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A Qualitative Assessment of Deaf Infant Cochlear Implantation
and Feelings of Acceptance by Hearing Peers

This qualitative methods final project will endeavor to create a research proposal that will attempt to begin to answer the following question: Do Deaf infants with cochlear implants feel accepted by their Hearing peers as Hearing or are they still viewed as being Deaf or as Something Else?

Research Problem

The cultural crevasse between Deaf Culture and the Hearing World is one of great concern for Deaf children and their Hearing parents. Cultures are built on language and only those who can at least rudimentarily express the language of the culture have the opportunity for acceptance by the community.

What happens, then, when a Deaf-born infant whose native language is visual and not aural then has a surgical procedure to impose an audible language via implantation? Is a child's native or natural pattern of visual language development forsaken by technology? Are those implanted Deaf infants destined to be stuck in a cross-cultural language contamination?

On April 29, 2005 Reuters News reported one in every 800 births consists of some form of hearing impairment and 60% of people over the age of 70 have a loss of hearing. Over 90% of Deaf children are born to Hearing parents and many of those parents see their Deaf infants as broken and in need of fixing on order to find acceptance and success in the world.

A cochlear implant, as the medical community are loathe to disclose, does not make a child Hearing. A cochlear implant is merely a strong hearing aid that is stored within the body instead of attaching to the outside of the ear. Hearing is a cultural identification, as is Deafness, and implanted children, some believe, are robbed of any sort of cultural identity once the implant is placed into service in their heads.

This study will not try to determine if the implanted Deaf children are Hearing or not – for they can never truly be anatomically Hearing – but this study will try to determine if the implanted Deaf infants grow to feel accepted by their peers as “Hearing” or as Deaf or as Something Else.

Harlan Lane, an experienced researcher on Deafness and Northeastern University Distinguished Professor of psychology, believes Deaf children should not be “fixed” with cochlear implants by the medical community. Lane asserts that Deaf infants are born into a culture of the Deaf and to “fix” them by elective surgery is the same as bleaching the skin of Black babies in order to cure their perceived cultural deficits.

Fredericksburg, Maryland is a Deaf enclave where Deaf neighborhoods have grown to overtake entire sections of the town. In those havens, all the Hearing workers in the stores and gas stations and restaurants use Sign Language to communicate with their customers.

Fredericksburg is known in the Deaf community as a safe place where Deaf culture is accepted and Deaf families move there in order to preserve their culture and to protect their Deaf children from being mainstreamed into Hearing schools where they inevitably fall behind their Hearing peers.

The New York Times reported on March 21, 2005 that a new town called “Laurent” (named after Laurent Clerc, the French founder of American Sign Language during the 1800’s) is being created from scratch near Salem, South Dakota. The town of Laurent will be a new hometown for the Deaf and speakers of American Sign Language.

Some believe towns like Laurent and Fredericksburg separate the Deaf from the rest of the world but many Deaf people prefer to see these enclaves as areas of tranquility and not escape because it is impossible to escape from the Hearing world even if you live in a Deaf haven. The towns of Fredericksburg and Laurent are bold intellectual and emotional clues that the Deaf do not believe their hearing loss is a condition in need of healing.

The research problem in this qualitative study is one of conflicts: Conflicts between Deaf infants versus the Hearing world; Deaf infants against meeting the mainstream expectations of Hearing parents; the fight between the Deaf community and the medical community where the Deaf view their hearing loss as the definition of a culture and where the medical community views Deafness as a disease to be cured and, finally, the inner conflict of Deaf infants who, after cochlear implantation, are pressed into believing as they age that they are physiologically Hearing even though they are not.

Other research problems include language acquisition, the successful loss of “Deaf Speech” verbalizations made by Deaf children who use their voices, cultural acclimation and social emancipation of Deaf children from their parents in favor of peer acceptance.

All of these research problems relate to, and culminate in, a single research question of feelings of peer acceptance for Deaf children in the Hearing world who were given cochlear implants as infants.

Research Question

This research question is extremely sensitive from a cultural and familial view because it dares to touch the fiery core of an intensively smoldering issue: Who owns Deaf infants – those who share their culture or those who give birth to them? The answer is Deaf infants must belong to themselves but that idea is growing increasingly difficult to support when Deaf infants are being implanted as early as four months of age.

