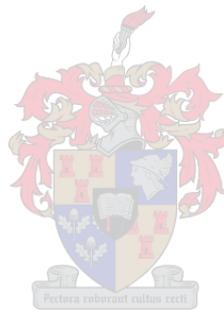


Moral perspectives on the problem of elective D/deafness

by

Alexandra Rosanna Gertrude Ukena - Kotzé



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Supervisor: Prof. AA van Niekerk

Faculty of Arts and Social Sciences

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Declaration

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Abstract

As empirical knowledge is progressing within the field of genomic medicine, the scope of medical treatments that are able to diagnose, cure or prevent disability widen and as a result, the questions regarding the ethical permissibility surrounding these procedures become more complex. While reproductive technologies were originally designed to assist with issues such as infertility or test embryos for genetic diseases before implantation, it has now become clear that these technologies can offer an even wider array of reproductive options. Morally speaking, it seems that parents have a duty to use reproductive technologies responsibly and should refrain from explicitly choosing a child with a disability. The claim that parents have a moral obligation to choose the “best” possible child has been very controversial. This thesis specifically focuses on the ethical questions that arise in cases where culturally D/deaf parents express the wish to ensure the birth of a deaf child by making use of modern prenatal screening methods such as Pre-implantation Genetic Diagnosis (PGD) that could in principle fulfil this wish. Selecting for a disability and particularly deafness through prenatal screening methods triggers a morally complex debate, firstly because the parent’s wish is based on the belief that deafness is not a disability and secondly, because the practice of prenatal selection for disability itself is questionable on the grounds that this selection could possibly harm the future child. In this thesis, the belief that deafness is not a disability will be subjected to critique by presenting both sides of the debate, on the one hand showing that our perception of normality is a concept that is shaped by various historical influences and contexts and on the other, suggesting that deafness, regardless of definition, is a very real limitation and therefore a disability that should be treated as such. If it can be shown that deafness is indeed a disability, then it follows that the use of reproductive technologies for the sole purpose of selecting a deaf embryo over a hearing one is unethical. The aim of this thesis is firstly to advance our understanding of the so-called disability challenge by bringing together information from various sources and perspectives, highlighting the ethical, social and legal issues regarding reproductive choices and secondly, to give a suggestion on how to deal with these choices. The arguments imply the need for stricter and more elaborate guidelines in terms of public regulation surrounding available genetic information and a reassessment of parental moral obligation in terms of reproductive liberty.

Opsomming

Soos wat die empiriese kennis binne in die veld van genomiese medisyne bevorder is, het die omvang van mediese behandelings wat gestremdheid kan diagnoseer, genees of voorkom verbreed. As gevolg hiervan het die vroeë oordeel oor die etiese toelaatbaarheid van hierdie prosedures al hoe moeiliker geword. Terwyl reprodutiewe tegnologie oorspronklik ontwerp is om te help met probleme soos onvrugbaarheid, of om embrios vir genetiese siektes te toets voor hul implanting, het dit nou duidelik geword dat hierdie tegnologie 'n groter verskeidenheid van reprodutiewe opsies kan bied. Moreel gesproke is dit die ouers se plig om reprodutiewe tegnologie op 'n verantwoordelike manier te gebruik en hulle word al hoe meer deesdae daarvan afgeraai om 'n kind met 'n gestremdheid te kies. Dit is wel omstrede dat beweer word dat ouers 'n morele verpligting het om die "beste" kind moontlik te kies. Hierdie tesis fokus spesifiek op die etiese vroeë wat na vore kom vir gevalle waar D/dowe ouers spesifiek vra om van moderne swangerskaptoetse en -metodes, soos Voor-implanting Genetiese Diagnose (Pre-implantation Genetic Diagnosis - PGD), gebruik te maak om te verseker dat die gebore kind doof is. Die keuse rondom 'n gestremdheid, veral doofheid, wat bewys kan word deur swangerskaptoetse, veroorsaak 'n komplekse morele debat, omdat die ouers se wense gebaseer word op die oortuiging en geloof dat doofheid nie 'n gestremdheid is nie en tweedens, omdat die praktyk van swangerskaptoetse en die keuse vir gestremdheid bevraagteken word as gevolg van die moontlike skade aan die kind se toekoms. In hierdie tesis sal die oortuiging en siening dat doofheid nie 'n gestremdheid is nie van albei kante gedebatteer word, om te bepaal of die siening van doofheid bloot 'n historiese sosiale konstruk is en of, ongeag van definisie, gestremdheid die persoon wel ernstig beperk en daarom sover moontlik behandeling vereis. As dit bewys kan word dat doofheid wel 'n gestremdheid is, beteken dit dat die gebruik van reprodutiewe tegnologie wat aan 'n dowe embryo, eerder as 'n horende een, voorkeur verleen, oneties is. Die doel van hierdie tesis is om kennis te verbreed rondom hierdie gestremdheidsdebat deur gebruik te maak van verskeie bronne en sieninge. Die fokus sal wees op die etiese, sosiale en regs kwessies met betrekking tot reprodutiewe keuses, asook om voorstelle te maak oor hoe mens te werk kan gaan met hierdie keuses. Die verskillende argumente vir en teen toon dat daar nie net 'n behoefte bestaan aan strengere en meer omvattende reëls en riglyne nie, maar ook aan vrylik beskikbare genetiese inligting en 'n herevaluasie van ouers se morele verpligtinge as dit kom by reprodutiewe keuses.

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*with my head bowed low
and my heart overflowing – with thanks*

*I acknowledge
that this is not because of me,
but because of You.*

The Godhead – three in One.

Father, Spirit, Son.

Thank You, Father.

~

Success never depends on one person alone. For this reason, I see this Master's thesis as a collaboration between myself and the people who have cheered me on from the spectator's benches and who believed in me when I didn't. Although there are many, here are a few people that deserve special mention:

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CHAPTER I

Introduction

The moral problem of the wish for D/deafness

In 1883, the Scottish born scientist Alexander Graham Bell delivered a speech to the National Academy of Sciences in the United States, which was later published as *Memoir upon the Formation of a Deaf Variety of the Human Race*. At this speech, Bell raised his concern regarding the rising tendency of deaf people to marry people of the same kind - namely other deaf people - and claimed that society was condoning the spread of what he called “a defective race of human beings” (Jankowski 1997:53). He argued that if this behaviour continued, a new variety of the human race would form. And to avoid this, he urged preventive measures to be taken and made some recommendations that would reduce the spread of hereditary deafness. Two of his recommendations were to remove the use of manualism¹ at residential schools and instead replace it with the oralist method² as well as encouraging coeducation with hearing children, so that deaf children would not be ‘isolated’ in a world of silence and instead become part of the hearing world through inclusive education (Lane 1984:357).

