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Quest for a Deaf Child: Ethics and Genetics

Teresa Blankmeyer Burke

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QUEST FOR A DEAF CHILD:
ETHICS AND GENETICS

BY

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B.A., Biology, Ethics & Society, Mills College, 1993
M.A., Philosophy, The University of New Mexico, 2003

DISSERTATION

Submitted in Partial Fulfillment of the
Requirements for the Degree of

Doctor of Philosophy
Philosophy

The University of New Mexico
Albuquerque, New Mexico

May, 2011

Dedication

I dedicate this dissertation to my family.

To my parents, Richard and Carol Blankmeyer, for the love, support, and encouragement they have shown me through the years, and for raising me in a home where books and ideas were central.

To my children, Austin Burke and Hypatia Venerable, for waiting patiently so many times while mom finished this “one last sentence,” for teaching me about parenting as I was writing about it, and for the questions – oh the questions!

And to Lloyd, who listened, ran errands, cooked, cleaned, hosted visitors, and carpooled during all those times when I needed “just a few more hours” and who never complained. Not once.

Thank you all.

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A very special shout out goes to Dr. Vardit Ravitsky for introducing me to the conditions of exit argument and for countless hours of discussion about genetics and bioethics in Santa Fe, Washington, and Philadelphia.

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I am grateful for the support and community provided by the Deaf Academics group. Writing a dissertation is always a solitary process, but even more so when direct communication accessibility with one's graduate student cohort is a challenge. This international group of signing Deaf scholars provided a venue for me to have those "water cooler chat" moments in cyberspace and at conferences. Very special thanks to Corrie Tijsseling, Breda Carty, Antti Raike, Carol Padden, Tom Humphries, Billy Ennis, Joe Murray, Derek Braun, Carrie Solomon, Paddy Ladd, Alison Bryan, Steve Emery, Hilda Haualand and Christian Vogler.

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Sign language interpreters are bound by a code of ethics that includes confidentiality. I'll honor this and them by not naming anyone, but I would be remiss if I did not acknowledge my great good fortune in getting to work with so many talented professionals in locations as diverse as Riyadh, Berlin, London, and Albuquerque. Their seamless interpretation offered me entry into many scholarly worlds, allowing me to obtain valuable feedback from audiences.

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ABSTRACT

This project investigates the question of whether it is morally justifiable to use genetic technology in order to bear a deaf child. Even though it may seem counterintuitive to hearing people, deaf people often desire to have deaf children. Reasons for this vary, but often include a deep longing to have a child who can fully participate in one's linguistic and cultural community. Many view using genetic technology to ensure or create a child with a disability as harmful and a dereliction of parental duty; dismissing the desire for a deaf child as misguided at best. I begin by situating this desire for a deaf child in historical context, identifying and analyzing ethical claims regarding deaf education, eugenics, civil rights, and cochlear implant surgery. Following this, three arguments are analyzed to consider whether, in certain situations, it may be morally justifiable to use genetic technology to bear deaf children. The first is a consequentialist approach to genetic selection, using a variation of the Non-Identity argument to evaluate the potential harms and benefits to the child who is born deaf. For genetic alteration, I evaluate an argument with roots in deontology that considers

the notion of bodily integrity as a principle of human dignity and autonomy, expanding it to include genomic integrity. The final chapter considers the question of deafness as a moral harm, including the question of harm within the family unit and harm to society.

I consider two major objections to these arguments: the child's right to an open future, and conditions of exit. In the right to an open future argument, parents have a duty to ensure that undue restrictions are not placed on the child's future. The conditions of exit argument asserts that parents have a duty to protect a child's potential future interest in exiting her cultural community. I conclude that these objections rightfully present challenges to the three arguments I consider, but are currently insufficient to fully overcome them and need further refinement.

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Chapter 1 Introduction

Introduction to the Problem

My dissertation evaluates the moral justification and permissibility regarding the use of genetic technology in order to create a deaf child. Typically, the search for genes that cause or contribute to an undesirable medical condition is motivated by the hope of finding a cure for such a medical condition or eradicating the condition altogether.

Deafness differs from most other medical conditions in that it is not universally viewed as an undesirable medical condition.¹ Two contrasting views of deafness exist in contemporary American society. The viewpoint shared by most people is that deafness is the pathological condition of profound hearing loss² and that deaf people suffer from a sensory deficit. The minority viewpoint regards Deaf people as ‘visual’ people whose primary orientation toward their deafness is based on shared cultural considerations, such as language and values, instead of viewing deafness as a pathological condition.³

This is not to say that Deaf people deny their audiological status (as some authors have mistakenly written) but to illustrate the primacy of culture over pathology.

Language choice is often used to distinguish members of these two groups – Deaf people

¹ Deafness is not unique in this respect – other typically undesired medical conditions, such as achondroplasia, may be considered highly desirable by persons with these conditions.

² *Dorland’s Illustrated Medical Dictionary*, 26th ed., s.v. “deafness”.

³ I follow the standard convention used by many scholars of Deaf Studies where the use of upper case ‘Deaf’ refers to cultural aspects, and the use of lower case ‘deaf’ to the audiological and physical condition of deafness. I have chosen in most cases, to refer to children using the lower case ‘deaf’, since their cultural identity may not be developed. This is clearly the case for potential persons, and probably infants as well.

use a signed language primarily, where deaf people prefer to use the spoken language of their community. I disagree with the use of this characteristic as the sole criterion: language choice is not sufficient to distinguish Deaf people from deaf people, and to rely on this as the sole criterion disregards the complexity of the deaf community. For example, some deaf people use a signed language or system, but their primary orientation is to the values and culture of the hearing world, and they do not consider themselves culturally Deaf.⁴ Other deaf people are truly bilingual and bicultural, and float between the Deaf and hearing worlds with ease, aligning themselves with both cultures and identifying with both. My question and analysis focuses on those members of the deaf community whose primary cultural affiliation is with the Deaf-World, and who consider the property of being Deaf to be a highly desirable characteristic.⁵

It may seem to the reader familiar with Deaf Studies literature that I have taken a vast leap by assuming that the Deaf community constitutes a separate culture, and disregarded the many arguments against such a position.⁶ Without delving into the controversial issue of whether Deaf people make up a culture or not, I would like to point out that there is plenty of evidence that the Deaf community differs from the non-Deaf community enough that it is considered separate from it. This distinction between the non-Deaf community and the Deaf community is the point I wish to impress upon the

⁴ For the purposes of this project, I use the terms ‘Deaf culture’ and ‘signing Deaf community’ to signify the population of signing audiologically deaf people who are most likely to consider using genetic technology in order to ensure a deaf child.

⁵ Carl Elliott, *Bioethics, Culture, and Identity: A Philosophical Disease* (New York: Routledge, 1999), 42.

⁶ See Padden and Humphries, *Inside Deaf Culture* (Cambridge: Harvard University Press, 2005), 3-10.

reader -- my argument turns on the ways in which deafness is viewed by members of these communities, and not on whether the Deaf community constitutes a full-fledged culture.

At the risk of oversimplifying a complex topic, the difference between the two community orientations boils down to the ‘deafness as pathology’ versus ‘Deafness as a cultural outlook’.⁷ Hearing loss is a necessary condition for being Deaf, but not a sufficient one – a person with a profound hearing loss can be completely immersed in the hearing world and may not even be aware of the existence of the Deaf community. At least in practice, the use of a signed language as a primary or first language is not sufficient for assigned status as Deaf. A hearing child of deaf parents may acquire a signed language as her first language, but that child is not regarded as Deaf. (Some scholars have noted the challenges of trying to combine a physical characteristic with the cultural definition – the work of Lennard Davis, a hearing Deaf Studies scholar and son of Deaf parents addresses this).⁸ A consistent definition of what counts as Deaf is unclear, and is a project beyond the scope of this project; for now, I will consider a person with an unspecified degree of hearing loss and who uses a signed language as a primary language to be Deaf.

The use of a signed language is a sociocultural marker. Members of the Deaf community use a signed language, but contrary to popular belief, signed language is not

⁷ Charlotte Baker-Shenk and Dennis Cokely, *American Sign Language: A Teacher’s Resource Text on Grammar and Culture* (Washington, DC: Clerc books, Gallaudet University Press, 1981), 54.

⁸ Lennard Davis, “Deafness and the Riddle of Identity,” *Chronicle of Higher Education*, January 7, 2007.

universal. In the United States of America and most of Canada, that language is American Sign Language (ASL).⁹ Not all Deaf people in the United States learn ASL as a first language, but all Deaf people hold tremendous respect for ASL and value it highly.¹⁰ Connected to the high valuation of ASL is a ‘sacred’ regard for the use of hands in communication;¹¹ consequently, the loss of the use of a hand is seen in much the same way that hearing people regard the loss of the ability to speak. As is the case for members of other minority groups existing in the larger culture, social relations in the Deaf community are particularly treasured. Cultural values and behavioral mores found in Deaf literature and stories are often transmitted in these social gatherings, as well as in the home and residential schools.

Most members of sociolinguistic cultural groups harbor hopes for the continued existence of their community. Deaf people are no different from others in this respect. I propose to look at a somewhat unconventional use of genetic technology desired by some Deaf parents, who hope to use these new technologies in order to assure the birth of deaf offspring. The desire to ensure that one’s children share one’s disability may seem a bit bizarre and easily dismissed as having no moral cogency. Yet, once this desire is explained within the context of a minority group trying to maintain their language and customs within a larger pluralistic society, it becomes more difficult to dismiss the moral certitude of such a use of genetic technology as simply wrongheaded.

⁹ ASL is the signed language used in English speaking regions of North America. In French speaking Canada, Langue des Signes Québécoise (LSQ) is the commonly used signed language.

¹⁰ Carol Padden, “The Culture of Deaf People” in *American Deaf Culture: An Anthology*, ed. Sherman Wilcox (Silver Spring, MD: Linstock Press, 1989), 9.

¹¹ *Ibid.*

Membership into the Deaf community typically occurs in two ways. A deaf child may be born to Deaf parents and, by dint of these circumstances, be fully immersed in the language and social behaviors of the community. A deaf child born to hearing parents usually gains entrée into the community upon attending a residential school for the deaf at an early age, though this has changed recently with the advent of charter schools. In some cases, deaf individuals with hearing parents may not be immersed in the Deaf community until they reach college age; the narrative of ‘discovering’ the Deaf community as a young adult is not unusual. Approximately five to ten percent of deaf children have Deaf parents, even though Deaf people marry other Deaf people about ninety percent of the time.¹² Since the vast majority of deaf children have hearing parents, the continued existence of the Deaf community depends to a great extent on the number of deaf children born to hearing parents.

Not all deaf children born to hearing parents will go on to enter the Deaf community; several factors influence the number of deaf children attending educational institutions for the Deaf. The first of these is the language (and language mode) chosen by the parents for the deaf child. If a deaf child’s hearing parents decide that their deaf child would be best served by communicating orally and aurally, that child will most likely receive a cochlear implant and attend a school where the focus is on strengthening spoken language skills. Some parents may decide against the cochlear implant, but still opt to have their deaf child focus on learning to speak and speechread. Most recent data

¹² Harlan Lane, Robert Hoffmeister, and Ben Bahan, *A Journey into the Deaf-World* (San Diego: DawnSign Press, 1996), 30. Also Ross Mitchell, Travas Young, Bellamie Bachleda, and Michael Karchmer, “How Many People Use ASL in the United States?” *Sign Language Studies* 6:3 (2006), 312.

suggests that this option has become less common; in most Western countries, cochlear implants are the most common treatment for congenital deafness.¹³

In the past, many schools that emphasized oral and aural education were private and costly, and a deaf child's educational path was often dependent on the means of his family.¹⁴ Parents with fewer resources sent their deaf child to the state school charged with educating deaf children. A variation of this is seen today; deaf children from lower income (hearing) families are less likely to obtain cochlear implants than those from families with more economic resources.¹⁵ The effects of this on the demographics of the signing deaf community remain to be seen.

Despite the swinging pendulum of deaf education at state schools that shifted from signed language instruction to spoken language instruction and back again, deaf children with hearing parents quickly learned to sign through their social interaction at school with Deaf children of Deaf parents. By communicating with native signers, deaf children with hearing parents acquired language transmission horizontally from their Deaf peers. This method of language acquisition is unusual; most instances of language transmission occur vertically, from adult (parent) to child. This horizontal pathway is also used to some extent for transmission of cultural mores. The presence of Deaf adults in the educational system, as residential dormitory supervisors, counselors, custodial staff, teachers, and administrators also plays a role in the acquisition and transmission of

¹³ Linda Komesaroff, "Introduction" in *Surgical Consent: Bioethics and Cochlear Implantation*, ed. Linda Komesaroff (Washington, DC: Gallaudet University Press, 2007), xi.

¹⁴ Carol Padden and Tom Humphries, *Inside Deaf Culture*, 18.

¹⁵ John B. Christiansen and Irene W. Leigh, *Cochlear Implants in Children: Ethics and Choices* (Washington, DC: Gallaudet University Press, 2002), 112.

language and culture, though this may be highly variable depending on the number of Deaf adults at the school and their amount of contact with children. Currently, there are reasons to believe that this model for conveying sociocultural norms within the Deaf community and mastering a signed language is endangered.

Two points are especially important for the reader to keep in mind: first, the low rate of hereditary deafness that is passed on from parent to child sets up this situation, in which parents who wish to have children like themselves are not likely to experience this as others do through natural biological processes. Second, the uniqueness of horizontal transmission of language and culture, which deaf adults of hearing parents respond to in a variety of ways, including the desire to parent children who are likely to share their cultural experiences. These experiences are not just confined to the physical experience of being deaf, but include the cultural experiences found in schools for the deaf and participation in horizontal transmission of language and culture, in addition to the vertical transmission that would occur in the case of Deaf parents using a signed language and conforming to sociocultural norms of the signing Deaf community. It is also notable that hearing children of Deaf parents will, to some extent, also experience horizontal transmission of culture, especially if they spend most of their pre-education years in the signing Deaf community. It is not unusual to see a delay in spoken language acquisition with these children, as well as some ignorance of social norms in the hearing community.¹⁶

¹⁶ See Naomi B. Schiff and Ira M. Ventry, "Communication Problems in Hearing Children of Deaf Parents," *Journal of Speech and Hearing Disorders* 41: 348-358 (1976); Brenda C. Seal and Lisa A. Hammett, "Language Intervention with a Child with

The Impact of Biotechnology on the Deaf Community Today

The current popularity of cochlear implant surgery among hearing parents of deaf children, with its post-surgical rehabilitation emphasizing aural and oral skills, has led to a reduction in the numbers of deaf children attending schools that emphasize signed language. This has contributed to the closure of some state residential schools for the deaf.¹⁷ When the FDA first announced the proposal in 1990 to provide children with cochlear implants, the members of the Deaf community and Deaf organizations initially reacted negatively and with a great deal of concern.¹⁸ In addition to ethical issues related to performing elective and somewhat experimental surgery on a child who had not consented to such a procedure, much was made of the potential for this surgery to decimate the numbers of future Deaf people. Some members of the Deaf community even referred to cochlear implant as “cultural genocide”.¹⁹

Nearly twenty years later, the ethical issues of cochlear implant surgery seem almost quaint and outmoded given current developments in biotechnology. Looming on the horizon is the newest potential threat to the continued existence of the Deaf

Hearing Whose Parents are Deaf,” *American Journal of Speech-Language Pathology* 4:15-21 (1995); and Jeanne M. Johnson, Ruth V. Watkins, and Mabel L. Rice, “Bimodal Bilingual Language Development in a Hearing Child of Deaf Parents,” *Applied Psycholinguistics* 13: 31-52 (1992).

¹⁷ Carol Padden and Tom Humphries, *Inside Deaf Culture*, 16.

¹⁸ John B. Christiansen and Irene W. Leigh, *Cochlear Implants in Children*, p. 120. Also Des Power, “Models of Deafness: Cochlear Implants in the Australian Daily Press,” *Journal of Deaf Studies and Deaf Education* 10 (4): 451-459 (2005).

¹⁹ Harlan Lane and Michael Grodin, “Ethical Issues in Cochlear Implant Surgery: An Exploration into Disease, Disability, and the Best Interests of the Child,” *Kennedy Institute of Ethics Journal* 7 (3): 231-251 (1997).

community: genetic technology. Widespread use of this technology has the potential to profoundly affect future generations of the Deaf community, possibly leading to the extinction or endangerment of this community.

In 1997, the discovery of Connexin 26, a gene for nonsyndromic deafness was announced. This autosomal recessive gene was found to result in a one in four chance of the birth of a deaf child if both parents were carriers. Connexin 26 is thought to be responsible for 50%-80% of cases of hereditary deafness in some regions and populations of the world, and 20%-30% of cases of deafness in the United States.²⁰ The threat of genetic technology, once seen as a matter for the distant future, became immediate upon identification of this first gene for deafness. To date, more than one hundred genes for syndromic and nonsyndromic deafness have now been identified.²¹ Currently clinical screening is only available for the Connexin 26 (GBJ2) and Connexin-30 (GBJ6) genes, though other screening may take place in research settings.²²

In 2002, an Australian hearing couple undergoing in vitro fertilization (IVF) requested embryo screening or preimplantation genetic diagnosis (PGD) for the Connexin 26 gene. The couple, who were both carriers of the Connexin 26 gene, did not want a

²⁰ Kathleen Arnos and Arti Pandya, "Genes for Deafness and The Genetics Program at Gallaudet University" in *Genetics, Disability, and Deafness*, ed. John Vickrey Van Cleave (Washington, DC: Gallaudet University, 2005), 115.

²¹ *Online Mendelian Inheritance in Man*, OMIM (TM). McKusick-Nathans Institute of Genetic Medicine, Johns Hopkins University (Baltimore, MD) and National Center for Biotechnology Information, National Library of Medicine (Bethesda, MD), accessed December 10, 2010 <http://www.ncbi.nlm.nih.gov/omim/>

²² Arti Pandya and Kathleen Arnos, "Genetic Evaluation and Counseling in the Context of Early Hearing Intervention and Detection," *Seminars in Hearing* 2006 27 (3): 208. Also per e-mail communication 15 July 2008 with Kathleen Arnos, plus genetics counselors Anna Middleton and Rachel Belk in the United Kingdom.

deaf child. Seven embryos were screened: one had two copies of the gene (deaf), five had one copy of the gene (carrier), and one did not possess any copies of the Connexin 26 gene. The embryo without any copies of the Connexin 26 gene was implanted, but pregnancy did not take.²³

This case caused a furor in the Australian Deaf community, a community whose numbers were already threatened due to the high percentage of cochlear implants taking place – one of the highest percentages for prelingually deaf children in the world at that time.²⁴ Many members of the Australian Deaf community felt that this was yet another attack on the continued existence of their community and way of life.²⁵ The Australian Infertility Treatment Authority responded to this outcry by stating, “Strict guidelines would allow screening only when it would improve the health or physical condition of the child. Deafness is a medical condition, not a frivolous or cosmetic use of technology.”²⁶

The desire of hearing people to minimize the possibility of giving birth to a deaf child may be part of what motivates Deaf people to consider the possibility of creating a deaf child, since the numbers of potential Deaf community members would likely be reduced by the use of PGD and other technologies. This is undoubtedly not the only motivation, and it may not even be a primary motivation. Other reasons for wanting to

²³ Tom Noble, “Embryos Screened for Deafness—a Quiet First for Australia,” *Sydney Morning Herald*, July 11, 2003, accessed April 28 2004.

<http://www.smh.com.au/articles/2003/07/10/1057783286800.html>

²⁴ Personal conversation in February 2004 with Deaf Studies historian Breda Carty of RIDBC Renwick Centre, University of Newcastle, Australia, who reports it was about ninety percent at the time this story broke.

²⁵ Power, 451-4.

²⁶ Noble.

have a deaf child center on what is perceived as best for the family unit, including the best interests of the potential child and his parents.

The use of genetic technologies can also be used to select for deafness, and in 2002 a case in the United States drew much international media attention to this issue. Two lesbian women, Sharon Duchesneau and Candace McCoullough, who wished to have a deaf child, went to a sperm bank for artificial insemination (AI), hoping to acquire sperm from a deaf donor. When notified of the sperm bank's policies, which forbade deaf donors, the women found a willing sperm donor in the Deaf community. Their donor, a Deaf man with a family history of deafness spanning many generations, was autosomally dominant for deafness, virtually guaranteeing that his offspring would be deaf.²⁷ While the approach used in this case was not PGD, but a low technology approach of 'playing the odds' in hopes of conceiving a deaf child, it points to the real possibility of Deaf parents wanting to use genetic and/or reproductive technology in order to bear deaf children.²⁸

The profession of genetic counseling places a high value on nondirectiveness, in which the genetic counselor leaves all decisions regarding future reproduction up to the parents.²⁹ Rather than offering prescriptive suggestions about what the individual or family ought to do, as is typical of other areas of medicine, genetic counselors are trained

²⁷ Liza Mundy, "A World of Their Own", *Washington Post Magazine*, March 31, 2002.

²⁸ I have chosen to refer to these (potential) children using the lower-case 'deaf' in order to emphasize the audiological status desired. In this situation, it is the case that, once born, these children would be raised in the Deaf community, making them also culturally Deaf.

²⁹ Lynn B. Jorde, John C. Carey, Michael J. Bamshad, and Raymond L. White, *Medical Genetics*, 3rd ed., (St. Louis: Mosby/Elsevier Science, 2003), 307.

to be value-neutral, and give their clients sufficient and accessible information so that they may make an informed decision. Genetic counseling revolves around five themes: risk determination, risk options, reproductive decision-making, medical management, and support services.³⁰ Potential parents consider information provided by genetic counselors, but make decisions on their own.

Prior to the advent of genetic technologies such as PGD, some Deaf couples sought genetic counselors in order to determine the chances of conceiving a deaf child. At that time, hereditary pedigrees, plus limited knowledge of syndromic and non-syndromic causes of deafness, were the only information available to genetic counselors about which to inform their clients about the likelihood of having children with certain genetic conditions. Despite the scanty amount of evidence available, some deaf couples who availed themselves of the services at the Genetics Center at Gallaudet University and elsewhere, decided to discontinue their relationships after learning of the slim to nonexistent possibility of conceiving a deaf child rather than a hearing child.³¹ For these couples, the possibility of using genetic technology in order to increase the chances of having a deaf child would be welcome, given the high value assigned to the desire to have deaf children. Services offered by such programs as the Genetics Center at Gallaudet University now make it possible to determine much more accurate odds for couples wishing to learn more about the types of hearing status likely to occur in their potential offspring.

³⁰ *Ibid.*, 313.

³¹ Arnos and Pandya, "Genes for Deafness", 117-119.

Now that the Human Genome has been mapped and more than one hundred genes correlated to deafness have been identified, it is possible in many cases to determine whether an embryo has a particular gene for deafness. Predicting the degree of hearing loss is another matter. Hearing status among individuals can vary even when it is attributable to the same genetic cause; it is not always possible to predict this since it depends on a number of factors, some of which are not completely understood. Even though hearing loss is a necessary condition for membership in the Deaf community, the degree of loss may have some bearing on how a deaf child interacts with the community. Current technology for selecting the physical trait of genetic deafness is relatively crude and is not sophisticated enough to allow potential parents to determine degree of deafness.

In addition to PGD, other technologies may soon be available to people wanting to have deaf children, such as gene replacement therapy, in which a 'normal' gene is inserted into a somatic (body) cell, correcting a loss-of-function mutation; and gene blocking therapies, which correct gain-of-function mutations.³² In other words, deafness could be created by inserting a deaf gene where the absence of such results in hearing, or deafness could be created by blocking the effects of a gene that causes hearing. Another possibility is germline therapy, in which a genetic modification for deafness is injected into an embryo, altering all cells of the body, including the gametes, which are responsible for passing the genetic material on to the next generation.³³ At this point, human germline therapy is highly experimental and is not funded by the National

³² Jorde, Carey, Bamshad and White, *Medical Genetics*, 296-300.

³³ *Ibid.*, p. 301.

Institutes of Health in the United States.³⁴ However, since this could potentially omit deaf genes from the genome altogether, I predict that this will become a great concern to the Deaf community as this technology is refined.

In November 2007, Deaf people worldwide became aware of the potential impact of genetic technology on signing Deaf communities when a clause prohibiting the use of PGD to select for disability was included in the United Kingdom's proposed Human Fertilisation and Embryology Bill (HFE Bill). Clause 14(4) (9) states:

Persons or embryos that are known to have a gene,
chromosome or mitochondrion abnormality involving a
significant risk that a person
with the abnormality will have or develop—
(a) a serious physical or mental disability,
(b) a serious illness, or
(c) any other serious medical condition,
must not be preferred to those that are not known to have
such an abnormality.³⁵

This clause raises two issues of concern for deaf people living in the United Kingdom (UK). The first deals with issues of reproductive liberty; under this clause, deaf people who possess genes associated with deafness may be prevented from being gamete donors,

³⁴ *Help Me Understand Genetics Handbook*, (Washington, D.C.: Lister Hill National Center for Biomedical Communications, U.S. National Library of Medicine, 2011), 129.

³⁵ United Kingdom Parliament, Human Fertilisation and Embryology Bill [HL] 2007-08 <http://services.parliament.uk/bills/2007-08/humanfertilisationandembryology.html> (accessed 17 May 2008).

or in some instances, have restrictions placed on their access to government supported reproductive technology services. The second concern involves the question of what kinds of people get to exist, or more precisely, government sanctioned preferences as to who can be born. The language of this clause explicitly states that certain kinds of embryos are preferable to others.

Additionally, explanatory note 109 to the HFEB specifically references deafness, as seen below.

Clause 14(4) contains a provision that relates to the provisions on embryo testing (see note on clause 11). New sections 13(8) to (11) amend the 1990 Act to make it a condition of a treatment license that embryos that are known to have an abnormality (including a gender-related abnormality) are not to be preferred to embryos not known to have such an abnormality. The same restriction is also applied to the selection of persons as gamete or embryo donors. [*This would prevent similar situations to cases, outside the UK, where positive selection of deaf donors in order deliberately to result in a deaf child have been reported* (italics added)].

Comments made during the discussion of this clause in the House of Lords indicated that the case of Duchesneau and McCullouch motivated the inclusion of preference against disability in this clause, prompting dialogue that to choose a fertilized egg/embryo that was genetically compatible with disability was immoral and undesirable. This is

supported in the discussion transcript of the second reading of the HFEB, where Baroness Deech, of the House of Lords and former head of the Human Fertilisation and Embryology Authority for the UK stated, “I hope that your Lordships will be pleased that the deliberate choice of an embryo that is, for example, [*likely to be deaf*] will be prevented by Clause 14” (italics added).³⁶

The response from the Deaf community in the UK to the HFEB was swift. In December 2007, the British Deaf Association issued a letter to the House of Lords asking that Clause 14 (4)(9) be dropped.³⁷ Deaf community members in the UK created a website, Stop Eugenics, which received considerable attention, leading to international press coverage featured by the London Times, BBC, CNN, and Der Spiegel, among others.³⁸

While this is the first law specifically addressing the issue of preference for and against disability regarding appropriate uses of contemporary genetic technology, it is not likely to be the last. Many of the questions and issues raised in the public debate and discussion of the HFEB are taken up in the following pages. The next section provides an outline of how these are addressed.

An Overview of the Dissertation

Although my research focuses narrowly on the moral justification for Deaf parents wanting to use genetic selection in order to have children who are deaf, this

³⁶ UK Human Fertilisation and Embryology Bill.

³⁷ Alison Byran, “HFEB: BDA Draft letter to Professor Marcus Pembrey” http://www.grumpyoldeafies.com/2007/11/hfeb_bda_draft_letter_to_profe.html, (accessed 17 May 2008).

³⁸ Stop Eugenics, www.stopeugenics.org (accessed 17 May 2008).

question has broader implications as well. People with achondroplasia, or little people, have also gone to genetic counselors in order to determine whether they might have children with achondroplasia.³⁹ Genetic selection, which is prohibited in many parts of the world, is currently done in the United States in order to select an embryo's sex as well as to select out certain kinds of disease or conditions, such as cystic fibrosis and Fanconi anemia. Evidence suggests that, at least in some cases, sexual orientation may have a genetic component;⁴⁰ if so, this may be another area of gene selection – one in which gay or lesbian parents could potentially select for sexual orientation.

The obvious difference between these examples and deafness is that deafness is the absence of the ability to operate one of the senses. Abilities related to sensory organs are often given special status and separated out from other physical abilities or attributes such as height. It is not immediately obvious why this is the case, or whether this is something grounded in culture, physiology or perhaps both. The other cases listed above do not involve the restrictions of sensory limitation; instead, other restrictions may exist, such as not having the phenotype required to play for the NBA or not being 'wired' for traditional means of sexual expression or procreation. The similarity between these examples and deafness is that gene selection motivated by sociocultural reasons held by individuals may not mesh with the sociocultural expectations of the larger society, and

³⁹ In the past, people with achondroplasia have been known as dwarves, which is considered offensive in some communities. "Little people" is the preferred term at the time of this writing.

⁴⁰ Stella Hu, Angela M. L. Pattatucci, Chavis Patterson, Lin Li, David W. Fulker, Stacey S. Cherny, Leonid Kruglyak and Dean H. Hamer, "Linkage Between Sexual Orientation and Chromosome Xq28 in Males But Not in Females," *Nature Genetics* (1995) 11: 248. doi:10.1038/ng1195-248.

this is the question that I wish to press regarding the use of genetic technology in order to bring about the birth of deaf individuals. The arguments I cover in Chapters Three, Four, and Five have relevance for the use of reproductive genetic technology that extend beyond the signing Deaf community and may be of use regarding the other issues I have mentioned above.

One distinction that I have glossed over until now is the question of whether there is an ‘active’ or ‘passive’ distinction regarding the use of genetic technology in the pursuit of a particular kind of child. (In this, I have something in mind analogous to the moral distinction of ‘active’ and ‘passive’ euthanasia that appeared in early bioethics literature, though that particular distinction is not widely held today).⁴¹ In the previous section, I note that a Deaf couple could use PGD to select an embryo with genes associated with deafness. This appears to be different in kind from altering the potential auditory status of an existing ‘hearing’ embryo to become a ‘deaf’ embryo. The latter is an action resulting in the *creation* of a deaf individual, where the former involves *selection* among choices provided by nature.

It may be that this analogy only goes so far. One could make the argument that it is logically possible for any genetic mutation to occur in nature, collapsing the distinction I have set up between active as human genomic intervention and passive as natural genomic process. Although this is correct, the reality of what is biologically possible and what is biologically probable differ enough that this classification works as a practical matter. As such, I have used these categories to frame my discussion.

⁴¹ See James Rachels, “Active and Passive Euthanasia,” *New England Journal of Medicine* 292:78-80 (1975).

I think a significant practical distinction exists between processes that are mostly caused by human action and those likely to occur naturally with human facilitation. However, I believe that the crux of the question of moral justification of using genetic technology to create a deaf child is less reliant on the manner in which such a child is created, and heavier weight should be given to the potential harm to that child. This harm should be based, in part, if not wholly, on his status as a deaf person in the world.

In the case in which a deaf child is born to non-signing hearing parents, the deaf child can be said to suffer a variety of harms ranging from partial access to language in the family home and society, the inability to hear environmental noise, the inability to fully participate in the culture of the hearing world, and so forth. This is the argument attended to by many bioethicists, who acknowledge the existence of a Deaf culture, but who gloss over what it means to be a Deaf child in a Deaf community.⁴² I hope to add a different voice to the literature on this topic by offering a carefully nuanced explanation of this cultural experience, and working through these arguments in light of this background information.

⁴² To the best of my knowledge, few authors arguing for what I shall call the Deaf community view regarding the use of biomedical technology to ‘cure’ deafness have extensive personal experience with the Deaf community. Many articles by bioethicists arguing against this issue offer superficial treatments of the Deaf community that indicate an academic knowledge of the community at best. At worst, the picture they paint of the Deaf community looks like a caricature of the Deaf world that I inhabit and live in. This is not an essentialist claim that only Deaf people can understand the experience of what it is to be Deaf, but simply an observation that a more comprehensive understanding of the community, including direct engagement with many members, is likely to lead to discussion of arguments that are more representative of those being articulated within the community.

In general, the current philosophical and bioethical literature is prone to two mistakes in addressing the use of genetic technology as a means to having deaf children. First, it conflates the experience of being deaf with the experience of being Deaf. While there is some overlap, this territory is not carved out satisfactorily. The second mistake is to neglect to provide sufficient cultural context for these kinds of decisions made by Deaf parents. I shall argue that many of the same arguments concerning harm applied to deaf child born to hearing parents are far less cogent when applied to a deaf child born to Deaf parents. This opens up the possibility of providing a moral justification for the use of genetic technology by Deaf parents in order to create a deaf child.