A year ago the average implantation age was 12 months and two years ago the average implantation age was four years old and a few years before that the threshold for implantation was ten years of age. The implants are not getting radically better or smaller. The doctors are getting bolder.

This study, because of the power for medical doctors to influence parents, accepts the fact that Deaf infants will now always be implanted as soon as their hearing deficit is identified. Hearing parents, supported by the medical community, believe they are serving the best interests of their infant with cochlear implantation but existing research already demonstrates few, if any, of those parents bother to investigate the topic or consult with the Deaf community or other children who were implanted before agreeing to have the surgery performed. Ideally Deaf children would be allowed to make their own decision later in life if they preferred to be implanted or not.

That lack of appropriately self-informed consent on behalf of the parents for their children has everlasting negative effects on implanted infants because the Deaf children are forever condemned to what some in the Deaf community call a netherworld, a purgatory, and a cultural graveyard that can never be restored or recreated after surgery. Cochlear implant surgery completely destroys the cochlea and the transmitting electrical wire that is wound into the cochlea just sits next to the auditory nerve to deliver sound impulses for nerve stimulation. The implanted infants, many sociological Deaf researchers believe, are stuck without a culture through no fault – or choice – of their own.

These infants, some researchers contend, are neither Deaf nor Hearing – they are “The Implanted” or the “Something Else.” Perhaps one day when all Deaf infants are implanted, a few Deaf activists suggest, those children will grow up to create a new culture of the Outcast Implanted where they can all suffer in loneliness together.

The feelings of peer acceptance in this study will be evaluated on three levels. The first level is one of formal learning sessions in school: Do the implanted children feel listened to, respected and able to effectively communicate with their peers?

The second level will be one of informal play in school: Do the implanted children feel they are able to communicate on an equal level with their Hearing peers or are they left out and ignored?

The final level will deal with informal social interaction at home and elsewhere outside of school: Do the implanted children feel included in informal interactions with their Hearing peers beyond the schoolyard, are there any communication problems?

The study will evaluate the peer acceptance from two angles: The clinical observations of the researchers and the personal perceptions of the implanted children. The clinical and the personal may not agree on the issue of peer acceptance and that possible disagreement is where the riches of the study will be mined for meaning.

Brief Review of Literature

There are several books, monographs, periodicals and journals that concern cochlear implants but few of them directly address the idea of this research proposal. This brief review of literature will deal with current scholarship on the sociology of the Deaf, the acquisition of language in Deaf children, the Deaf community, medical scholarship and philosophy, advantages of cochlear implants and the plusses and minuses of implanting Deaf infants.

Journals and Periodicals

Journals and periodicals are rich with current articles on the practicality and practice of cochlear implants in infants and children.

In October 2004, *Nature* reported in a news article titled *Deaf by Design* that Deaf parents are using genetic testing to determine if their children are Deaf or not. If the fetus is not genetically determined to be Deaf then the pregnancy is aborted and the Deaf couple tries again to give birth to a Deaf baby in order to continue the existence of a strong Deaf culture.

Tael Bat-Chava, Daniela Martin and Joseph G. Kosciw write for *Journal of Child Psychology and Psychiatry* an article titled *Longitudinal Improvements in Communication and Socialization of Deaf Children with Cochlear Implant and Hearing Aids: Evidence from Parental Reports* (March 2005). Their work provides a longitudinal

research study that shows implanted children who use hearing aids or cochlear implants for 6-11 years show remarkable improvement in speech, communication skills and socialization in daily living. The study demonstrates that while cochlear implanted children get a later start in language mastery than children who use hearing aids they catch up quickly over time and age-appropriate social and education development is achieved using either hearing aids or cochlear implants.