Another one of his more controversial recommendations was to create a new law that would prohibit the deaf to marry (Lane 1984:357). Realizing that enforcing a new law would take time, Bell urgently advised the committee of the National Academy of Sciences that the preventive measures have to be put in place. He also believed that these preventive measures would suffice for the time being until the new law would be officially approved and subsequently passed (Lane 1984:358). The *Memoir upon the Formation of a Deaf Variety of the Human Race* soon received wide-spread attention all over the United States and a lot of people knew about Bell’s reservations regarding deaf intermarriage as well as his

¹ Manualism – the method of education of deaf students using sign language within the classroom

² The oralist method – also referred to as oralism – is the education of deaf students by the use of spoken language. This method uses lip-reading and speech instead of sign language in the classroom. Oralism became popular in the United States around the 1860’s and the *Clarke School for the Deaf* (since 2010 called *Clarke Schools for Hearing and Speech*) in Northampton, US, became the first school to embrace this method of education for the deaf, opening its doors in 1867.

recommendations regarding a law that would restrict and ultimately control the spread of hereditary deafness which he planned to submit to Congress (Lane 1984:358). As the story goes, a reporter saw the memoir on a congressman's desk and assumed it to be a formal petition dealing with compulsory marriage laws, so he wrote a story about it, which led the public to believe that laws prohibiting the deaf to marry were already in place (Lane 1984:358). Following the publication of the memoir, on the one hand, proposals were made to segregate the deaf and on the other, people tried to protect the deaf by proposing to allow them to live freely, as long as they didn't reproduce (Lane 1984:358). Understandably, there was an outcry amongst the general public, who were disgusted with Bell's outspokenness regarding the deaf and how he believed they should be living their lives. Bell's theories were termed 'erroneous' in the voice of his critics, who claimed that he had no understanding of what he was talking about (Lane 1984:358).

Heeding Bell's advice, however, the government intervened and soon the use of sign language at schools was forbidden and the oralist method became more and more common in most American schools for the deaf. The aim was to successfully integrate deaf people into a hearing society and promote marriages between deaf and hearing individuals to reduce the chances of a couple producing a deaf child. Bell did realize, however, that there were practical problems with his proposed plan. For one, forcing the deaf not to marry 'one of their kind' could lead to (deaf) children born out of wedlock, which in itself wasn't what Bell wanted. Secondly, Bell himself realized that it was difficult to prove whether a person was born deaf or not and thus forbidding them to marry proved to be problematic, because back in the 1800's there was no way to identify whether the person was a carrier of the gene that caused hereditary deafness or not (Lane 1984: 357).

It was only after the 1950's that the branch of molecular genetics became better understood and attempts were made to understand the human genome in more detail. Knowing the problems resulting from his proposal, Bell instead suggested that "*legislation forbidding the intermarriage of persons belonging to families containing more than one deaf-mute would be more practical. This would cover the intermarriage of hearing parents belonging to such families, but more data are needed before we can justify the passage of such an act*" (Lane 1984:357).

Bell's speech is significant, because it shows our human tendency to want to make people fit into the status quo, irrespective of disabilities where normality seems to be the guiding standard. It shows that the majority of society wants people to conform to a norm and, in the

words of Harlan Lane, we strive to “*make people like ourselves*” (Lane 1984: xiv). And most importantly, Bell’s memoir touches on a fundamental principle that is in many ways a characteristic trait in our society: We are drawn to people who are like us. We enjoy being with people who share the same values, beliefs, experiences and culture. In other words: Society sets a standard of normality that it implicitly wants people to conform to.

The same is true for deaf people – most of them are drawn to people with whom they can identify and share a state of being and ‘belonging’. For most deaf people, this sense of ‘belonging’ reaches deeper than merely accepting the status quo and conforming to a standard of normalcy to fit into the mould of society. To them, ‘belonging’ means creating another – alternative – sense of identity that no longer fits into society’s preconceived ideas. When we talk about deafness as a disability, we don’t only talk about people who share a certain physical ‘disability’; we are also talking about people who have created a new sense of identity for themselves because they do not feel a sense of belonging anywhere other than within the new identity they have created. These deaf people see their deafness as their identity and their culture, not as a disability.

In 2006, a paper was published in the *Journal of Deaf Studies and Deaf Education* titled “*A Compelling Desire for Deafness*”. In this paper, author Dr David Veale, a psychiatrist in Cognitive Behaviour Therapy from London, describes one of his hearing patients, a 36 year old woman, who has a persistent and compelling desire to become deaf. In search for complete silence, his patient would place oil – dipped cotton wool into her ears to achieve minimal hearing and teach herself sign language (Veale 2006: 369). Her desire to become deaf is deeply rooted in avoidance behaviour as a result from suffering from a range of psychological disorders like Hyperacusis and Misophonia (Veale 2006:369). Hyperacusis and Misophonia are both disorders defined as abnormally strong emotional reactions to sound without any significant activation of the auditory system (Veale 2006:371).

Having suffered from this disorder since childhood, she started seeking the help of a sympathetic surgeon to make her deaf as she did not want to take the risk upon herself by e.g. taking ototoxic drugs that can cause hearing loss (Veale 2006: 370). Even though she has been tested and confirmed to have ‘normal’ hearing, she describes herself as “*a deaf person in a hearing person’s body*” (Veale 2006: 370). She has no desire to wear a hearing aid and declines psychological intervention in the form of therapy sessions to help her overcome her sensitivity to sound (Veale 2006: 370). Furthermore, she teaches herself British Sign Language (BSL) and enjoys attending Deaf clubs, as they offer her a sense of belonging and confidence as she suffers

from low self-esteem and social anxiety in the hearing world. In her words, spending time at Deaf clubs feels like “*coming home*” (Veale 2006:370).

She states that she is looking forward to “*being welcomed into the Deaf community*,” as opposed to being “*only a tourist in their midst*” (Veale 2006:370). She also joined a “D/deaf³ wannabe” group on the internet and met other people who share her desire to become D/deaf (Veale 2006:370).

In another widely debated case, a deaf lesbian couple from Washington, DC., Sharon Duchesneau and Candy McCullough, made headlines on BBC news on the 8th of April 2002 when they publicly disclosed their decision to use a deaf sperm donor by private arrangement with a history of genetic deafness to ensure the birth of a deaf child (Spriggs 2002:283). Both Duchesneau and McCullough suffer from congenital hearing impairment which contributed to their wish of increasing their chances of having a deaf child (Scully 2008:60). Even though they did not reject the idea of having a hearing baby, they stated that having a deaf one would be their *preference* (Scully 2008:60). While pregnant, Duchesneau said that, “*It would be nice to have a deaf child who is the same as us...A hearing baby would be a blessing, but a deaf baby would be a special blessing*” (Glover 2006:5).

