becoming more and more routine for children and newborns who are candidates, and are finding that this is increasing better success as it is improving "communication and language development" (*The Ear Foundation*, "Cochlear Implant Sheet", 2016). The importance of oralism helps is a huge factor with the cochlear implant to allow deaf people to co-exist in a world with hearing people.

The Deaf Culture and Debates about the Cochlear Implant Technology

The history of the Deaf culture was created based on the community and relationships between one another through the use of sign language. While it is not a culture based on native land, it is a global culture, through the existence of a linguistic minority. This approach emerged as the foundational idea of a Deaf social movement of adult children who grew up in segregated environments (institutions), in a context where their own family members could not communicate with them. They were often against the term "disabled", because their families and teachers treated them as though they were. Some of the authors explore the cultural history (Padden & Humphries) and consciousness (Brueggemann).

> "For many people within the deaf community, 'deaf' is less about audiology than it is about life and culture. Individuals who identify as culturally deaf (in contrast to audiologically deaf) perceive themselves as a linguistic minority group because of their use of American Sign language (ASL), a visual language with its own grammar and syntax. Their visual orientation, which differs from the reliance on sound by those who hear or those who depend completely on aural amplification, has facilitated shared ways of behaving that reinforce the bond within the deaf community" (Christiansen et al., 254).

Deaf people believe that the Deaf culture claims the right to their ethnicity, language and culture, as well as "the right to 'personal diversity,' which is 'something to be cherished rather than fixed and erased.' In short, they claim the right to their "birthright of silence" (Tucker, 172). It is the value of being part of a historical and traditional culture that inherits a common language of sign language by a means of primary communication and connection to the culture as a whole. There are beliefs and practises that make up the Deaf culture, which includes the controversy of not seeing their deafness as a disability and going against audism and oralism (speech). The Deaf culture did not emerge until

> the "early to mid-nineteenth century with the founding of permanent residential schools for the Deaf. The first permanent school, established in 1817, was the American Sign Language Preservation and America's Deaf Community School for the Deaf (ASD) in Hartford, Connecticut. French Deaf educator and co-founder of ASD Laurent Clerc, established a linguistic and pedagogical precedent of Sign Language-based education for Deaf schools in the next five decades. These schools not only provided Deaf people an isolated and supportive

> environment-a "place of their own"-but also codified a common Sign Language across the nation. (…) In 1864, Deaf people gained the opportunity for advanced education with the establishment of Gallaudet College, to date the only liberal arts university exclusively for the Deaf. By the mid-1800s, Deaf cultural self-awareness was established and expanding (Burch, 443-444).

Gallaudet University was previously called the “Columbia Institution for the Instruction of the Deaf and Dumb and Blind”, where Edward Miner Gallaudet, son of the founder of the first school for the deaf, Thomas Hopkins Gallaudet, became the new school`s superintendent (History of Gallaudet, *Gallaudet University*). In 1954, it became a federally charted private institution named after the first founding father, Thomas Hopkins Gallaudet, and was renamed Gallaudet College (since 1894). Gallaudet was granted university status in 1986 by the U.S. Congress. Being the only liberal arts institution for the Deaf, Gallaudet`s academic studies are focused on a bilingual learning environment with courses taught in American Sign Language and English. The undergraduate program includes more than 40 majors of bachelor of arts and bachelor of science degrees, as well as certificates and Masters programs designed for careers providing professional service for deaf and hard of hearing citizens. Hearing students are also accepted to Gallaudet for those who wish to pursue careers related to the deaf and hard of hearing community. Gallaudet “strives to become the leading international resource for research innovation and outreach related to deaf and hard of hearing people” (The Vision of Gallaudet University, *Gallaudet University*).

The Deaf community struggled with the prospect of mainstreaming schooling, as well as preserving their signed language, when oralism was introduced to replace manual

language for schools of the deaf. “At the Milan Conference of Deaf Educators in 1880, the controversy was over methodology (…) The conference delegates passed a declaration that identified oralism as the sole method of instruction at deaf institutions. Moreover, it banned sign language and labelled it a detriment to deaf education”(Jowers-Barber, *The New York Times,* 2011). Some, including Edward Miner Gallaudet, opposed to the declaration, which is why Gallaudet University was created.