In a September 2004 article published in *Journal of Child Psychology and Psychiatry* titled *Theory-of-Mind Development in Oral Deaf Children with Cochlear Implants or Conventional Hearing Aids* by Candida C. Peterson suggests the theory-of-mind (ToM) is seriously delayed in Deaf children who do not use sign language early in their language development. ToM is a philosophical conceit that contends the “mind” and the “brain” are one in the same – to use your mind is to describe, on a cellular level, how the brain operates understanding and provides meaning. 52 children between 4 and 12 years were tested with “false belief” ToM tests. 26 were oral Deaf, half were implanted and the other half wore hearing aids. Groups were fairly split between oral-only against sign-plus-oral in formal learning environments. Peterson also added comparison groups using aged-matched high-functioning children who had autism along with younger Hearing children. No significant differences were noticeable between the implanted and the hearing aid children and no differences were noticed between children in oral-only and sign-plus-oral schooling. Deaf children did not achieve higher ToM results than their age-matched autistic peers. Hearing children under five years performed much better than any group.

When Hearing Loss Occurs with Multiple Disabilities by Jackson Roush, Meredith A. Holcomb, Patricia A. Roush and Maria Luisa Escolar was published in *Issues in Family-Centered Pediatric Audiology* (November 2004) and the paper examines how language develops in children who have more than one disability. Usher Syndrome is common in many Deaf families and the Deaf-Blind population is underrepresented in communication, language-acquisition and peer acceptance research. This study examines how multiple disabilities affect long term socialization and educational opportunities.

Michael Smith, in the *Medical Post* (March 2004) periodical, provided an article called *Cochlear Implants Should be Gradual Process* that suggests Deaf infants should not be implanted because their cochlea is not mature enough to accept the surgery. He also contends advances in genetic testing and gene therapy may one day nullify the need for the Deaf to be implanted and that sometimes it is better to wait for technology to mature instead of rushing to irrevocably implant the latest version of a currently popular medical theory.

Beginning to Communicate After Cochlear Implantation: Oral Language Development in a Young Child found publication in *Journal of Speech, Language, and Hearing Research* (April 2003) and David J. Ertmer, Lynette M. Strong and Neeraja Sadagopan share the findings of their longitudinal case study of “Hannah” who was cochlear implanted at 20 months. Hannah was studied between 2 and 4 years of age and results suggested normal to above-average in correct word usage, synonymic vocabulary learning and expression, type-token ratio, repetitive compound word construction, and long phrase understanding. Below-average rates were indicated in observer understanding of spoken speech, multiple token word types and lack of sustained

morpheme use. The relationship between parent and child appeared to grow stronger during the third year of implantation. Long term conclusions suggest changes in development of language learning decayed over time as more complex linguistics were mastered by her Hearing peers but not by Hannah.

Cochlear Implants written by George A. Gates and Richard T. Miyamoto in *The New England Journal of Medicine* (July 2003) explains the how and why of cochlear implantation benefits as a standard treatment for Hearing people who are losing hearing function as well as for the Deaf. The study prefers implantation over hearing aids because even well-fitting hearing aids do not help allow better oral communication – only those with implants demonstrate ongoing linguistic understanding and growth. The article also goes on to provide a brief history of the Food and Drug Administration’s role in pushing forward cochlear implantation and, at the time of publication, the article said the FDA recommended age for implantation was 12 months but “implantation performed even earlier may be advantageous for language development.”

Books

Harlan Lane and Oliver Sacks will help provide the necessary scholarly qualitative background examination of the Deaf and Deaf culture to help frame the sociological expectations and requirements of the Deaf and Hearing communities. Both scholars have dedicated much of their lives to researching issues of Deaf communication and each routinely supply cover quotes for the other’s books.

Oliver Sacks’ *Seeing Voices: A Journey into the World of the Deaf* (1989) is an exceptional book that investigates how Deaf culture is formed and how and why the Deaf see themselves as strong, independent, sure and unbroken. He also discusses the history

of Sign Language and why exposure to visual grammar learning is important for Deaf children to master at an early age.

Harlan Lane is a master of Deafness research with over 190 published articles and 170 of those articles deal with issues of Deafness and Hearing. Of his 17 books 11 of them concern Deaf culture. This research proposal will not discuss all of Dr. Lane's articles or books even though they will be examined in depth before the research study begins because to evaluate them all here might be perceived as padding the literature review portion of this assignment. A few of Dr. Lane's most noteworthy work will be briefly discussed here to set the expectation of what may be found in the rest of his research canon.