In Chapter Two, *Historic Context and the Signing Deaf Community*, I attempt to sketch out a history of ideas about deafness that will provide a foundation for subsequent chapters. First, I offer an overview of Deaf history, focusing on a few select events that have shaped discourse about what it means to be deaf and how this is perceived by mainstream (hearing) society in the United States. I argue that an understanding of this history, and particularly the ways in which signing Deaf people have been discriminated against or dismissed, is imperative to unpacking the desire for a deaf (Deaf) child. Second, I consider the issue of cochlear implant surgery on prelingually deaf children and offer an analysis of several ethical arguments related to the practice of this surgery. In doing this, I attempt to establish that the arguments related to new biotechnologies, such as genetics, are part of a historic chain of resistance and self-determination in the signing Deaf community. I also note that identification and analysis of the arguments used in the discourse on cochlear implants, in some cases, can be extended to genetic technology.

Chapters Three and Four reflect the active/passive distinction I've noted earlier. Chapter Three, *Genetic Selection: Choosing Deaf Babies*, takes on the issue of genetic selection. By genetic selection, I include all instances of choice regarding existing genetic material. Technologies covered under this classification include prenatal genetic screening as well as preimplantation genetic diagnosis (PGD). In this chapter, I have chosen to focus on genetic selection through PGD, applying a version of philosopher Derek Parfit's Non-Identity Problem. The Non-Identity Problem adopts a utilitarian ethical analysis as to whether it is morally justifiable to implant an embryo that possesses genes for deafness. By weighing the purported harm of disability against the benefit of existence, Parfit concludes that in many cases, the net amount of harm is such that it is justifiable. After considering challenges to the Non-Identity Problem, namely Dena Davis's conception of the Child's Right To An Open Future, I extend Parfit's reasoning to the case of genetic deafness, and argue that argument remains a cogent approach to genetic selection and as it currently stands, provides moral justification for genetic selection of deafness.

Chapter Four, *Genetic Alteration: Creating Deaf Babies*, addresses the ethical issue of altering genes in embryos and fetuses for the purpose of creating particular physical characteristics in these individuals once they are born. In order to avoid the normative associations provoked by the term "gene therapy," I have chosen to refer processes that modify genes as genetic alteration. Although it is the case that many of the arguments I consider in Chapter Three could also be applied to genetic alteration, I do not engage these arguments in Chapter Four. Instead, I consider a folk argument used frequently in the signing Deaf Community discourse on cochlear implant technology.

This argument, which I call “Ten Fingers, Ten Toes,” makes the case that (a) the deaf body is complete as it stands, and (b) attempts to fix or cure the deaf body are not morally permissible for this reason. Since this is a folk argument and not an academic argument, I have identified a philosophical concept within this argument, the notion of bodily integrity, in order to develop a more nuanced analysis of this argument’s cogency.

I begin by considering the question of bodily integrity in general, starting with an evaluation of what it means for something to have bodily integrity, and noting under what conditions this concept is typically employed. Following this, I hone in on established arguments for culturally acceptable practices of “non-pathological” bodily alteration, such as male circumcision, in trying to determine cogent reasons justifying cultural practices of children’s bodily alteration. Parents are given considerable latitude in the kinds of decisions they can make regarding their child’s body; typically the state only intervenes when the child’s life is at risk. Recently, body-altering practices such as female circumcision have called into question the issue of parental decision-making regarding the extent to which parents control their children’s bodies. Issues of the child’s ‘right’ to bodily integrity square off against the parent’s conception of what kinds of physical alterations are important for a good life. While the argument for parental decision-making in the case of life-saving medical intervention is cogent and can override the argument for bodily integrity, this is not as clear for non-essential practices carrying partial or no medical benefit.

An obvious question regarding this approach is whether alteration of one’s genome counts as bodily alteration. I argue that it does by providing an argument of composition as partial justification for this claim – in short, since one’s genome is a

physical part of one's body, it is consistent to consider individual genetic or genomic integrity⁴³ as an extension of bodily integrity. I also consider the philosophical issue of identity-determining bodily alteration raised by philosopher Jeff McMahan, placing it in the context of the bodily integrity debate. Following this is a section on Ravitsky's conditions of exit argument, in which the moral permissibility of genetic alteration is evaluated in terms of a child's right to belong to and exit a cultural community. I conclude that the bodily integrity approach, while initially promising, ultimately raises more questions than it answers, and that if this approach is to be helpful in answering questions of moral justification for genomic alteration, much work remains to be done.

Chapter 5, my final chapter, sketches out a long range view of the implications of my work regarding the question of whether it is morally justifiable to use genetic technology in order to bring about the birth of a deaf child. I address the issue of deafness as a harm in two ways. I start by considering the philosophical question of whether deafness is a harm, and what sort of difference an answer to this question might make for my project. Next, I outline some of the potential social and political issues ensuing from the consequences of using genetic technology in order to cause the birth of a deaf child. In addition to connecting my work to the practical questions of bioethics, this move also broadens the question of harm from my focus on the individual to questions about potential harm to the group and society. This move is akin to the elective disability

⁴³ The terminology here is challenging. Genetic integrity is typically used to refer to maintain the genetic composition of a species; this is sometimes synonymous with genomic integrity. As I understand it, genome refers to the range of normal genetic expression within a species; it appears that genetic integrity can apply to an individual or cluster of individuals within a species. I will use genetic integrity to refer to the genetic material of a species, and genomic integrity to refer to an individual.

argument used in the debate over cochlear implants. The elective disability argument, which is first introduced in the cochlear implant discussion in Chapter 2, assumes that people who have chosen to remain disabled, or who have not actively pursued measures for ameliorating disability, have not lived up to their responsibility to society. In the case of genetics, this argument turns on the responsibilities of the parents to society, and less so on the deaf child, who had no choice regarding her particular genetic composition and thus bears no responsibility for existing with this particular characteristic.

While this chapter concludes my dissertation, it reaches no neat or singular conclusion regarding the moral justification of using genetic technology in order to bear a deaf child. Rather, the contributions of this chapter, and those preceding, rest on the detailed (and sometimes novel) ways which the broad question is parsed and evaluated. It is my hope that I leave the reader with a roadmap offering several avenues for continuing the discussion of this question in depth.

Chapter 2 Historic Context and the Deaf Community

The Desire for a Deaf Child

A preference for a deaf child over a hearing child does not occur in a vacuum, but in a particular context that is influenced by historical and contemporary social factors. The desire to have a deaf child is often dismissed as one propelled by ignorance or a lack of experience; underlying this dismissive and somewhat paternalistic attitude is the assumption that if the potential (Deaf) parents had experiential knowledge of the ability to hear, all things being equal, they would never consider deliberately bearing a deaf child. One unstated premise in this argument is that it is better to hear than not to hear, but this is seldom argued for and usually viewed as a *prima facie* claim. I will take up this argument again in the final chapter; at this point I wish to impress upon the reader that this claim has yet to be argued. Another issue seldom considered in depth when discussing the preference of some Deaf people for deaf children is the importance of the historical record in shaping Deaf people's attitudes towards their cultural community, and by extension, ideas about their own place and their family's place within this community.

In order to develop an understanding of why Deaf parents might wish to have Deaf children, it is helpful to understand some of the history of the signing Deaf community, as well as narrative themes and arguments used by this community in the past. My aim in this chapter is twofold: first, to provide a brief overview of the historical background with an analysis of how certain key events and responses to those events have shaped the current desire and preference for deaf children. Second, to provide an analysis of some of the arguments used in the evaluation of the ethical issues related to cochlear implant surgery for prelingually deaf children, a topic that bears many relevant

similarities to the issues regarding uses of genetic technology for the signing Deaf community. My discussion of these topics assumes the sociocultural framework of the Deaf-World, a concept popularized by Bahan, Lane and Hoffmeister in their book *A Journey into the Deaf-World*.⁴⁴ The Deaf-World refers to the international signing Deaf community, who view themselves as part of a transnational sociolinguistic community with a shared ownership and direct connection to multi-national historical events involving or affecting signing Deaf people.

I will focus the next three sections on events that have definitively shaped the signing Deaf community (Deaf-World), starting with a sea change in the education of deaf children. The story of Deaf education is enshrined in a folk narrative that begins in the mid-eighteenth century with a chance meeting between the Abbé De l'Epée and two deaf sisters, which led him to found the first school for the deaf using signs.⁴⁵ The Abbé De l'Epée's legacy of establishing schools for deaf children that stressed signed language as the best means for educating these children was rejected in 1880, when educators of the deaf at the 1880 World Conference for the Deaf in Milan voted to educate deaf children through the oral method.⁴⁶ After considering the effects of this policy on deaf educational practices, I follow this with a look at the concomitant eugenics movement, which had an equally powerful impact on the signing Deaf community, devaluing signed languages and users of signed languages for what I believe are similar reasons. Another seminal event in the signing Deaf community takes place approximately one hundred

⁴⁴ Lane, Hoffmeister and Bahan, 6-9.

⁴⁵ Carol Padden and Tom Humphries, *Deaf in America: Voices from a Culture* (Cambridge MA: Harvard University Press, 1988), 27-31

⁴⁶ *Ibid.*, 34.

years later: the Deaf President Now (DPN) protest at Gallaudet University. This event marks a significant transition in how the signing Deaf community defines its community and frames its arguments, rejecting the pathological definitions of deafness focusing on the burden of deafness in favor of a sociolinguistic communitarian definition that emphasizes justice and civil rights claims. This change in thinking is also reflected in the initial response of the signing Deaf community to the emergence of cochlear implant surgery on prelingually deaf children as a potentially effective treatment for deafness, which occurs around the same time as DPN, and which I address in my final section.

Each of these historic events is notable because of the alterations in discourse that emerged around these particular contexts – shortly after the Milan conference we see an emphasis on the use of normative language proclaiming the superiority of educating deaf children through spoken language and relying on the calculus of benefits and burdens oft cited by supporters of eugenics. Prior to this, many professionals associated with deaf education and signing deaf people relied on an ethical framework that prioritized recognizing the human dignity inherent in each individual. This is exemplified in Abbé De l’Epée’s decision to educate deaf children so that they could more fully partake in the life of the community including participation in religious rituals, which was the primary impetus behind De l’Epée’s actions.⁴⁷ A little more than a century later during the DPN protest at Gallaudet University in 1988 the signing Deaf community’s discourse transformed from consequentialist leanings regarding the burdens of being a signing Deaf person in and to society, shifting to ethical arguments stressing claims of fairness and

⁴⁷ Harlan Lane, *When the Mind Hears* (New York: Random House, 1984), 58.

justice derived from civil and human rights. This rights-based discourse also emerges as one of the primary themes in the debate about cochlear implant surgery on prelingually deaf children. Admittedly, these arguments may be a bit too neatly categorized, and I acknowledge that there is more to the story than the labels I have assigned; still, these classifications serve as a useful shorthand for evaluating the impact of key historical events on today's signing Deaf community.

I devote the final section of this chapter to an argument analysis of the ethics of cochlear implant surgery on prelingually deaf children. Cochlear implant surgery is the first instance of medical technology aimed at deaf children that has had a significant impact on their lived experience as it relates to their ability to process sound. While cochlear implants do not perfectly restore hearing, in some case children function well enough with them to rely primarily on audition. Thus, by removing potential signers from the community, cochlear implant technology has had a much more pronounced effect on the signing Deaf community. Early community recognition of the potential impact of the cochlear implant on the signing Deaf community resulted in position papers and other written documents representing a variety of views expressed within the community; among other things, dissemination of this information in written English provided a way for scholars who did not know ASL to access these viewpoints and evaluate them.

Another class of cures for deafness deals with the treatment of diseases with the potential for causing deafness as a secondary effect. Vaccines developed for preventing the onset of rubella and mumps, while not initially aimed at reducing the number of deaf children, created this effect by reducing the number of children who contracted these diseases, and the secondary side effects, which could include deafness or hearing loss.

The development of these vaccines, which occurred well before the civil rights movement of DPN, did not engender the response that cochlear implant surgery did. One reason is that as a preventive measure, the beneficiaries of these vaccines are viewed as hearing, not as potential members of the signing Deaf community. Those who might have become deaf are not identifiable, since it is not possible to know which children would have contracted these diseases and become deaf as a result. This contrasts with cochlear implant surgery, which is performed on children who are already deaf and therefore seen as potential, even rightful, members of the signing Deaf community.

Awareness of the potential effects of genetic technology on the signing Deaf community is starting to develop within the community; resources articulating these issues, such as position papers, are just beginning to appear. As a case in point, the impact of genetic technology was addressed for the first time in 2007 in a plenary address at the 15th World Congress of the World Federation of the Deaf in Madrid.⁴⁸ Since knowledge of the potential consequences of genetic technology on the signing Deaf community is just starting to become part of the public discourse in these communities worldwide, philosophically complex arguments related to these issues has not been widely circulated or delineated. In November 2007, the international signing Deaf community became aware of proposed changes to the Human Fertilisation and Embryology Bill in England due in part to a letter released by the British Deaf Association letter that expressed their concerns about a particular clause limiting genetic

⁴⁸ World Federation of the Deaf, *Abstracts Book of Presentations and Papers of the 15th World Congress of the World Federation of the Deaf* (Madrid: WFD, 2007), 43.

preference.⁴⁹ The letter, drafted by deaf academics with scholarly expertise in conjunction with the British Deaf Association president Francis Murphy, elicited lively discussion in cyberspace on this topic.⁵⁰ Since the effects of genetic technology on the signing Deaf community are analogous in relevant ways to the effects of cochlear implant surgery on the community, some of the arguments used to evaluate the ethics of cochlear implant surgery on prelingually deaf children are likely to be indicative of the discourse regarding ethical use of genetic technology within the signing Deaf community. Initial review of internet discussion on vlogs, blogs, and popular media stories on the HFEB appears to support this.⁵¹

Benefits and Burdens: Deaf Education in the 19th Century

Starting with education, the signing Deaf community has experienced several challenges to its continued existence. In addition to education, scientific campaigns to relieve deaf people (and society) of the burden of deafness include the eugenics movement occurring during the late nineteenth to the mid-twentieth centuries, the

⁴⁹ Francis Murphy, “BDA draft letter to Professor Marcus Pembrey”, Grumpy Old Deafies, http://www.grumpyoldeafies.com/2007/11/hfeb_bda_draft_letter_to_profe.html#more (accessed February 23, 2008)

⁵⁰ Some examples of these discussions can be seen in the comments sections of the following blogs: Shane Feldman “Is it Selfish to Intentionally Make a Deaf Child?”, DeafDC, <http://www.deafdc.com/blog/shane-feldman/2007-12-28/is-it-selfish-to-intentionally-make-a-deaf-child/>; Teresa Blankmeyer Burke “British Bioethics and the Human Fertilisation and Embryology Bill”, DeafDC, <http://www.deafdc.com/blog/teresa-blankmeyer-burke/2007-12-05/british-bioethics-and-the-human-fertilisation-and-embryology-bill/>; Comments to StopEugenics website www.stopeugenics.org at <http://feeds.feedburner.com/StopEugenics-comments> (all accessed February 23 2008). 7. The website www.stopeugenics.org has an archive of internet and newspaper articles, transcripts of radio broadcasts, blogs and vlogs related to the HFEB that is frequently updated.

development of cochlear implant surgery in the twentieth century, and today's genetic technologies. Although the players in deaf education are starkly depicted as favoring the use of signed languages or opposing them, the lines are less clearly drawn in biomedical science. One complicating factor is that in some ways, projects aimed at curing deafness can be seen as having a double effect. Researchers set on identifying a cure for deafness may not hold the view that the signing deaf community ought to be eradicated, and may in fact agree that signed languages have intrinsic and instrumental value.⁵² However, if cures for deafness are pursued, the subsequent impact on signed language communities may lead to the unintended consequence of reducing the number of potential signed language users. Since linguistic communities need a critical mass of language users to sustain the viability of a language, the secondary effect of medical cures for deafness on signed languages is likely to be quite significant in the near future.

Whether working in the field of deaf education or biomedicine, researchers are likely to be motivated by a desire to do good, or to improve the quality of deaf peoples' lives. What is up for question is how good is to be defined; another challenge is determining how to go about measuring one's quality of life, including making distinctions between those factors that are socially constructed and those that are much more reliant on the physical aspects of deafness. One concept that has recently gained popularity with social constructivists is audism.

⁵² Teresa Blankmeyer Burke "Comments on Trevor Johnston's 'W(h)ither the Deaf Community? Population, Genetics, and the Future of Australian Sign Language", *Sign Language Studies* 6: 2 (2006), 178.

While there is some dispute over the range and depth of how audism should be defined, I will set this aside and offer a working definition of audism for the purposes of my analysis in this chapter. Audism deals with a kind of thinking analogous to racism or sexism or ableism – it refers to instances when members of a particular group are treated in specific ways (usually discriminatory) based on beliefs about collective characteristics possessed by members of the group. In the case of audism, these beliefs affirm a preference for and assumed superiority of hearing people and hearing people’s behaviors over those of culturally Deaf people, though I argue elsewhere for a broader definition.⁵³ Some examples of these beliefs are that signed languages are not real languages, but picture languages; that Deaf people are incapable of carrying out many of the duties of citizenship; that it is better to be Hearing than to be Deaf; and that spoken languages are always superior to signed languages.⁵⁴

Institutional audism refers to institutional practices and assumptions that promote audist attitudes, behaviors, and priorities. The professions of education, medicine, (and to a lesser extent) religion, have contributed to institutional audism in their quest to normalize, fix, cure, or heal deaf people. The devaluation of both signed language and social mores and behaviors within the signing Deaf community is frequently associated

⁵³ Teresa Blankmeyer Burke “An Argument Analysis of Technology and Deafness” (paper presented at the Second International Deaf Academics and Researchers Conference, Gallaudet University, Washington, D.C., 19 February 2004).

⁵⁴ These beliefs are not only held by the general public, but can be found in peer-reviewed academic journals as well – two recent publications that make this claim are Charles E. Zimmerman’s article “There’s a Deaf Student in Your Philosophy Class – Now What?”, *Teaching Philosophy* (December 2007) 30(4): 421-442, and Martin Harvey’s article, “Reproductive Autonomy Rights and Genetic Disenhancement: Sidestepping the Argument from Backhanded Benefit in *Journal of Applied Philosophy* (2004) 21(2): 125-140.

with these professions; I am not fully persuaded that the cause and effect of these judgments is necessarily as straightforward as some have claimed.⁵⁵ It may be the case that the patronizing and belittling attitudes aimed towards Deaf people simply reflect attitudes already present in Hearing society and do not originate within these professions. At minimum, advocating for the primacy of spoken language over signed language and codifying this belief into professional practices likely reinforces audist attitudes about the capabilities of Deaf people. Genetic technology is viewed by many members of the signing Deaf community as one more story in the narrative of mainstream society's oppression of Deaf people, or audism.

Education of the deaf was one of the first spheres of contention against audist attitudes and practices, and in many ways, continues to be the site of similar discourse today. Debate still rages today regarding who 'owns' a language, who should have the authority to decide how a deaf child is best educated, and what educational and biomedical pathways are best suited for deaf children (and less so a particular deaf child). From the eighteenth century into the mid-nineteenth century, deaf education was mostly manualist. Primarily conducted in signed systems and signed languages, this changed radically in 1880 at the infamous International Congress of Educators of the Deaf in Milan.

This movement against the use of fully accessible signed communication and language in deaf education is forever marked by the decision made at the Milan Congress, which decreed that educational instruction in signed languages should be

⁵⁵ H-Dirksen Bauman, "Audism: Exploring the Metaphysics of Oppression", *Journal of Deaf Studies and Deaf Education* 9.2 (2004): 241.

forsaken in lieu of an oral/aural approach to education that focused on speaking and speechreading. Due to some political outmaneuvering, teachers who were themselves deaf were not permitted to vote on the instructional recommendation to change from manualism to oralism; after the International Congress passed its resolution, educators of the deaf were forbidden to use signed languages in schools, though some countries followed these practices more stringently than others.⁵⁶ Members of the signing Deaf community believed the move from a fully accessible language to a partially accessible language to be burdensome rather than beneficial. Hearing educators of the deaf viewed this differently, focusing instead on the benefits of knowing a spoken language, rather than the difficulty of trying to function in mainstream society with only partial access to spoken language.

As seen below, the language of the two resolutions passed at the Congress in Milan offers reasons supporting these decisions.

1. The Convention, considering the incontestable superiority of speech over signs, (1) for restoring deaf-mutes to social life, (2) for giving them greater facility of language, declares that the method of articulation should have preference over that of signs in the instruction and education of the deaf and dumb.

2. Considering that the simultaneous use of signs and speech has the disadvantage of injuring speech and lipreading and precision of ideas, the Convention declares that the pure oral method should be preferred.⁵⁷

In addition to offering clear evidence for supporting audist beliefs that spoken languages were better than signed languages and that deaf people were socially isolated and less adept with language and clarity of thought, these resolutions resulted in two

⁵⁶ *Ibid.*

⁵⁷ Katherine A. Jankowski, *Deaf Empowerment: Emergence, Struggle & Rhetoric*, (Washington, DC: Gallaudet University Press, 1997), 51-52.

other consequences that greatly affected the signing Deaf community worldwide. First, it removed signing Deaf people from educating deaf children, since the emphasis was now on speech and sound which they could not access or assess. By taking this work away from deaf people, the burden of deafness was reinforced. Second, it created circumstances in which signed communication was discouraged and forbidden, driving this method of communication underground in schools for the deaf, and to some extent, elsewhere in the community that used it. Combating social isolation in mainstream hearing society was a priority; encouraging social interaction among signing Deaf people was not. The Milan legacy against signing as a pedagogical mode continued in deaf education for more than 70 years, becoming part of the historical narrative that pitted the mores and preferences of signing Deaf people against those who believed Deaf people would be better off fully assimilated into the Hearing world. What those supporting the Milan policy neglected to consider was that deaf people, no matter how skilled in speechreading they might become, would never have the same level of access to spoken language as a hearing person in the same situation. The deaf person would always be at a disadvantage, effectively living as a second-class citizen in mainstreamed society due to the consequences of missed and misunderstood information.

One reason the pendulum of deaf education had swung to oralism at that time was because of the support of Alexander Graham Bell, a public figure and strong advocate of oralism with several connections to the deaf community, including his early years as an

educator of the deaf, and his deaf mother and wife.⁵⁸ Bell used his bully pulpit to appeal to the public in a variety of ways: offering public exhibitions showcasing the oralist abilities of deaf people; founding the *Volta Review*, a journal advocating the oralist approach; and establishing the American Association to Promote the Teaching of Speech to the Deaf. This organization later became the Alexander Graham Bell Association of the Deaf, an organization still in existence today that promotes oralist education as a means of assimilating deaf and hard of hearing children into mainstream society.⁵⁹

The primary argument offered for making the change from education provided through signed language to oralist education was that deaf people would be better equipped to assimilate into mainstream society, making sure that the deaf child was being prepared for a future that fit the mainstream (Hearing) conception of the good life.⁶⁰ Although this vision of the good life equated spoken language acquisition with economic security and self-sustenance, many educators of the deaf considered spoken language acquisition an unrealistic goal. In their view, the tradeoff for learning to speak and speechread was too high – countless hours that could have been devoted to the acquisition of information that would help the deaf student better understand the world she lived in would be sacrificed for hours spent on ensuring that a word was pronounced correctly, a difficult task for one with no residual hearing.

The manualist viewpoint of the good life has deep roots in the history of American deaf education. Harlan Lane's seminal book, *When the Mind Hears: A History*

⁵⁸ Oliver Sacks, *Seeing Voices: A Journey into the World of the Deaf* (New York: HarperPerennial, 1990), 27.

⁵⁹ Jankowski, 24.

⁶⁰ *Ibid.*, 53.

of the Deaf, covers the story of deaf education by using surviving documents as a basis for relaying this story from the viewpoint of Laurent Clerc. Clerc, a Deaf intellectual in Paris during the eighteenth century, came to the United States at the behest of Thomas Gallaudet, the founder of the first school for the deaf in America. The American School for the Deaf in Hartford, Connecticut, established in 1817, not only provided instruction in signed language that eventually became American Sign Language, but also established a standard for deaf education in the United States. A signing Deaf man, Clerc developed a strong belief informed by personal experience that education through the language of signs was the best way to enlighten deaf students.⁶¹ His views are illustrated in this entreaty to an audience of prominent Bostonians regarding the establishment of a school for deaf children to provide instruction in signed language.

It is to speak to you more conveniently of the deaf and dumb, of those unfortunate beings who, deprived of the sense of hearing and consequently of that of speech, would be condemned all their life to the most sad vegetation if nobody came to their succor, but who intrusted to our regenerative hands, will pass from the class of brutes to the class of men.

It is to affect your hearts with regard to their unhappy state, to excite the sensibility and to solicit the charity of your generous souls in their favor; respectfully to entreat you to occupy yourselves in promoting their future happiness.⁶²

Clerc's use of the concepts of happiness and unhappiness here and elsewhere underscores the importance of framing education as not merely a means to gain admission to the world of hearing people, but also reminds his audience that for deaf people, it is through one's hands that the goal of becoming fully human can be realized.

⁶¹ Laurent Clerc, "Autobiography", in *Deaf World: A Historical Reader and Primary Sourcebook*, ed. Lois Bragg (Washington, DC: Gallaudet University Press, 2001), 7.

⁶² *Ibid.*, 6.

Clerc's vision of education contrasts sharply with the oralist educational pedagogy offered sixty years later by the educators who proposed and passed the resolution at the Milan Congress. These (mostly hearing) educators valued assimilation into mainstream society most of all and believed that acquiring speechreading skills and spoken language was the way to achieve this. This oralist-manualist debate continues in deaf education today, and is far from over. The cochlear implant offers a contemporary twist to this longstanding issue. Although it does not exactly replicate the sense of unaided hearing, children with cochlear implants are much more likely to attend schools that emphasize oral education. Typically, their ability to acquire spoken language with the implant is better than attempting to do so without the implant. Thus, most parents who opt to educate their deaf child using spoken language will also obtain a cochlear implant for that child. Yet, recent evidence suggests that children with cochlear implants who are exposed to both a signed language and a spoken language develop language acquisition in both languages, and that signed language does not impair the acquisition of spoken language.⁶³ In fact, scholars now suggest that it may help spoken language acquisition.⁶⁴ Given this it will be interesting to see whether a bilingual approach for children with cochlear implants becomes the standard.

⁶³ Debra Nussbaum, "Your Child Has a Cochlear Implant: Why Include Sign Language?", Laurent Clerc National Center for Deaf Education, Gallaudet University, accessed 10 December 2010. <http://clerccenter.gallaudet.edu/documents/clerc/20091216-0003.pdf>

⁶⁴ Poorna Kushalnagar, Gaurav Mathur, Christopher J. Moreland, Donna Jo Napoli, Wendy Osterling, Carol Padden, and Christian Rathmann, "Infants and Children with Hearing Loss Need Early Language Access," *Journal of Clinical Ethics* (2010) 21: 1-13.

I have provided this background to provide context to the discussion of emerging technologies that promise to cure or eradicate deafness. I contend that variations of the questions surrounding the best way to educate children ultimately surface in discussions about the uses of genetic technology related to the physical characteristics of hearing variation - ranging from preference for species-typical hearing ability to preference for audiological deafness. Questions about what constitutes the good life, what kinds of opportunities and options are available to a signing Deaf person or oral deaf person, as well as questions about the kinds of commitments one ought to expect from a just society all play a part in this discussion. The historical record of this educational debate offers a rich repository for evaluating and developing arguments related to genetic technology. Unfortunately, this task lies beyond the scope of my dissertation, but it is worth noting here and I hope that others will consider pursuing this project.

Benefits and Burdens: Eugenics and the Deaf Community

Around the same time that the Milan conference occurred, the pseudo-science of eugenics was taking hold in Britain and the U.S., led by none other than the inventor of the telephone, Alexander Graham Bell, who argued for fostering ‘positive’ eugenics among deaf people, including signing Deaf people. Positive eugenics promoted mating and marriage of those of ‘good stock’; negative eugenics restricted procreation of those viewed as genetically unfit.

In 1883, shortly after the passage of the Milan Congress resolutions, Bell published his address to the National Academy of Sciences titled *Memoirs upon the*

Formation of a Deaf Variety of the Human Race.⁶⁵ This paper is said to have been prompted in part by Bell's visits to Martha's Vineyard, which had a high percentage of deaf individuals living on the island due to a recessive gene brought over by an English settler in 1694.⁶⁶ Bell's address is often misinterpreted as a wholesale attack on the right of deaf people to exist; historian Brian Greenwald offers a more complex interpretation of Bell's position that takes into account the social mood of the times and Bell's associations with deaf people, including those who used signs.⁶⁷ Greenwald points out that Bell's thinking on eugenics was developed as part of his response to support Bell's already formed beliefs about the superiority of oralism and spoken language. Through the promotion of hearing-deaf marriages such as his own and that of his parents, Bell believed that fewer deaf children were likely to be born and the corresponding decrease in numbers of deaf children would ultimately impact the sustainability of signed languages, which he viewed as a major obstacle in the education of the deaf. Signing Deaf people, of course, viewed the potential eradication of their language quite differently.⁶⁸

What is often overlooked in Bell's eugenics commentary is his awareness and knowledge of the signing Deaf community. Bell's desire to prevent the spread of Deaf culture was not borne of ignorance about the community – he was well acquainted with

⁶⁵ Alexander Graham Bell, *Memoirs upon the Formation of a Deaf Variety of the Human Race* (New Haven: National Academy of Sciences: 1883).

⁶⁶ Nora Ellen Groce, *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard* (Cambridge: Harvard UP, 1985), 23.

⁶⁷ Brian H. Greenwald, "The Real 'Toll' of A.G. Bell: Lessons About Eugenics" in *Genetics, Disability and Deafness*, ed. John Vickery Van Cleve (Washington DC: Gallaudet University Press, 2004), 36-37.

⁶⁸ Carol Padden, "Translating Veditz" in *Sign Language Studies*, (2004) 4 (3): 244-248.

the signing Deaf community and could sign and fingerspell. His address noted the many ways in which deaf people were separated from the mainstream, positing this as a threat to mainstream American society that was not dissimilar to the threat posed by immigrants who clung to their language and customs instead of assimilating into the customs of their new home.⁶⁹

One of the objections often posed to arguments supporting the desire of Deaf potential parents for deaf children is that hearing children of Deaf parents (CODAs) have the same opportunity to partake of Deaf culture as deaf children do.⁷⁰ Given this, one could argue that a hearing child in a Deaf family obtains the benefits of Deaf culture and a signed language without directly experiencing the burdens of audism. Yet, their experiences are necessarily different because of their additional ability to enter mainstream Hearing society in a way that differs from that of their Deaf counterparts. This significant difference shapes the way in which hearing adult children with Deaf parents view the signing Deaf community, leading to a variety of outcomes. It is striking that one of the leading proponents of eugenics and opponents to the signing Deaf community was not only the child of a deaf mother and hearing father, but also married a deaf woman. I will provide a more detailed analysis of the issues presented by what I call the CODA objection in Chapter 5 of my dissertation, but at this point I'd just like to flag the blanket assumption that hearing children of deaf parents will be honorary members of

⁶⁹ Greenwald, "The Real Toll", 39-41.

⁷⁰ Hearing children of deaf adults are often referred to in the signing Deaf community as CODAs. It is unclear if this term was popularized only after the founding of the international organization Children of Deaf Adults (<http://www.coda-international.org/chistory.html>) in 1983 or if this term was in use prior to this. In any case, it is now a widely used acronym in ASL and the U.S. signing Deaf community.

the signing Deaf community and act as ambassadors for this community within the hearing world. The counterexample of Alexander Graham Bell serves to remind us that this is not necessarily the case.

One of the more trenchant observations that Greenwald makes about Bell's contributions to the American eugenics movement is that Bell's status may have protected Deaf people from being subject to negative eugenics policies such as sterilization.⁷¹ Bell's prominence as an inventor, plus his expertise on deafness, gave his opinions credence in scientific circles. Even though many of the eugenicists Bell interacted with supported negative eugenics measures, this effort was not constructed to include deaf people. Greenwald offers the explanation that Bell's thorough knowledge of Deaf people helped forestall this by setting Deaf people apart from the groups that were targeted for such practices. He notes, "Bell knew that Deaf people were not feebleminded, and he did not confuse the lack of intelligible speech or poor English language skills with mental retardation." Since eugenicists relied on concepts such as abnormality to determine what kinds of lives and people burdened state resources, with a deaf wife, it is likely that Bell would have rejected the of abnormality label for deaf people, substituting his vision of oralism as a more appropriate way for Deaf people to gain normal status and persuading those around him of the same.⁷²

Even though there were no laws on the books in the United States specifically mandating the sterilization of deaf people, as there were for other kinds of people deemed

⁷¹ Greenwald, "The Real 'Toll'", 40.