While I appreciate that such a culture has been created, I have trouble understanding some of their beliefs. The fact that they do not see the reality of the characteristics that come with the understanding of deafness as a disability, such as a linguistic deprivation and a deviation from a norm that focuses on ‘hearing as an essential characteristic’ (Christiansen et al., 254), poses a huge problem for me. I understand if they don`t want to look at their disability as a negative factor, and turn it into a positive one, such as the community aspect, however, what they lack is the ability to hear, which is a disability, defined as “a restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” by the World Health Organization`s International Classification of Impairments, Disabilities and Handicaps (Crow, 56). They find that focusing on negative terminology associated with hearing loss, such as “hearing impairment”, emphasizes the “disabled functioning in the guise of broken ears that need fixing rather than an achieved way of functioning in daily life” (Christiansen et al., 254-255).

Deaf culturists and advocates are opposed to the idea of “curing” or finding solutions to mainstream children who are deaf. They view this as harshly as comparing it to a form of genocide, which will lead to the obliteration of the “Deaf race” (Tucker,

1998). They believe that the cochlear implant is the antithesis of Deaf culture. They view parents as "child abusers" for allowing doctors and medical professionals to invade and cut open a child`s skull without their consent. They believe that children who are deaf should be raised in a Deaf community and be exposed to the Deaf culture and history, like learning American Sign Language. Deaf culturists also believe that cochlear implants are not worth the medical, moral and ethical risk of "altering" a child (Tucker, 1998). Deaf culturists argue that parents should not be making the decisions about the implant for the children, but rather children should wait until they are older to make the decisions themselves (Tucker, 1998). I have read and heard this comment many times throughout my research, and it angers me to the core. First of all, calling parents "child abusers" is wrong, when I can easily argue that Deaf culturists are "abusers" for denying a Deaf child access to hearing and sound. Secondly, children do not have the mental capacity to make decisions for themselves, nor will they understand the importance of surgery. Also, we cannot wait until children are older to make the decisions themselves as evidence has shown that the brain development will be affected and the chances of a successful outcome is limited. The reality is, hearing people will not learn sign language and will not know how to communicate with the Deaf child. The child will struggle and be reliant on limited people who know ASL, which is usually family members or sign language interpreters. Deaf culturists argue that parents are too quick to go the cochlear implant route, without approaching Deaf people and evaluating their lifestyle in the Deaf community. They feel that parents` "mindset, assumptions and cultural backgrounds will generally predispose them to search out ways their deaf children can participate in majority culture" (Christiansen et al., 2002). Because American Sign Language has its

own grammar and syntax, it means that “children who cannot speak, do not know English, and have not been exposed to the hearing world have no options. They are stuck” (Tucker, 1998). This why it is important for parents to determine the importance of making their child oral, and it is not up to the “Deaf culturists to make that choice for other parents” (Tucker 1998). Deaf people believe that the cochlear implant will make the Deaf culture obsolete. Their trouble in trying to understand why hearing parents have an “obsession” with trying to “fix” their child`s deafness, is lost in translation. In my personal (and obvious opinion), the cochlear implant will not aim to obliterate hundreds of years of history with Deaf culture. What it`s doing is becoming a tool to integrate and combine deaf people and hearing people as one. Having a cochlear implant is a choice, just like being in the deaf culture is a choice, and with that includes having a cochlear implant and communicating in sign language as a choice as well.

With all of this being said, I do need to bring forth your attention to a changing environment in 2018. While the events described before actually happened, we are changing into a new generation where on television shows like *Switched at Birth* and *Deaf Out Loud*, the idea of unifying the Deaf Culture with cochlear implants is still a new concept but prevalent. While there are still debates about purifying the Deaf culture, it is there to show that a deaf person is able to live in both worlds. I also wanted to make a note that although it seems like I am against the Deaf culture, I really am not. I just don`t want children to go through what I went through as a child. If there is a way for a child to have a better lifestyle, I want them to have it. And maybe, the cochlear implant is not better for them. Some people are not eligible for the cochlear implant and therefore have no choice but to use sign language. Some people have a cochlear implant, and may be