The Mask of Benevolence: Disabling the Deaf Community (1992) by Harlan Lane begins with June 27, 1990 approval of the cochlear implant ("bionic ear") by the United States Food and Drug Administration. From there Lane goes on to examine the monetary benefit of implanting the device in children and the grim and prescient pattern of behavior in the medical community that Deaf children need to be fixed by surgery. The book is a watershed moment in the history of cochlear implantation, Deaf Culture, and Hearing surgeons. Oliver Sacks said the book "expresses a terrifying reality." If one could read only one book about cochlear implants and repression of the Deaf experience then this must be the one book. The book is prefaced with a quote from Michel Foucault expressing criticism of the political violence institutions hide by pretending to be both neutral and independent and that it is our responsibility as members of society to unmask the deception and reveal the actual ends of the institutions.

When the Mind Hears: A History of the Deaf (1988) by Harlan Lane is another historic book that chalks a line of understanding around the idea that Deaf Culture can not only be qualified but quantified as well. The book researches the history of Deaf language acquisition throughout history and the concerted attempt by the Hearing to remove any sort of visual signing from the lives of Deaf children. Lane also examines the failure of mainstreaming Deaf children using hard research data and how depriving Deaf children of Sign Language not only denies them an equal education but also their rightful heritage.

A Journey into the Deaf-World (1996) by Harlan Lane, Robert Hoffmeister and Ben Bahan is a wide-reaching book that discusses speech-language pathology and individual stories of Deaf education successes and failures. The book provides a unique world view on how other countries handle Deaf education.

Kathryn P. Meadow's *Deafness and Child Development* (1980) is a wonky, quantitative, look at how Deaf children hear. The book is filled with audiograms and incremental definitions of Deafness and the difference between being Hearing, Hard-of-Hearing, Hearing-Impaired, Deaf and Profoundly Deaf and how those categorizations are defined medically. She also provides a theory for how those labels have cultural resonance beyond the research in the Hearing and Deaf worlds.

Sherman Wilcox is the editor of *American Deaf Culture: An Anthology* (1989) that details the individual experiences of the Deaf, CODA ([Hearing] Children of Deaf Adults) and, Deaf parents of Deaf children and Hearing parents of Deaf children and how each intricate intra-cultural base brings with it responsibility and joy and terror when an

infant is determined to be Deaf. Labeling an infant Deaf after implantation, Wilcox contends, has deep and wide implications for the Deaf infant's acceptance into a culture.

Language Disorders from Infancy Through Adolescence (2001) by Rhea Paul provides research experimentation into language disorders, aphasia and Deaf speech acquisition from a historical perspective.

Grammar, Gesture, and Meaning in American Sign Language by Scott K. Liddell (2003) provides an impressive structural analysis of ASL that details its parts and its importance in space and time. Liddell proves gestures have a grammar that constructs universal meaning. He also seeks to widen the definition of a "language" by comparing and contrasting the ideas of gestures, symbols and gradient issues in all languages including American Sign Language.

Linguistics of American Sign Language by Clayton Valli and Ceil Lucas (2000) is a structured method of learning ASL through imitation. Imitation is important to this research project because, as Aristotle taught us, we all learn through imitation. If a Deaf infant is born to Hearing parents there is an immediate cultural and language deficiency in the ability to express common understanding. This book investigates precisely how language is expressed through the body.

Language Learning Practices with Deaf Children (2004) by Patricia L. McAnally, Susan Rose and Stephen P. Quigley reveals how Deaf children study and learn using the "Deaf means of communication" and English sentence structure. The book is an interesting study because the focus is on Deaf children who already employ a vivid form of glossing, slang and home signs beyond the core structure of American Sign Language.

Perceptual Learning (2002) by Manfred Fahle and Tomaso Poggio examines how cochlear implants affect perception and understanding in Deaf children. This is a heavily technical medical book but the research is well-designed, thorough and convincing.

Cochlear Implants (2000) by Susan B. Waltzman and Noel L. Cohen provides detail into changes on the cellular level following implantation as well as an examination into the long-term effects of constant artificial electrical stimulation of the cochlea. The beginning of a warning against the long-term efficacy of cochlear implants is suggested in this book.