⁷² *Ibid.*, 40.

unfit to reproduce, Deaf people were still subject to involuntary sterilization.⁷³ Evidence of sterilization of deaf people is difficult to obtain, though it is thought to occur more often when the Deaf people were considered mentally unfit or deficient.⁷⁴ Additionally, restriction of deaf people's reproductive capabilities was often left as a decision for family members, who could make these decisions without the knowledge and consent of the parties involved.⁷⁵

In her book *Signs of Resistance*, historian Susan Burch recounts one of the most egregious sterilization cases to come to light: the story of Junius Wilson, a Deaf African-American man who was sent to the residential program in the Colored Department of the North Carolina School for the Deaf and Blind in 1915 at age seven. After a series of events, he moved back home, where communication was difficult since his family did not know the sign dialect that he used. About a year after he returned home, Wilson was accused of raping his aunt. Shortly afterward, Junius Wilson was found incompetent to stand trial; Burch infers this was at least in part because no one could communicate with him in the sign dialect he preferred. He was given indefinite housing at the State Hospital for the Colored Insane. In 1931, after sterilization laws had been passed by the state of North Carolina, Junius Wilson was castrated. He remained at the state hospital for seventy-six years, until his social worker filed suit against the state of North Carolina for wrongful incarceration based on hospital records in 1970 that identified Wilson as sane.

⁷³ Susan Burch, *Signs of Resistance: American Deaf Cultural History, 1900 to 1942*, (New York: New York University Press, 2002), 136.

⁷⁴ *Ibid.*, 138.

⁷⁵ PJ Waardenburg, "Intermarriages of Hereditarily Deaf Mute and of Hereditarily Blind People, Marriage Counselling and the Question of Sterilization" in *Acta Genetica et Statistica Medica* (1956) 6 (1):113-21.

Wilson's case was settled out of court; he was given a small house to live in, with provisions for his continued care on the grounds of the hospital where he had spent most of his life.⁷⁶

Burch makes two key points about the Junius Wilson case in her analysis. First, she acknowledges that cases such as these are rare; second, she notes that stories such as this reinforce concerns that members of the Deaf community are vulnerable to the policies and practices of the dominant Hearing society. Medical attitudes towards the moral permissibility of sterilizing deaf people with the intent of preventing the social burden incurred by the birth of more deaf individuals were accepted well into the mid-twentieth century; and this continues to be part of the eugenics narrative recounted in the signing Deaf community.⁷⁷ This ties into additional speculation within the Deaf community that African-American deaf females may have been sterilized as an extension of the socially accepted practices for sterilizing black women in the American South during the mid-twentieth century,⁷⁸ though this is currently undocumented as those affected have not been willing to share their stories publicly.⁷⁹

Prohibitions against using signed language in the schools and pressures on procreative liberty through proposed legislation prohibiting the intermarriage of deaf people were two strong social forces working against Deaf people from the late

⁷⁶ Susan Burch, 130-132.

⁷⁷ Clarence J. Gamble, "Human Sterilization" in *American Journal of Nursing* 51 (10): 625.

⁷⁸ Dorothy Roberts, *Killing the Black Body*, (New York, New York: Vintage Books, 1997) 90-91.

⁷⁹ Dr. Glenn Anderson, personal conversation, Gallaudet University, Washington, DC 13 April 2007.

nineteenth century into the mid-twentieth century. Motivations for each practice stem at least in part, from the desire to reduce the strain on social resources at the time and in the foreseeable future. With this as the backdrop to the technological advances of science and medicine of the twentieth century, it is no doubt easier to understand why the Deaf community has not been eager to embrace technologies, such as cochlear implant surgery, that purport to both fix them and simultaneously have the potential to threaten the continued existence of their linguistic minority community.

Surprisingly, this issue of historical and contemporary context has largely been ignored in the bioethics and philosophical literature surrounding the question of genetic selection for hearing loss. Scholars from these fields typically frame the question in a much simpler way, positing the desires of Deaf potential parents as primarily related to wanting a child who is like the parents, without much regard for the motivations of the Deaf potential parent or the complexity of the reasons underlying the desire for a Deaf child. Reasons for neglecting the historical context of the signing Deaf community may also stem from a general lack of scholarly philosophical analysis of parental reasons for preferring a particular characteristic for their child. Cases such as sex selection have not been as thoroughly examined in developed countries like the United States as they have in countries, such as China, that have regulations indirectly encouraging the selection of one sex over another. Analyzing the ascription of reasons to sex preference in the United States, such as wanting a child who is male like oneself, for ‘family balancing’, or preferring females because they are perceived as easier to raise, may prove fruitful in

trying to flesh out a more complex picture of why parents desire certain characteristics in their children.⁸⁰

It is well known that the eugenics movement in the United States and Britain was picked up by Germany in the early twentieth century. Initially, Germans viewed the German Deaf community as the ‘model disability’, in part due to the German propaganda film, *Verrkannte Menschen*, put out by the German deaf community in an attempt to sidestep the racial hygiene policies that were being considered by Hitler and the Third Reich.⁸¹ These commendatory attitudes towards Deaf people did not endure for long, as documented in Horst Biesold’s book, *Crying Hands: Eugenics and Deaf People in Nazi Germany*, which describes the impact of these racial hygiene policies on the Deaf community. Some of his most striking claims are the high degree of collaboration among educators of the deaf with the Nazi regime. These include supporting the eugenicist policies of forced sterilization of Deaf people, of recommending Deaf people for sterilization once they had married another Deaf person, and of forced abortions of deaf women’s fetuses and the killing of deaf people’s children.⁸² More widely known, but no less disturbing, is the systematic killing of deaf people as a targeted group, including (but not limited to) deaf Jews.

⁸⁰ Marcy Darnovsky, “A New Chapter in the Sex Selection Debate: Revisiting Sex Selection” *GeneWatch* 17:1, retrieved online on 18 March 2008 <http://www.gene-watch.org/genewatch/articles/17-1darnovsky.html>

⁸¹ John Schuchmann, “Misjudged People: The German Deaf Community in 1932” in *Deaf People in Hitler’s Europe*, ed. Donna Ryan and John Schuchmann, (Washington, DC: Gallaudet University Press, 2002) p. 98-9.

⁸² Horst Biesold, *Crying Hands: Eugenics and Deaf People in Nazi Germany* (Washington DC: Gallaudet University Press, 1999), 13, 84-87.

Biesold's book, a revision of his doctoral dissertation, contradicts the commonly held belief that most teachers of the deaf worked to shelter their students against the racial hygiene policies. He does not connect the decision of the Milan Congress to shift deaf education from a manual emphasis to an oral education to the behavior of the hearing educators of the deaf in Nazi Germany, but it is interesting to speculate as to whether teachers of the deaf would have less likely to collaborate with the Nazi regime if the educators of the deaf had been Deaf themselves.

Reasons offered for the establishment of eugenics practices such as sterilization have been well documented.⁸³ A partial list of the motivations includes the desire to reduce the burden on society – this is usually interpreted as direct economic costs, though other kinds of costs could also apply.⁸⁴ Biesold cites A. Abend, a teacher of the deaf, who wrote the following words in his journal: “The severely, genotypically degenerate deaf constitute a burden on the people. The people's need can demand the prevention of their reproduction.”⁸⁵ Biesold notes that part of Abend's motivation for determining deaf people as burdensome is tied to the ineffectiveness of deaf education.⁸⁶ What is interesting here is that this is not viewed as a social problem inasmuch as it is considered

⁸³ A small sampling of sources includes Henry Friedlander, *The Origins of Nazi Genocide*, (Chapel Hill, NC: University of North Carolina Press, 1995); Horst Biesold, *Crying Hands: Eugenics and Deaf People in Nazi Germany*, trans. William Sayers, (Washington, DC: Gallaudet University Press, 1999); *Deaf People in Hitler's Europe*. ed. Donna Ryan and John Schuchmann. (Washington, DC: Gallaudet University Press, 2002).

⁸⁴ Horst Biesold, *Crying Hands: Eugenics and Deaf People in Nazi Germany* (Washington DC: Gallaudet University Press, 1999), 17.

⁸⁵ A. Abend, “Was sagt die Rassenhygiene dem Taubstummenlehrer” *Blätter für Taubstummenbildung* (1925) in Horst Biesold, *Crying Hands: Eugenics and Deaf People in Nazi Germany* (Washington DC: Gallaudet University Press, 1999), 19.

⁸⁶ *Ibid.*

a problem that rests with the individual. Deaf education in Germany in the post-Milan Congress era was oriented to an aural/oral approach, which likely contributed to Abend's conclusions about the worth of deaf people.

The twentieth century framing of the social construction of disability challenges this assumption that the problem of disability lies with the individual person, who ought to be fixed. In the early twentieth century, before technologies such as cochlear implants and genetic intervention became available, sterilization was a palatable option for many who believed that society's duty was both to reduce the economic burden on itself and to prevent further human suffering. In some cases, the argument for sterilization was given further justification by noting that in return for supporting sterilization of certain populations, education and other services would be offered as a *quid pro quo*.⁸⁷ Despite contemporary scholarly attention to the social construction of disability and legislation such as the Americans with Disabilities Act (ADA), this propensity to blame the person with a disability rather than blame society for not assuming the responsibility of ensuring access is still readily apparent even in policy discourse.⁸⁸ Variations on this theme, such as the elective disability issue introduced later in this chapter and also discussed in chapter 4, are still considered viable options today.

Finally, any review of the effects of eugenics policy and practices on people with disabilities would be incomplete without mentioning Henry Friedlander's seminal book, *The Origins of Nazi Genocide*, in which Friedlander connects the Nazi racial hygiene

⁸⁷ Horst Biesold, *Crying Hands: Eugenics and Deaf People in Nazi Germany* (Washington DC: Gallaudet University Press, 1999), 27.

⁸⁸ Ronald Amundson and Shari Tresky, "On a Bioethical Challenge to Disability Rights," *Journal of Medicine and Philosophy* 32:6 (2007): 546.

policies initially aimed at disabled people to the creation and development of the ‘Final Solution’ by setting this in historical context. Although Friedlander’s book does not discuss the German Deaf community at great length, he subsequently authored an article, “Holocaust Studies and the Deaf Community,” which applies his thesis about the Nazi’s relationship to disability to the German Deaf community.⁸⁹ Here, Friedlander cites the sterilization law put forth by Hitler and his cabinet in 1933, the Law for the Prevention of Offspring with Hereditary Diseases, which defined those suffering from hereditary disease and qualifying for sterilization, including hereditary deafness.⁹⁰ The implementation of this law and records kept as a result of sterilizations and the subsequent Marriage Health Law made it easier to identify and locate disabled person when a killing program aimed at disabled individuals was instituted in 1939. This program, known as Operation T-4, started with the killing of disabled infants and children, including those with hearing impairments. Later, disabled adults were added to the list; in order to facilitate killing, gassing was used for the first time by the Nazi regime.⁹¹ Friedlander concludes his account of the Operation T4 programs by noting that “to this day, the German state has not fully recognized and compensated disabled people, including deaf persons, for their persecution in the Nazi period.”⁹²

The history of eugenics in Germany and in the United States is living history; survivors of these practices still exist as members of signing deaf communities. I believe

⁸⁹ Henry Friedlander, “Holocaust Studies and the Deaf Community”, in *Deaf People in Hitler’s Europe*, eds. Donna Ryan and John Schuchmann, (Washington, D.C.: Gallaudet University Press, 2002.) pp. 15-16.

⁹⁰ *Ibid.*, 20-21.

⁹¹ *Ibid.*, 24-26.

⁹² *Ibid.*, 29.

that skepticism and disregard for medical professionals present in signing Deaf communities can be traced (at least in part) to their complicity in these practices. Just as many African-Americans still remember the egregious practices by the United States Public Health Service studies on the treatment of African-American men with syphilis in Tuskegee, Alabama, viewing health care research with some skepticism and caution, signing deaf people evince a similar skepticism borne of long memories of less than humane treatment by medical professionals. Many deaf people are still aware that the professions of medicine and education essentially reified the status of signing Deaf people as people placing a burden on society that could best be treated by assimilation, repairing and curing. This set the stage for the civil rights movements discussed in the next section – which reframed the debate about how society should deal with deaf people from the language of burdens and benefits to the language of justice and fairness.

Justice Claims and Rights: DPN and Cochlear Implant Surgery

Later in the twentieth century two movements emerged to powerfully affect the signing Deaf community. The 1960s saw the return of signs to the classroom. This in part reflected a change in deaf education including a willingness to consider that visual communication in the form of signed communication systems and signed languages could support better language acquisition for deaf children than purely oral methods. This shift was supported by the groundbreaking scholarship of William Stokoe, who offered an argument for considering American Sign Language (ASL) a full-fledged language in its own right, having demonstrated visual equivalents of standard auditory linguistic

features present in spoken languages.⁹³ Another benefit of this pedagogical turn was the return of more Deaf teachers to academic subjects in the classroom, providing an opportunity for frank discussions about how to best structure signed communication in the classroom.⁹⁴

The return of signs to the classroom did not necessarily mean the return of natural signed languages to the classroom. Instead, the trend was to use signed systems of manually coded English, which borrowed signs from ASL and modified them to fit the rules of these invented communication systems. According to Jankowski, deaf educators initially were willing to compromise on the issue of language purity for a few reasons.⁹⁵ Some felt that this was a pragmatic approach to ultimately bringing natural signed languages into deaf education; by introducing signed systems, which were easier to learn and become adept with, the thought was that hearing teachers would be more willing to later accept the transition from manually coded English to ASL. Additionally, once any form of manual communication was permitted in the classroom, it became much easier to hide the use of ASL than it was when all signing in the classroom was forbidden.

Deaf pride rose in the 1960s through the 1980s along with many other social consciousness and civil rights movements of the era. Social awareness manifested in several different ways within the signing Deaf community, including the development of the National Theater of the Deaf, the professionalization of signed language interpreters,

⁹³ William Stokoe, "In His Own Words" in *Sign Language and the Deaf Community: Essays in Honor of William C. Stokoe*, ed. Charlotte Baker and Robbin Battison, (Silver Spring, MD: National Association of the Deaf, 1980), 266.

⁹⁴ Jankowski, 30-31.

⁹⁵ Katherine Jankowski, 77-78.

and the establishment of several federal laws that promised equal access to people with disabilities, including deaf people.⁹⁶ Padden and Humphries refer to this time period as marking the explosion of the “technology of voice,” in which deaf people’s management of spoken human voice interaction alters the ways in which discourse takes place, including use of sign-to-voice interpreters.⁹⁷ Each of these changes contributed in some way to shape the signing Deaf community, but none was as visible on the national stage as the Deaf President Now (DPN) protest at Gallaudet University in 1988.

Gallaudet University is the world’s only liberal arts college for deaf and hard of hearing students, and is seen as the center of Deaf intellectual life in the Deaf-world. The primary language of instruction is American Sign Language. Authorized as a college by the United States Congress in 1864 with its charter signed by President Abraham Lincoln during the United States Civil War, it has been a haven for manual communication since its inception, even after the 1880 Milan Congress declarations, and is often referred to as the “Deaf Mecca” – a place signing Deaf people consider a metaphorical homeland.⁹⁸

⁹⁶ Reference to the professionalization of signed language interpreters can be found on the website of the Registry of Interpreters for the Deaf at <http://www.rid.org/aboutRID/overview/index.cfm> (retrieved 12 March 2008) and also in Dennis Cokely, “Sign Language: Teaching, Interpreting, and Educational Policy” in *Sign Language and the Deaf Community: Essays in Honor of William C. Stokoe*, ed. Charlotte Baker and Robbin Battison, (Silver Spring, MD: National Association of the Deaf, 1980), 151. Information about the various laws and policies regarding education of the deaf can be found in Frank Bowe’s monograph, *Approaching Equality: Education of the Deaf*, (Silver Spring, MD: T.J. Publishers, Inc., 1991).

⁹⁷ Padden and Humphries, *Inside Deaf Culture*, 101.

⁹⁸ John Vickery Van Cleve and Barry A. Crouch, *A Place of Their Own: Creating the Deaf Community in America*, (Washington, DC: Gallaudet University Press, 1989), 141, 169-171. (Author’s note: I recognize that using religious terminology in this context may be offensive; despite this, I have decided to cite the phrase because of its prominent usage in the community).

Despite this, for more than one hundred years hearing administrators sat at the helm of the university. Until 1988, Gallaudet University had never had a deaf president, although its first president, Edward Miner Gallaudet, as the son of a Deaf woman, was fluent in ASL.

In 1987, the sixth (hearing) president of Gallaudet University, Jerry C. Lee, resigned. Shortly after this, the Gallaudet University Board conducted a search for a university president. At the same time, several groups, including the college's President's Council on Deafness, an advisory and advocacy group of deaf faculty and staff members; the National Association of the Deaf, and a loose-knit group of alumni known as the Ducks, began various campaigns lobbying for a deaf president of the university.⁹⁹ Upon naming six semi-finalists, three of whom were deaf, advocacy efforts and strategies for promoting a deaf president became more pronounced. In order to promote the general idea of a deaf president without throwing support to one of the three candidates, the Ducks sponsored a rally on campus. The flyer advertising this rally was one of the first to use language that evoked civil rights struggles, comparing the appointment of a deaf resident to other historic moments in higher education, including the selection of the first woman president at Wellesley College in 1875, the first Jewish president at Yeshiva University in 1886, and the first African-American president of Howard University in 1926.¹⁰⁰

⁹⁹ John B. Christiansen and Sharon N. Barnartt, *Deaf President Now: The 1988 Revolution at Gallaudet University* (Washington, DC: Gallaudet University Press, 1995), 6-8, 11.

¹⁰⁰ *Ibid.*, 21-22.

The rally was a turning point; people on campus who were not particularly convinced that Gallaudet University needed a deaf president became more open to the idea in part due to structuring this claim as a civil rights entitlement.¹⁰¹ Shortly after the rally the field of semi-finalists was narrowed to three finalists, two of whom were deaf. The general sentiment on the campus was that a deaf president was inevitable; when Elisabeth Zinser, the sole hearing finalist, was announced as the next president of Gallaudet University, the campus erupted in protest.

Deaf people and their hearing allies, including hearing politicians, civil rights advocates, postal workers (an occupation that has traditionally had a high proportion of deaf employees), and neighborhood residents rallied around to protest the selection of Zinser. After several days of protest, including two marches and extensive media coverage, Elizabeth Zinser stepped down from her post, citing, “the imperative for deaf people to be recognized in this way had risen through all of the other issues to the top.”¹⁰² The subsequent selection of I. King Jordan as president continued this theme of civil rights rhetoric, with Jordan remarking, “We have overcome our reluctance to stand for our rights...the world has watched the deaf community come of age. We will no longer accept limits on what we can achieve.”¹⁰³

The significance of DPN to the signing Deaf community worldwide should not be overestimated. Unlike the eugenics movement and the oralism/manualism conflict, where the signing Deaf community responded to outside challenges on their community as a

¹⁰¹ *Ibid.*, 38.

¹⁰² *Ibid.*, 140.

¹⁰³ *Ibid.*, 162.

whole regarding such fundamental issues as language use, marriage, and procreation, DPN dealt with the issue of community leadership. This issue was easier for the general hearing public to grasp, in part because the timing was right – in popular culture, the well-traveled Broadway hit *Children of a Lesser God* had been made into a movie and Marlee Matlin, the deaf lead actress had picked up an Academy Award for her performance; parents of children watched Linda Bove, another deaf actress, on Sesame Street; and other public portrayals of the signing Deaf community served to make the life of Deaf people intriguing rather than pitiful or tragic.

Numerous scholars have suggested that DPN serves as a seminal moment in Deaf history. Christiansen and Barnartt have suggested that the use of frame extension, where civil rights discourse is extended to the Deaf community's right to choose their own leader in 'Deaf spaces' was a critical ingredient to the success of DPN.¹⁰⁴ The civil rights lens is also supported by Susan Burch's historical analysis, although she notes the complexity of the relationship between disability rights and the rights of the signing Deaf community, which do not neatly map on to one another – in part because of the Deaf community's desire to view itself first as a linguistic community and second (if at all) as disabled.¹⁰⁵ Jankowski's analysis notes that DPN transformed the self-image of the Deaf community, noting that "the strategies adopted by Deaf people throughout the protest effectively destroyed many of the negative images maintained by dominant discourses

¹⁰⁴ *Ibid.*, 171-173.

¹⁰⁵ Burch, 173.

and substituted a newer image of the able competence of Deaf people.”¹⁰⁶ This concurs with John Vickery Van Cleve’s view. He writes,

DPN then, was clearly in the mainstream of the history of American deaf activism. It demonstrated that the principles of self-determination that played such an important role after the first two decades of the nine-teenth century were still important in the late twentieth century. The impetus for reform and change came from deaf people themselves.¹⁰⁷

Claiming a position that soundly rejected audism, replacing it with self-determination and a positive community image founded on community self-definition, set the stage for more cohesive and focused responses to threats against the signing Deaf community, including those brought about by developments in biomedical technology.

The story of the cochlear implant controversy begins well before the events of DPN. In the 1970s, several decades after the dissolution of the eugenics movement, the pendulum of deaf education began to swing back to the manualist view, allowing and encouraging the use of signs in the classroom. Despite the ban against signing in the classroom, the international eugenics movement, and other legal discrimination challenges (including driving rights), the signing Deaf community managed to persist as a sociolinguistic community.¹⁰⁸ Yet, another challenge to the survival of the Deaf community was just around the corner. At the same time that deaf education was opening up again to the signed languages of the Deaf community, researchers in France and the United States (the two countries where the signing Deaf community was first

¹⁰⁶ Jankowski, 53.

¹⁰⁷ Van Cleve and Crouch, 173-174.

¹⁰⁸ Burch, 164-165.

nurtured and supported flourished hundreds of years ago) began work on a new technology, the cochlear implant.

Initially cochlear implant surgery was performed on adult volunteers, most of whom had been hearing, and who had expressed a preference for living in the hearing world.¹⁰⁹ This was not seen as a problem by most members of the Deaf community, who felt that surgery on deaf people who were (for the most part) not members of the signing Deaf community, did not threaten the existence of the Deaf community. At least, not in the way that forbidding the use of signed language in schools and the practices of the eugenics movement had affected the community.¹¹⁰

In 1977, two deaf children, ages 10 and 14, received cochlear implant surgery.¹¹¹ This practice infuriated many members of the Deaf community, who felt that it was one more attack on the continued existence of their community, due to the potential for excluding the largest group of potential members of the signing Deaf community, deaf children of hearing parents, from becoming acculturated into the community through residential schools for the deaf, as had historically been the case. Since the post-surgery standard of care recommended against exposing the child to a signed language or signed system lest the ease of using on a visual system reduce their motivation for working to

¹⁰⁹ John Christiansen, Irene W. Leigh, and Patricia Elizabeth Spencer, “History of Cochlear Implants” in *Cochlear Implants in Children: Ethics and Choices*, (Washington, D.C.: Gallaudet University Press, 2002), 18-22.

¹¹⁰ Thomas Balkany’s letter to the editor in the *New England Journal of Medicine* suggests that there was some initial resistance on the part of the deaf community to cochlear implant surgery in adults – that was later abandoned once the issue of providing cochlear implant to prelingually deaf children surfaced. See Thomas Balkany, “A Brief Perspective on Cochlear Implants” in *New England Journal of Medicine* (1993) 328: 281.

¹¹¹ Christiansen, Leigh, and Spencer, “History of Cochlear Implants”, 29-30.

achieve spoken language communication, deaf children who were once considered potential members of the Deaf community would no longer have that option.

The literature on the ethics of cochlear implant surgery, while limited, is richer in discussion of ethical issues than the eugenics literature discussed earlier in this chapter. It is generally assumed that the eugenics movement of forced sterilization and marriage restrictions in the United States was immoral on grounds of violation of human rights, individual autonomy, and human dignity; likewise for the ‘racial hygiene’ practices and atrocities committed under Nazi policies in Germany. Given this assumption, ethics discussion regarding eugenics focuses on questions of moral depravity and the banality of evil, rather than differing sociocultural and biological constructions of what it is to be “normal,” which is the primary focus of the cochlear implant debate.

The decision to pursue cochlear implant surgery on deaf children marks the emergence of the use of ‘rights’ language to defend the existence of the Deaf community, as well as to defend the decision of hearing parents to obtain a cochlear implant for their child. Most of the arguments regarding the use of genetic technology to ‘cure’ deafness are framed similarly, appealing to the rights of the Deaf community, the rights of parents to determine the ‘best interests’ of their children, and the rights of the child to an ‘open future. As seen in discussions of the HFEB, other issues in play are those of reproductive rights, such as a ‘right’ to IVF, and the right to decline specific practices in reproductive medicine that could potentially result a in parent being forced to acquiesce to government preference and practices regarding definitions of genetic normality.

An Argument Analysis of the Ethical Issues in Cochlear Implant Surgery

The earliest articles offering a moral justification for cochlear implant surgery were written by physicians and published in medical journals and symposia or conference proceedings. Not surprisingly, these articles assumed a pathological view of deafness, and typically argued that the “efforts to discourage the use of cochlear implants in deaf children are not in the best interests of many children or their families.”¹¹² Several organizations of and for the Deaf released position papers arguing against allowing the surgery on prelingually deaf children, but it was not until Harlan Lane’s book, *The Masks of Benevolence: Disabling the Deaf Community*, was released that more carefully structured arguments were advanced against cochlear implant surgery for children.

Lane developed a two-pronged approach to this topic by looking first at the physical risks of subjecting the child to elective surgery with purported little gain, and then considering the psychosocial harm ensuing to the child who is between two worlds – the world of the Deaf and the hearing world. Lane’s argument on the risks of elective surgery considers the usual risks involved with medical surgery and anesthesia, and also lists complications specifically associated with cochlear implant surgery, such as damage to the facial nerve, the structural damage to the cochlear required for placement of the implant (essentially, the cochlea is destroyed), and the high percentage of children with adverse reactions and complications.¹¹³

¹¹² Balkany, 282.

¹¹³ Harlan Lane, *The Mask of Benevolence: Disabling the Deaf Community* (New York: Vintage, 1993), 217.

Twelve years later, some of these arguments resting on empirical data are less cogent due to improved medical techniques and technology. Additionally, the efficacy of the cochlear implant, while far from perfect, has improved significantly. Children receiving the implant today do much better on hearing evaluations, including open set discrimination tests, which evaluate the child's ability to understand speech.¹¹⁴ Two concerns that have yet to be fully resolved are the long term effects of long term electrical stimulation near the brain (an issue paralleling current concern expressed about the proximity of holding cell phones next to the ear), and studies offering evidence for increased risk of bacterial meningitis in cochlear implant users.¹¹⁵ At this point, the potential harm presented by these concerns is probably sufficient to maintain the cogency of Lane's medical harm argument. I suspect that similar arguments regarding the harms of using of genetic technologies to create deaf children will likely be advanced. A twist on this would be that the use of existing technologies such as PGD used for screening out deafness would likely not be included in such arguments based on medical risks for the fertilized egg, but rather focused on the risks to the potential mother.

Lane acknowledges that his arguments resting on physical data may be less persuasive over time, and offers a hypothetical syllogism argument based on the concept of a 'perfect' implant in a later article coauthored with philosopher Michael Grodin, "Ethical Issues in Cochlear Implant Surgery: An Exploration into Disease, Disability,

¹¹⁴ Comparison of results cited in Lane's *The Mask of Benevolence*, 220-5 and N.L. Cohen and S.B. Waltzman "Cochlear Implants in Infants and Young Children" in *Mayo* 17, 2 (1996) 215-s222.

¹¹⁵ Noel L. Cohen, J. Thomas Roland Jr., Michelle Marrinan, "Meningitis in Cochlear Implant Recipients: The North American Experience" in *Otology & Neurotology*: (2004) 25 (3): 275-281.

and the Best Interests of the Child.”¹¹⁶ The argument is summarized as follows: If the cochlear implant restores a child’s hearing perfectly and carries no medical risk, then the cochlear implant is still ethically questionable since it fundamentally alters that child’s psychological identity. Keeping in mind that the child with the perfect implant is still deaf when the implant is turned off, Lane and Grodin offer several arguments by analogy with varying degrees of cogency to justify their claim that performing cochlear implant surgery on prelingually deaf children has dubious ethical merit.

One argument proposed in both of these of these pieces is the argument by analogy that compares a deaf child of hearing parents to a black child living with her adoptive white parents. Lane and Grodin argue that if the child’s difference and minority identity is not acknowledged, the child runs the risk of developing a ‘cultural homelessness’ in which the deaf child is not fully a member of the signing Deaf community or the hearing world.¹¹⁷ There are several problems with this analogy. One is the assumption that biological difference is somehow connected to one’s cultural home. In the case of a child with phenotypic features associated with the American definition of “black,” it is difficult to understand the reasoning that possessing these features is sufficient to determine sociocultural membership, which seems to be the point that Lane and Grodin are attempting to make here. Still, the obvious disanalogy of the biological ties of the deaf child to his hearing parents and the lack of those biological ties of the

¹¹⁶ Harlan Lane and Michael Grodin, “Ethical Issues in Cochlear Implant Surgery: An Exploration into Disease, Disability, and the Best Interests of the Child” in *Kennedy Institute of Ethics Journal* (1997) 7 (3): 231-251.

¹¹⁷ Harlan Lane, *The Mask of Benevolence*, 228.

black child to her adoptive parents remains and ought to be considered when evaluating this argument for cogency.

Additionally, I do not find this argument convincing given the premise of the perfect implant, for it seems to me that the child with hearing perfected by the implant would be able to fully participate in the hearing world, thus negating the argument. Yet another issue at stake is the question of ‘full community membership’; as defined, it seems to exclude the possibility that one could fully belong to more than one sociocultural community. Alternatively, the assumption of full membership as good and (one presumes) partial membership as bad or less good, is given and not rigorously argued for. Considering the state of cochlear implant technology today, though, the analogy holds up slightly better. In the absence of a perfect implant, an assumption that Lane and Grodin hold throughout their argument, in some ways, it does make sense to ask these questions about community membership. The problem is that community membership claims resting on language modes necessitated by physical variation are quite different in kind from membership claims based on phenotypic differences such as hair texture and skin color, which have no bearing whatsoever on language acquisition or modality.

A different argument by analogy offered by Lane and Grodin compares the Deaf community’s interest in the deaf child to the interest of Native American communities expressed in the Indian Child Welfare Act of 1978, in which the courts must consider the best interests of the tribe as well as the best interests of the child.¹¹⁸ A variation of this

¹¹⁸ Lane and Grodin, 240.

argument appears elsewhere, in which an appeal to the United Nations Declaration of the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, as well as the United Nations Convention on the Prevention and Punishment of the Crime of Genocide.¹¹⁹ By defining the Deaf community as a linguistic minority, Lane and Grodin set up the analogy for minority community rights, including the right for a community to secure its existence.

This is of course more challenging given the horizontal method of sociocultural transmission in the signing Deaf community, since it leads to questions regarding assumptions and claims as to how a child becomes a member of a cultural community, and who is charged (implicitly or explicitly) with imparting such knowledge. As stated earlier, in most cases sociocultural and linguistic transmission is vertical, occurring from parent to child. (In cases of vertical transmission where parent-child transmission is not the norm, such as children reared in a kibbutz, there are rarely physical barriers that intervene with the ability of parents and children to communicate directly with one another).

In the signing Deaf community, there are two notable differences when a deaf child with hearing parents is brought into the community. First, is the role of horizontal cultural transmission from child peer to child peer; second is the issue of non-familial cultural transmission, whether from unrelated Deaf child to deaf child or unrelated Deaf adult to deaf child. The role of family ties in determining sociocultural membership is rarely questioned; the case of acculturation to the signing Deaf community is unusual and

¹¹⁹ *Ibid.*, 237-8.

raises questions about what kinds of roles and duties are appropriate for Deaf adults to assume with deaf children who are not their legal progeny. It also raises questions about the role of hearing parents' rights and interests regarding their deaf children. The use of cochlear implant surgery, while not intended to decimate the numbers of the Deaf community, results in fewer potential members for the Deaf community, reverts back to the vertical model of language and cultural transmission of parent to child. The widespread use of genetic technology, including PGD, would likely result in an even greater effect on the Deaf community by reducing the numbers of potential community members being born.

Bonnie Tucker's article, "Deaf Culture, Cochlear Implants, and Elective Disability" attempts to tackle these analogies head on, but fails to offer a cogent argument against them.¹²⁰ She begins her article with an argument that Deaf culture is not a true culture. Whether the 'culture' moniker is correct seems to be a red herring, though, for regardless of whether it is a Deaf culture or a Deaf community, there still remains a group of people who share a language and set of social behaviors, and who wish to see their community flourish and continue to exist. The outcry against the use of cochlear implants on prelingually deaf children and the use of genetic technologies to eradicate deafness comes from this community. Even though the Deaf community is but a small percentage of the total population of deaf and hard of hearing people, this fact does not invalidate their arguments.