Following this decision, an outcry occurred amongst the general public, expressing disgust at the nature of this decision and arguing that McCullough and Duchesneau’s decision to deliberately choose a deaf child is morally wrong. Even sympathetic journalists revealed an underlying sense of incomprehension about the nature of their decision. To the majority of people, the lesbian couples’ decision to choose to have a deaf child just seemed intuitively wrong. Various disability activists, however, remarked that their decision to have a deaf child was rooted in their belief that deafness is not a disability, but rather “*the constitutive condition of access to a rich and valuable culture*” (Levy 2002:284). Similarly, for Deaf people, being deaf is just ‘a different way of being in the world’ (Scully 2008:61).

³ The Deaf culture makes a linguistic distinction between the words deaf (lower case d) and Deaf (upper case D). Deaf, when spelled with a lower-case d (deaf) refers to the physical condition of deafness and includes those who typically only see deafness as a physical and therefore medical condition and who do not identify with the Deaf community and rather associate themselves with hearing people. Deaf spelled with an upper-case D refers to those who identify themselves as being culturally Deaf and who have a strong Deaf identity. Deaf (in capital D) will therefore be used in all references to the Deaf culture and deaf (lower case) will be used as a reference for deafness when exclusively referring to the medical condition.

It must be pointed out that in both the above mentioned cases, the desire to become D/deaf and to become part of a community of other people who share the same ‘disability’ seems to be the underlying motivating factor that ultimately influenced the decision to become deaf. Both Duchesneau and McCullough wanted a child with whom they could share their ‘deaf world’.

For Dr Veale’s patient, an additional factor plays a role – the desire to live in a world of absolute silence. In both cases, however, the deaf person’s identity is linked to their ‘deafness’. In this regard, the Deaf culture proves to be very attractive to individuals who are looking for a sense of belonging and acceptance. Of course, it seems unusual to suggest that the Deaf culture seems to be the only place in which D/deaf people feel this sense of belonging, acceptance and identity. Surely, there must be other places in which this desire to ‘belong’ can also be fulfilled – like, for example, church communities, self-help groups etc.? The difference for a D/deaf person between being accepted by the Deaf community and, say, a church community is that the former embraces their belief that deafness is their identity, while the latter group finds their identity in, say, believing in a higher Being. We can see here that the nature of what it means to find an identity in something is a bit more complex than what it seems on the surface. It’s essentially a search for meaning within an identity.

In the first example, Dr Veale’s patient sought help to become D/deaf because she felt no longer ‘at home’ in the hearing world and suffered from an oversensitivity to sound and wanted to escape into a world of silence. In the second example, a deaf couple chose a deaf child over a hearing one by selecting a deaf sperm donor, in the hopes of their child being able to partake in ‘their world’ and enter into the same kind of ‘being’. These kinds of choices are also termed ‘elective deafness’. In other words, ‘elective deafness’ means deliberately choosing deafness out of one’s own free will – either for oneself or for another human being.

Even though both cases are very different and relatively rare, they both ask the same question: What is it that drives people to choose one form of identity over another? Why would parents choose a deaf child over a hearing one? And most importantly: Is ‘choosing deafness’ a morally right thing to do?

These questions got raised at another incidence that occurred in Melbourne, Australia, sometime after the Duchesneau/ McCullough case. In this instance, a couple chose to use a pre-implantation diagnostic procedure called Pre-implantation Genetic Diagnosis (PGD) to ensure the birth of a hearing child (Scully 2008:61). As opposed to the case of Duchesneau/ McCullough, there was virtually no demand for justification in explaining why ‘choosing a

hearing child' as opposed to choosing a deaf one would be better and even morally right (Scully 2008:61). Most people just didn't question the decision made by the Australian couple, but they did question Duchesneau/ McCullough's decision. Once again it seems that, intuitively, most people think that choosing deafness is wrong. Subsequently, a local Australian Regulatory Body, the Infertility Treatment Authority, was assigned the difficult task of deciding whether the screening against deafness was indeed a legitimate request (Scully 2008:61). At the core they had to answer the question as to whether deafness could indeed be classified as a genetic disease and hence worthy to be screened against. Here we need to remember that for most hearing people i.e. the majority, deafness is a serious medical condition and a disability as opposed to another way of 'being'. Therefore, to most hearing people, the request or choice for elective deafness as seen in cases such as the one described by Dr Veale and the Duchesneau/ McCullough case, seems bizarre and even shocking.

Why would someone choose deafness as a way of life? What Dr Veale describes in his paper is just one of a wider variety of cases in which individuals have chosen a life of deafness – either for themselves or their children – above living in a hearing world. The reasons for deafness are multifaceted and range from genuine psychological disorders where people have a desire for self-inflicted deafness to parents who wish to have deaf children simply because they themselves are deaf and see deafness as a ticket to a rich and diverse culture – the Deaf culture, which offers them a sense of belonging and identity. Those parents want to ensure that their children share this 'deaf' experience and way of life.

On instinct, most hearing people respond negatively towards the request for elective deafness because they cannot identify themselves with it. Whether deafness is self-inflicted, as in the case of Dr Veale's patient or whether deafness is a chosen condition for one's offspring – talking about elective D/deafness proves to be a moral problem. To put it simply - when we talk about the *moral problem* of elective D/deafness, we are talking about the possible harm that can be caused when the decision for or against elective D/deafness is made. In biomedical ethics, this 'harm principle' is also called 'the principle of nonmaleficence', and it imposes an obligation not to inflict unnecessary harm on others (Beauchamp et al. 2009: 149).

This principle is often creatively expressed in the maxim *Primum non nocere* – “Above all, do not harm” (Beauchamp et al. 2009:149). Because the prevention of harm is such a fundamental principle in biomedical ethics, it is important to determine whether harm is done to the child where elective D/deafness is concerned. Because 'harm' is such a broad term that encompasses

many things, different people have different opinions and ideas about what ‘harm’ might entail in this context - on an individual and on a public level.