In 2003 Helen E. Cullington wrote *Cochlear Implants: Objective Measures* as a response to the Waltzman & Cohen book. In this handbook for surgeons and audiologists Cullington is on the side of the implanting Deaf infants and children with cochlear devices because she believes the advantage of immediate stimulation of the auditory nerve outweigh any long term cultural identity deficiency the surgery may cause.

Cochlear Implants in the Education Setting (1995) by Mary Ellen Nevins and Patricia M. Chute write about strategies for helping implanted Deaf children find educational success in mainstream classrooms. The book is a bit outdated in terms of its technological thinking but the in-school issues for Deaf children are still burning and important and this book effectively sets up that conflict for examination.

Research Design

The research design for this qualitative study will include rationale for the logic of the study, how samples and cases will be determined and a review and how appropriate qualitative research methods will be conducted.

Logic of Study

The research question will focus on cochlear implanted infants to discover if they feel accepted by Hearing peers as they grow and become members of society after implantation or if they feel Deaf or Something Else. The logic of the study must adhere to the impartial standards of qualitative methods but the lead researcher's experience and training suggest paths for explorations and hint at where the study may lead.

The feelings of the parents, Hearing peers and the medical community, while important, will not be the focus of this study except to help frame the issue for the peer acceptance of the Deaf child.

This study may help provide expression for Deaf infants who are born without a cultural advocate while a life-changing decision is made on their behalf. This study may impartially suggest a touching of the brake of cultural caution and to gently press for a more comprehensive understanding of the whole-body effects of a cochlear implant on a life before a surgeon's knife ever touches Deaf infant flesh.

Sample/Cases

The sample cases for this qualitative study will consist of nine recently implanted infants less than six months of age, three from upper-income families, three from middle-income families and three from low-income families and they all will be studied for ten years. In what ways might money, access to cultural cultivation and the power of social standing make a difference in acceptance by Hearing peers?

All hospitals that conduct cochlear implant surgeries will be contacted for leads on families willing to participate in the study.

Finding significant outliers may be a problem because the surgery is irreversible once the decision has been made to implant so all cases in the study will consist of identical samples in that all samples will always remain affected by the same surgery though the paths and destinations may differ enough to provide an outlier or two even in the small sample. Each family will receive a \$1,000 stipend for each year of participation in the study.

Research Methods

This qualitative study of the feeling of peer acceptance by Deaf children in the Hearing world will be researched using a variety of research methods. The topic is rich with qualitative issues for investigation: feelings of belonging; cultural identity; satisfaction with decisions made without the participation of the person affected and how one copes with cultural identity losses and gains.

Since the budget for this project is unlimited every possible angle for discovery and observation will attempt to be employed to give this research study depth and breadth of a quasi-mixed methods study.

Ethnography

This research study will be a long-term ethnography that will track and examine the lives of the implanted Deaf children and the growth and realization of their feelings of peer acceptance early in their lifetime. This ethnography will impartially observe and report and provide scholarly results.

There may be a methodological passion and strong point-of-view provided in this proposal based on existing research and the lead researcher's current experience in the

Deaf community but every effort will be made to let the experiences of the implanted Deaf children define the study.

If implanted children believe they are accepted by their Hearing peers as Hearing and not Deaf that will be a ground-breaking and unique study never before been examined in a decade-long ethnography.

Interviews

An important part of the qualitative research for this study will be interviews with the Deaf infants' parents and peers and even though the infants will be unable to express themselves for several years all the interviews will be focused only on the feelings of peer acceptance of the Deaf infant as the child grows.

Interviews will also include medical professionals, surgeons, implanted Deaf adults and children of varying ages, Deaf scholars, Hearing scholars on Deafness, language anthropologists, sociology professionals and Hearing peers of the Deaf children who were implanted as infants.

The Hearing peers may change over time along with the Deaf children's feelings of acceptance and rejection but those are perils of the study that must be tolerated and accepted. There will likely be other undiscovered scholarly resources that will be realized and then included in the routine interview cycle.

Focus Groups

With an unlimited budget this project will include Deaf and Hearing focus groups that will address the perception of Deafness in society and to discover if there are any preconceived notions or prejudices concerning the Deaf and their native visual language.