¹²⁰ Bonnie Tucker, "Deaf Culture, Cochlear Implants, and Elective Disability," *Hastings Center Report* (1998) 28 (4):7

Tucker writes, “Although Deaf culturists equate being deaf to being a member of a racial or tribal minority, many deaf people find the analogy nonsensical. Deaf people lack one of the five critical senses. True deaf people such as this author are physically incapable of talking on the telephone alone....”¹²¹ Tucker makes (at least) two errors here: she dismisses the Deaf community argument by analogy without offering much of a reason for doing so, she also confuses the issue by conflating Deaf with deaf, which does nothing to advance the dialogue, since it is the minority worldview of the Deaf that is at issue against the majority view, which is held by deaf and hearing people. The concern about cochlear implants for prelingually deaf children comes from the signing Deaf community, who do not wish to see the existence of their community threatened. Tucker’s motivation for distinguishing ‘true deaf people’ from others (whom I suppose might be considered ‘inauthentic Deaf people’?) is perplexing, but it nicely serves the function of confusing the issue, since a less than careful reader of her article might conclude that ‘true deaf people’ advocate on behalf of deaf children to receive cochlear implants.

Not all of Tucker’s article is this disingenuous; in fairness to her, she offers a more compelling argument on elective disability. The concept of elective disability is developed from the concept that individuals must assume responsibility for their choices. The argument relies on two premises, the first of which is that individuals must take reasonable measures, such as cochlear implant surgery, to eliminate or minimize their disabilities, and the second is that such measures are available to the individual. Neither

¹²¹ *Ibid.*, 7.

of these hold true today in the United States -- the expense of the cochlear implant surgery and rehabilitation is not covered by all insurance plans, nor can the risks of such surgery could be said to outweigh the benefits, given the unpredictability of the surgery's success. Tucker holds that without first taking the steps to reduce the effects of one's disability, the individual has no claim upon the state to provide accommodations for said disability.

What is novel about Tucker's argument is the notion of applying personal responsibility to disability. Traditionally, disability has been viewed as an act of nature far removed from the sphere of personal responsibility, as seen in this quote by Rawls:

Other primary goods such as [*health and vigor*], intelligence and imagination, are natural goods; although their possession is influenced by the basic structure (of society), they are not so directly under its control.¹²² [Italics mine].

Tucker's notion of elective disability suggests the liberal state might at some point be able to refuse accommodations if the individual has refused to take steps to reduce his burden on the state. Tucker allows for the possibility of an individual to refuse, say, a cochlear implant due to personal or religious reasons, but she does not believe that this refusal results in the individual's entitlement to certain goods, such as interpreting services or closed captioning, provided by the state or others.

In part, Tucker's paper was a response to an article published by Robert A. Crouch, "Letting the deaf be Deaf: Reconsidering the Use of Cochlear Implants in Prelingually Deaf Children" which argues against cochlear implants for the prelingually

¹²² John Rawls, *A Theory of Justice*, (Cambridge: Belknap Press of Harvard University Press, 1971), 62.

deaf child. Crouch does not use the approach suggested by Lane and Grodin of offering arguments by analogy; instead, he proposed the ‘right’ of the child to be a full member of a community, in this case, the Deaf community. Crouch argues that a parent’s decision not to provide her child with a cochlear implant, “Far from condemning a child to a world of meaningless silence, opens the child up to membership in the Deaf community, a unique community with a rich history, a rich language, and a value system of its own.”¹²³ Crouch acknowledges that the child with a cochlear implant (who is at best, functionally hard of hearing) has the potential of being stuck between two worlds – not having enough hearing to fully participate in the give and take banter of the hearing world, but not having the signing skills to move into the Deaf community. He writes,

...the decision to pursue cochlear implantation and auditory habilitation for one’s child also has burdens associated with it beyond the failure to achieve oral competence. The child whose life is centered on disability and the attempt to overcome it grows up in a context that continually reinforces this disability, despite his or her own best efforts to hear and to speak and despite the diligent work of the educators of the deaf and hearing-impaired. These children are therefore always aware that they are outsiders, and not merely outsiders, but outsiders attempting to be on the inside. This narrative of disability within which the deaf implant-using child lives is not the only one available to her. There is an alternative narrative reference to which the child may judge her own life and it is the one that exists within the Deaf community.¹²⁴

I suggest that the two narratives offered by Crouch are correct; however, I am skeptical that these may be the only choices for such children. Another alternative exists, that is, to provide the implanted deaf child with two languages, a signed language and a spoken language. In fairness to Crouch, this may not have been a formal option offered to

¹²³ Robert A. Crouch, “Letting the deaf be Deaf: Reconsidering the Use of Cochlear Implants in Prelingually deaf Children,” *Hastings Center Report* (1997) 27 (4):17.

¹²⁴ *Ibid.*, 18.

parents of implanted children at the time he wrote his article. It is an option currently offered by several programs and schools in the United States, although the structures of such programs may vary.¹²⁵

Although Crouch's argument depends on the inability of the cochlear implant to restore hearing fully to its users, and at first blush seems to have little to do with the use of genetic technology, I think that the argument he offers extolling the benefits of belonging to the Deaf community is just the sort of argument that would be offered by potential Deaf parents wanting deaf offspring. The question is: does the argument resting on intangible benefits of community membership offer enough support to morally justify Deaf parents making such a choice?

Arguments related to the ethical issues of providing cochlear implants to prelingually deaf children can be grouped into categories. Those listed below have particular relevance to the ethical arguments that may be used by the signing Deaf community regarding moral justifications for using genetic technology to bear deaf children. The first category contains arguments that deal with potential risks and benefits – these include the risks inherent in the medical procedures themselves, as well as long term harms and benefits. These concerns apply to many procedures used in genetic technology; in particular, genetic screening, in vitro fertilization (IVF) with preimplantation genetic diagnosis (PGD) and gene therapy carry varying degrees of risks for both the potential parents and the potential offspring. Significant setbacks in gene

¹²⁵ Cochlear Implants and Sign Language: Putting it all Together (Identifying Effective Practices for Educational Settings) conference, Gallaudet University, April 11-12, 2002. <http://clerccenter.gallaudet.edu/CIEC/conference-proceedings.html>

therapy research have contributed to it still being classified as experimental treatment at this point in time.¹²⁶

Another category of argument deals with identity. The notion of identity is itself a complex topic – determining what counts as an identity, who has the authority to determine identity claims, and whether identity is fixed to specific criteria are some hard questions associated with this concept. The particular topics raised in discussions about cochlear implant surgery ethics include such issues as a child’s right to full and unfettered communication, and also the question of whether a person’s biological characteristics are sufficient to determine identity, and if so, how this determination is meant. In the arguments by analogy listed earlier, a key premise of each argument relied on physical difference between parents and their children. Implied in this category of argument is the claim that cultural identity depends (at least in part) on a person’s physical characteristics. This notion is fraught with many difficulties, not the least of which is the question of how physical characteristics can influence or determine cultural identity claims.

Variations of this question surface in several aspects of the signing deaf community; a few of these directly bear on the question of whether using genetic technology in order to ensure the birth of a deaf child is morally justifiable. Determining who has standing as a full-fledged member of the signing Deaf community turns on several factors, one of which is the physical characteristic of hearing loss. Hearing

¹²⁶ Human Genome Project Information, “Gene Therapy: What is the Current Status of Gene Therapy Research?” Human Genome Project, (accessed 3 March 2008). http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetherapy.shtml

children of signing deaf parents, many of whom claim a signed language as their first language, are often viewed as members of the community with mixed status. In *Deaf in America: Voices from a Culture*, authors Carol Padden and Tom Humphries note that one way that hearing children of deaf parents (CODAs) are treated differently than deaf children of deaf parents is in sports leagues. Cultural convention restricts participation on Deaf sports teams to those with measureable audiological indicators of hearing loss; thus hearing children of Deaf parents cannot participate in one measure of community activity. Padden and Humphries recount an instance in which a hearing child of this Deaf parents tried to pass as hard of hearing in order to play for a Deaf basketball team; when the individual was asked to prove this status by showing his audiogram, he was not able to do so.¹²⁷

The story above is but one illustration of the difficulty of determining membership and identity in the signing Deaf community. Even though this situation could be remedied by simply changing the rules to permit hearing children with signing Deaf parents to participate in Deaf community team sports, this has not been done. I suspect this is at least partly because deafness is a necessary condition for one to claim full community membership, though it may not be the only such condition. In the case of cochlear implant surgery on prelingually deaf children, some members of the signing Deaf community argue that by virtue of their deafness, all deaf children have a right to natural language acquisition. Since these children cannot hear at least some of the sounds in spoken language and since speechreading alone is insufficient for natural language

¹²⁷ Padden and Humphries, *Deaf in America*, 49.

acquisition, this leaves signed languages as the only natural languages fully accessible to deaf children without any medical intervention. One could extend the claims of the right to a natural signed language argument further, interpreting this to mean that deaf children have a right to membership in the signing Deaf community by virtue of their physical characteristic of deafness.

If genetic technology is used to ensure that a deaf child is born, the parents' motivations for making such a choice are likely to be questioned. Different questions may arise depending on which genetic technologies were used to obtain a deaf child. I have stated in my Introduction my intention to cover these in detail in subsequent chapters that sort out the issues according to same and different child choices. In particular, the following two chapters focus on this issue, with Chapter Three considering the problem of genetic selection as a different person problem and using harm as the primary measure of ethical permissibility using a utilitarian framework of benefits and burdens. Chapter Four evaluates the issue of genetic manipulation as a same person problem, inasmuch as genetic determinism claims consider alteration of the genome a same person problem; it also considers issues of identity and autonomy, both of which have been introduced in this chapter.

In wrapping up this chapter, I hope that my presentation of a more detailed account of the history of the signing Deaf community will remedy a gap found all too often in accounts regarding the use of genetic technology in the signing Deaf community. The history of a community that has dealt with various kinds of audism throughout recent history, including the obstruction of fundamental rights claims related to language use, marriage, and procreation is critical to understanding current debates about appropriate

uses of genetic technology in this community. I believe that Deaf people's desire for deaf children goes beyond simply wanting children like themselves. In many cases, it also reflects the complexity of what it means to be a member of a sociocultural group that has historically experienced discrimination, and has been targeted, directly and indirectly, for extinction. In conclusion, it is my hope that this chapter has at least partially satisfied my goal of providing the reader unfamiliar with the signing Deaf community with a deeper understanding of why Deaf people might be inclined to use genetic technology in order to bear a child most likely to be a full-fledged member of their community.

Chapter 3 Genetic Selection: Choosing Deaf Babies

Augustus and Lydia are a Deaf couple. Augustus comes from a family with several Deaf family members— his mother, brother, cousins, and grandparents are Deaf, and Augustus's father is an American Sign Language (ASL) interpreter whose first language is ASL. Lydia's family is hearing; Lydia was born hearing and became deaf at age 4 as a result of contracting spinal meningitis. Lydia attended a bilingual school for the deaf shortly after losing her hearing, and is comfortable using ASL and written English. Augustus and Lydia both treasure the signing Deaf community, spending most of their social activities within this community— from participating in sports activities in deaf leagues to working in environments with mostly deaf people. Regardless of whether their children are deaf or hearing, Augustus and Lydia plan to raise their children in this community. However, for many reasons that have come up in their discussions about this topic, they would prefer a Deaf child.

In order to find out their chances of having a Deaf child, Augustus and Lydia have seen a genetics counselor. As it turns out, both Augustus and Lydia have a recessive gene that is correlated to hearing variation, the GBJ2 gene (Connexin 26). Augustus has two copies of this gene, which has caused his deafness. He will pass on one copy of this gene to all of his biological children, barring any random genetic changes.¹²⁸ Although Lydia's deafness is not genetic, she happens to be a carrier with one copy of this gene.¹²⁹ The odds are fifty-fifty that she will pass this gene to her children. The chance of Augustus and Lydia having a child with hearing (loss) variation is one in two, or fifty percent. Since Lydia has a fallopian tube anomaly, Augustus and Lydia must use in vitro fertilization (IVF).

Because of their strong preference for a deaf child, Augustus and Lydia ask their genetics counselor if it is possible to only implant embryos that carry two copies of the GBJ2 gene. The counselor mentions that it is technologically possible through preimplantation genetic diagnosis (PGD) in which embryos are screened for certain genetic characteristics before implantation. The question is whether the medical staff would be willing to conduct PGD screening for this purpose, given the ethical issues of choosing an embryo that codes for disability over an embryo that does not code for disability. In other words, is it morally permissible to use PGD in order to ensure the birth of a deaf child?

¹²⁸ The odds of genetic change are very small; although this consideration is a logical possibility, it is extremely unlikely.

¹²⁹ Arnos, etc. have found that thirteen percent of the general population in the U.S. carries one copy of the GBJ2 gene.

This chapter addresses the question of whether or not it is morally justifiable to select for the trait of hearing loss, or deafness. The question of moral justification is a thin one, and leaves out the complexities that often arise in discussions about whether deciding to continue pregnancies or implant embryos to begin pregnancies that will result in the existence of individuals with ‘abnormal’ characteristics is morally honorable.¹³⁰

I will argue that selecting for deafness *is* morally *permissible*, and I will use the Non-Identity problem as the basis for my claim. I further argue that what is widely regarded as the strongest challenge to the Non-Identity problem, the concept of the Right To An Open Future, has several problems, and as it is currently framed, does not constitute a sufficient challenge to the Non-Identity argument, leaving the conclusions of the Non-Identity problem standing. Namely, I argue that one of the reasons the Right To An Open Future objection account fails is due to a profound misunderstanding of the quality of Deaf people’s lives. I also argue that framing this problem as a matter of parental autonomy versus the autonomy of the child is too narrow, and this omits some of the central issues of concern for the signing Deaf community, namely the social construction of disability and the continued existence of the community. Finally, I consider and reject the argument that choosing for existence is itself morally impermissible.

Deafness and the Non-Identity Problem

It is important to be clear on the distinction between what I call genetic selection and genetic manipulation, especially since the literature on this topic often lumps the

¹³⁰ I credit a conversation with Margaret Little for helping me make this distinction and simplifying the structure of my question.

process of selection for deafness together with what I will call designing or creating deafness. I treat these as separate issues. This chapter focuses on genetic selection. Simply put, this genetic selection involves decisions regarding genetic screening of genetically intact and unaltered fertilized eggs, zygotes, and embryos. There are two types of genetic screening: genetic screening of embryos, which occurs during pregnancy; or preimplantation genetic diagnosis (PGD) screening, which occurs prior to implanting a fertilized egg into the womb. Currently, genetic screening for deafness is possible for both prenatal and PGD types of screening; it is somewhat limited since not all genes associated with deafness have been identified or have commercially available tests. As mentioned in the example given at the beginning of this chapter, it is possible at this time to conduct genetic screening for the GBJ2 gene (Connexin 26).

Another important point to keep in mind when reading this chapter is that the focus on genetic *selection* of deafness does not involve any alteration of genetic material. If we return to the example of the Australian couple in the introduction whose fertilized eggs were screened for the presence of the Connexin 26 gene, the potential parents were faced with making a choice to implant fertilized eggs containing their own genetic material. All things being equal, it is within the realm of logical possibility that these zygotes could have been conceived without the assistance of any reproductive technology whatsoever, taking into consideration timing and other factors.

Selection for deafness can only occur when the potential parents already have compatible genetic material that codes for deafness. This is an important point that bears repeating: selection for deafness is only possible when both contributors of genetics material, (the biological parents) possess genes compatible with hearing loss. This

process is to be distinguished from the mainstream media's concept of designer babies, in which potential parents select from genes from the 'genetic supermarket'¹³¹ to create the child of their dreams. In other words, given old fashioned reproduction without technological assistance, potential parents Augustus and Lydia could have a deaf child; technology such as IVF with PGD shifts the odds from say, 1 in 2 to a near certain possibility.

Creation for deafness, on the other hand, occurs when the potential parents who wish to bear a deaf child do not have the genetic material necessary to bring this about. We could imagine a case where each potential parent has a genetic basis for hearing loss, but taken together these are not compatible with the birth of a deaf child. Consider this simple example, where two parents possess the following pairs of genes: Parent 1 has pairs Aa and BB , and Parent 2 has pairs AA and Bb . (Upper case letters signify dominant genes, and the lower case letters represent recessive genes). Suppose each recessive gene causes deafness, such as a and b . This will only be the case when there are two copies of the same recessive genes. In this case, since recessive genes are paired with dominant genes (Aa and Bb), each parent is a carrier for a specific kind of genetic deafness, but is not deaf. Parent 1 has two dominant B genes (BB) and no recessive b genes; Parent 2 has two dominant A genes (AA), and no recessive a genes. Given this, there is no possible way that deafness can ensue, since genetic deafness in this example requires two copies of recessive genes, such as aa or bb , one copy from each parent.¹³²

¹³¹ Robert Nozick, *Anarchy, State and Utopia*, 315.

¹³² It is within the realm of logical possibility, though extremely unlikely, that the parent with 2 copies of the dominant gene might somehow develop a mutation that would result in the particular recessive gene needed to cause deafness. From conversations with geneticists I've learned that this scenario is so unlikely

As another example, imagine the case of two Deaf potential parents who wish to have a deaf child, but since their hearing losses result from illness or accident they do not possess genes that code for hearing loss. If they were somehow to create deaf children by altering genes, this process could be associated with the previously mentioned notion of “designer babies” though it should be noted that this is a term only used in mainstream media and popular culture, and is not formally associated with scientific, bioethical, or philosophical nomenclature.

Genetic selection for deafness is impossible when the potential parents do not have the genetic material necessary to bring about deafness. For these potential parents to bring about a deaf child, the genome of the embryo must be altered by gene insertion or deletion. Genetic manipulation, or gene insertion or deletion is currently experimental, and has not occurred in order to create a child with hearing loss. The ethical issues related to genetic manipulation, or the creation of a deaf child, will be discussed in the following chapter, “Genetic Alteration: Creating Deaf Babies.”

Genetic Selection: Some Assumptions

In addition to establishing the difference between genetic selection and genetic creation, I establish some assumptions regarding genetic selection. I make four assumptions in order to sharpen the focus of the question, ‘Is it morally justifiable to select for deafness?’

First, I assume that the people wishing to select for deafness are Deaf. That is, they have both the audiological condition of hearing loss and use a signed language. By

that it would only be considered as a philosophical logical possibility and not a possibility grounded in biological reality.

and large, Deaf people do not exist in isolation; they are members of a linguistic community that uses a signed language such as American Sign Language. (This is in contrast with deaf people, who have the audiological condition of severe to profound hearing loss and who use the dominant spoken language of their community). While it is possible that some hearing people may wish to select embryos with genes that are associated with deafness, studies have indicated this is highly unlikely.¹³³

Second, I assume that the potential parents have extended family and friends who are proficient signers, ranging from fluency in ASL to the ability to use a signed system such as signed English. This assumption is important because it assures that the child will be surrounded by people who can communicate directly with the deaf child. By ensuring that the deaf child has full access to a visual language, I am setting aside the ethical issue regarding deaf children's partial or fragmented access to spoken language. This is important because limited or partial access to the language used in the home can affect the deaf child's ability to acquire language in a timely manner; deaf children with hearing parents often fall into this category because they are unable to fully access the sounds of spoken language. This is not an issue for visual modes of language or communication; provided the deaf child has no vision difficulties, he or she should be able to acquire language naturally in much the same process as the hearing child surrounded by spoken language users.

¹³³ Anna Middleton, "Deaf and Hearing Adults' Attitudes Toward Genetic Testing for Deafness" in *Genetics, Disability, and Deafness*, ed. John Vickrey Van Cleve (Washington, D.C.: Gallaudet University Press, 2004), 134.

Third, for the purposes of my discussion of genetic selection, I also assume that audiological deafness is a harm. Although this assumption is usually taken as a prima facie claim, it is not altogether clear that this is as simple as proponents of this view assert. In order to assert this claim without prejudice, one must first provide a justifiable definition of harm, followed by an examination of whether audiological deafness satisfies this definition. I will take on this question in Chapter 5 of my dissertation; for now, I will adopt the prevailing view that audiological deafness is a harm, which is the received view on disability set forth in the general Non-Identity argument I adopt in this chapter. It is important to note that if this assumption is problematic or incorrect, and audiological deafness is not a harm, the impact on the cogency of the Non-Identity argument is minimal.

Finally, I assume that genetic selection for deafness is limited to non-syndromic genes that only cause hearing loss and are not associated with any other genetic anomaly. My reason for this is that I wish to focus my discussion on the case of deafness, and do not want to confuse or complicate the issue by bringing in other kinds of disability or human variation. Although I do think these issues are worth considering at some point, I believe it best to initially investigate the issue of genetic selection for deafness based on single trait genes; it is likely that the answer to this question will influence and inform the question of genetic selection for syndromic kinds of deafness.

The Non-Identity Problem

When evaluating whether selection for deafness can be morally justified, there are at least three questions under consideration:

- 1) Is it possible to do harm to individuals who otherwise would not have existed?
- 2) Is being deaf (a person with hearing loss) rather than hearing a harm?
- 3) Is being Deaf rather than deaf a harm?

Is it possible to do harm to individuals who otherwise would not have existed? It is important to remember that this is not a “same person choice,” but a “different person choice.” It is not a matter of one individual having the potential of being born deaf or hearing, but whether a given individual with a unique genome will be born at all.

Selecting a fertilized egg that codes for deafness confers the possibility of existence on that particular egg, with all the characteristics inherited within. The issue at stake is whether it is morally justifiable to select such an embryo and bring it into existence.

Reframing the question, I ask, has this selected individual been harmed by being brought into existence? Remember, this specific biological individual could not have been born hearing, given its unique genetic make-up.

Suppose that audiological hearing loss is a disability (not everyone accepts this premise) and by virtue of being a disability, it is a harm. In *Reasons and Persons*, Derek Parfit introduces this issue of disabled existence versus nonexistence as the Non-Identity Problem.¹³⁴ Using a slightly altered version of Parfit’s example, imagine a woman who can become pregnant at time T_1 , knowing that the child she gives birth to will have a mild disability, such as being colorblind, due to an temporary teratogenic environmental factor. The same woman can wait until the teratogenic influence lifts one month later,

¹³⁴ Derek Parfit, *Reasons and Persons*, 359.

and become pregnant at time T_2 and give birth to a *different* child – one who does not have the mild disability. One could say that if the woman waits for a month to get pregnant, her child will be born without a disability. But this is mistaken reasoning, for the embryo conceived at time T_1 could not have been born without being colorblind. Therefore, the question is not whether this child could have been born without being colorblind, but whether the child has been harmed by coming into existence. Would it have been better for this child if the child had never existed? Parfit uses several versions of Person-affecting Principles of Beneficence to argue that this cannot be the case. In other words, “if someone is caused to exist, and has a living worth living, this person is benefited.”

In the case of a person whose life is arguably not worth living, it could be claimed that existence itself is a harm to the child. This argument has been advanced to support the case of selecting against genetic conditions such as Lesch-Nyhan Syndrome, which involves tremendous physical pain, a short lifespan, and self-mutilation. It is a more difficult issue when a child is born in less than ideal circumstances, such as to an uneducated teenage single mother or with a mild disability. Our common sense morality tells us that in these cases, the child has been harmed. Yet, this is deceptive. Recalling the example of the woman who goes ahead and gives birth to the colorblind child rather than waiting a month to conceive – the common moral view is that this child has been harmed as a result of the mother’s wrong action to conceive at time T_1 rather than T_2 . The philosophical problem is how to reconcile our common moral view that the woman has acted wrongly in not preventing her child’s disability with the view that it is better for the child with the disability to exist than not to have existed at all.

Especially in the case of mild disability, it does not seem persuasive to argue that the child would have been better off not existing. Philosopher Dan Brock extends Parfit's discussion of the Non-Identity Problem into what he calls the "wrongful handicap" conundrum: "A wrongful action must be bad for someone, but a choice to create a child with its handicap is bad for no one."¹³⁵ Since this is not a "same person" choice, but a "different person" choice, the disabled person who is born is not harmed, since she could not have existed in any other way. In other words, the person with a disability may still have a worthwhile life, one that is better than no life at all. The answer to my first question, "is it possible to do harm to a child who otherwise would not have been born at all?" seems to be no. For Parfit, at least, it is better for an individual to exist with a hearing loss, than not to exist at all.

Genetic Selection and Wrongful Handicaps

The Non-Identity Problem focuses our attention on the child who gets to exist as a result of this moral calculus. As mentioned earlier, Dan Brock offers a way out of this puzzle by shifting the locus of morality from the child who has benefitted to a non person- affecting analysis.¹³⁶ With this analysis, the scope of the problem is widened to include the effects of such a decision on the larger community. Brock supposes that these effects would include any harm visited on the parents as a result of having to care for a child with a disability, and any harm imposed on society, in which might include the allocation of additional resources for that child's care.

¹³⁵ Dan Brock, "The Non-Identity Problem and Genetic Harms – The Case of Wrongful Handicaps", *Bioethics* 9 (3/4):271.

¹³⁶ Brock, 272.

In removing the child who has reaped the benefit of existence (as a deaf person) from this analysis, Brock generates several non person-affecting principles, including the principle of avoiding suffering or limited opportunity. By attaching the harm done to a person, Brock claims this misunderstands the nature of the Non-Identity Problem – the core of a Non-Identity Problem is that no person is harmed, and the disability that ensues is not a loss.¹³⁷

Suppose that a deaf child has been created, and this is morally justified using the reasoning from the Non-Identity Problem. This child benefits from existence, and even if deafness is a harm, it is not such a great harm that the child is better off not existing. Yet on Brock's account, the Deaf potential parent ought to consider the following non person-affecting principle:

N: Individuals are morally required not to let any possible child or other dependent person for whose welfare they are responsible experience serious suffering or limited opportunity if they can act so that, without imposing substantial burdens or costs on themselves or others, any alternative possible child or other dependent person for whose welfare they would be responsible will not experience serious suffering or limited opportunity.¹³⁸

The Deaf potential parent who wishes to have a Deaf child may have many reasons for wishing to have a Deaf child, but it is doubtful that the Deaf potential parent views a Deaf person's life as experiencing serious suffering, otherwise why would she want to have a Deaf child? (I will assume that the Deaf potential parent is like most potential parents and wishes a full and happy life for her offspring). This illustrates one problem with the non person-affecting principle – how one defines harm. Serious

¹³⁷ *Ibid.*, 275.

¹³⁸ *Ibid.*, 273.

suffering and limited opportunity are not universal concepts. The suffering from discriminatory behaviors aimed at an Arab-American man as a result of Flying While Arab (FWA) may be deemed serious depending on the duration and frequency of these experiences, where the frustrations felt by the deaf person tend to be more along the order of not being able to access her favorite television show on the internet due to a lack of captions. Both are harms, but the degree and nature differ. The same holds for limited opportunity, which may occur as a result of whatever properties one has won in the genetic lottery, or may be a direct result of the opportunities proximal to where one lives.

Genetic Selection and Social Arguments

An argument by analogy likens the experience of being Deaf to the experience of being a racial or ethnic minority. Levy and Anstey use this analogy to illustrate the negative effects of being Deaf, and to assess whether the claim that harms experienced by the signing Deaf community are relevantly similar to the harms encountered by members of racial or ethnic minority groups.¹³⁹ Since the harms experienced by members of racial and ethnic minority groups are those of social injustice, the argument runs, so are the harms experienced by members of the signing Deaf community.

Levy argues that this is a flawed analogy. The harm resulting from racial or ethnic prejudice is not a consequence of physical appearance, but an artifact of it.¹⁴⁰ The harms created by social barriers to access are only part of the harm that a Deaf person would experience. Even if society could eliminate all of the barriers and provide Deaf people a

¹³⁹ K.W. Anstey "Are Attempts to Have Impaired Children Justifiable?" *Journal of medical Ethics* 28:28-88 (2002). N. Levy, "Deafness, Culture, and Choice" in *Journal of Medical Ethics* 28: 282-5 (2002).

¹⁴⁰ N. Levy, "Deafness, Culture, and Choice," 282.

fully inclusive experience in the public sphere, that would include captioning, sign language interpreting, and other accessibility services, Deaf people would still not be on an even playing field.

One reason for this, argues Levy, is that the logocentric nature of culture is organized around the spoken voice. No matter what barriers are removed in the public arena, the Deaf person will always be harmed by her inability to access information that is spoken in certain fora. The (potential) deaf person who is genetically selected does not only experience harmful discrimination via the negative effects of a society that has not adequately addressed disability access, but also experiences harm as a result of being somewhat alienated from mainstream non-Deaf social discourse.

I think that Levy is correct in pointing out the importance of the spoken voice in everyday social discourse; however there is another element present today that may serve to ameliorate this harm. I would argue that mainstream culture is more phonocentric (based on sound) than logocentric, and that some of the logocentric nature of mainstream non-Deaf culture discourse is now accessible to literate Deaf people through the variety of social media that were not present when Levy and Anstey wrote their articles. In particular, the casual nature of social discourse exchanged on social media sites like Facebook and Twitter have had the effect of opening a window to Deaf people for what used to be water-cooler chat. Other Web 2.0 services like blogs and their accompanying comments section, signed vlogs, and other signed media present on sites like YouTube have also contributed to breaking down some of the communication access barriers in non-public domains. To be sure, there are still inaccessible aspects to the internet, and it is likely that as new technologies emerge, accessibility to those technologies will always

be somewhat behind. Yet the difference in the quality of life for Deaf people, due to more direct opportunities for informal communication is significant and should not be overlooked when performing the calculus of moral harm.

Levy and Anstey both rely on the disanalogy with the social argument to conclude that genetic selection is morally unjustified. For Levy it is partly a matter of harm that cannot be addressed by social policy, and partly a matter of the claim that Deaf potential parents wish to bear deaf children so that they may share their rich culture with these children. For Levy, the best solution to this is for Deaf people to have hearing children – children who will be able to participate in Deaf and non-Deaf cultural communities with equal ease.

Anstey makes a similar suggestion after considering the argument that Deaf people may also wish to use genetic selection as a tool for ensuring that the signing Deaf community has sufficient critical mass to continue as a thriving linguistic community. By noting that there is nothing that prevents hearing children of Deaf parents from learning the signed language used in the home as a first language, Anstey argues that the genetic selection for the continuation of community is not a sufficient reason. The nature of reciprocity is also addressed, since whatever technology is used to select for deafness can also be used to select against deafness. For Anstey, the burden of reasons for genetic selection falls squarely on the potential Deaf parents – they must move beyond the harms/benefit calculus of the Non-Identity argument and establish reasons for genetic selection that address the issue of imposing social harm on Deaf children.¹⁴¹

¹⁴¹ Anstey, “Attempts”, 287.

Reproductive Liberty and Genetic Selection

Up to this point, the discussion has focused on the harms resulting from genetic selection. American bioethics not only uses the consequentialist principles of nonmaleficence and beneficence to assess the moral permissibility of actions, it also considers principles of autonomy and justice. Several authors have argued that genetic selection should be addressed as a matter of parental reproductive liberty; this section takes a look at those arguments and weighs them against the potential child's autonomy.

Julian Savulescu uses the example of McCulloch and Dushesneau (the Deaf lesbian couple) to frame his analysis of genetic selection.¹⁴² He argues for a strong parental claim to reproductive liberty for this case (which he notes is not precisely the same as genetic selection), and concludes from this case that reproductive liberties should be extended to all parents provided that the child is not harmed. Savulescu uses the Non-identity argument as evidence that the children of McCulloch and Dushesneau were not ultimately harmed by being born as Deaf since the benefit of existence outweighs the harm of deafness.

In constructing an argument for reproductive liberty, Savulescu considers the issue of access to genetic technology. He makes four claims: (1) that genetic tests should be available to couples who wish to use them to select the child (of all possible options) who will have “the best opportunity of having the best life”; (2) couples should use these genetic tests to have the child who will have “the best opportunity of having the best life”; (3) couples should be free to refuse to use these genetic tests for themselves or their

¹⁴² Julian Savulescu, “Deaf Lesbians, ‘Designer Disability’, and the Future of Medicine”, *British Medical Journal* 325: 772.

offspring, provided that this does not result in harm to the child; and (4) couples should be free to request and receive genetic testing, even if the child resulting from this does not have average or better opportunities.¹⁴³ This access to genetic technology does not absolve the potential parents of any responsibility. Savulescu thinks that parents have a moral obligation to use genetic selection to select the child with the “best life prospects.” The question here is how might one go about determining what the “best life prospects” are, and who gets to make this determination?

Since Savulescu’s point of reference is the United Kingdom, the issue of access to genetic services is a matter of National Health Service policy. In the United States, access to genetic services and testing is currently a patchwork that varies according to one’s insurance company coverage; people can also opt to pay for these services out of pocket. One of the challenges for policy makers is to determine what sorts of funding should be provided to ensure reproductive liberties, especially if some of these choices may result in more expensive costs to society. At this point, couples are free to refuse genetic testing; there is no duty (legal or otherwise) that requires couples to undergo genetic testing. Savulescu points out that this lines up with the tenet of non-directiveness in genetic counseling.¹⁴⁴

John Fletcher also argues for parental reproductive liberty using the Duchesneau and McCulloch example, using the principle of fairness to ground his reasoning. He writes: “if parents are responsible for deciding which genetic disorders are ‘serious’, it seems only fair that a deaf couple should be able to decide that deafness is not only ‘not

¹⁴³ Savulescu, 771.