going through a negative experience, such as a malfunction in the device not performing at its best to provide quality sound for the recipient. I am not against the Deaf culture, and I do believe that having sign language is great to have. If anything, I want to promote a biculturalism, so that the Deaf culture doesn't feel like they are "decreasing". The community is full of a lot of important history that many deaf people should learn about, no matter how they identify their deafness. Being at the *Canadian Hard of Hearing Association`s* Youth Forum gave me faith that our generation has changed for the better. The rise of biculturalism was prevalent and celebrated. There was no "division" of the Deaf culture vs. lowercase "d" deaf community, or remarks made to show that. Instead a community was made with the understanding of one commonality- our deafness.

Changing Nature of Deaf Identity as a Consequence of CI Technology

> It is especially important to be aware of how a person's understanding of him/herself is closely related to recognition given by other people: our identity is partly shaped by recognition or its absence, often by the misrecognition of others, and so a person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them a conflicting or demeaning or contemptible picture of themselves. Nonrecognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being. (Taylor, 1994, p.25) (Ohna, 22).

There are many people who have been diagnosed with a hearing loss and have identified as lowercase "d" deaf, "capital D" Deaf or hard of hearing. The categories are then defined through a community who accept and label themselves as such. The words deaf and Deaf hold two specific meanings, so in this paper I will identify "capital D" Deaf, for

those who identify as part of the linguistic minority community, the Deaf Culture, where they predominately speak in sign language. “small d” deaf and hard of hearing people, are medically diagnosed as deaf, but may not identify as “capital D” Deaf for reasons such as, choosing to communicate orally. They also identify as having an auditory disability, whereas members of the Deaf community do not see their deafness as a disability. “In an ironic twist, a media device is being rejected by many members of the community it was ostensibly designed to serve” (Clay, 1997). The Deaf community have fought against the prospect of the cochlear implant, mainly citing the fear that the cochlear implant would eliminate a culture that they fought so hard to keep. The fear is also instilled that people with cochlear implants would want to be a part of mainstream society and speak, rather than be a part of the Deaf history and learn sign language.

Identity for a deaf person is “recognized as an important factor in psychological well-being and other life incomes for people who are deaf” (Chapman et al., 2017). Glickman measured the meaning of deaf identity in four categories that reflect all levels of deafness.

> These categories of identity are *deaf* (signifying positive identification as deaf and immersion in Deaf culture), *hearing* (signifying positive identification with the hearing majority and likely perception of deafness as a disability), *bicultural* (signifying positive identification with both the deaf and hearing cultures), and *marginal* (signifying lack of identification with both the Deaf and hearing cultures) (Chapman et al., 2017).

I identify Glickman`s definition of “hearing” from my upbringing. I see my deafness as an auditory disability in a hearing majority community. Throughout my research with the

relationship between deaf identity and cochlear implants, I have come across a few different results. One study found that children with cochlear implants identify as having an audiological hearing loss rather than the cultural sense, and often wanted to explore sign language and the Deaf culture when reaching their adolescence years (Chapman et al., 2017). Another study, done by Mance and Edwards (2012), reported that "for adolescents with CIs, the more closely they identified with their hearing peers, the greater their overall psychological well-being" (Chapman et al., 2017). The understanding of "identity" is tricky and weird to process. Just like some people embrace their gender identity or sexual identity, the d/Deaf and hard of hearing community also has an additional identity to process.

> Although the construct of identity is complex and the definition is evolving, researchers agree that a positive self-perception is important in order to achieve success. For example, adolescents who have hearing loss and who see themselves as disabled may tend to limit themselves and seek out fewer challenges (Hauser-Cram, Durand, & Warfield, 2007). There is some tension in the social sciences field regarding the perspectives about defining identity. In brief, individuals develop an identity via forming thoughts about themselves that help to connect them to specific social groups (Baumeister, Storch & Geffken, 2008; Grotevant, 1992; Moskowitz, 2005). One's identity is individualized but may be a collection of several ideas about oneself in conjunction with forming a group affiliation (Ashmore, Deux, & McLaughlin-Volpe, 2004). Identity forms in adolescence yet evolves during the lifetime (Grotevant, 1992) […] Wheeler et al. (2007) reported, "The majority recognize themselves as intrinsically deaf in the sense that they

> cannot hear without their implant but do not demonstrate a culturally deaf identity" (Wheeler et al., 2007, pp. 136). (Spencer et al., 3).