Hearing and Deaf focus groups would also be convened to examine peer perception of Deaf people who have been implanted with cochlear devices.

Historical

Harlan Lane and Oliver Sacks will help provide the historical frame of the argument against implantation of infants. Interviews with existing implanted Deaf and cochlear implantation surgeons and sociology experts will also help set the context of the past. Gallaudet University and the National Technical Institute for the Deaf at the Rochester Institute of Technology have extensive libraries that deal with Deaf education and language acquisition.

Visual

Deaf culture is a visual culture so 24 hour video surveillance will be provided in the home and videographers will selectively follow the Deaf children as they grow and interact with their peers. Many implanted Deaf children use American Sign Language as well as voice even after implantation.

The advice of medical experts is to not encourage the children use sign at home and many Hearing parents and cochlear implant specialists refuse to allow children to rely on their eyes and not their ears for communication. The problem with that philosophy is that Deaf children, even when implanted as infants at four months of age, perceive the world visually and their native, natural, tendency is to communicate with their hands despite the attempts to force verbal-only communication.

Alexander Graham Bell believed in tying the hands of Deaf children behind their backs in order to force them to use their voice and while the Bell method of Deaf education has been widely discredited, the “medical” reasoning behind making cochlear

implanted children use only their voices is a not-so-subtle resurrection of the Bell method.

Action Research

There will not likely be much, if any, action research for this qualitative study because team action research concerns collaborative inquiry to make an organization workable and to make its performance better. Since this research proposal concentrates on individual feelings of acceptance and not on the execution of an organization no action research should be required at this moment.

Observations

Observations will provide the core of this ethnography. Each research assistant will interact with the family in an observer's role at least a few times a week for a decade. Research assistants will likely rotate every year or so as they move onward and upward so standardized observation techniques will need to be repeatedly taught and the observers will need to be observed at the beginning of their time with the Deaf child to ensure continuity and comfort for both the observed and the observer. Researchers will not insinuate themselves into the fabric of the family. There will always be physical and ethical distance between the observer and the observed.

Observers will not engage in idle chatter or participate in or begin conversations. Researchers will not initiate activity in the house nor will they interact in a meaningful role in the life of the Deaf infant or the family unit. Researchers will not be allowed to continue to contact those they are observing when observations are complete and those being observed will be made aware of that fact before any observer enters the home.

Mixed Methods

This study finds merit in a quasi-mixed methods approach as discussed in the following paragraphs. The use of quantitative data sets and surveys in addition to the main qualitative inquiry of this research problem will help round out the study.

Quantitative Data Sets

Quantifying hearing from a numbers point-of-view is extremely popular in the medical community. Audiograms and other computerized measures of hearing and speech perception help define, from a medical viewpoint, how much hearing loss a person has to overcome.

Preexisting data sets concerning cochlear implants and increases or decreases in perception of sound will be helpful to this study as a way to frame the advantages of technology against the requirements of cultural integrity. Pre- and Post- implantation audiograms and computer testing will also be of great value in comparison against the feeling of peer acceptance for implanted Deaf children.

Surveys

The use of surveys will greatly enhance, in human terms, the universality of this qualitative study. A variety of Cochlear implanted Deaf, their families and their Deaf and Hearing peers from around the world can place on a Likert scale feelings of peer acceptance and other applicable issues to help give depth and a sense of context to the questions this study seeks to answer. This random sample survey can then provide greater information that will either compliment or contrast the discovery of the directly observed in this ethnography.

Time Table

Ten years is a long time for a study to unfold. The original thought for this study was to break the study into three age-specific categories with three people being observed in each category. Category one dealt with infant implantation up to four years; category two dealt with children implanted at five years of age and observed them until age nine; the final category would have observed children who were implanted at age 10 and followed them until they were 15.

While those three categories might add variety to the project it was ultimately decided that infant implantation is currently a much more ominous and unknown entity and that studying as many implanted infants as time and an unlimited budget would allow would better help break important research ground.

This study may help give voice to implanted infants who never had a chance to discover, unfettered, their native culture through natural development of their birthright language.