¹⁴⁴ *Ibid.*, 773.

serious', but is actually preferable in their family situation."¹⁴⁵ Fletcher and Savulescu both note that parental reproductive liberty is constrained somewhat by the concept of causing harm to the child. The Duchesneau and McCulloch case, while not specifically a case of genetic selection, shares the feature of the deaf child emerging from a natural combination of genetic material (no genes were altered) and the deaf child receiving the benefit of existence.

The question of "best life prospects" was raised, but not yet answered satisfactorily by Savulescu. Fletcher offers a partial explanation for this by situating the notion of "best" with the Deaf parents and their assessment of their family. For Fletcher, the desire to have a deaf child is not so much motivated by selfishness as it is by the Deaf parents claim that they could be better parents to deaf children than to hearing children. Unfortunately, this claim is merely stated, not defended. So how might Deaf potential parents come to this conclusion? Hearing children of Deaf parents learn signed language as their first language, figure out how to get their parents attention using Deaf cultural norms, and experience (all things being equal) a home life that would not seem to have any significantly different features than it would were this a household of Deaf children.

Two considerations come to mind. The first is that Deaf parents believe that they can be good parents to hearing children, but better parents to Deaf children. They may feel a special obligation to parent Deaf children because they are Deaf – they can provide the vertical transmission of language and culture from parent to child that is rare in the signing Deaf community and have the satisfaction of knowing that they have passed on

¹⁴⁵ John Fletcher, "Deaf Like Us: The Dushesneau-McCullough Case." *L'Observatoire de la Génétique* 5 (July-August):4.

their cultural values to children who are very likely to remain attached to the signing Deaf community. Even if the Deaf children at some point decide to situate themselves partly in the non-Deaf world, the fact of their physical status as deaf, plus their original enculturation, makes it very likely that these children will not leave the signing Deaf community entirely. This is not always the case for hearing children of Deaf parents.

The other issue is one of potential harm to the hearing children living in a Deaf family. By virtue of their ability to understand and communicate directly in a signed language and in a spoken language, hearing children are often put in the position of interpreting for their parents. One possible harm is that this may disrupt the parent's power and authority – when the parent has limited access to information and must rely on the child's interpretation, this can create problems. Another related issue is the child's maturity level; a child is not a professionally trained interpreter and not an adult. Being put into situations where that child is expected to interpret may cause harm to the child. Even if the parent is vigilant and adamant about not placing the child in this position, other adults may not respect this decision, putting the child in a quandary, especially if say the child is dealing with two authority figures, such as a parent and a teacher, or a parent and a grandparent. Other harms that may occur include overhearing negative or derogatory comments about one's family in the presence of one's parents, or making choices about what kind of information to convey to parents so as to avoid causing further harm. In choosing to bear a Deaf child, the Deaf parents avoid bringing this harm to their family.

The Child's Right to an Open Future

A criticism that is often levied against Deaf parents who would consider the use of genetic selection to have a deaf child is that this is a selfish decision that places unfair limits on the child's future, condemning the child to fewer opportunities and lifestyle choices. By deliberately choosing to bear a child with a genome that codes for hearing loss, Deaf parents have forced that child into their notion of "the good life." In Kantian terms, the child has been used as a means to the parents' ends, and has not been respected as an end-in-itself. Dena Davis uses Joel Feinberg's conception of a child's right to an open future to critique selection for disability.¹⁴⁶

The concept of a "child's right to an open future" presupposes freedom of lifestyle choices. The more opportunities an individual has, the more open her future. Liberal societies stress the maximizing of opportunity and offsetting the negative effects of the "natural and social" lottery in order to promote individual autonomy and lifestyle choice. Genetic selection seems to move against this project. Davis writes:

Good parenthood requires a balance between having a child for our own sakes and being open to the moral reality that the child will exist for her own sake, with her own talents and weaknesses, propensities and interests, and with her own life to make. Parental practices that close exits virtually forever are insufficiently attentive to the child as end in herself. By closing off the child's right to an open future, they define the child as an entity who exists to fulfill parental hopes and dreams, not her own.¹⁴⁷

I have identified at least two ways in which to evaluate Davis's argument for a child's right to an open future. First, one could assess whether her deontological move is

¹⁴⁶ Dena S. Davis, "Genetic Dilemmas and the Child's Right to an Open Future," *Hastings Center Report* 27 (2): 12.

¹⁴⁷ *Ibid.*, 9.

sufficient to counter Parfit's consequentialist claim – I'm not convinced that it is, but I will set this aside for now in order to focus on the second approach, which is to determine whether Davis's argument for the child's right to an open future holds when applied to the particular case of Deaf parents using genetic selection to select a deaf child. Davis specifically addresses the case of selection for deafness, claiming:

If Deafness is considered a culture, as deaf activists would have us agree, then deliberately creating a Deaf child who will have only very limited options to move outside of that culture, also counts as a moral harm. A decision, made before a child is even born, that confines her forever to a narrow group of people and a limited choice of careers, so violates the child's right to an open future that no genetic counseling team should acquiesce in it. The very value of autonomy that grounds the ethics of genetic counseling should preclude assisting parents in a project that so dramatically narrows the autonomy of the child to be.¹⁴⁸

In this quote, Davis makes several assumptions. First, she claims that Deaf children will have very limited options to move outside of the signing Deaf cultural community; second, she claims that the Deaf child is confined forever to a narrow group of people; and third, she claims that the Deaf child is restricted to a limited choice of careers. I would like to evaluate each of these claims separately.

First, what might Davis mean when she claims that a created Deaf child (or deaf person) will have very limited options to move outside the Deaf culture? What is the basis for this claim – is it a claim based on solely on restricted communication access to hearing people, or is it a claim about the closed nature of the signing Deaf community, making this analogous to say, some kinds of religious communities that have strong rules against contact with outsiders? To be charitable, I'll take it as a claim about restricted access to the broader hearing community. So what might this mean for the Deaf child

¹⁴⁸ *Ibid.*, 14.

selected by Deaf parents? (This seems to be no different than for the Deaf child who just happens to be born to Deaf parents, but that is another topic.) The deaf child born to Deaf parents has an advantage over most other deaf children who are born to hearing parents who do not know signed language. So the Deaf child with Deaf parents has the advantage of parents who can communicate with her from the “get go.” The Deaf child with Deaf parents is likely to spend much of her time with other Deaf people, but this in itself does not entail limited options to move outside the signing Deaf community. In fact, it might entail the opposite, as the Deaf child here is able to acquire social experiences under the condition of full access to language. This knowledge of social interaction could provide a basis for building the social and interactive skills necessary to move outside of the community. Additionally, consider what kind of Deaf person might pursue genetic selection for deafness? It is likely to be a Deaf person who believes a culturally Deaf existence to be worth living, and is sophisticated enough to be aware of the possibility of genetic selection/technology as a means for bearing a deaf child. While these factors are not necessarily correlated to the ability to move between the deaf community and the hearing world, I suspect in practice there is a high correlation. Deaf people live in a hearing world; Deaf parents teach their Deaf children how to manage in the hearing world.

Davis’s second claim, that the Deaf child is confined to a narrow group of people, is perplexing because I cannot determine what she means by this. Is it an essentialist claim about the nature of Deaf people and the signing Deaf community? Is it a claim about the restrictions that the disability of hearing loss places on people and their life projects? The Deaf child with Deaf parents who spends most of her time in the Deaf

community could meet a variety of Deaf people, ranging from blue collar to white collar professional, to artists and writers, of a variety of ethnic and education backgrounds. It seems that this claim ignores that the Deaf community is as richly diverse as the hearing world, including people with a wide range of views and broad and varied experiences. The restriction to a narrow group of people seems more likely to be a reflection of the parent's preferences, and not of the nature of the signing Deaf community. But perhaps I have missed her point.

Finally, the constraint imposed on a Deaf child in terms of limited career options. Commentators writing on the open future question and Deafness use this 'argument by example' prolifically, generating lists of the kinds of career opportunities foreclosed to Deaf people. Unfortunately, they mistakenly take their beliefs and assumptions of what counts as employment restrictions on Deaf people for facts. In the course of my research, I have learned of the following restrictions on Deaf people: "no driving, limited participation in sports, no piloting, no membership of the armed forces, no capacity to enjoy music, and so on."¹⁴⁹ (This quote is taken from a 2004 article in the *Journal of Applied Philosophy*, a reasonably well-respected peer-reviewed journal in the field.) Here's the problem: Deaf people do drive, they do participate in sports, they do pilot planes, they have been members of the armed forces, they do have the capacity to enjoy music. Scholars who write about the signing Deaf community, but who have little to no experience with this community do not need to engage with the community – they do

¹⁴⁹ Martin Harvey, "Reproductive Autonomy Rights and Genetic Disenhancement: Sidestepping the Argument from Back-Handed Benefit", *Journal of Applied Philosophy* 21 (2): 125-140 (2004).

have an obligation to verify their assumptions and beliefs about what it must be like to be a Deaf person. (This also goes for the peer reviewers). While this may seem like a minor quibble about facts, there is a deeper issue at hand, which goes to epistemic authority.

Deaf people do know what it is like to experience life in a signing Deaf community; they are also likely to be more aware of the experience of life in a non-Deaf spoken language community.¹⁵⁰

I think that the question of limited employment opportunity is a good question, however, and it deserves a more careful analysis. Just what kinds of careers might really be foreclosed to Deaf people? These would be jobs that depend on the combined abilities of hearing and voice, such as opera singer, 911 call center person, air traffic controller, soldiers on the frontlines of battle, and perhaps military pilot. These can be roughly categorized into 2 groups: jobs with aesthetic requirements based on sound (ability to judge and produce sound of a specific quality) and jobs where ability to hear is integral to safety. Now, my next suggestion may sound a bit farfetched, but given the advances in technology, some of these jobs where the ability to hear is related to safety issues may not be out of the realm for a deaf person the future, given voice recognition technology and shifts to text-based communication. I think the limit on jobs with aesthetic requirements based on the ability to judge and reproduce sounds is a much more difficult objection to overcome, and I think it stands. Yet, I'd like to follow up with a question related to aesthetic experience and the concept of an open future. A deaf person whose deafness was genetically selected may be precluded from participating in certain kinds of

¹⁵⁰ This topic of epistemic authority is covered in more detail in the following chapter.

aesthetic experiences based on sound. But is this sufficient to claim that the child's right to an open future has been curtailed? If we consider the natural lottery alone, all people are born with a particular set of physical conditions that preclude certain abilities, and consequently, certain career options. So the task is to somehow separate the limitations imposed by the natural lottery from the limitations imposed by genetic selection for deafness. But if the number of careers limited by hearing loss is not significantly different from those imposed by the natural lottery, this objection seems to lose its force. (A person who is tone-deaf may not have the ability to pursue a career in music that requires the ability to judge and reproduce a sound – how is this person different from the deaf person who cannot do this?) If we assess it in terms of the kinds of career options that are foreclosed, such as those based on aesthetic requirements, the argument carries more merit.

By evaluating Davis's assumptions about the quality of life experienced by Deaf people, I hope to have shown two things: the first is an important point, though not a philosophical one, which is that when making claims about Deaf people's lives, it helps to get the facts straight about what Deaf people can and cannot do; the second, and I think *more important* claim is to carefully evaluate what is meant by limitations on an open future for Deaf people, separating out restrictions based on physical conditions from those based on social barriers, which are far more onerous.

I've been leading up to a final objection about the right to an open future question, which is what counts as an open future? Anita Silvers, a philosopher who writes on disability issues and philosophy uses an analogy of a restaurant buffet:

because the child has only one life to plan, the ultimate benefit to the child's autonomy of having fewer life plan options from which to choose may be negligible, more like having a varied menu with ten rather than twelve main courses than like being a vegetarian in a steak house.¹⁵¹

I think Silvers is on the right track here, but she neglects another important consideration. I argue that social barriers place far more restrictive limitations on an open future for the Deaf person than the physical inability to hear. So it could be argued that social limitations placed on Deaf people shore up the right to an open future argument more than the physical fact of hearing loss. But this seems to be a dangerous move, for many kinds of people face discrimination, not just Deaf people or people with disabilities. White people have an easier time in our society than blacks, but the recognition of social barriers against African-Americans does not imply that their numbers should be reduced due to less open futures. Arguing against genetic selection of deafness due to less open futures based on social constraints is not sufficiently convincing.

If “the right to an open future” argument is to prevail against the Non-Identity Problem regarding genetic selection for Deafness/hearing loss, it must answer two questions: first, it must carefully define an open future, and second, it must explain why a truncated future is worse than no future at all. Until these questions are answered, the conclusion of the Non-Identity Problem stands – that is, that it is better to exist as Deaf, than not to exist at all.

¹⁵¹ Anita Silvers, “On Not Iterating Women’s Disability: A Crossover Perspective on Women’s Dilemmas” in *Embodying Bioethics: Recent Feminist Advances*, eds. Anne Donchin and Laura Martha Purdy (Lanham, MD: Rowman and Littlefield, 1999), 198.

Better Not to Exist?

I conclude my assessment of the arguments on genetic selection by briefly considering a provocative claim by David Benatar, who argues that existence is a harm. If this claim stands, then the benefits/harm calculus made in the Non-Identity Problem cannot hold. To be clear, Benatar's claim is a general claim about the harm of existence – it is not directed at deafness or any other particular formulations of existence.

So what, exactly, is Benatar's claim? Coming into existence is always a harm, and this rests on an asymmetry of judgments about pleasure and pain related to existence. Benatar asks us to consider two scenarios – of a person who exists and one who does not exist. The person who exists will be in the presence of pain, which is bad; but this person will also be in the presence of pleasure, which is good. The person who does not exist will have the absence of pain, which is good; and also the absence of pleasure, which is not bad.¹⁵² Therefore, it is better to have never existed than to exist.

Benatar's argument from asymmetry raises some obvious problems for my whole project. If it is better to have never existed, then the nature of how one comes into existence, whether genetically selected or altered as a Deaf person, does not matter. In addition to this argument, Benatar also raises the question of whether there is a duty not to procreate.¹⁵³ The duty not to procreate can be grounded on the serious harm that is conferred by existence. If there is such a duty, this also renders my project moot.

Even if one accepts Benatar's conclusion about the harm that is conferred on individuals as a result of coming into existence, the duty not to procreate may be too

¹⁵² David Benatar, *Better Never to Have Been*, (Oxford; Oxford University Press), 38.

¹⁵³ *Ibid*, 95.

demanding. While it can be agreed that sometimes humans have a duty not to create – under certain circumstances, including some of the arguments offered against permitting Deaf children to be deliberately brought into existence, the idea of a universal duty not to procreate seems quite harsh. The human drive to procreate (as distinguished from the drive to have coitus or the drive to parent) is a strong one.

How might one challenge Benatar's conclusions? One possible response is to argue that the harms of coming into existence are not as great as Benatar claims. (Benatar claims that our lives are very bad, and that many of us are in psychological denial about this, believing that our lives are not so bad as they actually are).¹⁵⁴ Still, even if most people have very bad lives, not everyone has a very bad life. So one way to escape the conundrum that Benatar has created is to allow for the possibility of procreation for those whom it is not anticipated will have very bad lives. Justifying this against the harms of being deaf – whether a result of social construction, a lack of species-typical functioning, or the absence of a sense – is a formidable project.

Summary

I have provided a context for genetic selection, distinguished between genetic selection and genetic alteration, and offered an argument for genetic selection, the Non-Identity argument. I have considered the objections to the Non-Identity argument, namely Dan Brock's non-person-affecting principle, and also David Benatar's argument that existence in itself is a harm. I have also considered other arguments regarding genetic selection, including an analogy of social discrimination and the right to reproductive

¹⁵⁴ Ibid, 87.

autonomy. Additionally, I have explicated Dena Davis's variation on Feinberg's Right to an Open Future, providing an analysis of these claims.

Chapter 4 Genetic Alteration: Creating Deaf Babies

Genetic Alteration Case Study

Bennett and Io are both Deaf. Bennett was born to a hearing family and became deaf at age 2 as a result of contracting meningitis. He has no family history of deafness, and his genetic screening test results do not indicate any genes associated with deafness. Io's family has some Deaf members and some hearing members. Her genetic screening results indicate that the presence of the GJB2 gene (Connexin 26), which is assumed to be the cause of Io's deafness. Io and Bennett are both active members of the signing Deaf community and feel so strongly about having a deaf child that they have discussed not having children at all if they cannot have Deaf children.¹⁵⁵ Soon after getting their genetics testing results, Io and Bennett learn about a successful attempt of gene therapy that changes the genes of a fertilized egg. Since their genetic profiles indicate a very high chance that they will bear a hearing child, they have inquired about the possibility of using gene therapy to alter the genes of their potential child so that it will be born deaf.

In 2005, a team of scientists published an article reporting a successful gene therapy protocol that restored hearing to a group of guinea pigs whose hearing was deliberately destroyed from antibiotics.¹⁵⁶ This news led to speculation in the signing Deaf community as to whether a similar procedure could be done before conception or *in utero* to create deaf offspring. For many in the signing Deaf community, altering genes

¹⁵⁵ This is an uncommon view within the signing deaf community; in a study conducted at Gallaudet University in 2002, only 3 percent of culturally Deaf respondents indicated that they would consider aborting a hearing fetus. Stern S.J., K. Arnos, L. Murelle, K.O. Welch, W.E.Nance, and A. Pandya, "Attitudes of Deaf and Hard of Hearing Subjects Towards Genetic Testing and Prenatal Diagnosis of Hearing Loss," *Journal of Medical Genetics* 39 (2002): 452.

¹⁵⁶ Masahiko Izumikawa, Ryosei Minoda, Kohei Kawamoto, Karen A Abrashkin, Donald L Swiderski, David F Dolan, Douglas E Brough, and Yehoash Raphael, "Auditory Hair Cell Replacement and Hearing Improvement by Atoh1 Gene Therapy in Deaf Mammals" in *Nature Medicine*, 2005 (11): 276.

was viewed as a substantially different ethical issue than deliberately causing a hearing child to become deaf, most notably because it involved changing a physical characteristic before birth. This chapter will explore this moral intuition by addressing the question: are considerations of moral justification for genetic alteration substantially different than genetic selection?

Genetic Alteration Versus Genetic Selection

In the case of genetic selection through preimplantation genetic diagnosis (PGD) discussed in the previous chapter, the fertilized egg is selected for implantation in the womb based on specific criteria, such as the presence of genes associated with deafness. The cogency of this variation of the Non-Identity argument relies on the fact that the fertilized egg is not altered in any way, save for what processes might affect it during PGD.¹⁵⁷ The potential parent selects a particular genomically intact embryo to be brought into existence, rather than playing the odds in hopes of producing an embryo with the desired genetic trait. Genetic selection is thus an option only available to potential parents who have genetic traits that are mutually compatible with producing a deaf child through normal old-fashioned reproductive techniques. PGD can be used to tremendously boost the odds of having a child with hearing loss; it does not create these

¹⁵⁷ John A. Robertson, "Extending Preimplantation Genetic Diagnosis: The Ethical Debate" in *Human Reproduction* (2003) 18 (3): 469-470. doi: 10.1093/humrep/deg100 and Yu Y, Wu J, Fan Y, Lv Z, Guo X, Zhao C, Zhou R, Zhang Z, Wang F, Xiao M, Chen L, Zhu H, Chen W, Lin M, Liu J, Zhou Z, Wang L, Huo R, Zhou Q, Sha J., "Evaluation of Blastomere Biopsy Using a Mouse Model Indicates the Potential High Risk of Neurodegenerative Disorders in the Offspring," *Molecular Cell Proteomics* (2009 Jul 8) 7: 1490-500.

odds. As such, the use of this reproductive technology to bear deaf children will only apply to a subset of potential parents in the Deaf community.¹⁵⁸

Geneticists studying on population genetics in the Deaf community have argued that rates of intermarriage among deaf individuals (assortative mating) in the United States over time have likely increased the occurrence of recessive genes such as those associated with deafness in the Connexin 26 gene locus.¹⁵⁹ This is not unexpected; in communities where individuals choose their own mates it is not unusual to select a mate who shares one's language. Historic and recent studies conducted on deaf individuals and marriage show high rates of intermarriage among deaf individuals ranging from seventy-five to ninety percent; computer simulation models using historic mating data about deaf individuals have indicated that assortative mating has “has doubled the frequency of DFNB1 deafness in the United States”.¹⁶⁰ For many Deaf couples in the U.S., genetic selection for deafness is a possible option – at least in regards to possessing compatible genetic material.

What about Deaf potential parents, such as Io and Bennett in the case study at the beginning of this chapter, who long for a Deaf child, but who do not have mutually

¹⁵⁸ Walter Nance, “The Genetics of Deafness” in *Mental Retardation and Developmental Disabilities Research Review*, Special Issue: Infants and Children with Hearing Loss, Part One, (2003) 9 (2) 109-119. DOI: 10.1002/mrdd.1006

¹⁵⁹ W. Nance, X. Liu, and A. Pandya, “Relation between Choice of Partner and High Frequency of Connexin-26 Deafness” in *The Lancet*, (2000) 356 (9228): 500-501.

¹⁶⁰ S.H. Blanton, Nance, W. E., Norris, V. W., Welch, K. O., Burt, A., Pandya, A. and Arnos, K. S., “Fitness Among Individuals with Early Childhood Deafness: Studies in Alumni Families from Gallaudet University” in *Annals of Human Genetics*, (2010) 74: 28-9. doi: 10.1111/j.1469-1809.2009.00553.x

compatible genetic material necessary to produce a child with hearing loss?¹⁶¹ There are at least two options available to them if they wish to use some of their own genetic material. If one or both of the potential parents have genetic material that is compatible with producing a deaf child given a different partner, one option is sperm or egg donation using donor material that is compatible with the potential parent's genetic material coding for hearing loss.¹⁶² For purposes of this discussion, set aside the fact that many clinics and sperm banks will eliminate sperm and egg donors with this trait – a very real problem, to be sure, but one that does not make any difference for the purpose of analyzing methods of how infants with hearing loss could be conceived. This would result in the genetic selection scenario previously described.

If neither potential parent has genetic material compatible with producing a child with genetic hearing loss, then genetic selection is not an option. If one potential parent has genetic material that is compatible with producing a child with genetic hearing loss and the potential parents are insistent on bearing a child with genetic hearing loss that is biologically related to both potential parents, genetic selection is also not feasible. For potential parents who are unable to conceive a child with hearing loss, genetic intervention therapy (genetic alteration) offers an opportunity to bear a child with hearing loss who is biologically related to both parents. In this case, the embryo's genetic makeup would be altered so that its genes would constitute a genotype consistent with hearing loss. This could be done through either germline gene transfer or somatic cell

¹⁶¹ Hearing loss is a necessary condition, but not a sufficient condition for being culturally identified as Deaf.

¹⁶² Mundy, W22.

gene transfer. In other words, an embryo with the potential phenotypic status of “hearing” would be genetically altered *in utero*, resulting in the phenotypic status and physical presentation of “hearing loss” once born.

The moral permissibility of such a move is unclear. Unlike the problem of genetic selection, where an embryo’s shot at existence (via selection and implantation) depends on parental preference for a given physical characteristic or phenotype generated by the presence or absence of a particular genotype, in this case there is a particular embryo already *in utero* that does not possess the desired genetic trait as detected by genetic screening. The potential parents have three options available: (1) continue the pregnancy despite the absence of the desired trait of hearing loss; (2) terminate the pregnancy due to the absence of the desired trait of hearing loss; or (3) continue the pregnancy provided that the desired trait can be produced through genetic alteration. Adding the variable of genetic modification transforms the issue from a different person problem, involving the choice of one embryo over another, to a same person problem that weighs two potential kinds of existence for the same person (with or without hearing loss) and the option of nonexistence.¹⁶³ The metaphysical question of whether an individual remains the same if a different kind of existence is chosen is no easy question, and will be taken up later in this chapter.

If the same utilitarian reasoning used in the genetic selection case study is applied to the genetic alteration case study, the benefit of existence once again trumps

¹⁶³ While I am aware that I’ve made a significant conceptual leap by considering two slightly different genomes to be assessed as the same person, for now I will assume the layperson’s view that since all other factors remain the same, this is one and the same person, who may exist with hearing or exist with hearing loss.

nonexistence whether or not the potential child is born with hearing loss or born able to hear. For the person who accepts the cogency of the Non-Identity class of utilitarian arguments, the analysis of moral justification stops here. Following the conclusions of Chapter Three, in these two cases, the benefit of existence outweighs the ‘harm’ of hearing loss or the ‘harm’ of being a hearing child in a Deaf family, rendering the question about the morality of modifying an embryo moot, overridden by the Non-Identity utilitarian calculus.

There are other grounds on which to consider this question of the moral justification of genetic alteration and these are these issues I will press for this chapter. Regarding changing the question from a different person choice to a (seemingly) same person choice, new issues are presented. Two key issues now at hand are whether a potential person has any claim to a particular kind of existence, and whether transforming a potential individual’s physical characteristics based on a surrogate’s decision can be morally justified.

Ten Fingers, Ten Toes

As previously mentioned, the possibility of changing a potential person’s genome raises a number of substantive issues in philosophy and bioethics. These include questions about attributing rights to a potential person to questions regarding the inviolability of the body and, by extension, the genome. One of the challenges I was faced with in writing about genetic alteration in the deaf community was how to situate my analysis. Should I ground it in the historic dogma of American bioethics, principlism? Or would it be best positioned as a project with roots in the history of philosophy? On the other hand, maybe it would be best to try a bioethics ‘topics’ approach to bodily integrity,

including surrogate decision-making and children's rights. Each of these approaches held some appeal, yet none of them seemed quite right. In order to establish an analysis of a question that mattered enormously to a specific population, it seemed to make sense to consider this population. Ultimately, I decided to look to the American Deaf community in order to identify a starting place; my personal experiences and academic knowledge suggested that the philosophical notion of bodily integrity would best represent what I understood as a common perspective shared by many in the community.¹⁶⁴

One of the most frequently occurring sentiments in the signing Deaf community is the idea that deaf children are whole and not in need of medical intervention. In numerous conversations with signing Deaf adults about whether prelingually deaf children ought to be given cochlear implants, one expression came up frequently, which I gloss as "TEN FINGERS TEN TOES PERFECT" in American Sign Language. This expression appeared to symbolize the wholeness of the deaf child's body; the idea that a child born deaf was as whole as a child with ten fingers and ten toes, that is a child who fit the signer's view of normalcy. The significance of ten fingers and the importance of

¹⁶⁴ Here I want to acknowledge both formal and informal academic experiences with the Deaf community, including discussions following my presentations at the University of Virginia, the University of New Mexico, Georgetown University and the University of Pennsylvania, and the 2006 Deaf History International and Deaf Academics conferences. I also owe a huge debt to students in my Bioethics and Deafness classes at Gallaudet University, who humored my persistent efforts to distill this concept into philosophical lingo, as well as members of the Gallaudet and New Mexico communities who sat with me through numerous informal conversations and graciously tolerated my many questions.

the hands and fingers to signing Deaf people is well documented; there is a high value attributed to body parts necessary for the production of language.¹⁶⁵

This description can be viewed as a folk argument against the medicalization of deafness. More nuanced versions of these arguments are well articulated in the discussion regarding moral justifications for providing prelingually deaf children with cochlear implants, those opposed to this procedure call for a rejection of this elective surgical procedure by appealing to principles of human dignity, autonomy, and bodily integrity.¹⁶⁶ Positing Deaf people as complete and whole individuals contrasts with the pathological view of deaf people as individuals with broken ears in need of repair, offering a different theoretical lens through which to view this problem.

This argument that a child's body is inviolable runs into trouble when considering genetic alteration. If the child's body ought not to be altered based on a desire to allow that child to have autonomy over her body, or to preserve her dignity, or to uphold her right to bodily integrity, how is it possible to maintain this position and also maintain that it is morally justifiable to alter a potential child's genetic material? I raised this question many times in my discussions with signing Deaf adults who held strong views against cochlear implants for prelingually deaf children, but also held the view that Deaf parents ought to have the ability to create (as well as select) potential offspring who would possess the characteristic of being deaf. Maintaining the simultaneous positions that upheld the notion of bodily integrity for deaf children while allowing for genetic

¹⁶⁵ Carol Padden and Tom Humphries, *Deaf in America*, 119.

¹⁶⁶ Crouch, "Letting the deaf be Deaf," 18-20; Lane and Grodin, "Ethical Issues in Cochlear Implant Surgery," 235, 245.

alteration that would cause potential hearing children to become deaf seemed to be an inconsistency. It was not clear to me initially whether this indicated a confusion in reasoning or a deeply coherent position based on moral intuition held by members of the signing Deaf community. Given the possibility of different cultural mores in the signing Deaf community, I decided to explore this position further in hopes of unearthing the reasoning offered by many members of the signing Deaf community in support of genetic alteration for deafness. The question of whether a potential being could be deaf versus the deaf/hearing status of an actual being seemed to be the point on which this argument turned.

Modifying genetic material prior to an individual's existence is without precedent and raises difficult, though not necessarily unique, questions about the moral permissibility of such procedures. Under what circumstances, if any, might it be appropriate to modify a potential person's genetic material? Who has the moral warrant to make this decision and how is this determined? Are there limitations on what kinds of genetic alterations are permissible? In order to consider these questions, several concepts must be unpacked. First, there is the notion of a potential person who is (by definition) incapable of making a decision at this point and whose moral standing not at all clear; second, there is the issue of surrogate decision-making on the part of the potential parents, which includes the issues of the scope and grounds for their decisions; third, there is the issue of genetic essentialism, and whether our genes constitute the essence of our person. The science of genetic alteration is still in its infancy, but the concepts embedded in these questions are not new; they have a rich and complex history in both philosophy and bioethics. I will sketch out my analysis with a look at the scope and

limitations of parental surrogate decision-making as informed by the notion of bodily integrity, returning to the issues of the moral standing of potential persons and genetic essentialism at the end of the chapter.

At first glance, the Ten Fingers Ten Toes argument seems to suggest a possible inconsistency in how reasoning about bodily integrity is applied in the Deaf community regarding cochlear implant surgery and genetic alteration. The issues here are complicated by the question of what counts as bodily alteration. It seems clear that a macro level invasion and shifting of bodily tissues counts as bodily alteration; what is visibly changed to the naked eye – even if it is just a scar and a lump – is evidence that something has been altered. A change of function from pre-alteration to post-alteration also offers us such evidence.

In the case of genetic alteration, this question is more difficult on a number of levels. First, there is the question of what counts as a “body”? Is it any material substance with the potential of becoming a human being? This would seem to include any biological material with a complete copy of human DNA, the blueprint for a particular human being. If this definition is too general, one might want to consider the idea that it must be a cohesive and integrated substance with the potential of becoming human, such as a zygote, blastocyst, embryo, or fetus. Again, there are objections, since a zygote has not yet attached itself to the uterus, and has not yet established a way of sustaining itself, making it similar in some ways to a human hair cell flaked off during hair brushing. The requisite information for life is present, but the potential for this information to be embodied as life involves the artificial work of a laboratory instead of the natural process of human conception.

Suppose for the reasons above, we opt for defining the body in the following way: as an integrated biological substance with human genomic properties that has the potential to become human through natural processes. This definition would include both the embryo and the fetus. Biologically speaking, the distinction between the two involves a change from the emergence of specific body structures to the development of said structures. Or perhaps it is possible that the most cogent definition of what counts as a body is not just what is material, but what most closely resembles a living human being. In this case, the fetus would qualify as having met this definition.

Once the question of defining the body is settled, the next question is at what point, practically speaking, can gene therapy or genetic alteration of the body occur? Is it a matter of some options, such as sex cell genetic alteration pre-zygote stage, being practically foreclosed – though not logically so? Or rather, is it a matter less of options being logically foreclosed as it is a matter of determining what counts as a human body? This is important in the matter of bodily integrity if the position of noninterference put forth in the Ten Fingers Ten Toes argument is to be consistent. If the genetic alteration does not happen to a body, the issue of bodily integrity does not apply.

Bodily Integrity and Bioethics

Before tackling the analysis of bodily integrity and genetic selection, it is important to remember a key difference between the analysis of the genetic selection case described in the previous chapter and the genetic alteration case described at the beginning of this chapter. In the genetic selection case, the problem is assessed through a teleological lens; benefits and disadvantages are weighed in order to reach the conclusion that the advantages of existence outweigh the ‘harm’ of deafness, especially when given

the alternative of nonexistence. It is certainly possible to use this approach of weighing the benefit of existence against the harm of disability for genetic alteration, generating a similar conclusion. One could imagine a scenario in which a couple, intent on bearing a deaf child and unable to avail themselves of PGD, would pursue the only means of technology, genetic alteration, in order to have a deaf child possessing biological material from both parents, but would terminate any pregnancy that was inconsistent with these goals.