Growing up, I didn't think twice about the belonging of my hearing identity. But my environmental and family surroundings made me aware that I was not like "everyone else". I grew up in a town that was majorly hearing and ableist (non-deaf and non-disabled), and went to a mainstream (non-deaf) school. My mainstream school had a hearing center that consisted of teachers of the deaf and other students who had a hearing loss. It was from the hearing center where I learned that I was deaf and hard of hearing. I use both of those terminologies because I don't know which term fit me more. I often tell strangers I am "deaf", rather than "hard of hearing", because I feel like they understood the severity of the term more. But I had a hard time expressing that I was "deaf", because that term related closely to American Sign Language and Deaf Culture. (The non-deaf population`s only understanding of "deafness" is through pop culture or knowing someone who is deaf, which is most of the time painted as the "ASL" Deaf person) The next question I always get ask after saying "I am deaf" is, "Do you sign?/How do you sign this word?/But you speak so well and clearly!". (And other times I get asked "Have you seen *Switched at Birth"* to which I respond, "Yes, but I am not a fan of the show, due to their perception of cochlear implants"). But when I tell strangers that I am "hard of hearing", they receive it as "not deaf enough" or they just don`t understand what it really means. In the past, having a cochlear implant also meant you were a "robot" and not human, according to the Deaf Culture, which only makes it stranger to realize because technically it is a computer and electronic device that is controlling my hearing. "The

question would seem to be not the "either/or" one (will the implant make the child a hearing person or the non-fitting make them a Deaf person) but a question which results in the best ethical appreciation of the risks and the benefits that eventuate" (Hyde et al., 2006). I identify more closely to "hard of hearing" than "deaf" because medically, I am not 100% deaf, as I still have some residual hearing in my left ear, but I am aware that I am DEAF because medically I am not 100% hearing. I am not ashamed of either of those terms, and I will still continue to identify as both terms.

Misconceptions About Cochlear Implants

There are a lot of misconceptions about the cochlear implant that are changing the viewpoints and perceptions of the candidate choosing or not choosing the implant, and as a cochlear implant user myself, I feel the need to discuss it in my paper. I found that these two misconceptions have been falsely implementing fears or disappointments. The biggest misconception of the cochlear implant is that it fixes and cures hearing loss. "For most Deaf people, cochlear implants are seen as tools that "fix" deafness and many believe that it is a way to cure deafness" (Jodlowski, *Reporter Magazine,* 2015). *The Young and The Restless*, a soap opera drama, presented a storyline where their character Devon found out he was deaf and needed a cochlear implant. My mother was the one watching this show and she was proud of the show raising awareness for cochlear implants. Being that it was a soap opera, they needed to elevate their drama. A couple of months later, Devon stopped wearing his cochlear implant because suddenly he could hear again. He was no longer *deaf*. This was incredibly disappointing and misleading. The age demographic of this show was geared towards those who are 40 years old and

older, the age where many viewers could be parents of children with hearing loss, (or candidates themselves) and portraying the cochlear implant device as a miraculous device that cures hearing loss is the most terrible thing I have ever seen. As a cochlear implant recipient, it`s already hard enough to see a lack of deaf representation and lack of cochlear implant representation in the media, especially with the stereotypical "deaf person" always being one with sign language. So when I hear about cochlear implants in the media, I feel a little happy knowing that someone can watch this and feel inspired to get one themselves, but not when there are wrong facts about the cochlear implants, creating more problems and mistrust. A person`s hearing comes from the hair cells of the cochlea. A person becomes deaf when the hair cells are damaged, and unfortunately will never be able to regrow again. A hearing loss is a permanent disability that can never be fixed, cured or gained back again. "I have heard countless remarks about how cochlear implants are made to cure deafness or that it takes away a huge part of Deaf culture. Cochlear implants are not made to cure hearing loss or take away deaf culture; like hearing aids, they exist as an aiding tool" (Jodlowski, *Reporter Magazine*, 2015). When I take off my cochlear implant, I am still deaf. I will not be able to hear sounds like the alarms, birds, even people talking to name a few. Sometimes it is incredibly dangerous for me to not wear my cochlear because of the sounds I miss, and that is what parents, candidates and people need to understand.