One of these views on the principle of harm can be found in a famous work titled *On Liberty*, published in 1859 by the 19th century British philosopher John Stuart Mill. In this work, Mill talks about this issue of harm in great detail. In essence, he asks to what extent society should have the right to interfere, control and impose limits to the thoughts, beliefs and actions of autonomous individuals. To answer this question, he investigates the nature and limits of power which society can legitimately exercise over an individual. Power, according to Mill, can be exercised on two levels: On a governmental and on a societal level. Every society has come to adopt a “right” and a “wrong” way of thinking and to “fit” into a society, we have to adhere to and adopt the society’s status quo, where the status quo simply refers to those opinions and attitudes that are accepted by the majority. These opinions and attitudes we can also call ‘the norm’. Individuals who show rebellion against the norm are consequently ostracised by society (the majority). This ‘social force’ that pressures individuals to conform to the norm Mill terms ‘the tyranny of the majority’, which he claims to be the main reason of conformity. Echoing the words of Mill, Harlan Lane says the following: “*People are afraid of human diversity and look to their social institutions to limit or eradicate it [diversity, divergence from the ‘norm’]*” (Lane 1984: xiiiv).

While the government coaxes individuals to conform to a country’s standard by laws and regulations i.e. coercion by force, the tyranny of the majority imposes their way of living on individuals by threatening to alienate them if the standard which the norm imposes aren’t followed. According to Mill, however, there are limits on the amount of power a society can exercise on an individual. To illustrate where the execution of power is appropriate by the ‘tyranny of the majority’, Mill makes a distinction between two types of actions: The actions that affect others and the actions that affect only ourselves (Mill 1959:137). The actions that affect others, according to Mill, are the only actions that warrant the exercise of power over an individual. Self-affecting actions, however, are not to be interfered with by society. Those actions are actions that concern and affect the individual alone and that are of no consequence to anyone else. In other words: An individual’s actions are only justified in as far as those actions do not cause harm to others. In Mill’s words:

(..) The sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their member, is self-protection. That the only purpose for

which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others (Mill 1959:16).

Similarly, as scientist James Watson, the co-discoverer of the structure of the DNA double helix puts it: *'I am against society imposing rules on individuals for how they want to use genetic knowledge. Just let people decide what they want to do.'* Watson believes that parents ought to decide whether they want a child with Down syndrome, a child who has blue eyes or a child who is deaf. In supporting parental procreative autonomy, and echoing the words of Mill, he also states that *'I am for using genetics at the level of the individual...it is best to let people try and do what they think is best. I wouldn't want someone else to tell me what to do.'* And then he adds *'as long as you are not hurting someone else'* (Glover 2006:73).

Both Mill and Watson place a lot of value and emphasis on the personal autonomy of the individual – i.e. we, as human beings, should be free to make our own choices, as long as these choices are not hurting others. As we shall see, this statement becomes a little more problematic when we start talking about procreative rights and parental autonomy versus the child's future autonomy. In the case of elective deafness, we are looking at physical harm i.e. physical harm in the form of 'creating' a disability, either by self-inflicted physical harm or by 'choosing' deafness for someone else, e.g. parents who choose to bring a deaf child into the world. Even though philosophers differ about the exact definition of harm, it is important to remember that harm – expressed in whichever definition one chooses- should be avoided if at all possible. In principle, most people agree that causing even significant bodily harm, in this case 'choosing deafness', falls into the 'harm' category, whether it involves pain or not. 'Harm' in this case does not refer to physical pain, but rather refers to parents deliberately choosing to impair their child by removing their child's option to hear by, for example, selecting a deaf embryo over a hearing one. The question that arises here is whether the parent's decision to 'choose' deafness is indeed in the best interest of the child. Once again, different notions of the word 'harm' arise.

Once again, in this case, we are not talking about 'harm' in the sense of physical pain, but rather 'harm' in the sense of parents withholding opportunities from their children by not granting them access to opportunities in the hearing world by a.) choosing deafness for their child in the first place and by b.) withholding enhancement technologies that could restore hearing. One such opportunity, in the case of deafness, would be granting a child access to enhancement technologies such as the cochlear implant where enhancement *"is directed towards the improvement of human functioning"* (Hall 2012:4). In this case this enhancement is realised *"by the correction of capacities that are damaged by the presence of disorder or*

disease, and the restoration or achievement of normal functioning [...]” (Hall 2012:5). In this respect, philosopher and bioethicist Susan Hall asks another significant question:

If enhancement technologies become readily available, would it be a moral mistake to refrain from making use of them? To illustrate her argument, she quotes Erik Parens who asks whether “[making people] *better [is] always good*” in the context of human functioning (Hall 2012:6). Even though in her case the question is more directed towards genetic enhancement, the same question can be asked in the case of elective deafness. If it can be demonstrated that ‘better is always good’, e.g. in this case by allowing a child access to a cochlear implant to restore hearing, thereby ‘making him/her better’ and if it can be shown that this ‘good’ should be actively pursued, wouldn’t failing to pursue this good amount to the infliction of harm? (Hall 2012:6).

The moral concern is thus, whether parents are indeed choosing the ‘right thing’ for their child by choosing deafness for him/her. This choice raises additional issues that revolve around procreative rights and parental autonomy. And not only that, it also raises the question of the respect for autonomy of the child as discussed in Beauchamp and Childress’s book *The Principles of Biomedical Ethics* and asks the question as to whether the prospective child would also choose deafness for him/herself. Although less relevant in this thesis, an additional moral question arose at the beginning of this chapter: Should autonomous individuals be allowed to choose elective deafness for him/herself as in the case of Dr Veale’s patient? If so, does this choice really mean that no harm is inflicted to anyone else, but on the individual alone, as stipulated by John Stuart Mill’s principle of harm?

In this thesis, I will focus on the moral issues in cases where competent D/deaf parents deliberately choose to have a deaf child by the means that are currently available in the field of genomic medicine. I will start off by explaining the moral issue of the above-mentioned case scenario – i.e. D/deaf parents choosing a deaf child and the moral dilemmas that arise out of such a choice.

In Chapter 2, I will examine how elective D/deafness can be achieved by taking a look at current reproductive technologies such as embryo screening and implantation and how those technological advances aid the procreative choices that parents are able to make. Further, I will have a look at Pre-implantation Genetic diagnosis within the international and the South African context and will explain the current legal framework that governs these procedures.

In the third Chapter, the focus will shift to an examination of the D/deaf culture, describing who they are, and what they stand for, and why members of the D/deaf culture sometimes have a strong desire to bring deaf children into the world in order to sustain and safeguard their culture and cultural identity. I will present a short overview of the history of the deaf and will explain how this history ultimately contributed to the creation of the Deaf community. Closely linked to the D/deaf culture's identity is their personalized interpretation of the word 'deafness'.

In Chapter 4, I will take a look at the different models of disability and its definitions, while at the same time trying to define the concept of normality by explaining how this term changed throughout history. I will explain both the social and the medical model of disability and how these models came about and how they ultimately shaped the Deaf community to what it is today. Each of these models is unique in their own right and I will take a look at the merits and pitfalls of each. The aim of this chapter will be to give a broader perspective of key historical events that led to the creation of both these models of disability.