Adding the possibility of altering the genetic material of an embryo or fetus raises the question of bodily or genomic integrity. In addition to the Non-Identity problem redux suggested in the previous paragraph, this opens up a deontologically-oriented line of ethical inquiry. There are two reasons why such an analysis may be useful: first, I believe that a deontological analysis of the question of whether children with hearing loss ought to be created is likely to expose a different set of ethical issues for consideration; second, despite the marked difference between teleological and deontological methods in applied ethics cases, it is not unusual for their conclusions to be similar. Exploring possible responses from a deontological orientation to determine whether similar conclusions to the Non-Identity argument are also reached in this case or whether a different answer results may shed some light on the Ten Fingers Ten Toes folk argument used in the signing Deaf community.

Even though I've narrowed my focus in this chapter to deontological analyses of bodily integrity, this still leaves considerable leeway with regard to what kinds of deontological analysis might be most appropriate for this case. Here, I have found the mid-level bioethics approach of principlism helpful, but not for the usual reasons. As

developed by Beauchamp and Childress, principlism relies on weighing and balancing four core bioethics principles with roots in traditional western moral philosophy. These principles are: nonmaleficence, beneficence, justice, and autonomy.¹⁶⁷ Nonmaleficence and beneficence roughly correspond to teleological approaches; justice and autonomy are usually associated with deontological theories, especially if the principle of justice is defined to include rights-based theory. I have chosen not to apply the whole of principlism to the question of genetic alteration, but to focus on the two deontologically based principles of autonomy and justice as a starting point for my analysis of bodily integrity.

The principle of autonomy in American bioethics is most often constructed as respect for persons (so long as their actions do not harm anyone else) or as the right of noninterference with one's autonomous actions.¹⁶⁸ In the first version of the principle of autonomy above, the emphasis is on respect for a person's decisions and actions, provided their action does not cause harm to others. This permits the possibility that one may harm oneself, but prevents one from causing harm to others. In contrast to this, the second definition of autonomy asserts that all people have a right not to be interfered with, provided that their actions are autonomous. In mainstream Anglo-American bioethics, concepts of bodily integrity are often subsumed under autonomy and typically defined in one of two ways, 1) respect for persons (and by extension, respect for their bodies) or 2) self-determination. In contrast, European bioethics and biolaw specifically

¹⁶⁷ Tom L. Beauchamp and James Childress, *Principles of Biomedical Ethics*, (Oxford: Oxford University Press, 2001), 13.

¹⁶⁸ Bernard Gert, Charles M. Culver, and K. Danner Clouser, *Bioethics: A Return to Fundamentals*, (Oxford: Oxford University Press, 1997), 77-8.

mention integrity as a primary principle of bioethics,¹⁶⁹ including bodily integrity within this broader concept.

Dekkers, Hoffer and Wils suggest that western philosophy defines bodily integrity as person-oriented and body-oriented.¹⁷⁰ The distinction between the two relies on how the body is regarded; in person-oriented bodily integrity, the body is considered the property of the person, and only the person to whom the body belongs has authority and control over what can be done to the body. Locke expresses this as a right of noninterference, writing ‘every man has a property in his own person: this no body has any right to except himself.’¹⁷¹ In body-oriented bodily integrity, a person is charged with the duty to maintain her body as a whole. This notion of bodily integrity, as seen in Aquinas and Kant, argues that the intrinsic value of the human body restricts the class of morally permissible actions that can be done to the body.

Person-Oriented Bodily Integrity

The concept of self-determination over the body is well established in medical ethics as the principle of autonomy.¹⁷² A person is granted considerable latitude regarding his health care decisions, even to when those decisions are thought to lead to harm, so long as that person maintains decisional capacity. This right to self-determination over the body is constrained for surrogate decision-makers, who are

¹⁶⁹ Jacob Dahl Rendtorff, “The Second International Conference in Bioethics and Biolaw: European Principles in Bioethics and Biolaw” in *Medicine, Health Care and Philosophy*, (2005) 1 (3): 271. DOI: 10.1023/A:1009992509904

¹⁷⁰ W. Dekkers, C. Hoffer and JP Wils, “Bodily Integrity and Male and Female Circumcision”, *Journal of Medicine, Health Care and Philosophy*, (2005) 8 (2):184.

¹⁷¹ John Locke, *Second Treatise of Government*, ed. C.B. MacPherson, (Indianapolis: Hackett Publishing, 1980), 19.

¹⁷² Beauchamp and Childress, 58.

charged with making decisions regarding another's body using either the standard of the person's best interests or substituted judgment. In the case of parents making decisions about their child's body, since the child has not yet developed a capacity for judgment, the required standard is that of the child's best interests.¹⁷³ If parents are perceived to be acting in a manner other than their child's best interests, their standing as surrogate decision-makers can be revoked (legally, if not morally).

Locke notes that parents are given only temporary rule and jurisdiction over their children until the children have reached the age of reason. Until this occurs, parents have "an obligation to preserve, nourish, and educate the children they had begotten; not as their own workmanship, but the workmanship of their own maker, the Almighty, to whom they were to be accountable for them."¹⁷⁴ The duty of parents is to preserve and enlarge their children's freedom until the children can take it on themselves. Parents are thus constrained in the choices they can make regarding their children's bodies, and may not interfere with the child's life or property, including their bodies.¹⁷⁵ While some may take issue with Locke's premise that parents are ultimately accountable to God for their behavior towards their children, it is not necessary to accept this premise in order to accept the argument that bodies belong to those who inhabit them, and that parents ought to have a limited say in what can be done to their children's bodies, focusing only on those decisions necessary to preserve life. Consequently, these constraints extend to all alterations of the child's body, except those necessary for the preservation of life.

¹⁷³ Beauchamp and Childress, 103.

¹⁷⁴ Locke, 32.

¹⁷⁵ Locke, 36.

The tenets of self-ownership and self-determination offer a highly restricted view of morally permissible decisions that parents can make regarding their children's bodies; one challenge is that this does not accurately reflect the range of parental decisions that actually occur and are permitted under law, if not social custom. These range from only permitting life-saving intervention to cosmetic body modification. Autonomy as self-determination is widely accepted as a central principle governing American bioethics, yet in practice, parental preference frequently supersedes children's autonomy and bodily integrity. In some cases, a child's body may be intervened with in order to reduce pain and suffering; these are potentially justifiable interventions because they improve the quality of life. Purely cosmetic body alterations of the child, such as ear piercing, are widely practiced, though these seem to be clear cases where parental authority has overstepped its bounds and are not morally justifiable according to the principles of self-determination and self-ownership. Determining the moral justification for parental consent to modifying a child's body for cultural reasons would also seem to fall under this category, even when psychological and physical benefits may occur as a result of such procedures. I will consider two such cases, cochlear implant surgery and circumcision.

A person-oriented analysis of cochlear implant surgery must keep in mind the following facts: cochlear implant surgery is elective and not medically necessary; children receiving cochlear implants at a young age are much more likely to benefit from

them in terms of language acquisition;¹⁷⁶ and cochlear implant surgery, as with all surgical procedures, bears a certain amount of risk. The parent considering cochlear implant surgery for her prelingually deaf child will need to consider the issue of bodily integrity, since the process of the surgery involves removing parts of the cochlea from the body, damaging part of the (possibly still functioning) auditory apparatus, and replacing it with an artificial mechanism that permits sound to be processed. The child's physical appearance is not noticeably altered when the child is not wearing the external processor, though attentive people may see a slightly raised area where a magnet has been placed under the skin to facilitate the connection between the internal and external components. Functional capacity for hearing is likely to improve after the cochlear implant surgery; though this outcome is not guaranteed, the psychological benefit that the child receives from being able to hear something is thought to be sufficient justification for parental usurpation of the child's claim to self-determination.

If we take a strict Lockean view of self-ownership and self-determination, parents should not have the authority to consent to cochlear implant surgery for their prelingually deaf child since it is not a matter of life and death. Yet this is a minority view, though one supported by a vocal segment of the signing Deaf community. Instead, the default position in mainstream hearing American society is that parents have the moral authority to consent to this procedure on behalf of their children, despite the elective nature of the procedure. Timeliness of the procedure is often cited as one reason for permitting parents

¹⁷⁶ J.G. Nicholas and A.E. Geers, "Effects of Early Auditory Experience on the Spoken Language of Deaf Children at 3 Years of Age," *Ear and Hearing* (2006) 27 (3): 288.

to make this decision, since early implantation increases the chances of spoken language comprehension and production.¹⁷⁷ Parental conceptions of the good life and human flourishing are also cited as justificatory reasons, though strictly speaking these are not in accord with the narrow Lockean interpretation used above.

In the United States, infant male circumcision is routinely practiced and parents have the authority to consent to the alteration of the child's body. If we consider circumcision solely through the lens of self-determination, setting aside religious considerations, it seems that this is a decision that ought to be made by the child once he is capable of making this decision. Unlike elective cochlear implant surgery, there is no absolute medical indication conferring an advantage to this surgery occurring before the boy is able to express his preferences regarding his body, though medical evidence suggests that some medical advantages of circumcision are related to sexual activity and there may be some advantage to this procedure occurring before sexual activity commences.¹⁷⁸ Person-centered bodily integrity does not support infant male circumcision, since this is an elective surgery that involves the removal of healthy body tissue. Yet the default position on circumcision in mainstream American society is that parents are given the moral authority to alter a child's body without that child's consent. From the narrow Lockean perspective, this is morally unjustifiable, despite the potential medical and cultural benefits.

¹⁷⁷ M.A. Svirsky, S-W Teoh, and H Neuburger, "Development of Language and Speech Perception in Congenitally, Profoundly Deaf Children as a Function of Age at Cochlear Implantation," *Audiology and Neurotology* (2004) 9: 224. DOI: 10.1159/000078392.

¹⁷⁸ S.E. Lerman and J.C. Liao, "Neonatal Circumcision," *Pediatric Clinics of North America*, (2001) 48 (6):1539.

One final consideration for the person-centered notion of bodily integrity is whether any limits ought to be placed on what a person with full decisional capacity may do with his body. The child in each case above may opt for a cochlear implant or circumcision once he reaches the age of reason, and these decisions are largely viewed as within the bounds of autonomy and self-determination of the body, perhaps in part because these already exist as socially accepted practices within the signing Deaf community. Does the right of self-determination extend to any and all action, or are some constraints necessary? Once children have reached the adulthood and/or the age of reason, are they permitted to do whatever they want with their bodies? One answer is the nod Locke gives to madmen – those without reason. Locke claims that one can do whatever one likes with one's body, so long as it doesn't fly in the face of reason. But how is this standard of reason measured? Locke defines it by equating reason with the desire to maintain or improve one's condition: "no rational creature can be supposed to change his condition with an intention to be worse."¹⁷⁹ This doesn't really clear up matters, for one person's improved lot may be another's worse. This is sharply delineated in the recent discussion of apotemnophilia, bodily integrity, and Body Dismorphic Disorder in Scotland, where the decision of surgeon Robert Smith to honor two individual's requests for limb amputation and surgically remove their limbs after psychiatric evaluation, was met with outrage and immediately banned.¹⁸⁰ It also opens

¹⁷⁹ Locke, 68.

¹⁸⁰ AnneMarie Bridy, "Confounding Extremities: Surgery at the Medico-ethical Limits of Self-Modification," *Journal of Law, Medicine & Ethics*, 32 (2004): 148–158.

the door for preferring some kinds of bodily alterations over others, such as those that confer enhancement in the form of increased functioning or improved aesthetics.

Body-Oriented Bodily Integrity

Body-oriented bodily integrity requires a person to abide by the duty to maintain her body as a whole. This argument is not as well articulated argument in the literature on bodily integrity as person-oriented bodily integrity. I speculate that this may be due to more widespread acceptance of the concepts of self-ownership and self-determination; body-oriented bodily integrity relies on philosophical projects that articulate duty in ways that are less familiar in contemporary mainstream American discourse. The philosophical grounding of this duty is dependent on particular definitions of duty – whether Kantian or otherwise.

For the sake of illustration, consider Kant’s description of a universal imperative of duty: “act as if the maxim of your action were to become by your will a universal law of nature.”¹⁸¹ In *The Groundwork of the Metaphysics of Morals*, Kant provides four examples of how one ought to apply this imperative, including the case of suicide. This case has particular relevance for the issue of bodily integrity because it calls on a principle of self-love. In the case of suicide, Kant argues that the principle of self-love is not sufficient to count as a universal law of nature or a perfect duty. The principle of self-love that would encourage one to end one’s life when it is very difficult cannot uphold the duty to further life. Engaging in the various interpretations of Kant’s analysis is

¹⁸¹ Immanuel Kant, *Groundwork of Metaphysics of Morals*, ed. Mary Gregor (Cambridge: Cambridge University Press, 1998), 31.

beyond the scope of this project; instead, I offer a brief sketch of how the principle of self-love might play out in a discussion of duty and body-oriented bodily integrity.

Assume that the principle of self-love is grounded in the desire to experience pleasure rather than pain (physical or psychological). One might infer that this includes the capacity to love the whole of one's physical body, provided that the experience of the body is more pleasurable than painful. Suppose this is not the case, and one's body is subject to more pain than pleasure. Kant has argued that the principle of self-love cannot be employed to support a duty to commit suicide, since it is inconsistent with the law of nature, i.e. sustaining life. If the preservation of one's life depends on breaching the wholeness of the body, this would invalidate the principle of self-love as a candidate for supporting a universal duty to maintain the wholeness of the body. From this example, at least, it seems that the duty of body-centered bodily integrity cannot be a perfect duty that is contingent upon the individual at all times.

In most cases, bodily integrity is not a matter of life or death, but a matter of whether one opts to exist with one's body unaltered or altered. In the two cases of cochlear implant surgery and neonatal circumcision, a straightforward interpretation of body-centered bodily integrity suggests that body parts, such as hair cells within the cochlea or the foreskin, cannot be removed, altered, or damaged. In sketching out the reasons why body-oriented bodily integrity is not a perfect duty, I have left open the possibility that it may be an imperfect duty – one that applies under some conditions, but is not universal. One way to assess this is to enumerate the conditions upon which one might be justified in breaching the duty to preserve the wholeness of the body. Preservation of life appears to be an excellent candidate for this list of conditions

(provided that one accepts the premise that the preservation of life is, all things considered, generally a good thing). What other criteria might count as good reasons for breaching the wholeness of the body? In particular, for those who are not able to consent for themselves, such as children or those otherwise incapacitated, what reasons could be appealed to by surrogates making decisions based on body-oriented bodily integrity in order to satisfy a duty to preserve the wholeness of the body?

One approach is to consider how wholeness of the body is defined. If this means a strict accounting of the presence of physical components at birth or another designated moment in time, body wholeness is simply a matter of counting. But wholeness of the body need not be limited to anatomical parts. If wholeness of the body is defined as functional rather than anatomical, and functional is further defined as species-typical functioning, this opens up other interpretations. Consider the cochlear implant, which is a medical procedure designed to restore species-typical functioning. By this interpretation, cochlear implant surgery could be viewed as an attempt to return the body's function to wholeness, thereby satisfying the duty to maintain one's body as a whole through functioning.

Yet another interpretation of body-centered bodily integrity could rely on a cultural conception of what it means for the body to be whole. The Jewish ritual of Brit Milah, in which infant males are circumcised eight days after birth, considers the act of circumcision a sign of the covenant between the male descendants of Abraham and God. The uncircumcised body is viewed as incomplete or flawed from this cultural conception,

since the male who is not circumcised is outside of the community.¹⁸² Through the act of circumcision – a body altering act – the infant becomes whole, that is, a full-fledged member of the community.

This brief treatment of body-oriented bodily integrity shows that this approach needs further refinement and analysis. Imposing a duty of bodily integrity relies on an adequately articulated argument of what it means to have a duty toward one's body, how that duty is justified, and accounting for the scope of that duty. It also requires that terms such as "body" and "wholeness" are delineated and consistent with the concepts of duty that are employed.

The discussion of bodily integrity has focused on the macro level of the body. Procedures such as cochlear implant surgery and male infant circumcision result in changes that are visible to the naked eye or by equipment that allows one to view the internal workings of the body, such as X-ray equipment or magnetic resonance imaging machines. There is no reason why discussions of changes to the body should not also include changes that are quite small; surgeries using microscopes and or lasers can also change the body from its original state – including at the cellular level. Does this extend also to one's genes? Genetic material is physical; changes in this material can be observed with the proper equipment. Do genes, by virtue of their properties, deserve special consideration?

If an argument of composition is employed, the answer to the question of whether bodily integrity extends to genes is a solid yes. Genes are part of the physical substance

¹⁸² Gen. 17.9-14 NRSV.

of the human body; as physical parts of the human body they are also subject to bodily integrity, regardless of whether person-oriented or body-oriented frameworks are employed. Setting aside the question of whether genes ought to be accorded special status for now, how might this notion of genomic integrity play out in the context of bodily integrity? Are there any issues unique to genomic integrity that do not occur with bodily integrity?

The bodily integrity discussion up to this point has focused on the bodily integrity of actual persons. Whether those persons are adults who are capable of making decisions in accordance with reason or children who are incapable of making decisions, their moral status as individuals whose claims, present or future, to self-ownership, self-determination, and autonomy, are readily granted from a rights-based perspective. By defining the body to include the whole of one's genetic material, decisions about this for actual persons, including children, who are subject to surrogate's decisions regarding their bodily integrity, would be subsumed under the criteria of bodily integrity, whether person-oriented or body-oriented. To distinguish genetic alteration from all other body alterations, let's call this genomic integrity. Just as this holds for those with bodily integrity, individuals who possess genomic integrity are considered to have self-determination and self-ownership over their genetic material. Granted, ownership of one's own genetic material is a contentious and unsettled issue in the courts and is an issue that extends beyond the scope of this project. For the purposes of the discussion of genomic integrity assume a simple claim to one's genetic material as one's own, setting aside issues of whether an individual who adds his work can lay claim to this as well.

If genomic integrity is viewed as simply a subset of bodily integrity, the discussion of genomic integrity could be framed according to bodily integrity issues – self-ownership of one’s genetic material, self-determination, and a duty to wholeness. Actual persons making decisions about whether to modify their genetic material could appeal to some or perhaps all of these concepts in working out their reasoning. Surrogates making decisions for actual persons, such as children, could also appeal to these concepts for justification. Parents considering genetic enhancement for their children could appeal to these concepts. How bodily integrity, or genomic integrity, might apply to potential persons and those making decisions for potential persons is trickier. The following section offers some suggestions for exploring this issue.

Moral Standing of Potential Persons

Bodily integrity arguments do not completely foreclose or expressly permit moral justification to culturally Deaf parents who wish to modify the genetic material of their potential offspring. The person-oriented approach to bodily integrity emphasizes self-determination, autonomy, and a right to not to be changed without consent. The body-oriented approach to bodily integrity emphasizes wholeness of the body, but various answers emerge, depending on whether that wholeness is constructed through notions of duty, anatomical wholeness, functional wholeness or cultural wholeness.

The discussion of bodily integrity up to this point has relied on several concepts that may not be a good fit when applied to the issue of genetic alteration. The most important question is whether the issue of bodily integrity and genomic integrity can be said to apply to a potential person. If the answer to this is yes, culturally Deaf potential parents making decisions about whether to modify genetic material of a fetus, embryo,

blastocyst, morula, or fertilized ovum could consider these concepts in determining the moral justification for their decision. In this section, I attempt to sketch out of the reasoning that needs to be evaluated in order to answer this question.

To start, working definitions of a potential person, surrogate decision-maker, and actual person must be established. Once the criteria for defining for a potential person are addressed, the issue of when a person assumes the role of a surrogate decision-maker can be addressed. Parental surrogate decision-making regarding bodily alterations of their children typically occurs in the context of actual children, not potential offspring, but this is not always a bright line. Bioethical discussions surrounding consent procedures for fetal surgery have raised questions about autonomy – specifically weighing the woman’s autonomy claims and bodily integrity against the fetus.¹⁸³ At the present time, fetal surgery is reserved for interventions that are “life-saving,” though even the use of this term is problematic, since it disregards the fact that the fetus is not capable of sustaining life on its own and therefore does not yet have a life to be saved. Fetal surgery could be considered a potential violation of bodily integrity, if this concept applies to potential persons.

In the special case of applying genomic integrity and genetic alteration to potential persons, this analysis is limited to the fetuses, embryos, blastocysts, morulas, zygotes and fertilized eggs (before and after implantation). For purposes of this discussion, assume the physical matter of the fertilized ovum, zygote, morula, blastocyst, embryo, or fetus is concomitant with the concept of potential person. Additionally,

¹⁸³ Anna Smajdor, “Ethical Issues in Fetal Surgery,” *Journal of Medical Ethics* 37 (2011): 88-91, accessed December 10, 2010, DOI:10.1136/jme.2010.039537

assume the potential person is incapable of an independent existence at the time of genetic alteration.

Some literature on the moral status of potential persons deals with the distinction between same person problems and different person problems.¹⁸⁴ Since genetic alteration must, by definition, deal with a particular clump of cells, for now I will treat this as a same person problem, holding off on the question of whether some genetic alterations might be significant enough to transform this into a different person problem. (The section immediately following this one will address that issue.)

At this point, a working definition of a potential person includes the existence of conjoined living human tissue that has the capacity to develop into a human being, provided that it is placed in an environment that permits this development, plus the inability of this conjoined living human tissue to sustain itself independently before its development reaches fruition or is born.

Assessment of the moral standing of such a potential person can be conducted at various stages of development. I will start at the most primitive stage of development, reasoning that if moral standing can be given to a fertilized egg, then the argument for this can be extended to more developed forms such as zygotes, morulas, blastocysts, embryos, and fetuses.¹⁸⁵ Arguments that claim the moral standing of potential persons

¹⁸⁴ Parfit, *Reasons and Persons*, 351-5; Brock, "The Non-Identify Problem and Genetic Harms," 272-4; Häyry, "There is a Difference Between Selecting a Deaf Embryo and Deafening a Hearing Child," 510-511.

¹⁸⁵ The term fertilized ovum is something of a misnomer, since upon the complete conjoining of sperm and ova, the body becomes a zygote. I use it here to refer to the earliest possible moment in which human biological material takes on the potential for existence as a unique individual.

occurs at the moment of conception begin with the fertilized egg. One class of these arguments appeals to the sanctity of human life, claiming that the moral standing of a fertilized egg is equivalent to that of an adult human being. Given that there is no clear point along the continuum from conception to human biological maturity that demarcates the start of personhood, one should regard the entity at the earliest stage of human conception as having the same moral status as adult humans.

This argument is vulnerable to several challenges. The first is that there is a significant difference between a zygote and an adult human being, analogous to the difference between an acorn and an oak tree.¹⁸⁶ Another objection is that the inability to identify a specific moment in time when personhood is conferred does not entail that fertilized eggs are human beings. Even the answer that personhood begins at birth is not sufficient, since this opens up the objection of the moral permissibility conducting medical research on a late term fetus, i.e. one that is less than 24 hours from its due date.¹⁸⁷

Other arguments that attempt to confer moral standing are consequentialist in nature. S.I Benn proposes using infants as the entity that is granted moral standing and reasoning backwards to extend this standing to fetuses. His reasoning runs like this - if infants are treated with love and consideration, this will result in the good consequences for them as adults. Joel Feinberg expands Benn's argument to include the reduction of

¹⁸⁶ Michael Sandel, *The Case Against Perfection: Ethics in the Age of Genetic Engineering*, (Cambridge, MA: Belknap Press of Harvard University Press, 2007), 116-7.

¹⁸⁷ Sandel, 117.

harm – noting that those infants who are treated with love and consideration are less likely to cause harm to others.¹⁸⁸

What I find most interesting is Benn’s move from treating infants with special consideration to treating the fetus with special consideration. Strong notes that Benn restricts this to that moment in which “we can reasonably associate the way we treat them with the way we treat babies – at a stage, that is, at which we think of them, vividly enough, as a baby in the womb.”¹⁸⁹ At what point does one “reasonably associate” treatment of a zygote, morula or embryo with the way one treats babies? Given that the heartbeat of an embryo can be ascertained at seven weeks and potential parents avail themselves of frozen embryo adoption services, this is less clear than it was when Benn developed his argument. For some of these potential parents, listening to the heart beat of their embryo initiates the point at which they begin to think of them as babies; for others, this point may be marked by the decision to preserve unused embryos (which are technically not embryos but blastocysts) in hopes of having them be “adopted” by loving families.¹⁹⁰ While it may be that the loving and considerate treatment accorded to infants is most often extended to late term fetuses, the language used by those working with frozen embryo (blastocyst) donors seeking to place their embryos (blastocysts) with families that will provide homes where the formerly potential child is loved and cared for suggests that this is not easily delineated.

¹⁸⁸ Carson Strong, “The Moral Standing of Preembryos, Embryos, Fetuses, and Infants” *Journal of Medicine and Philosophy* 22 (1997): 463-4.

¹⁸⁹ *Ibid.*

¹⁹⁰ “Snowflakes Frozen Embryo Adoption and Donation Program”, Nightlight Christian Adoptions, accessed December 20, 2010. <http://www.nightlight.org/adoption-services/snowflakes-embryo/default.aspx>.

Adrienne Asch's work on the distinction between any embryo and particular embryos provides another useful lens for interpreting this. In writing about preimplantation genetic diagnosis and screening for traits associated with disability, Asch argues that acquiring knowledge about the traits of a blastocyst or an embryo influences how that potential parent will regard it. Prior to the acquisition of this knowledge, the potential parents regard the blastocyst or embryo as an unopened book, albeit one that is desired. This is referred to as "any" embryo. Once information about one or more physical traits is revealed, the potential parents may shift their thinking about their potential offspring based on its particular traits.¹⁹¹

For some potential parents, genetic testing of a blastocyst before implantation (preimplantation genetic diagnosis) might be the moment at which they begin to regard their potential offspring with love and consideration. The conception of a savior sibling - one selected for specific genetic material whose body tissues could be harvested to save the life of an already existing sibling - might be regarded in this way. Parents who have lost their only two children to a recessive genetic condition might regard their successfully implanted and screened embryo with love and consideration, especially if it is thought this may be their last chance at biological parenthood. One could envision a culturally Deaf couple making a similar argument for genetically altering their embryo to obtain genes associated with deafness, based on the love and special consideration that particular child would receive as a cherished member of the signing Deaf community.

¹⁹¹ Adrienne Asch and Erik Parens, "The Disability Rights Critique of Prenatal Genetic Testing," in *Prenatal Testing and Disability Rights*, ed. Erik Parens and Adrienne Asch, (Washington, DC: Georgetown University Press, 2000), 15.

The consequentialist argument is subject to at least one more objection, which is the difference between regarding something with love and consideration and treating something with love and consideration. Regard is a one-way street; regarding something with love and consideration can be passive, or at least not require that specific action(s) take place. Treatment seems to imply action and reciprocity – one treats, and another is the recipient of that treatment. One can demonstrate love and consideration by certain actions with an infant – ensuring that the infant is not hungry, or is dry, or is warm. It is arguable that treatment of a fetus is also possible – pregnant women often note that certain environmental conditions are correlated to increased fetal movement and will respond to this by changing those conditions. As an example, one may note that being in the presence of very loud rock music is correlated with increased fetal activity; this activity settles down to a more normal level when the music is turned off. Infant and fetus behavior can be quickly assessed in response to actions that are treated as loving and considerate. Actions that are loving and considerate and occur before quickening cannot be measured for reciprocity at that time. While this does not demolish the consequentialist argument, it does point out the need for a more refined distinction between the acts of treating something or someone with love and consideration and regarding something or someone with love and consideration.

Much of the remaining literature regarding the moral status of potential persons centers on claims to existence, and not claims to bodily integrity or alteration. This is particularly the case when the discussion focuses on living physical matter that is human, such as fertilized ova, embryos and fetuses. The issue of existence is obviously an important and related one for proponents of bodily integrity; if the physical material in

question has moral standing as regarding claims to existence, whether rights-based or founded through some other approach, the door is opened to bodily integrity arguments. If the physical matter under evaluation is not granted moral standing, the (potential) person-oriented bodily integrity approach as it currently stands fails, since to lose moral standing relegates this physical matter to property status and property cannot assert claims of autonomy or self-determination. The failure of moral standing does not generate as clear results for the results for the body-oriented bodily integrity approach. As traditionally defined, duties are incumbent only upon moral agents. However, moral standing does not entail moral agency or even the potential for moral agency. One could assert a body-oriented bodily integrity approach without requiring moral standing for that body, appealing to a duty to maintain wholeness in certain kinds of living tissue, for example.

I have reviewed three basic approaches to conferring moral status to potential persons; the sanctity of life argument, the human development continuum, and a consequentialist argument. Each of these arguments is subject to significant objections when considering whether fertilized eggs, zygotes, blastocysts, morulas, embryos or fetuses have moral standing. If the concept of bodily integrity and/or genomic integrity is applied to potential persons, the above arguments for moral standing have not provided a solid foundation.

Genetic Essentialism and Identity-Determining Traits

Are genes special? Genes are bits of physical matter that contain the blueprint for building a human being. This is not to assume genetic determinism – genes are not always sufficient for creating a particular phenotype or physical expression, though under

most normal conditions one can assume a genotype-phenotype pathway.¹⁹² Some of the questions that are raised by the unique nature of the genes' function include the following: are genes our essence? Are some genes identity-determining? What constitutes an identity-determining trait – culture alone or a mixture of culture and biology? What are identity-determining traits?

As a reminder, for the purposes of simplification, imagine all instances of genetic alteration for deafness involve just the alteration of one gene, resulting in a fertilized egg having the potential quality of becoming deaf rather than hearing. Jeff McMahan creates a scenario in which he imagines genetic alteration occurring and that alteration is identity-determining. Just what would an identity-determining genetic modification be?

McMahan notes that any genetic alteration that moves towards cure or normalcy would be identity-preserving.¹⁹³ In making this move, he has limited identity-determining traits to those that are associated with disability. But is disability alone sufficient for determining identity or must the trait associated with disability confer a significant difference in functioning or capabilities? Colorblindness, while not satisfying the conditions of species-typical functioning, is probably not identity-determining. Blindness, on the other hand, just might be identity-determining. For one, the blind person is more easily and immediately *identified* as different by the way in which she navigates her environment; the colorblind person may be able to pass as having species-typical

¹⁹² See Jonathan Michael Kaplan, *The Limits and Lies of Human Genetic Research: Dangers for Social Policy*, (New York: Routledge, 2000) for an interesting discussion of how the case of PKU underdetermines genetic determinism, 12-21.

¹⁹³ Jeff McMahan, "Causing Disabled People to Exist and Causing People to Become Disabled," (2005) *Ethics* 116:77-99.

functioning until a specific instance occurs that reveals his colorblindness. If colorblindness were caused by one gene, altering that gene would bring the colorblind person closer to cure; this genetic alteration would be identity-preserving, to use McMahan's language. If the blind person experienced a gene replacement that allowed her to become sighted, this too would be an action that brings the blind person closer to a cure, and would also be considered identity-preserving. However, it has also significantly changed the way in which the formerly blind person experienced the world. In this case, has the formerly blind person been replaced by a different person, or is the newly sighted person one and the same person?

Perhaps this example is problematic because it deals with persons who are already in existence. Let's modify this example to a blastocyst that has the potential trait of being colorblind, but that has been altered to have the potential for species-typical color-sightedness. The entity in question, according to McMahan, has had its identity preserved through this alteration. Now imagine a blastocyst that carries a gene for blindness, and is altered so that it has the gene for sightedness. In the absence of experience, the identity-preserving claim loses some of its force. How can an entity that is incapable of experience preserve an identity when its potential properties have significantly changed?

One response to this question is that the concept of identity is centered on species-typical functioning and not the act of changing one gene. One's identity is determined by how far away one's ability to function strays from what is typical for the species. Imagine a circle in which the typical species members are in the core, and those with atypical functions reside far away from this. By this account, the genetic alteration that brings one

close to the center is curative and those alterations that cause one to diverge extensively from the center are problematic.

Yet where one situates the center has much to do with experience and cultural norms. In *Deaf in America*, Carol Padden and Tom Humphries provide an example of the *really* hard-of-hearing woman. From the Deaf perspective, a really hard-of-hearing person is someone who can use the phone and tends to behave more like a stereotypically hearing person than a deaf person. From the hearing perspective, someone who is really hard-of-hearing is much more like an audiotically deaf person (one who struggles to hear). For the Deaf potential parents who use genetic alteration to ensure the birth of a deaf child, the center is Deaf and the periphery is hearing.

Is identity determined only by functional characteristics or are other kinds or physical characteristics also in the running for identity-determination? Let's assume that an identity-determining trait is one that is on the periphery of species-typical functioning, but that a set of potential parents wished to maintain their embryo's species-typical functioning, but alter the potential physical appearance of their future child, giving the child dark brown skin and eyes. The child is born in a location where prejudice based on skin color exists. Has that child undergone an identity-determining alteration?