The second biggest misconception about the cochlear implants is about the following: "'I feel like Deaf people who are against it feel like doctors are trying to force kids to hear,' Pickett commented. (…) 'Without my implant, I would be lost. It would be

too hard for me to focus and I would be confused if I didn't have it,' she continued" (Jodlowski, *Reporter Magazine,* 2015). Would someone have the same reaction if a doctor or optometrist prescribed glasses? Are doctors forcing people to see? I personally believe that it is not a matter or action of being *forced* to hear, but rather finding an *option* and taking advantage of the available access to technology today. It is important to recognize the difference between the two. The decision to wear, obtain and commit your life financially, mentally and physically with a cochlear implant is exactly that- a decision. It is not easiest or simplest decision a person can make. The decision is made knowing about both the benefits and risks that come with it, both from surgery and post-surgery recovery. The decision to obtain a cochlear implant is an exhausting one, with benefits that should hopefully outweigh the risks for long-term.

Reflecting on Deaf Identity

I, however, cannot accurately describe myself without using the word deaf.

Bonnie Tucker (1995, p. xix)

In creating an autoethnography about deaf identity, I would like to reflect on how my perspective and views on deaf identity has changed, as I almost come to the conclusion of my paper. Identity never used to be a big part of my life consciously until I became a young adult. "'Identity' is a frequently used concept, but it is understood in many different ways in the social sciences. As a point of departure, identity can be defined as 'a person's understanding of who they are, of their fundamental defining characteristics as a human being'"(Ohna, 21). Growing up, I was aware that I was deaf, and would always advocate on behalf of my deafness, which includes being a part of many conferences and events as a motivational speaker discussing my life as a deaf

person, but the sole idea of *identity* was not something I thought about before. We see other forms of identity being questioned, such as gender and sexual, and I would like to think that deaf identity acts the same way. I identify as a Caucasian, cisgender female with two disabilities, my hearing loss and heart condition.

In my experience of observing my deaf peers and people who identified as deaf or with a hearing loss, I have come across four types of deaf people. While this is inspired by Glickman`s categories of deaf identities, I have come up with my own based on my personal experience and observations. The first type is the person who identifies with "capital D" Deaf Pride. They communicate in sign language and do not see their deafness as a disability or part of the medical model scale. They often live in a majorly deaf community, and have a lot of friends who are also "capital D" deaf. They adapt and adjust in the hearing community with alternative modes of communication like typing on a phone and take pride in their independence. "Essentially, as deaf people fond each other, they created a Deaf centre that relied on language and thought expressed through visual relationships incorporating body movements, eye contact, facial expressions and other markers of signed languages (…) Auditory components of daily living, including the use of spoken language, were not seen as important" (Leigh, 22).

The second type is the person who almost qualifies as a "normal, hearing person"- who communicates orally, usually wears a cochlear implant or hearing aid, and did not experience any challenges growing up- such as speech impediment, bullying, or needing assistance, like an FM system and teacher of the deaf at their school. (And they treat their deafness, as I do with my prescription glasses, just something they need but acts as an

accessory, rather than a hindrance in their lives) They are not in touch with their Deaf culture or deaf community, as they have majorly hearing friends, and live life as a "hearing person", and have pride with their independence. I always wished I was this type of deaf person (minus being in touch with my deaf community).

The third type of deaf person, which is something I think I fit in to, a deaf person in a hearing world- a lowercase "d" deaf person, who communicates orally, usually wears a cochlear implant or hearing aid, and experienced challenges growing up- such as having a visible speech impediment, bullying, and grew up with assistance from a teacher of the deaf and had accommodations in the classroom. They too can have majorly hearing friends in a majorly hearing community, but their deafness makes them stand out. They are in touch with their deaf community, however some people may be shy and private about their hearing loss, and others are open about it and often advocate and educate about their hearing loss. "Some of them gravitate towards spending a significant amount of time within the hearing society surrounding them. "They feel at home using spoken language and in interconnections with hearing peers. They are comfortable replying on whatever auditory skills they can develop and depend on technology to enhance their ability to interpret sound and linguistic inputs. They feel "culturally hearing" and attempt to conform to norms for spoken language" (Leigh, 22).