Chapter 5 will focus on arguments in favour of elective D/deafness and how those arguments fit into the different models of disability. I will use the analogy of Martha's Vineyard to explain the normality of difference and how the concept of normality ultimately acts as a claim on the Deaf community's cultural identity. In this chapter, I will place deafness in perspective and will also put some emphasis on the respect for parental autonomy as well as procreative liberty and discuss Savulescu's notion of procreative beneficence.

The sixth Chapter will then present the other side of the coin - namely the arguments against elective deafness. This chapter will include a discussion of Joel Feinberg's notion of the Open Future argument, different arguments about harm and why it might be beneficial to give a child the opportunity to live in both the deaf and the hearing world and the role Human Enhancement Technologies (HET) like cochlear implants play in this regard.

In Chapter 7, I will conclude my thesis by providing a summary of the above, while at the same time pointing out some of the implications of the arguments I presented. Lastly, I will be giving some recommendations regarding future research as well as suggestions on how to go about the elective deafness debate.

CHAPTER II

Deaf by choice - How can elective D/deafness be achieved?

2.1 Pre- implantation Genetic Diagnosis (PGD)

Over the last 60 years, the field of biomedical ethics has undergone dramatic changes. With the invention of innovative and advanced medical technology, particularly those technical advances in the field of reproductive technology, new opportunities for parental procreative choices arise. These choices can be made with the help of genetic counselling services due to the access of genetic data through so-called sequencing initiatives like Pre-implantation Genetic Diagnosis (PGD). These technical advances allow for the detection of gene loci – the specific location of a gene – at a prenatal and postnatal stage to identify, amongst other things, abnormalities that can cause birth defects or fatal illnesses in an embryo (Sermon et al. 2004: 1633; Scully 2008:797).

Pre-implantation Genetic Diagnosis (PGD) has been introduced in a clinical setting as an alternative to Prenatal Diagnosis (PND) after a ground-breaking report was issued in 1990. Prior to this report, preliminary experiments involving PGD had been carried out as clinical trials, but only in 1990 did the procedure gain official recognition by research ethics committees (REC's). In fact, the above-mentioned report gained so much recognition that the UK legislation regarding embryo research was reviewed and changed to regulate the practice of in-vitro fertilisation (IVF) and the creation, use and disposal of embryos that are produced in this way (Sermon et al. 2004:1633).

Prior to the official introduction of PGD, the only method of embryo screening available was a procedure called Prenatal Diagnosis (PND). Prenatal Diagnosis allows prospective parents to screen their embryo for certain diseases, including autosomal recessive disorders such as cystic fibrosis and autosomal dominant disorders like myotonic dystrophy before the baby is born (Appold 2014:1). The PND procedure itself is not a pleasant one, as it involves other procedures like amniocentesis, a procedure where a needle is inserted into the mother's lower abdomen and into the amniotic cavity inside the uterus to sample fetal cells which can be found in the amniotic fluid. These fetal cells are then biopsied for chromosomal abnormalities. Because amniotic fluid needs to be present for the procedure to show reliable results, it can typically only be performed from the 14th week up until the 20th week of gestation, where the fetus is already about the size of a lemon. If certain diseases are found to be present, the parents

have the choice to have the embryo aborted and the pregnancy terminated. This choice is for many parents a difficult one for cultural, religious and moral reasons (Mand et al. 2009:722). To avoid this type of invasive procedure and to avoid obvious moral dilemmas, PGD was introduced.

In comparison to Prenatal Diagnosis, PGD is still a relatively new technique that combines in-vitro fertilization (IVF) and genetic testing (Sermon et al. 2004:1633). This means that when PGD is performed, embryos are created in vitro (lat. 'in glass' – in a test tube) by fusing human sperm and ova in a fluid medium in a laboratory. To ensure the success rate of implantation and testing, various embryos are then analysed to identify genetic abnormalities. Only those embryos free from specific defects are transferred into the womb with the intention of establishing a successful pregnancy. In other words, Pre-implantation Genetic Diagnosis in conjunction with IVF enables couples to screen their offspring *before implantation* that would otherwise have a high risk of being born with severe genetic conditions that could, in the long term, pose a health risk to the child. The need to terminate the pregnancy, due to the fact that the embryo is found to contain a serious inherited genetic condition, is thereby greatly reduced, as one naturally tends to select *against* those embryos that would have a serious genetic defect at birth. Nowadays PGD is widely available for a vast array of known genetic mutations and prospective parents can choose which embryo is used for transferral (Scully 2008:798).

Interestingly, approximately one in every 1000 children born will be born deaf or will develop profound hearing loss later in life (pre-lingual hearing loss) (Mand et al. 2009:722). Deafness can occur either as the result of environmental causes, such as a burst eardrum due to exposure to extremely loud sounds or as the result of genetic mutations. It is estimated that nearly half of all causes for deafness are the direct result of such genetic mutations and more specifically single gene mutations (Mand et al. 2009:722). In 1997, a research team from the University of Leeds administered a self-completion questionnaire to deaf delegates during an international conference held at the University of Central Lancashire (Middleton et al. 1998:1175). Eighty-seven of those delegates returned the questionnaire and it was found that 16% said they would consider making use of the PGD procedure in general and of those, 29% stated that they would use the PGD procedure to specifically select for deafness (Middleton et al. 1998:1175).

2.2. Pre-implantation Genetic Diagnosis (PGD) across borders

Different countries have different approaches, laws and regulations with regards to PGD screening. In the United States, there are no federal regulations regarding PGD, as PGD is only regulated by professional standards. Similarly, Canada is still in the process of formulating stricter guidelines with regards to PGD screening. The only thing Canada currently prohibits against is sex selection for non-medical purposes when PGD is performed (Camporesi 2010:86). In Europe, the laws that govern PGD vary widely from country to country. While PGD is illegal in Austria, Ireland and Italy, and illegal use of PGD would be seen as a violation to the Constitution, other European countries like Spain, Belgium, France and the Scandinavian countries allow PGD screening in certain instances - e.g. to screen for severe genetic disorders or in instances of tissue typing⁴ (Camporesi 2010:87). As of 2011, Germany allows PGD only for life-threatening genetic defects (Hayder 2011). As a result of this heterogeneity, a lot of couples cross borders into neighbouring countries so that they can legally make use of the PGD procedure if the need arises (Camporesi 2010:87). The most liberal country to accept the PGD procedure is the UK, where PGD is officially licensed by the Human Embryology and Fertilisation Authority (HFEA) (Camporesi 2010:87). The HFEA is an organization that is responsible for granting licenses to all clinics requesting the use of the PGD procedure within the UK (Emery et al 2010:160).