One of the difficulties in using the identity-determining concept is that the identity of culture and the identity of number are often conflated. By changing one's physical appearance, one may experience a very different way of being in the world. Likewise, by changing a significant functional trait, one may also experience a different way of being in the world. And sometimes identity can have both a cultural and a physiological component. In the case of gender, biological sex can drive identity.

Adrienne Asch argues that one functional characteristic does not determine identity, and that decisions to alter or abort an embryo because it carries one undesirable trait are not well-founded since any individual, upon birth and gaining some experience in the world, is going to have a compilation of species-typical and atypical functionality. The decision to genetically alter those characteristics that are species-atypical expresses an attitude about disability that Asch views as prejudicial and lacking respect for the individual. She does not use the language of “bodily integrity,” yet her concept of respect for the entire being seems to be not very far from the body-centered bodily integrity discussed earlier in the chapter. Asch consistently applies this concept of respect for the whole person, arguing that to use genetic alteration to create a person with a disability is as wrongheaded as using it to create an able-bodied person, ultimately undermining the willingness to accept all people and treat them with respect.¹⁹⁴

The arguments of McMahan and Asch provide some answers to the question of whether genetically altering an embryo to make it deaf is morally justifiable. On McMahan’s account, since this action takes the embryo further away from species-typical functioning and does not move toward a cure, it is unjustifiable. For Asch, any act of genetic alteration is morally unjustified, precisely because it is grounded in a lack of acceptance and respect for people with differences, including disabilities. Even though the couple wishing to use genetic alteration to bear a deaf child would seem to support Asch’s claim about respect for differences, her argument is that ultimately any form of genetic alteration undercuts respect for human diversity.

¹⁹⁴ Asch, “Disability Rights Critique,” 14.

Conditions of Exit Objection

The previous section evaluated the moral justification of genetic alteration from the standpoint of the action of altering the gene, that is, genomic integrity. In this next objection to genetic alteration, the moral evaluation is consequentialist. Determining whether genetic alteration is morally permissible depends on the consequences available to the person whose genes were altered.

Ravitsky argues that parents have been shaping children for a very long time; genetic alteration is seen as just another tool by which parents can raise their children according to their vision of what it means to have a flourishing life.¹⁹⁵ William Ruddick provides an analogy where parents are both guardians and gardeners.¹⁹⁶ Ronald Green offers a similar account, saying that parents are charged with protecting the future interests of their children, but they also raise their children to satisfy aims of their own. Ravitsky's Conditions of Exit argument requires parents to strike a balance – allowing them to shape their children up to a point, but drawing a line when the children's future interests appear to be curtailed. Unlike Davis's argument arguing for the Child's Right to an Open Future, Ravitsky's scope is narrower, and hones in on whether a child who has been genetically altered would be able to leave her cultural community or whether her altered genetic make-up would make this prohibitive.

¹⁹⁵ Vardit Ravitsky, "Genetics and Education: The Ethics of Shaping Human Identity." *Mount Sinai Medical Journal* 69 (5): 312.

¹⁹⁶ William Ruddick, "Parents and Life Prospects", in Onora O'Neill and William Ruddick, eds., *Having Children: Philosophical and Legal Reflections on Parenthood* (New York: Oxford University Press, 1979), 124-137; Ronald M. Green, *Babies By Design: The Ethics of Genetic Choice* (New Haven: Yale University Press, 2007), 125.

Ravitsky amplifies an argument about autonomy-based liberalism and communities within liberal democracies from Joseph Raz, appealing to an argument about Amish and ultra-orthodox childrearing practices to ground her argument. When a cultural community does not permit sufficient autonomy, particularly around children's future liberties, that cultural community has closed off the ability for children to easily leave. Ravitsky proposes that the state has a duty to protect the child's future mobility; additionally, she frames the parents' obligations as mediating between the child's right to belong to a cultural community and the child's right not to be trapped in that community as a adult.

Is the Deaf community one in which the genetically altered Deaf child might be trapped? Consider the choices faced by the potential parents in the genetic alteration case. If they decide against genetic alteration and continue the pregnancy, they will have a hearing child who is born into the signing Deaf cultural community. This child would be able to move into the non-Deaf community fairly easily, because she would have the ability to hear and speak and interact directly with the non-Deaf community without any assistance.¹⁹⁷

If the Deaf couple proceeds with genetic alteration, they will bring a deaf child into a signing Deaf cultural community. Provided that the child receives a bilingual education, and acquires the ability to write and read and otherwise communicate in the language used by the non-Deaf community, that child will also be equipped with the cultural mobility skills needed to leave the signing Deaf community. Additionally, it is

¹⁹⁷ Levy makes a similar point in "Deafness, Culture, and Choice," 284.

extremely likely that the Deaf child will learn from her Deaf parents how to navigate the non-Deaf world. The Deaf case differs from Ravitsky's religious cases because the Deaf cultural community does not have a set of carefully prescribed norms as to how a Deaf child ought to be educated; it also differs in that the lack of species-typical functioning makes it more difficult for the Deaf child as a grown adult to function with ease in the non-Deaf world.

There are two other practical options for the Deaf adult who wishes to enter the non-Deaf world. One is to obtain a cochlear implant, which is an invasive surgical procedure with all the risks surgery entails. Not all culturally Deaf people would be willing to make this decision. The other option is a particularly American solution, which is to use the federal laws that secure accessibility for Americans with disabilities (including Deaf people), particularly for employment and educational situations.¹⁹⁸ This is another distinction (though not a moral one) between the religious cases and the Deaf case; the Deaf have greater legal recourse should they want to gain access to the non-Deaf society.

Further Considerations

I have not said much about reproductive liberty and genetic alteration. Part of the reason for this is because this particular example of genetic alteration presumes that one has reproductive capability. Unlike genetic selection, which relies on IVF with PGD, and could pose a scenario of a couple who is faced with selecting no embryos for implantation (since they all have genes that correspond with being deaf) or having a deaf

¹⁹⁸ These laws include the Americans with Disabilities Act, as well as other laws ensuring access in education, transportation, and telecommunications.

child, the example of genetic alteration offers three different outcomes, none of which constrain reproductive liberty. Either they opt for genetic alteration and bear a child who is deaf (as they desire) or they opt to continue the pregnancy with the embryo intact (hearing) or they opt to terminate the pregnancy. Unlike the genetic selection case, which could deny reproductive liberty to the couple based on the genetic (deaf) status of each of their embryos, insofar as the right to reproduce is concerned, reproductive liberty is not threatened in the genetic alteration example.

I began this chapter with the aim of reconciling some of the arguments I have seen used in the signing Deaf community, namely the Ten Fingers, Ten Toes argument and the supporting right to bodily integrity, to see if these could offer moral justification to genetic selection. After working through person-oriented and body-oriented bodily integrity, the path to moral justification became more difficult. With person-oriented bodily integrity, grounding the right to have one's body altered was a challenge; with body-oriented bodily integrity, the difficulty was generating an argument for the wholeness of the body that provided consistent reasoning support for one's decision to modify genetic material. I considered the concept of genomic integrity as a possible extension of bodily integrity, and I identified several questions that must be addressed regarding this issue. Additionally, several objections to genetic alteration were considered, including the role of bodily integrity with genes that are possibly identity-determining, and the question of how much parents may be morally justified in shaping their child through physical and other means via the Conditions of Exit argument.

While utilitarian calculations weighing and balancing harms with benefits generate the conclusion that genetic intervention to create hearing loss is morally

permissible, Kantian and deontological approaches relying on notions of respect for persons and bodily integrity generally lead to a different result. At this point, the answer to the question, “is it morally permissible to bring about the birth of a deaf child?” is mixed.

Chapter 5: Deafness As Moral Harm

Deafness and Moral Harm

In Chapter One I held out a promissory note regarding the question of deafness as a moral harm. This chapter is my attempt to satisfy this promise. Since I have limited my analysis of genetic selection and genetic alteration to cases that involve culturally Deaf potential parents who wish to bring Deaf children into the world, my discussion of harm likewise focus on identifying potential harms experienced by or conferred upon the signing Deaf population. This will, in some cases, include the potential harms associated with the auditory classification of deafness, since I believe that audiological deafness is a necessary condition of being Deaf. Even though there is a much larger population of deaf people who are not associated with the signing Deaf community and who do experience harm as a consequence of being deaf, the kinds of harms this population may experience is not directly addressed. It should be noted that some of the harms experienced by signing Deaf people are also experienced by oral deaf people, including those who use cochlear implants.¹⁹⁹

When signing Deaf people talk about the kinds of harms they experience, a term that frequently emerges is audism, which is signed by the hands marking off a square around an ear, first sketching the top and bottom of the square, then flipping to mark the sides. In boxing off the ear, making it the sole and central focus, one begins to see how members of the signing Deaf community might regard those who are outside their community. For this population, the harm comes from being regarded by what one is

¹⁹⁹ Cochlear implant users may or may not use a signed language.

missing, by what one cannot do with that boxed-off ear. The sign is in some ways just as ambiguous as the question of whether deafness is a moral harm.

What exactly is harmful about deafness? Where is the harm located? Is it a moral harm or some other sort of harm? Most discussions of this issue assume that the notion of physical disability is sufficient for naming deafness as a moral harm.²⁰⁰ In asking whether deafness is a moral harm, several questions are conflated into one. These need to be unpacked and identified as discrete questions. The question may mean whether one is harmed by being in the physical state of audiological deafness because one does not have access to species-typical functioning. It may be that one is harmed because one does not have sufficient access to information. It may be that one is harmed because one is a member of a sociolinguistic minority group. It may be that one is harmed because one is identified as a user of a different language mode (signed rather than spoken), a class of languages that are frequently viewed as less than spoken languages. Indeed, they are sometimes insultingly referred to as monkey languages, implying that the users are subhuman.

Furthermore, the harms resulting from the experiences associated with the state of being Deaf can be addressed in various ways. How one acquires the property of audiological deafness, which is a necessary condition for being Deaf, is one angle from which to evaluate this claim. That is, is harm partially located in *how* deafness is acquired? This project has focused on genetic means of acquiring the state of audiological deafness, yet deafness has many causes, including illness and accident, as

²⁰⁰ See Brock, “The Non-Identity Problem;” Harman, “Can We Harm;” Harvey, “Reproductive Autonomy Rights;” and Levy, “Deafness, Culture, and Choice”.

well as those that cannot yet be explained. Whether deafness is imposed deliberately on the individual once that individual begins to exist, as might happen through genetic alteration if we take existence to begin at some point after conception, or whether deafness is imposed prior to existence (if existence starts at some point after genetic alteration takes place) is another issue that must be considered.

This brings me to the question of moral agency and its role in moral harm. If moral harm requires an agent who deliberately acts to inflict harm, then only those cases in which a decision occurs to bring about the birth of a deaf child are potentially harmful. That is, provided that deafness is a harm. These cases would not only include genetic alteration, but also any case in which biological parents contributing genes that they know will result in the birth of a deaf child. Yet, if a couple know from genetic testing and counseling that they will bear only deaf children, the reality for that couple today (since genetic alteration is not possible at this point in time) is that they are faced with the choice of either creating a deaf child or using biological material that is at least partially not their own to create a child or not having children at all. If the couple does not have the economic resources for pursuing reproductive technology, their options may be to have a deaf child or to have no child. Questions of moral harm in this case not would only extend to the potential harm caused to the deaf child but also to the potential parents' reproductive liberty.²⁰¹

²⁰¹ For further discussion of this topic, see John Robertson, *Children of Choice: Freedom and the New Reproductive Technologies*, Princeton, New Jersey: Princeton University Press, 1994.

What limitations or harms might be imposed by society? Other kinds of moral harm associated with being Deaf are harms dependent on the social construction of disability. If the society is set up in such a way that people with disabilities have access to public activities and can participate in these without barriers, the effects of social harm caused by disability status have been reduced. If, on the other hand, a society is structured such that a Deaf person cannot vote, serve on a jury, drive, reproduce (due to state-enforced sterilization or birth control), work, acquire an education, attend accessible sporting or cultural events, or travel on one's own, these are harms created by society and not a logical consequence of deafness or the state of being Deaf.

If there is no agent culpable of inflicting harm, can the state of being deaf be properly described as a moral harm? Once the cause of deafness has been identified and attributed, another issue emerges – the doctrine of double effect. This refers to the idea of harm that is knowingly imposed, but it is an unintended consequence of another action. An example of this is the infant who is deafened as a result of ingesting life-saving antibiotics. The action of giving the infant life-saving treatment had an intended consequence of saving her life, and an unintended consequence of causing her to become deaf. Assigning moral responsibility here is tricky, since the consequence of deafness could be predicted, but the reason for giving her antibiotics is tied to saving the infant's life, not causing deafness.

There are other examples where the causation of deafness is not intended, but is associated with the actions of individuals. These cases do not always satisfy the requirements for the doctrine of double effect. Consider the child who becomes deaf in a car accident, or a hearing couple who, unbeknownst to them, each carry a copy of a

recessive gene for deafness. In the case of the child deafened by an automobile accident, the cause of the accident may have been a mechanical failure or a driver operating under the influence of mind-altering substances. If the accident was caused by a moral agent, but unforeseen, it does not satisfy the conditions of the doctrine of double effect. This is also the case for the hearing couple with no reason to think that they might bear a deaf child. If the couple does not believe that there is a good reason to avail themselves of genetic testing and foregoes this, yet acts in a way that results in the birth of a deaf child.²⁰²

Another question is whether harm should be located in the experience of living as a Deaf person. Are there harmful consequences resulting from belonging to the signing Deaf community unique to one's status as a member of this community? This question has been addressed in Chapter Three through via the Right To An Open Future argument, and also in Chapter Four in the Conditions Of Exit argument. In the Right To An Open Future argument, the harm of being Deaf is tied to the harm of belonging to a small and limited social community, and consequently having limited opportunity.²⁰³ The Conditions Of Exit argument locates harm according to the restrictiveness imposed by the community.²⁰⁴ That is, if the child is shaped, physically or otherwise, in such a way that she cannot leave the Deaf community and join another (Hearing) community, she has suffered harm.

²⁰² Amy Harmon, "As Gene Test Menu Grows, Who Gets to Choose?" New York Times, July 21 2004.
<http://query.nytimes.com/gst/fullpage.html?res=940DEED8113AF932A15754C0A9629C8B63>

²⁰³ Davis, "Genetic Dilemmas", 9-10.

²⁰⁴ Ravitsky, 315-6.

I have offered specific objections to these accounts in Chapter 4, and so will not repeat them. There is another important question to be considered with these objections – what does it mean to say that a Deaf person lives in the Deaf world? As this is described by Davis, it depends on two assumptions: that Deaf people inhabit the Deaf community and do not simultaneously inhabit Deaf and hearing worlds; and that Deaf people do not leave the Deaf community on a permanent basis. It is unusual for a signing Deaf person to cut off all ties with the Deaf community, but there are those who have made this decision. More common is the decision of some Deaf people to obtain cochlear implants, which enables them to move more easily between Deaf and hearing communities, something Deaf people have done their entire lives. Others getting cochlear implants decide to base the majority of their life experiences in the hearing world and significantly reduce their contact with the Deaf community. Still others never consider leaving the signing Deaf Community – not because it is easier or more accessible, but because it is home.

Harm Caused to the Deaf Individual

Just how might the moral harm of deafness be calculated? Is it the change of audiological status from hearing to deaf that denotes harm? The loss of the capacity to hear? The social prejudice (audism) experienced by Deaf individuals? The absence of species-typical functioning? Each of these explanations has been proposed as a way of

assessing the moral harm of deafness, but a careful analysis of the moral harm of deafness and the state of being Deaf has been mostly neglected.²⁰⁵

One explanation for deafness as a moral harm is to consider any variation from species-typical functioning as harmful. This could include a change in physical status harmful, depending on the particulars. For example, a healed broken wrist that has healed with a limited range of motion is such a harm, given that a person's ability to function have been constrained.

This is in many ways a good analogy for audiological deafness since it emphasizes the concept of range, which is often neglected in discussions about genetic selection and alteration. Most Deaf people have some residual hearing; profound audiological deafness is rare. The person who experiences a change in audiological status may go from being hearing to being moderately hard of hearing or to being severely deaf over the course of several decades or in a matter of days. Species-typical functioning is not static; functional abilities change over the course of a lifetime. Given this, how does one measure species-typical functioning? Does this pose an incommensurability problem? If harm is equivalent to loss, and loss is variable, how might the standard for harm be calculated? Is deafness always a significant harm, or are there some circumstances in which deafness might be considered a trivial harm?

²⁰⁵ Anita Silvers, David Wasserman, and Mary B. Mahowald, *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Policy* (Lanham, MD: Rowman and Littlefield, 1998), 85-91. See also Melissa Seymour Fahmy, "On the Supposed Moral Harm of Selecting for Deafness," *Bioethics* (2011) 25 (3): 128-136 for one treatment of this issue.

The question of who or what can experience a loss is another issue attached to the issue of moral harm. In the case of genetic selection, there is no loss experienced by the embryo selected for existence. That embryo's genetic material is unchanged, and absence, not loss, is the proper description. With genetic alteration, change has taken place, but the question now shifts to whether existence as a person or potential person is a condition for satisfying the conditions of loss. This suggests that perhaps defining harm in terms of loss is incomplete. Those who never experience a change of status from hearing to deaf cannot claim to have lost something they never had. Their claim is better described as an absence of species-typical functioning. Is harm more comprehensively defined as lacking a species-typical function?

The absence of species-typical functioning in one capacity does not preclude species-typical functioning in other capacities. It also does not foreclose the possibility that one may attend more to other capacities – in the case of deafness, the absence of the sense of hearing may lead to increased awareness of the senses of touch and vision, both sensory modes that convey some of the information that is typically obtained through hearing. Additionally, evidence indicates that those who are Deaf and have used a signed language since childhood have highly developed spatial abilities as a result of their use of a spatial (signed) language.²⁰⁶ If deafness encourages the development of more attention to certain ways of being in the world, including the acquisition of some skills that

²⁰⁶ Jennie E. Pyers, Anna Schusterman, Anne Senghas, Elizabeth S. Spelke, and Karen Emmorey, "Evidence from an Emerging Sign Language Reveals That Language Supports Spatial Cognition" in *Proceedings of the National Academy of Sciences* 107 (27): 12116-20 (2010), accessed December 10, 2010. <http://www.pnas.org/content/107/27/12116.full> DOI: 10.1073/pnas.0914044107.

supersede special-typical functioning, how then is deafness to be measured as a moral harm? Is deafness a difference or a disability?

Anita Silvers points to an exchange between blind philosopher Martin Milligan and sighted philosopher Bryan Magee to highlight another issue, that of considering whether having physical characteristics that are not species-typical are simply differences or deficits that are intrinsically bad. She notes that the burden of proof for establishing the difference claim is uneven, and usually falls on the person with a disability, such as Milligan, who points out that blind people are likely to know more about sight and sighted people than sighted people know about blind people.²⁰⁷ This is very likely true as well for deaf and Deaf people, who must learn to make sense of hearing people and sound in order to function capably in society. The claim that being Deaf is a moral harm is likely to be best articulated by those who have spent considerable time thinking about what grounds this harm. By disregarding the testimony of those who live as Deaf people, a weaker argument ensues.

Harm Within the Deaf Family Unit

The Deaf child living with a signing Deaf family has full access to language. This may change as she interacts with her extended family. In the genetic selection case described in Chapter 3, one assumption was that the child's primary community of extended family and friends would be able to communicate with her using a signed language or sign communication. In the case of a deaf child created through his Deaf parents using genetic alteration, odds may be higher that he may have some relatives who

²⁰⁷ Silvers, *Disability*, 87-8.

are not able to communicate in signed communication. Is the child harmed by this, and are there any unique features regarding to this issue of partial access to language associated with deafness or his status as a Deaf person?

The analogy of a bilingual three generation (hearing) immigrant family may be helpful for understanding this issue of harm as it is connected to access to language. Assume the oldest members of this family are not proficient in the language of their new country (language A); the second generation is close to holding true bilingual status, with fluency in their parents' language (language A) and the primary language of their new country (language B), and the third generation is fluent in the language of the country in which they were raised (language B) and has a limited vocabulary in the language spoken by her grandparents (language A). Now imagine two Deaf parents who have used genetic technology to bear Deaf children. The Deaf children's grandparents know a few words in the signed language used by their family members, but full and direct access to communication is limited, just as it is with the immigrant family.

There are some differences. In the immigrant family case, the oldest members of the family are most isolated from the external community by their lack of a second language, but their children (the middle generation) have always had the ability to communicate directly with them as first language users. The largest gap in direct and fully accessible communication is between the oldest and youngest generations, with the two youngest generations having full access to the language used in the larger community. In the Deaf family example, the two youngest generations share full communication access, but the language they use is not the dominant spoken language of the larger community. The largest gap in direct and fully accessible communication exists

between the oldest generation and the two youngest generations. The oldest and hearing generation has full access to this linguistic community, while the middle and youngest generations have partial access. Are these relevant differences? Do the reasons for the language and communication gaps make a moral difference?

In the case of the immigrant family, one can assume that the immigrants chose to immigrate, perhaps due to a desire to seek a better life for their children. As adult immigrants, they were aware that their partial access to the language used in their new country could impose hardship upon them. Despite this, they opted to immigrate, reasoning that overall it would be best for the family. It is important to note that up to the point of migration, their experience in their home country was one of full access to language. In the immigrant example, each generation has full and direct linguistic access to the generation immediately preceding their generation and the generation immediately following.

Circumstances differ for the hearing grandparents as they did not consciously choose a life course that could affect language use within their family; there was no element of choice connected to having deaf children. Since these deaf children eventually became Deaf, the deaf children grew up to use a different language than their parents' native spoken language. In this example, each generation does not have the experience of full and direct access with the generation immediately preceding it or the one immediately following. The first generation of Deaf children is limited to partial access to language with their parents. (If they are outfitted with cochlear implants from a very young age, even the most successful cochlear implant does not provide full linguistic access.) The youngest Deaf generation is similar to the middle immigrant generation in

having full linguistic access to their parents, but dissimilar in having partial access to the larger community.

Impeded linguistic access to the dominant community counts as a harm because it restricts one's freedom; without full access to information, one cannot be aware of the choices that are available. In both examples, this is an instance of a social restriction. One could imagine a bilingual society in which information is accessible to all. Partial access to language is not equal in these examples; the immigrant family is presumably all hearing. Hypothetically, all members of the family could learn the two languages of discourse used by the family members. The barrier to access is linguistic, not sensory. The Deaf family members experience a sensory barrier to linguistic access; complete and full linguistic access to the spoken language is not possible.

There is one more element to this analogy. The creation of a society that supports full linguistic access in two languages, whether spoken or signed, can be imagined. There are many places in the world where bilingualism of spoken languages is already the norm. Nora Groce's book, *Everyone Spoke Sign Language Here*, illustrates a historic account of a signed language use by communities on Martha's Vineyard. It is easy to assume that Deaf people experienced no barriers to communication access, but this is not the case. There were spoken and signed languages in this community; bilingualism was not complete for all language modes as the deaf signing members of the community had full language access to written English, but not spoken English. The hearing members of the community had full access to both signed and spoken languages, and could, one supposes, acquire literacy if they were unable to read or write in English. It is arguable

then, that in any bilingual environment where Deaf people exist along with spoken language, that access to language will be partial.

Enforcing social policies of bilingualism in public spaces is not without precedent. The question of how this applies to private space is another matter – particularly private space where the barrier to full access to language is not just linguistic, but sensory. If one is unable to acquire full access to language because of physical differences in capability, does this impose a greater linguistic duty upon those who face no physical or sensory restrictions? Is harm not only done to those who cannot obtain full access to a language, but also to those who must assume a greater share of the communication responsibility by learning a second language, not as a child, when language acquisition is easiest, but as an adult?

Finally, even if the hearing adults in the older generation develop proficiency in a signed language in order to communicate with their Deaf offspring, the effort required to adjust to communicating in a visual language mode may be challenging, even frustrating, at times. Unlike the bilingual immigrant family member, who learns both languages at young ages and in the same auditory mode, the older hearing second language learner must learn not only a new language, but a new mode of linguistic communication. Even those with the best intentions may at times forget visual communication requirements and express their frustration with the dreaded phrase “never mind,” which can be interpreted by the deaf person as dismissive of the individual, not the content.²⁰⁸ I was unable to identify any studies that compare the use of second language user behavior who change

²⁰⁸ Claudia Dewane, “Hearing Loss in Older Adults – Its Effect on Mental Health”, *Social Work Today* 10(4):18.

language modes in addition to languages (such as signed to spoken), and so what follows is speculation, but it seems reasonable to think that signing Deaf people encounter harm related to partial access to language in two ways. The first is the inability to comprehend what words are communicated (spoken). The second is partial access based on the limitations of the second language user communicating in a nonnative mode. Although one can conclude that partial access to language in the family is a harm associated with the state of deafness or being Deaf, the degree to which such a harm is experienced will likely be highly variable and dependent on the individual's family.

Harm Caused to Society: Scarce Resources and Elective Disability

A frequently cited objection regarding the creation of Deaf children is that Deaf people use disproportionately more of society's resources than do non-Deaf people.²⁰⁹ The good citizen argument maintains that the duty of a citizen is to be prudent when considering how the consequences of his actions will affect resource allocation within society, and suggests the choice to deliberately bear a child who will consume a larger portion of society's resources harms society and is morally unjustified for this reason.²¹⁰ This is not just limited to the costs of educating the Deaf child; the Deaf adult will continue to harm society by relying on services and accommodations that cost disproportionately more than those for non-Deaf people, further perpetuating this harm. On this account, harm to society is primarily a resource allocation problem; those for whom disability has occurred through no fault of their own are more deserving. Space and scope considerations prevent a detailed treatment of justice, resource allocation and

²⁰⁹ Tucker, "Deaf Culture," 11-12; Savelescu, "Deaf Lesbians," 773.

²¹⁰ Häyry, "Selecting a Deaf Embryo," 511.

disability.²¹¹ My object here is simply to note one of the ways in which bringing a Deaf child into the world can be viewed as harmful.

Another argument that holds deliberately bringing a deaf child into the world is harmful is a business argument constructed by Cooley, who claims that this action violates the duty not to harm another community citizen without permission, including businesses.²¹² In order to arrive at this conclusion, Cooley appeals to a claim of reciprocity, stating that businesses are often evaluated in terms of the moral duties they owe to community stakeholders, but the corresponding obligations of community stakeholders to business are frequently overlooked. The federal legislation that requires businesses to provide access for people with disabilities, whether employees or community stakeholders, imposes one sort of harm on businesses. This includes not only the costs of providing access, but of creating processes and tracking them.²¹³ Another harm occurs when businesses (as well as other community members) must pay taxes to cover the costs of social programs for people with disabilities.

From what I can tell, Cooley's assessment regarding the economic costs to businesses of providing accessibility and other kinds of support for people with disabilities is correct. One small practical objection concerns the numbers of people who will actually decide to create or select a child with a disability. Studies posing this inquiry to deaf people indicate this is a very small percentage; the available data from IVF-PGD

²¹¹ See Anita Silvers, David Wasserman, and Mary B. Mahowald, *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Policy* (Lanham, MD: Rowman and Littlefield, 1998).

²¹² D.R. Cooley, "Deaf By Design: A Business Argument Against Engineering Disabled Offspring", *Journal of Business Ethics* 71:209-227 (2007).

²¹³ *Ibid.*, 209, 216.

clinics indicates that only three percent of couples have sought to use PGD for this purpose.²¹⁴

A more pressing obligation is the question of whether businesses ought to have any role in private decisions about reproduction. Cooley acknowledges this is an issue and offers two reasons why businesses should not be involved. The first deals with the question of medical privacy and the second with the burden of establishing the circumstances related to the disabled person's birth.²¹⁵ Since the potential harm to the innocent in carrying out these tasks is significant, another approach is suggested – that of offering incentives. One possible incentive is to offer IVF with PGD, but with the caveat that embryos to be implanted are regulated.²¹⁶ This seems to raise more problems than it solves since it could result in a two-tiered system for IVF with PGD that might impact reproductive liberty. That is, suppose a couple who needed IVF had the genetic luck to only have the genetic material to create fertilized eggs that were potentially deaf. If the choice is reproductive liberty with deaf children or no children at all, this could make for tricky policy decisions or regulatory interpretation.

Arguments based on economic costs related to Deafness are problematic in another way. The primary economic expenditures for deaf people can be roughly broken down into four kinds of costs: the cost of deaf education, the cost of social services for

²¹⁴ Suzannah Baruch, David Kaufman, and Kathy Hudson, “Genetic Testing of Embryos: Practices and Perspectives of U.S. IVF Clinics,” *Fertility and Sterility*, 5. DOI:10.1016/j.fertnstert.2006.09.003.

²¹⁵ Cooley, “Deaf by Design”, 220.

²¹⁶ *Ibid.*, 221.

Deaf people, and the costs to businesses who hire or serve Deaf people. We have covered the issue of business, but what of education and social services?

In applying the good citizen argument for Deaf children born to Deaf parents, one must be careful that the claims about the expense of deaf education apply to this subgroup. Unfortunately, I was not able to locate any studies that isolated this variable. Is it more expensive for society to educate Deaf children? That is, children who, unlike deaf children, have had full access to language in the home. Do deaf children cost more to educate than Deaf children? Are there significant differences in the educational needs of Deaf children? Infrastructure? Is it because a higher percentage of deaf children have other disabilities than is found in the general population of hearing children, thus compounding the cost of educating this population by increasing the kinds of services needed? The answers to these questions are complicated, and figure into the calculus of the good citizen argument.

The costs of interpreters in mainstream programs and of maintaining and staffing state residential schools that pull together a critical mass of deaf children are expenses that do not occur when educating hearing children. What is the extent of the costs of additional resources needed to support language development in young children who have been language deprived? More than ninety percent of deaf children are born to hearing parents who do not sign. Even if the deaf child's parents immediately immerse themselves in learning a visual language after they discover their child is deaf, the amount of time needed to acquire language fluency is congruous with the child's prime time for language acquisition. Given this and other factors, there are many deaf children who arrive at school with limited language capabilities. Is it because a higher percentage

of deaf children have other disabilities than is found in the general population of hearing children, thus compounding the cost of educating this population by increasing the kinds of services needed? In order to evaluate this claim, more information is needed, not only about how the costs of deaf education are incurred, but also answers to metaquestions about the assumptions regarding deaf education, including those related to design and purpose.

In addition to primary through secondary education costs, there are the costs of social services for deaf people such as vocational rehabilitation, relay services, emergency notification systems, and emergency interpreter services. Equipment is expensive. Auditory tools such as hearing aids are frequently not covered through health insurance and these expenses are often picked up by public social service agencies. Accessibility equipment such as computers with video relay software functionality and pagers may be paid for through government vocational rehabilitation programs. The argument runs like this - it is one thing to provide these services for those who become Deaf through no fault of their own, but it is another thing entirely to provide services for those who elect to become deaf through deliberate choices and actions. The Deaf Wannabe population is an example of such people. An internet group exists for this group of people, some of whom have “crossed the bridge” and detail their process of becoming deaf. Upon becoming deaf, several of them report using social services to obtain hearing aids and other accessibility assistance.²¹⁷

²¹⁷ Deaf Wannabe Yahoo Group, accessed January 12, 2011.
<http://groups.yahoo.com/group/Deaf-Wannabee/>

Bonnie Poitras Tucker labels those who choose to become (or remain) deaf as people with elective disabilities.²¹⁸ Her article focuses on cochlear implants and the deaf individual's responsibility to cure, restore or ameliorate his deafness. She acknowledges that forcing an individual to have surgery is problematic, but counters this with the charge that individuals must be responsible for the consequences of their actions.²¹⁹ She argues that responsibility not only extends to deaf individuals who might refuse to get cochlear implants or otherwise treat their deafness medically, but that this should also extend to parents of deaf children who refuse to obtain cochlear implants for their children or other medical treatment.

For the deontologist, there is an important distinction between those who deliberately cause their own deafness (the Deaf wannabes) and those who have had deafness and Deafness imposed upon them. A society that offers different levels of participation based on an individual's own choices is one thing; a society that visits the "sins of the father upon the son" sends a very different sort of message. Preventing a felon from voting while she is in prison for having willfully committed a crime is different in kind than punishing a Deaf child by denying him an accessible education because his parents deliberately brought about his birth as a Deaf child.

Providing closed captions on television and the internet, making emergency notification services accessible, paying for interpreting services for Deaf employees, and offering emergency legal and medical interpreting services are just some of the ways that

²¹⁸ Bonnie Poitras Tucker, "Deaf Culture, Cochlear Implants, and Elective Disability," *Hastings Center Report* 28 (1998): 6-14.