The fourth type of Deaf person is fairly new in my opinion, but a great one to speak about, the bicultural person. Throughout my paper I've spoken about the Deaf culture`s lack of acceptance with the cochlear implant, and how that angered me. But recently, I have seen a much more embrace and unification between the two from people

I have met. So far, a few people I know who grew up with a *Deaf Pride* identity have opted to receive the cochlear implant and are now learning to cohesively live in a sign language world with hearing from the cochlear implant. They still communicate in sign language as their first language, but are also learning to do speech therapy with their cochlear implant. Their identity recognizes the importance of both worlds, the Deaf culture and the hearing society, which is important.

Another observation I would like to mention, while understanding a deaf person`s identity, is from those who identify as "hearing", and not for the right reasons. While I believe that it is incredibly important to have a positive outtake on life, I do not believe in those who don`t believe they are not deaf at all, especially while wearing a cochlear implant. Just because I wear glasses and don`t think or talk about being visually impaired, I *know* I am visually impaired because there is a device that acts as a "middle man" in between my eyes and the object in front of me. Without my glasses, I cannot see. Without my cochlear implant, I cannot hear. I have trouble comprehending why those who wear a cochlear implant don't identify as "deaf "or don't see themselves as "deaf" because in reality they are not fully "hearing". They have a loss and they need to recognize that. It's one thing to say you're "hearing" because you're in a hearing community, but to not identify as deaf at all raises concerns for me. I think that`s why I wanted to write this paper, because I need to understand the meaning of what it means to be deaf and what it means to be deaf with a cochlear implant. It`s important to realize that it is okay to accept and understand that you have a hearing *loss* as a disability. By understanding the

disability, does not mean you have to live your life in sadness, tragedy or pity because of the disability. However, it is not okay to ignore it either.

The four types of identities I present, Capital D "Deaf Pride, "Almost Hearing" Person, deaf person in a hearing world and the bicultural person, are only through my observations and experience, as there is no "right" or "wrong" identity (even though I questioned a few). I think I need to realize that the deaf identity is very dependent on a deaf person`s upbringing and environment. The reason why I may be questioning another person`s view on identity could be because I didn`t live with the mindset and frame of seeing deafness as equal to "hearing", while others may have and would probably be questioning my identity for seeing my deafness through a disability lens. I often question if I had that "hearing" mindset, how that would change my viewpoints on life and the decisions I make. Deafness has sometimes become a factor of my decisions, especially when I was sixteen. That was a hard year because as a teenager, that was the year where you would get your first part-time job and your driver`s license. I had a hard time already applying to jobs because I knew I had to disclose my hearing loss, and even then I was discriminated against. While every classmate of mine was gearing up for their license, I was scared. I really thought I would never be able to drive because of the fear of not being able to hear the ambulance, the horns and all other sounds that come with it. I am proud to say that at the age of 22, last year, I got the courage to get my driver`s license. Getting my license was an accomplishment because it was a verification that even with my hearing loss, I could do it. I am no longer scared when I drive, and that is the most

important part. But if I had had that “hearing” mindset, would I have gotten the license right away? Would I become more confident in job interviews and applications?

When I speak of independence, I talk about not having to depend on a translator or interpreter or a personal friend to speak on behalf of them. The accuracy of each identity varies amongst deaf people. Every young adult with a hearing loss will experience different emotions and feelings. Some are happy with their identity, some question their identity, such as why they were never exposed to sign language as a child and chose to further educate themselves about it as they are old enough to make that decision, and some question their identity as a cochlear implant recipient. I believe that our deaf identity is also generated by our upbringings. Our family life and environmental factors play a large role in how we identify ourselves, for example, growing up in a deaf family and deaf community, verses being the only deaf person in your family in a hearing, mainstream community.