Currently, the HFEA lists approximately 350 diseases which are approved for the PGD procedure, with a further list of about 16 diseases pending approval (HFEA).

2.3 Pre-implantation Genetic Diagnosis (PGD) in South Africa

The South African Constitution recognises the right to bodily integrity which includes the right to make autonomous decisions concerning reproduction (S12 (2) (a) of the Constitution). Broadly speaking, this right includes the freedom of individuals to decide whether they want or don't want children. It can be argued, however, that this right should also include the right

⁴ Tissue-typing is a procedure in which the tissues of a donor and a recipient are tested for compatibility before implantation takes place. Amongst other things, this procedure allows to check whether the embryo that is implanted qualifies as e.g. a stem-cell donor for a sick sibling. For more information, see: <http://www.iconcancercare.com.au/wp-content/uploads/2014/01/TissueTyping.pdf>

of parents to choose how and what kind of child should be born. This includes choices regarding the use of in-vitro fertilization and the use of the Pre-implantation Genetic Diagnosis procedure – a procedure that is still controversial within the South African context, as it lacks clear guidelines within the legislative framework.

With regard to the lacking of clarity within the current legislative framework, South Africa can learn a lot from foreign law, as South African law has – in some respects - not caught up with the elaborate guidelines of its overseas partners. This refers specifically to guidelines pertaining to genetic research and specifically to the circumstances in which certain practices are legal or illegal (DuPlessis et al. 2014:232).

Within the South African legislation, the National Health Act 61 of 2003 is the most up to date document that needs to be consulted to determine the framework in which PGD may or may not be performed within the South African Republic. The aim of this Act is to “*provide a framework for a structured uniform health system within the Republic, taking into account the obligations imposed by the Constitution and other laws on the national, provincial and local governments with regard to health services; and to provide for matters connected therewith.*” (National Health Act 61 of 2003: 2)

These ‘matters’ could certainly include the ethical issues that arise out of the use of – for example - the Pre-implantation Genetic Diagnosis procedure. In summary, even though the South African National Health Act itself does not specifically refer to the practice of PGD, the Act in principle seems to permit it, as it refers to another document that talks about the PGD procedure, but it provides no specific guidelines on the circumstances in which PGD may be performed.

Within the South African legislative framework, the National Health Authority (NHA) is important to the health legislation, as the NHA is responsible for the policy formulation and planning of all health matters within the Act (DuPlessis 2014:238).

The National Health Act (NHA) came into force on the 2nd of May 2005 (Pepper 2012:736). It is important to note though, that amendments and regulations have been made and added to the NHA on different occasions since then – e.g. sections 54 as well as sections 57-67 of the Act came into force on the 1st of March 2012 (Pepper 2012:736). Before that time, all matters regarding the use of human tissue were documented in the Human Tissue Act (HTA) No. 65 of 1983 (Pepper 2012:736). Since then, the NHA – and specifically chapter 8 within the NHA has played a major role in providing a guideline for practices relating to the use of human

tissue and embryo transfer. Important to note is also, that there are other legislations that influence the guidelines in the NHA such as the Children's Act No.38 of 2006 (Pepper 2012:736).

When the HTA was drafted, a lot of change happened regarding the scientific discoveries surrounding e.g. artificial fertilisation, stem cell research et cetera and subsequently the HTA had to be revised (Pepper 2012:736). As a result, the NHA was born and is currently the most up to date document that can be consulted with regard to issues surrounding human tissue transfer (this includes embryo transfer). What is important to note is the fact that, apart from the NHA document, there is another document that was published in the Government Gazette on the 2nd of March 2012, which acts as an added regulation complementing the original National Health Act 61 of 2003. This regulation is titled "*Regulations Relating to Artificial Fertilisation of Persons*" (Government Gazette 2012). This regulation specifically mentions Pre-implantation Genetic Diagnosis and mentions one guideline regarding this procedure: Pre-implantation Genetic Diagnosis is allowed, except for embryo sex-selection, with the exception in cases where severe sex-linked genetic conditions would threaten the pregnancy or the survival of the embryo. Before this document was published, the only document that could be consulted regarding PGD was the National Health Act 61 of 2003 (in which the word Pre-implantation Genetic Diagnosis wasn't even mentioned) and a number of concerns were raised that dealt with the insufficiency and vagueness of the guidelines surrounding the 'Control of Blood, Blood Products, Tissue and Gametes in Humans'. Hence, before the publication of the Regulations in the Government Gazette in 2012, no explicit reference existed within the National Health Act that referred specifically to the Pre-implantation Genetic Diagnosis procedure.

Prior to the '*Regulations Relating to Artificial Fertilisation of Persons*' which was published in 2012, the only guideline available with regard to the PGD procedure could be found in Chapter 8 of the National Health Act which deals with the 'Control of Use of Blood, Blood Products, Tissue and Gametes in Humans' (National Health Act 61 of 2003:50). Having said this, it is important to note, once again, that Pre-implantation Genetic Diagnosis is never explicitly mentioned in the Act. Instead, in Section 56 the guidelines surrounding the 'use of tissue, blood, blood products, or gametes removed or withdrawn from living persons' are listed (National Health Act 61 of 2003:51). Furthermore, section 56 states that "A person may use tissue or gametes removed or blood or a blood product withdrawn from a living person *only*

for such medical or dental purposes as may be prescribed “(emphasis mine) (National Health Act 61 of 2003:56 (1)).

Then, Section 56 (2) (a), explains for which purposes tissues, blood, a blood product or a gamete from a living person may not be removed or withdrawn:

- (i) Tissue, blood, a blood product, or a gamete from a person who is mentally ill within the meaning of the Mental Health Care Act;
- (ii) Tissue which is not replaceable by natural processes from a person younger than 18 years;
- (iii) A gamete from a person younger than 18 years; or
- (iv) Placenta, embryonic or foetal tissue, stem cells and umbilical cord, excluding umbilical cord progenitor cells.

While Section 56 (2) (a) (iv) (National Health Act 61 of 2003:51-52) clearly states that embryonic or foetal tissue may not be removed from any living human being, Section 56 (2) (b) comments on the above statement and adds [but] “*the Minister may authorize the removal or withdrawal of tissue, blood, a blood product or gametes contemplated in paragraph (a) and may impose any condition which may be necessary in respect of such removal or withdrawal*” (National Health Act 61 of 2003:52).

Understandably, a lot of people felt that the Act was too vague in so far that Section 56(1) neither lists, nor defines the circumstances or purposes in which a ‘*person may use tissue or gametes removed or blood or a blood product withdrawn from a living person*’. It only lists the circumstances in which tissue or gametes etc. may not be removed. And even in the ‘may not’ list, the list remains vague and only states that ‘*placenta, embryonic or foetal tissue, stem cells and umbilical cord, excluding umbilical cord progenitor cells*’ may not be removed, but it doesn’t state specifics.