²¹⁹ Tucker, "Deaf Culture," 10-11.

public and private entities spend money to make their products and services accessible to Deaf and deaf people. Some argue that this significant amount of money could be better spent on other endeavors, and that prohibiting or discouraging people from bearing deaf children will free up this money. There are three major objections to this line of argument. The first is the issue of bearing the burden of proof of the circumstances surrounding one's birth or one's child's birth. The loss of privacy for those who have not deliberately conceived a deaf child is considerable, and ought to be weighed against the anticipated social gains of freed up resources. With the small numbers of Deaf people, and the even smaller percentage of those who would actively seek IVF with PGD to bear a deaf child, the amount of money saved by not providing services to those who deliberately selected for a deaf child is likely to be negligible when considering the costs needed to implement and execute these social services. The second is that for the foreseeable future, Deaf and deaf people will continue to exist, including those who have not been deliberately created as Deaf. Since deafness does not have a universal cause, it is highly unlikely that all of its causes will be addressed in the future. The final objection once again raises the issue of moral agency and punishment – is punishing a Deaf individual for his Deafness justified if his parents made this decision and he had nothing to do with this matter?

Deafness and Moral Good

This chapter has identified a selection of harms associated with the state of being culturally identified as Deaf, including the audiological condition of deafness. Discussions about moral justification and the moral permissibility of actions are usually couched in terms of harm, whether that is defined as a change in the status of one's well-

being, the presence of pain, an absence of dignity or another of the other moral virtues, or restrictions upon one's liberty. Scholars who have investigated this question of whether the decision to use genetic technology to deliberately bring a deaf child into existence have focused by considering the harms that might ensue. While the harms of existing as a Deaf or deaf person in society cannot be discounted or minimized, I would feel remiss if I were to end this project on this note. For in addition to harms, there are corresponding benefits. These can be experienced by the Deaf individual in isolation or in community. These benefits may be intrinsic or instrumental; they may encourage the expression of liberty by supporting the expression of minority views, they may allow the flourishing of minority sociolinguistic communities, they may provide insight into the human condition and create situations in which virtues like compassion can be cultivated.

Of course, many of these benefits are not unique to the signing Deaf community or to the experience of being deaf. Still, these benefits are frequently not catalogued in the philosophical or bioethical discussions regarding the question of using genetic technology to bring about the birth of a deaf child. Even when these benefits are acknowledged, they are quickly described in terms of belonging to a community or cherishing a language – benefits that can be understood by most humans, deaf or hearing. The benefits are not situated in the uniqueness of this particular sociolinguistic group – the signing Deaf community. Dirksen Baumann notes that the signing Deaf community is about more than flashing lights and text phones; noting the birth of a deaf child into a family with Deaf parents provides “a visually centered episteme to emerge that results in lived experiences not predicated on the lack of a sense, but on the plenitude of a visual

culture with its own norms of language acquisition and identity development.”²²⁰ The benefit of visual culture accrues to the child born to *this* family in *this* environment, with full access to a language and a community where the child’s deaf audiological status is not marked as ‘different’, but as normal.

To this end, I wish to catalogue some of the benefits that attach to membership in the signing Deaf community. For purposes of clarification, this is not an attempt to back into the question of whether it is better to be hearing or deaf – or even whether it is better to be Hearing (e.g. a member of a cultural community of people who use a spoken language exclusively) or Deaf. That is a different question that deserves a more detailed treatment than space permits. This section simply addresses some of the benefits a Deaf person may lay claim to.

One benefit associated with Deaf community membership is the benefit of belonging to a community that is small in number – similar to the experience of belonging to any minority community that is situated within a larger community. In minority language communities with very small numbers there can be considerable diversity in terms of socioeconomic status and other markers, since the shared language often trumps these, though the historic record shows that communities with larger signing Deaf populations had Deaf clubs that were exclusionary based on race, religion, or ethnicity.²²¹ Two benefits with features that are arguably unique to Deaf community

²²⁰ H-Dirksen L. Bauman, “Designing Deaf Babies and the Question of Disability”, *Journal of Deaf Studies and Deaf Education* (2005) 10 (3): 311-315.

DOI: 10.1093/deafed/eni031.

²²¹ Padden and Humphries, *Inside Deaf Culture*, 80.

membership are the transnational Deaf-World community and the emergence of new signed languages in Deaf communities.

A benefit for Deaf individuals that is often overlooked is the benefit of belonging to a transnational community, the Deaf-World.²²² Transnational communities with users who are fluent in different languages are not unusual; what is unique about this community is that the users of different signed languages are better equipped to communicate across languages because of the expressive and receptive skills they have acquired through the use of their native signed language. The Deaf-World holds many transnational events such as Deaflympics, Deaf Way, World Federation of the Deaf Congresses, Deaf History International, that are held in different locations on a regular basis, becoming temporary loci for the Deaf-World to gather.

Deaf anthropologist Hilde Hualand has conducted research on this phenomenon, which she describes as “challeng[ing] profound anthropological assumptions of durable physical locations as the prime site for identification and belonging.”²²³ One of the benefits she has identified is the way in which knowledge of one signed language and participation in a signing Deaf community increases the opportunities for transnational engagement. Unlike spoken languages, in which knowledge of one language in a language family can make it possible to communicate with a speaker of a different language in that family, Hualand argues that sign language users have increased

²²² Bahan, Lane, Hoffmeister, *Journey*, 5-8.

²²³ Hilde Hualand, “The Two Week Village: The Significance of Sacred Occasions for the Deaf Community” in *Disability in Local and Global Worlds*, ed. Benedicte Ingstad and Susan Reynolds Whyte (Berkeley: University of California Press, 2007), 34.

opportunities for participation in transnational activities because “signed languages are more easily adapted to a form of international sign communication.”²²⁴

Haualand’s point applies to hearing users of signed languages as well as those who are Deaf. Yet there is an unstated factor that likely increases the ability of Deaf signed language users to gain facility with international signed communication. The typical Deaf signed language user has amassed hours of communications experiences with non-signing individuals. In order to facilitate this communication, the signing Deaf individual calls upon a variety of communication techniques, including gesture, to achieve effective communication. In most cases the hearing signed language user, upon learning that the person with whom she wishes to communicate is using a spoken language that she knows, will communicate directly in that spoken language. It is the knowledge of a signed language, plus the hours of experience of communicating with others through gesture, that contributes to the transnational communication benefit.

Another benefit unique to signing Deaf communities is the potential for revealing information about language. New signed language communities are more likely to emerge than new spoken language communities. Sometimes these come into being because a critical mass of deaf people are brought together by the state, at other times the presence of genes associated with deafness increases due to mating practices within a geographically isolated community.²²⁵ The opportunity to study a language as it emerges is relatively rare; this provides linguists with a living laboratory in which to gather information and test hypotheses about the human capacity to create language and the

²²⁴ Haualand, 47.

²²⁵ Margalit Fox, *Talking Hands* (New York: Simon & Schuster Publishers, 2007), 123.

evolution of language in a natural environment. (The ethical issues surrounding the design of a similar experiment using languageless hearing people to generate spoken language are hugely problematic, for obvious reasons). It is difficult to imagine any circumstances other than deafness in which a new language could emerge in a natural setting, since hearing children would have access to the language used by their community. Given this, the existence of a critical mass of deaf people in an isolated community and subsequent generations of deaf people appear to be necessary condition for the emergence of a new language. The benefit of acquiring knowledge about human language development is both intrinsic and instrumental. All knowledge arguably holds intrinsic value; the instrumental benefit of such knowledge has the potential to inform developments in cognitive science and linguistics, as well as related fields.

There are other arguments for benefits associated with the Deaf community. One is the Diversity Argument, which makes the claim that the presence of numerous diverse cultures and languages in the world enriches everyone; the unique nature of signed languages and the cultural communities associated with them increases this diversity. Another is the Argument from Compassion, which claims that the presence of people with fewer species-typical features encourages human compassion. (This is also expressed through examples about disability and can appear patronizing – e.g. the blind man in the subway needs assistance finding his way, and this presents me with an opportunity to express compassion towards him, bordering on munificence more than compassion). The Beauty of Sign Language Argument, or what I call the Aesthetic Argument, makes the claim that sign language is beautiful in its form and motion, and the

experience of watching it is a benefit; the argument also implies this beauty is an intrinsic good.

Perhaps the most difficult benefit to articulate and argue for is the idea that deafness and the state of being Deaf can be a gift. This is not the gift of silence, but the gift of the unbidden. Michael Sandel notes that what theologian William F. May describes as “an openness to the unbidden” not only includes the gifts of life, but a willingness to relinquish mastery and control.²²⁶ Whether one shops the genetic supermarket²²⁷ or plays the genetic lottery,²²⁸ one comes into existence with a particular set of characteristics. The combination of these characteristics, plus one’s environment, creates life experiences and opportunities. In other words, the social construction of disability not only erects barriers, it sometimes removes them in unacknowledged ways. The lone Deaf person in a family may, by virtue of his deafness and access to state vocational rehabilitation funds, be the first person in his family to attend college. The Deaf person who is a pioneer in her field may be singled out for career-making opportunities because of her unique status as a deaf person in that field. The senior citizen who attended a state residential school for the Deaf may still be in touch with every living member of her kindergarten class, due to the small and cohesive nature of the Deaf community. The talented Deaf athlete may not only compete in the Deaflympics, but through this transnational experience develop an abiding friendship that transcends language and endures through communication via International Signs conveyed through

²²⁶ Sandel, 45-6.

²²⁷ Nozick, 315.

²²⁸ Rawls, 107-108.

internet video. The Deaf couple who use IVF and PGD to ensure a Deaf child reap the benefit of not having to pay for their child's college education, as they would if they were hearing. For some Deaf people, the social goods that they are entitled to leads them to life path that otherwise might not have been open to them. For these people, Deafness is indeed a gift.

In addition to social gains as a benefit of being Deaf, there is a new concept that is being bandied about in the academy with regard to the state of being Deaf. This is the idea of Deaf-Gain.²²⁹ By inverting the concept of hearing loss, which asks, what does one lose when one is Deaf, the person engaged in exploring the notion of Deaf-Gain asks, what does one gain when one is Deaf? The gains may be socially constructed opportunity, neurological differences stemming from the spatial nature of a signed language or signed communication system, or they may be something else entirely – something as yet unnamed or undetermined.

Conclusion

This project has explored the question of whether it is morally justifiable to use genetic technology to ensure the birth of a deaf child. I have attempted to show that this desire for a deaf child emerges in part as a response to history; the educational, medical, and social experiences of Deaf people form the backdrop to this desire to share what they cherish with children who could be full-fledged members of this community. I have considered the question of whether it is morally justified to give nature an assist by using genetic selection, and concluded that the Non-Identity argument withstands the strongest

²²⁹ See Bauman, H-Dirksen and Joseph J. Murray, "Reframing: From Hearing Loss to Deaf-Gain," *Deaf Studies Digital Journal* 1:1, Fall 2009. <http://dsdj.gallaudet.edu/>.

objections posed against it. I have considered the question of genetic alteration using a folk argument drawn from my discourse in the Deaf community, situated this folk argument using the concept of bodily integrity and have concluded that this does not provide a conclusive answer to the question of moral justification and more work remains to be done on this problem. In addition to evaluating the above questions of the moral justification of genetic selection and genetic alteration, I have also sketched out a brief response to the question of whether deafness and the state of being Deaf are themselves moral harms in the final chapter, offering a roadmap for future philosophical work on this question.

Bibliography

- A. Abend, "Was sagt die Rassenhygiene dem Taubstummenlehrer" *Blätter für Taubstummenbildung*. [1925] 1999. In Horst Biesold, *Crying Hands: Eugenics and Deaf People in Nazi Germany*. Washington DC: Gallaudet University Press.
- Amundson, Ronald and Shari Tresky. "On a Bioethical Challenge to Disability Rights." *Journal of Medicine and Philosophy* 32 (6): 541-561 (2007).
- Anstey, K.W. "Are Attempts to Have Impaired Children Justifiable?" *Journal of Medical Ethics* 28:286-288 (2002).
- Arnos, Kathleen and Arti Pandya. 2005. "Genes for Deafness and The Genetics Program at Gallaudet University." In *Genetics, Disability, and Deafness*, ed. John Vickrey Van Cleve. Washington, D.C.: Gallaudet University.
- Adrienne Asch and Erik Parens. 2000. "The Disability Rights Critique of Prenatal Genetic Testing." In *Prenatal Testing and Disability Rights*, ed. Erik Parens and Adrienne Asch. Washington, DC: Georgetown University Press.
- Baker-Shenk, Charlotte and Dennis Cokely. 1989. *American Sign Language: A Teacher's Resource Text on Grammar and Culture*. Washington, DC: Clerc books, Gallaudet University Press.
- Balkany, Thomas. "A Brief Perspective on Cochlear Implants." *New England Journal of Medicine* 328: 281-282 (1993).
- Baruch, Suzannah, David Kaufman, and Kathy Hudson. "Genetic Testing of Embryos: Practices and Perspectives of U.S. IVF Clinics." *Fertility and Sterility* (2006). DOI:10.1016/j.fertnstert.2006.09.003.
- Bauman, H-Dirksen. "Audism: Exploring the Metaphysics of Oppression." *Journal of Deaf Studies and Deaf Education* 9 (2): 239-46 (2004).
- Bauman, H-Dirksen L. 2005. "Designing Deaf Babies and the Question of Disability", *Journal of Deaf Studies and Deaf Education* 10 (3): 311-315 (2005). DOI: 10.1093/deafed/eni031
- Bell, Alexander Graham. 1883. *Memoirs upon the Formation of a Deaf Variety of the Human Race*. New Haven, CT: National Academy of Sciences.
- Benatar, David. 2006. *Better Never to Have Been*. Oxford: Oxford University Press.
- Biesold, Horst. 1999. *Crying Hands: Eugenics and Deaf People in Nazi Germany*. Washington DC: Gallaudet University Press.

- Blanton, S.H., Nance, W. E., Norris, V. W., Welch, K. O., Burt, A., Pandya, A. and Arnos, K. S. "Fitness Among Individuals with Early Childhood Deafness: Studies in Alumni Families from Gallaudet University." *Annals of Human Genetics* 74: 27-33 (2010). DOI: 10.1111/j.1469-1809.2009.00553.x
- Bowe, Frank. 1991. *Approaching Equality: Education of the Deaf*. Silver Spring, MD: T.J. Publishers, Inc.
- Bridy, AnneMarie. "Confounding Extremities: Surgery at the Medico-ethical Limits of Self-Modification." *Journal of Law, Medicine & Ethics*, 32:148–158 (2004).
- Brock, Dan W. "The Non-Identity Problem and Genetic Harms – The Case of Wrongful Handicaps." *Bioethics* 9 (3/4):269-275.
- Byran, Alison. "HFEB: BDA Draft letter to Professor Marcus Pembrey." Accessed 17 May 2008.
http://www.grumpyoldeafies.com/2007/11/hfeb_bda_draft_letter_to_profe.html.
- Burch, Susan. 2002. *Signs of Resistance: American Deaf Cultural History, 1900 to 1942*. New York: New York University Press.
- Burke, Teresa Blankmeyer. "An Argument Analysis of Technology and Deafness." Paper presented at the Second International Deaf Academics and Researchers Conference, Gallaudet University, Washington, DC, 19 February 2004.
- Burke, Teresa Blankmeyer. "Comments on Trevor Johnston's 'W(h)ither the Deaf Community? Population, Genetics, and the Future of Australian Sign Language'." *Sign Language Studies* 6 (2):174-180 (2006).
- Christiansen, John B. and Sharon N. Barnartt. 1995. *Deaf President Now: The 1988 Revolution at Gallaudet University*. Washington, DC: Gallaudet University Press.
- Christiansen, John B. and Irene W. Leigh. 2002. *Cochlear Implants in Children: Ethics and Choices*. Washington, D.C.: Gallaudet University Press.
- Christiansen, John, Irene W. Leigh, and Patricia Elizabeth Spencer. 2002. "History of Cochlear Implants" in *Cochlear Implants in Children: Ethics and Choices* by John Christiansen and Irene W. Leigh. Washington, DC: Gallaudet University Press.
- Clerc, Laurent. "Autobiography." [1852] 2001. In *Deaf World: A Historical Reader and Primary Sourcebook*, edited by Lois Bragg. Washington, DC: Gallaudet University Press.

- Cohen, N.L. and S.B. Waltzman. "Cochlear Implants in Infants and Young Children." In *Mayo* 17 (2): 215-222 (1996).
- Cohen, Noel L., Roland, J. Thomas Jr., Marrinan, Michelle. "Meningitis in Cochlear Implant Recipients: The North American Experience." *Otology & Neurotology* 25 (3): 275-281 (2004).
- Cokely, Dennis. 1980. "Sign Language: Teaching, Interpreting, and Educational Policy." In *Sign Language and the Deaf Community: Essays in Honor of William C. Stokoe*, edited by Charlotte Baker and Robbin Battison. Silver Spring, MD: National Association of the Deaf.
- D.R. Cooley, "Deaf By Design: A Business Argument Against Engineering Disabled Offspring", *Journal of Business Ethics* 71:209-227 (2007).
- Crouch, Robert A. "Letting the deaf be Deaf: Reconsidering the Use of Cochlear Implants in Prelingually deaf Children." *Hastings Center Report* 27 (4):14-21 (1997).
- Darnovsky, Marcy. "A New Chapter in the Sex Selection Debate: Revisiting Sex Selection." *GeneWatch* 17:1. Accessed 18 March 2008. <http://www.genewatch.org/genewatch/articles/17-1darnovsky.html>
- Davis, Lennard. "Deafness and the Riddle of Identity." *Chronicle of Higher Education*, January 7, 2007.
- Davis, Dena S. "Genetic Dilemmas and the Child's Right to an Open Future." *Hastings Center Report* 27 (2):7-15 (1997).
- Dekkers, W., C. Hoffer and JP Wils, "Bodily Integrity and Male and Female Circumcision." *Journal of Medicine, Health Care and Philosophy* 8 (2):179-91 (2005).
- Dewane, Claudia. "Hearing Loss in Older Adults – Its Effect on Mental Health", *Social Work Today* 10 (4):18.
- Elliott, Carl. 1999. *Bioethics, Culture, and Identity: A Philosophical Disease*. New York: Routledge.
- Fahmy, Melissa Seymour. "On the Supposed Moral Harm of Selecting for Deafness" *Bioethics* 25 (3): 128-136 (2011).
- Fletcher, John C. "Deaf Like Us: The Dushesneau-McCullough Case." *L'Observatoire de la Génétique* 5 (July-August):1-8 (2002).

- Fox, Margalit. 2007. *Talking Hands*. New York: Simon & Schuster Publishers.
- Friedlander, Henry. 2002. "Holocaust Studies and the Deaf Community." In *Deaf People in Hitler's Europe*, edited by Donna Ryan and John Schuchmann. Washington, DC: Gallaudet University Press.
- Gamble, Clarence J. "Human Sterilization." *American Journal of Nursing* 51 (10) 625-6 (1951).
- Gert, Bernard, Charles M. Culver, and K. Danner Clouser. 1997. *Bioethics: A Return to Fundamentals*. Oxford: Oxford University Press.
- Glannon, Walter. *Genes and Future People*. Boulder, CO: Westview Press, 2001.
- Glover, Jonathan. 2006. *Choosing Children: Genes, Disability, Design*. Oxford: Oxford University Press.
- Green, Ronald M. 2007. *Babies By Design: The Ethics of Genetic Choice*. New Haven: Yale University Press.
- Greenwald, Brian H. 2004. "The Real 'Toll' of A.G. Bell: Lessons About Eugenics." In *Genetics, Disability and Deafness* edited by John Vickery Van Cleve, 35-41. Washington DC: Gallaudet University Press.
- Groce, Nora Ellen. 1985. *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard*. Cambridge: Harvard University Press.
- Häyry, M. "There is a Difference Between Selecting a Deaf Embryo and Deafening a Hearing Child." *Journal of Medical Ethics* 30: 510-2 (2004).
- Harmon, Amy. "As Gene Test Menu Grows, Who Gets to Choose?" New York Times, July 21 2004. Accessed January 23, 2005.
<http://query.nytimes.com/gst/fullpage.html?res=940DEED8113AF932A15754C0A9629C8B63>
- Harvey, Martin. "Reproductive Autonomy Rights and Genetic Disenhancement: Sidestepping the Argument from Back-Handed Benefit." *Journal of Applied Philosophy* 21 (2): 125-140 (2004).
- Haualand, Hilde. 2007. "The Two Week Village: The Significance of Sacred Occasions for the Deaf Community." In *Disability in Local and Global Worlds*, ed. Benedicte Ingstad and Susan Reynolds Whyte. Berkeley: University of California Press.

- Help Me Understand Genetics Handbook*. 2011. Washington, D.C.: Lister Hill National Center for Biomedical Communications, U.S. National Library of Medicine.
- Human Genome Project Information. "Gene Therapy: What is the Current Status of Gene Therapy Research?" Human Genome Project. Accessed 3 March 2008)
http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetherapy.shtml.
- Hu, Stella, Angela M. L. Pattatucci, Chavis Patterson, Lin Li, David W. Fulker, Stacey S. Cherny, Leonid Kruglyak and Dean H. Hamer, "Linkage between Sexual Orientation and Chromosome Xq28 in Males But Not in Females" *Nature Genetics* 11: 248-56 (1995). DOI: 10.1038/ng1195-248.
- Izumikawa, Masahiko and Ryosei Minoda, Kohei Kawamoto, Karen A Abrashkin, Donald L Swiderski, David F Dolan, Douglas E Brough, and Yehoash Raphael. "Auditory Hair Cell Replacement and Hearing Improvement by Atoh1 Gene Therapy in Deaf Mammals." *Nature Medicine* 11: 271-276 (2005). DOI:10.1038/nm1193
- Jankowski, Katherine A. 1997. *Deaf Empowerment: Emergence, Struggle & Rhetoric*. Washington, DC: Gallaudet University Press.
- Johnson, Jeanne M., Ruth V. Watkins, and Mabel L. Rice. "Bimodal Bilingual Language Development in a Hearing Child of Deaf Parents." *Applied Psycholinguistics* 13:31-52 (1992).
- Jorde, Lynn B., John C. Carey, Michael J. Bamshad, and Raymond L. White. 2003. *Medical Genetics*, 3rd ed. St. Louis: Mosby/Elsevier Science.
- Kant, Immanuel. 1997. *Groundwork of the Metaphysics of Morals*, ed. Mary Gregor. Cambridge: Cambridge University Press.
- Komesaroff, Linda. 2007. "Introduction." In *Surgical Consent: Bioethics and Cochlear Implantation*, ed. Linda Komesaroff. Gallaudet University Press.
- Kushalnagar, Poorna, Gaurav Mathur, Christopher J. Moreland, Donna Jo Napoli, Wendy Osterling, Carol Padden, and Christian Rathmann. "Infants and Children with Hearing Loss Need Early Language Access." *Journal of Clinical Ethics* 21: 1-13 (2010).
- Lane, Harlan. 1993. *The Mask of Benevolence: Disabling the Deaf Community*. New York: Vintage.
- Lane, Harlan. 1984. *When the Mind Hears*. New York: Random House.

- Lane, Harlan, Robert Hoffmeister, and Ben Bahan. 1996. *A Journey into the Deaf-World*. San Diego, CA.: DawnSign Press.
- Lane, Harlan and Michael Grodin, "Ethical Issues in Cochlear Implant Surgery: An Exploration into Disease, Disability, and the Best Interests of the Child." *Kennedy Institute of Ethics Journal* 7 (3):231-251 (1997).
- Lerman, S.E. and J.C. Liao. "Neonatal Circumcision." *Pediatric Clinics of North America* 48 (6):1539-57 (2001).
- Levy, N. "Deafness, Culture, and Choice." *Journal of Medical Ethics* 28: 284-5 (2002).
- Locke, John. [1690] 1980. *Second Treatise of Government*, ed. C.B. MacPherson. Indianapolis: Hackett Publishing.
- McGee, Glenn. 2000. *The Perfect Baby; Parenthood in the New World of Cloning and Genetics*. Lanham, MD: Rowman and Littlefield.
- McMahan, Jeff. "Causing Disabled People to Exist and Causing People to be Disabled". *Ethics* 116:77-99 (2005).
- Middleton, A., J. Hewison, R.F. Mueller. "Attitudes of Deaf, Hard of Hearing and Hearing Adults Toward Genetic Testing for Deafness." *Journal of Genetic Counseling* 7 (6): 492-3 (1998).
- Middleton, Anna. 2004. "Deaf and Hearing Adults' Attitudes Toward Genetic Testing for Deafness" in *Genetics, Disability, and Deafness*, ed. John Vickrey Van Cleve. Washington, D.C.: Gallaudet University Press.
- Mitchell, Ross, Travas Young; Bellamie Bachleda, and Michael Karchmer, "How Many People Use ASL in the United States?" *Sign Language Studies* 6 (3):306-335 (2006).
- Mundy, Liza. "A World of Their Own." *Washington Post Magazine*. March 31, 2002.
- Murphy, Francis. "BDA draft letter to Professor Marcus Pembrey." In Grumpy Old Deafies blog. Accessed February 23, 2008.
http://www.grumpyoldeafies.com/2007/11/hfeb_bda_draft_letter_to_profe.html
- Nance, Walter. "The Genetics of Deafness." *Mental Retardation and Developmental Disabilities Research Review*, Special Issue: Infants and Children with Hearing Loss, Part One, 9 (2): 109-119 (2003).

- Nicholas J.G., and A.E. Geers. "Effects of Early Auditory Experience on the Spoken Language of Deaf Children at 3 Years of Age." *Ear and Hearing* 27 (3): 286-289 (2006).
- Noble, Tom. "Embryos Screened for Deafness—a Quiet First for Australia." *Sydney Morning Herald*. July 11, 2003. Accessed April 28 2004.
<http://www.smh.com.au/articles/2003/07/10/1057783286800.html>
- Nozick, Robert. 1974. *Anarchy, State and Utopia*. New York: Basic Books.
- Nussbaum, Debra. "Your Child Has a Cochlear Implant: Why Include Sign Language?" Laurent Clerc National Center for Deaf Education, Gallaudet University. Accessed 10 December 2010.
<http://clerccenter.gallaudet.edu/documents/clerc/20091216-0003.pdf>
- Online Mendelian Inheritance in Man*, OMIM (TM). McKusick-Nathans Institute of Genetic Medicine, Johns Hopkins University (Baltimore, MD) and National Center for Biotechnology Information, National Library of Medicine (Bethesda, MD). Accessed December 10, 2010. <http://www.ncbi.nlm.nih.gov/omim/>.
- Padden, Carol. 1989. "The Culture of Deaf People." In *American Deaf Culture: An Anthology*, ed. Sherman Wilcox. Silver Spring, MD: Linstock Press.
- Carol Padden, "Translating Veditz." In *Sign Language Studies* 4 (3): 244-248 (2004).
- Padden, Carol and Tom Humphries. 2005. *Inside Deaf Culture*. Cambridge, MA: Harvard University Press.
- Padden, Carol and Tom Humphries. 1988. *Deaf in America: Voices from a Culture*. Cambridge, MA: Harvard University Press.
- Pandya, Arti and Kathleen Arnos, "Genetic Evaluation and Counseling in the Context of Early hearing Intervention and Detection", *Seminars in Hearing* 27 (3): 205-212 (2006).
- Parfit, Derek. 1984. *Reasons and Persons*. Oxford: Oxford University Press.
- Power, Des. "Models of Deafness: Cochlear Implants in the Australian Daily Press." *Journal of Deaf Studies and Deaf Education* 10 (4):451-459 (2005).
- Pyers, Jennie E., Anna Schusterman, Anne Senghas, Elizabeth S. Spelke, and Karen Emmorey. "Evidence from an Emerging Sign Language Reveals That Language Supports Spatial Cognition." *Proceedings of the National Academy of Sciences* 107 (27): 12116-20 (2010). Accessed December 10, 2010.
<http://www.pnas.org/content/107/27/12116.full> DOI: 10.1073/pnas.0914044107.

- Rachels, James. "Active and Passive Euthanasia." *New England Journal of Medicine* 292:78-80 (1975).
- Ravitsky, Vardit. "Genetics and Education: The Ethics of Shaping Human Identity." *Mount Sinai Medical Journal* 69 (5):312-6 (2002).
- Rawls, John. 1971. *A Theory of Justice*. Cambridge, MA: Harvard University Press.
- Rendtorff, Jacob Dahl. "The Second International Conference in Bioethics and Biolaw: European Principles in Bioethics and Biolaw." *Medicine, Health Care and Philosophy* 1 (3):271-274 (2005). DOI: 10.1023/A:1009992509904
- Roberts, Dorothy. 1997. *Killing the Black Body*. New York: Vintage Books.
- John Robertson. 1994. *Children of Choice: Freedom and the New Reproductive Technologies*. Princeton, New Jersey: Princeton University Press.
- Robertson, John A. "Extending Preimplantation Genetic Diagnosis: The Ethical Debate." *Human Reproduction* 18 (3):465-471 (2003). DOI: 10.1093/humrep/deg100
- Ryan, Donna and John Schuchmann, eds. 2002. *Deaf People in Hitler's Europe*. Washington, DC: Gallaudet University Press.
- Sacks, Oliver. 1990. *Seeing Voices: A Journey into the World of the Deaf*. New York: HarperPerennial.
- Sandel, Michael. 2007. *The Case Against Perfection: Ethics in the Age of Genetic Engineering*. Cambridge, MA: Belknap Press of Harvard University Press.
- Savelescu, Julian. "Deaf Lesbians, "Designer Disability," and the Future of Medicine." *British Medical Journal* 325:771-3 (2002).
- Schiff, Naomi B. and Ira M. Ventry. "Communication Problems in Hearing Children of Deaf Parents." *Journal of Speech and Hearing Disorders* 41:348-358 (1976).
- Schuchmann, John. 2002. "Misjudged People: The German Deaf Community in 1932." In *Deaf People in Hitler's Europe*, edited by Donna Ryan and John Schuchmann. Washington, DC: Gallaudet University Press.
- Seal, Brenda C. and Lisa A. Hammett. "Language Intervention with a Child with Hearing Whose Parents are Deaf." *American Journal of Speech-Language Pathology* 4:15-21 (1995).

- Silvers, Anita, David Wasserman and Mary B. Mahowald. 1998. *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Policy*. Lanham, MD: Rowman and Littlefield.
- Smajdor, Anna. "Ethical Issues in Fetal Surgery." *Journal of Medical Ethics* 37: 88-91 (2011). Accessed December 10, 2010. DOI:10.1136/jme.2010.039537
- Stokoe, William. 1980. "In His Own Words." In *Sign Language and the Deaf Community: Essays in Honor of William C. Stokoe*, edited by Charlotte Baker and Robbin Battison. , Silver Spring, MD: National Association of the Deaf.
- Stop Eugenics. Accessed 17 May 2008. www.stopeugenics.org.
- Strong, Carson. "The Moral Standing of Preembryos, Embryos, Fetuses, and Infants" *Journal of Medicine and Philosophy* 22: 457-498 (1997).
- Svirsky, M.A., S.-W. Teoh, and H. Neuburger. "Development of Language and Speech Perception in Congenitally, Profoundly Deaf Children as a Function of Age at Cochlear Implantation." *Audiology and Neurotology* 9: 224-233 (2004). DOI: 10.1159/000078392
- Tucker, Bonnie Poitras. "Deaf Culture, Cochlear Implants, and Elective Disability." *Hastings Center Report* 28: 6-14 (1998).
- United Kingdom. Parliament. Human Fertilisation and Embryology Bill [HL] 2007-08. Accessed 17 May 2008. <http://services.parliament.uk/bills/2007-08/humanfertilisationandembryology.html>.
- Van Cleve, John Vickery, and Barry A. Crouch. 1989. *A Place of Their Own: Creating the Deaf Community in America*. Washington, DC: Gallaudet University Press.
- Waardenburg, P.J. "Intermarriages of Hereditarily Deaf Mute and of Hereditarily Blind People, Marriage Counselling and the Question of Sterilization." *Acta Genetica et Statistica Medica* 6 (1):113-21 (1956).
- World Federation of the Deaf. 2007. *Abstracts Book of Presentations and Papers of the 15th World Congress of the World Federation of the Deaf*. Madrid: World Federation of the Deaf.
- Yu Y, Wu J, Fan Y, Lv Z, Guo X, Zhao C, Zhou R, Zhang Z, Wang F, Xiao M, Chen L, Zhu H, Chen W, Lin M, Liu J, Zhou Z, Wang L, Huo R, Zhou Q, and Sha J. "Evaluation of Blastomere Biopsy Using a Mouse Model Indicates the Potential High Risk of Neurodegenerative Disorders in the Offspring." *Molecular Cell Proteomics* 7: 1490-500 (2009).

Zimmerman, Charles E. "There's a Deaf Student in Your Philosophy Class – Now What?" *Teaching Philosophy* (December 2007) 30 (4): 421-442.