What does a cochlear implant mean to their deaf identity? Are they placed in their own category of deaf identity because, they are not “Deaf enough” for Deaf Culture or “hearing enough” for the hearing society? “ ‘Deaf in my own way’ is actualized when the person has recognized the consequences of alienation and affiliation and in spite of this, lifts his or her head towards the world and meets the stranger as a you, as a subject to be dealt with, one way or the other” (Ohna, 37). I know that no matter what, I am deaf. I cannot escape it or hide it, because of my speech impediment, my external cochlear implant device that sits on my outer ear and head, and the accommodations that come with me in order for me to function as a human being in my environment.

Conclusion

With the advancement of cochlear implants on the rise, the deaf culture fear for eradication, however, I do see more of a unification from my generation, which was evident at *The Canadian Hard of Hearing Association*`s Youth Forum. But as someone who has a cochlear implant, I do believe that it is still my duty to campaign for it. The cochlear implants allow for oral, auditory communication into the hearing world, where sign language is not needed. The cochlear implant has created a new community within itself that has a new identity. In the words of Tonya Titchkosky`s concept of a "cultural map", how have the cochlear implant recipients created their own cultural map?

> All maps of disability reflect a conception of its place and space within culture. The mapping of disability is an imparting of some version of what disability is and, thus, contains implicit directions for how to move around, through or with it. Disability is mapped differently by various societal institutions and cultural practises and these representations influence one`s relation to disability (Titchkosky, 101).

How has the medical advancements and technology shape their identify and status into the world? How can we inform the hearing world and the Deaf culture of this new and rising community? The need for this study can help set an example for the future. While it has been 30 years since the implant has been created, there were no references for parents to look back to, to see how their children will grow up. Parents who made the decision to implant their children in the 90`s era, were left with uncertainty of where the cochlear implant will impact their children`s future. They were only left with the doctor`s hopes. Their only references were from Deaf culturists who shamed them. Parents who

choose to implant their children today, can be able to look at a reference of how beneficial cochlear implants can provide their children- with speech, independence and freedom. The stories of cochlear implant recipients need to be told. Our stories need to be heard. The media needs to normalize it, just as much as they normalize American Sign Language. Parents are stuck between one option for their child, and need to explore all options. For some, hearing that their child is deaf can be a devastating blow, and being able to explore the option that there is hope for their child to be mainstreamed is a miracle.

I didn't accept my hearing loss before high school. I hated being deaf because I felt lonely being the only deaf person at my school, and I was constantly bullied for it. No one understood what it was like having a hearing loss and I hated the "singled-out attention" I got. High school made me feel more accepting of my loss and that it was ok to have a hearing loss. By accepting my hearing loss, I was able to blossom out of my shell and my comfort zone. Some kids identify as "hearing" even with a cochlear implant because of their integration into the hearing society, unfortunately I cannot come to the conclusion that I am "hearing" because my cochlear implant prevents me from doing so, my permanent hearing loss is a disability and furthermore, I don't know how to identify as "hearing". The process of searching for my deaf identity did not become prevalent until I became a young adult and observed what my deaf peers thought of themselves. With cochlear implants especially, it is also discovering *where exactly do we belong*, if anything, and most importantly why. Why is our deaf identity important to us, and why is it important that we find a sense of belonging? For me, to say that I am "hard of hearing",

the meaning is treated like someone`s grandma`s hearing loss, and to say that I am “deaf” provides the severity of the word, but doesn`t have the correct meaning for me. It is there where I find a conclusion to accept myself as both deaf and hard of hearing.

There have been many changes and improvements with the cochlear implant. It has adapted to advanced technologies and modern times to the point where it has changed from a body-worn wired device to a wireless, and almost discreet-on-the-ear device. Their latest exterior device includes a function that is made for smartphones, where almost all of the controls is functioned through an iPhone or Android app, and has Bluetooth settings. Their function includes taking phone calls and listening to music, which is wirelessly streamed directly into the cochlear implant, without additional accessories. In the span of 20 plus years, there has been an increase in children receiving the implantation with an immediate early intervention at birth. With the success of the surgery, more children are able to succeed in mainstreamed school and integrate within the hearing society. As someone who considers to be a prime example of a cochlear implant recipient, I hope that parents can use this reference to know that their child can lead a successful life with their cochlear implants. It won`t be a perfect life, and they will still struggle sometimes, but this is a device that can unify their child with their family, community and environment.

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