Even though individuals were able to submit a request to the Minister of Health to review the regulations and request to authorize the removal of placenta, embryonic or foetal tissue, it was unclear under which circumstances such a request could be made.

This picture changed a bit after the ‘*Regulations Relating to Artificial Fertilisation of Persons*’ were published. In this Regulation, explicit reference is made to the PGD procedure on page 14, Section 13 of the Regulations under the title “*Pre-implantation and prenatal testing for sex selection*” (Government Gazette 2012:14). It states that:

“Pre-implantation and prenatal testing for selecting the sex of a child is prohibited except in the case of a serious sex linked or sex limited genetic condition” (Government Gazette No 35099, 2012).

With regard to genetic testing for a disease, the Regulations state the following on page 13, Section 11 in the Government Gazette under the title *“Requirements for artificial fertilisation and embryo transfer”*:

“A competent person intending to effect the artificial fertilisation or embryo transfer to a recipient shall, before effecting the artificial fertilisation or embryo transfer

(c.) ensure that –

(iii) if the recipient or the gamete donor should be a carrier of a serious genetic condition –

(aa) the recipient and the gamete donor are tested to determine whether they are such genetic carriers; and

(bb) if it is determined that both the recipient and the gamete donor are such carriers or the gamete donor is such a carrier, a gamete from that donor is not used for artificial fertilisation of or the embryo transfer to the recipient.”

Here, the Regulation talks about the testing of the gamete donor and the recipient but makes no explicit reference to embryo testing – i.e. Pre-implantation Genetic Diagnosis. While the current framework appears to admit PGD as a procedure, there are still no regulations that specify under which circumstances the PGD procedure may or may not be granted (Strode 2012:23). Even though the Department of Health said that it would control the use of this procedure by frequently checking the databases and managing registration procedures, the normative standards for the circumstances in which the PGD procedure may be used or not are lacking (Strode 2012:23).

In South Africa, there are twelve main laboratories, most of them boasting academic affiliations, which offer genetic testing and screening (Kromberg et al. 2013:418). Of those, one of the largest academic departments in genetic screening is the Division of Human Genetics laboratory at the National Health Laboratory Service (NHLS) as well as the genetics laboratory of the University of Witwatersrand in Johannesburg (Kromberg et al. 2013:418). While genetic screening tests are offered in the academic/public domain at the major Universities throughout South Africa, there are also a whole number of smaller, private laboratories that offer genetic screening such as the MEDFEM and the Genesis Genetics fertility clinics, both situated in

Gauteng. The full range of medical genetic tests that are offered are often listed on the respective websites of these laboratories and are also documented in *Diagnostics Genetics Tests South Africa* (Kromberg et al. 2013:418). Unfortunately, however, there are very few instances in which the data regarding genetic tests e.g. what is screened for is made public by the private laboratories. For this reason, very little or in some instances no data is available that would provide information regarding which diseases are screened for or against on a private basis (Kromberg et al.2013:418). Also, genetic testing in South Africa is not centralised and therefore many laboratories offer testing for different genetic conditions (Kromberg et al. 2013: 418). Additionally, websites of private fertility clinics such as MEDFEM and the Genesis Genetics fertility clinic advertise an elaborate list of diseases, for which the Pre-implantation Genetic diagnosis can be performed. These lists currently include over 242 diseases that can be screened for – amongst them three different types of deafness: Recessive deafness GJB2 Connexin 26, recessive deafness GJB6 Connexin 30 and recessive deafness DFBN1. These lists, however, cannot be found within the draft Regulations or the National Health Act, nor is there a reference made to any list specifying when or for which diseases PGD may be used within the South African context. One of the reasons for this is a divide in opinions as to whether genetic services should be centrally coordinated by the National Department of Health and provided by the provincial Department of Health, as it is the case in the Western Cape and the Free State, or whether genetic services should be provided fully by the National Health Laboratory Service (NHLS), as is the case in the province of Gauteng (Kromberg et al. 2013:421).

In principle, however, the right to reproductive freedom and parental autonomy is a right that is protected by the Constitution and the South African State can only limit PGD to the degree in which this procedure would cause harm to the unborn child, in principle agreeing with Mills' theory, provided PGD isn't used for sex-selection, which is prohibited. And, even though the Regulations, specifically those published on the 2nd of March 2012 are an important step into the right direction towards more complete and clear guidelines, a clearer framework is needed that deals with more specific case scenarios (Pepper 2012:736). While these clearer guidelines will hopefully be drawn up in the near future, South Africa can learn from organizations such as the HFEA (Human Fertilisation and Embryology Authority) in the UK (Strode 2012:23).

2.4 Pre-implantation Genetic Diagnosis and disability screening

In the public eye, the prospect of a ‘designer baby’ is closely related to the PGD technique as it is in principle possible to ‘pick and choose’ which traits the child should have and is therefore highly controversial. On a similar note, many individuals have equated PGD with a form of ‘modern eugenics’ and ‘selective abortion’, as it is possible to screen out disabled children. It is important to note, however, that there are limits as to what PGD can achieve. Parents cannot assume that PGD will enable them to choose any kind of characteristic they would want in a child because the genetic information contained in a gene is and will remain a combination of genetic information possessed by both parents, even in instances where IVF was used for implantation (Baruch 2008:250). Also, not all diseases and non-health related traits have a strict genetic component that can be identified. Often, genetic mutations are the result of a combination of environmental factors as well as more complex genetic interactions. In summary, the PGD process is not to be understood as genetic manipulation or “engineering” of an embryo. Its purpose is first and foremost to screen the embryo’s DNA for any abnormalities that might result in severe disease and/or physical or mental disability (Baruch 2008:250).

Nevertheless, the use of PGD for any use other than the avoidance of severe genetic diseases has given rise to a number of ethical concerns. Ideally, Pre-implantation Genetic Diagnosis should only be used by patients who are known to be carriers of high-risk genetic diseases and abnormalities – or patients that want to be tested to see whether they are carriers. However, many people nowadays also use PGD for other purposes (Baruch 2008:256). Examples of these instances include determining the sex of a child either based on mere preference or to introduce gender variety into a family. Other controversial uses for PGD now also include the selection of embryos who qualify as a genetic match to an existing sick sibling, so that bone marrow or stem cells can be used as a cure for a disease (Baruch 2008:253). Another highly controversial use of PGD that has attracted a lot of attention in recent years includes the deliberate selection of a disabled embryo (Baruch 2008:253).

As I mentioned in chapter one, people are naturally drawn to people who are like them. Similarly, people with disabilities tend to identify themselves with people who have the same disability because they share a similar kind of ‘being’. It should come as no surprise then, that a number of D/deaf people have openly expressed the wish to use Pre-implantation Genetic Diagnosis to select a child with the same disability – namely deafness. Put bluntly, PGD now

enables parents to either prevent the birth of a disabled child – or in extreme cases where deafness is concerned – even ensure the birth of a child with a disability.

If parents wish to have a deaf child, their two theoretical options available would be PND or PGD. When Prenatal Diagnosis (PND) is chosen as a means to determine genetic abnormalities, embryos who do not carry the deafness gene will simply be aborted and when Pre-implantation Genetic Diagnosis (PGD) is selected, only the embryo who shows to have the ‘deafness gene’ is implanted and the remaining embryos are discarded (Mand et al. 2009:722). The other option available for individuals wanting to have a deaf child is, of course, to marry a deaf partner who has a history of genetic deafness in the family, exactly what Alexander Graham Bell argued against, or, as in the case mentioned in chapter one, selecting a deaf sperm donor. However, because marrying a deaf partner or choosing a deaf sperm donor does not always guarantee the birth of a deaf child, a lot of focus is placed on the Pre-implantation Genetic Diagnosis procedure when deaf parents express the wish to have a deaf child.

In 2006, a survey was conducted by the Genetics and Public Policy Centre at the Johns Hopkins University where 190 American Pre-implantation Genetic Diagnosis (PGD) clinics were asked to indicate whether their patients had requested PGD to purposely select an embryo with a disability. Of those clinics, 3% reported that they have had cases where embryos with a disability were chosen over a healthy embryo (Camporesi 2010:86; Baruch 2009:247). According to this survey, four US IVF clinics admitted to using PGD in cases where parents requested PGD to select for a certain type of disability (Baruch 2009:255). Additionally, one clinic admitted that they had been asked to perform PGD to select for hereditary deafness, but they never specified whether the procedure had in fact been carried out or not (Baruch 2008:255).

The findings of this survey didn’t only spark a lot of debate in the medical circles; it also encouraged a sense of honesty because for the first time, medical practitioners felt that they could - albeit anonymously - convey the purposes for which PGD was used in their respective institutions. Following this survey, some clinics openly admitted to using PGD to specifically select for a disability (Baruch 2008:255). While this number seems small and very insignificant, it still shows that the request for a disability is definitely ‘out there’ and that this number could increase, as knowledge about the procedure increases. One of the dilemmas regarding the PGD procedure is that it was originally used to select against disabled embryos and now the moral pendulum has swung into the opposite direction: Parents want to be able to

select for a disabled child, thereby using the PGD procedure exactly for what it was not expected to be used for, thereby creating a dangerous slippery slope.

2.5 The Human Fertilization and Embryology Authority on deafness

In 2010 a request was issued to the UK Human Fertilization and Embryology Authority (HFEA), requesting permission to use PGD to identify a mutation on the connexin 26 gene – a mutation known to cause autosomal recessive non-syndromic deafness. The request was approved by the HFEA committee and non-syndromic sensorineural deafness was subsequently added to the official list of diseases, for which PGD may be applied (HFEA). Sensorineural deafness, the type of deafness that the HFEA added to the PGD - approved list is the most common cause for genetic deafness in our society and also the type that is mostly screened for when a request for PGD regarding deafness is made (Robertson 2005:100).

In the above-mentioned case, the request to add deafness to the HFEA's PGD list was approved because the HFEA sees deafness as a 'serious disability' which should therefore be avoided if at all possible. This statement is reflected in Section 14 (4) of the Human Fertilisation and Embryology Act 2008:

“Section 14(4) of the Human Fertilisation and Embryology Act 2008 imposes – within the general licensing conditions listed in the Human Fertilisation and Embryology Act 1990 - a prohibition to prevent the selection and implantation of embryos for the purpose of creating a child who will be born with a ‘serious disability’.” (Porter et al. 2013:171).

Section 14(4) of the Human Fertilisation and Embryology Act 2008 is an amendment that was made to the original HFE Bill of 1990, and it implements a new prohibition regarding the deliberate selection of deaf embryos and – on a broader scale – the act seeks to ensure that the advances in science and genomic research do not lead to the development of 'designer babies' (Porter et al. 2013:171; Emery et al. 2010:158). Prior to the 2008 amendment, the UK legislative framework did not directly prohibit the screening of embryos with disabilities (Porter et al. 2013:173). It is also interesting to note that Section 14 (4) in the 1990 Act was passed in 2008 following publicity of the case mentioned in chapter one, in which a deaf couple deliberately chose a deaf embryo over a hearing one by knowingly selecting a deaf sperm donor to increase the chances of giving birth to a deaf child.

The aim of the amendment in Section 14(4) was ultimately to safeguard future “misapplications” of the PGD procedure – specifically when PGD results in the birth of a child with a “*serious physical or mental disability*” (Porter et al. 2013:171). Understandably, the implementation of this amendment was followed by a storm of dissatisfaction predominantly from members of the D/deaf community, who feel that the HFEA discriminated against them on the grounds that the amendment forbids them to choose children who are ‘like them’ (Porter et al. 2013:171). This attack against the HFEA was specifically directed at paragraph 110 of the original version of the Explanatory Notes which were attached to the Section 14(4) Act:

“Clause 14(4)...make[s] it a condition of a treatment licence that embryos that are known to have an 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. Outside the UK, the positive selection of deaf donors in order deliberately to result in a deaf child has been reported. This provision would prevent selection for a similar purpose.” (Porter et al. 2013:172).

To the members of the Deaf community, Section 14(4) of the Human Fertilisation and Embryology Act of 2008 contradict anti-discriminatory laws, such as the Disability and Discrimination Act (Stevens 2008). The real problem with this Act is though, that the HFEA did not define the term “serious disability” within the legislative framework (Porter et al 2013:171). Even though a petition was filed to drop Clause 14(4) of the Human Fertilisation and Embryology Act, the petition was rejected on August 20, 2008, on the grounds that the HFEA stood by its belief that “*it is in the best interests of the child not to prefer embryos that have a significant risk of developing a serious medical condition*” (Camporesi 2010:87).

Even though the direct reference to deafness was eventually removed from the Explanatory Notes, it didn’t change the fact that the Parliament implied that they felt that deafness can be understood as being “*a serious disability*” (Porter et al. 2013:172).

Regardless of the fact that the Deaf community takes offence with the implementation of the HFE Act, the moral questions resulting out of this debate become increasingly more relevant as genomic knowledge advances and as PGD screening becomes more common. While the HFEA implies that deaf embryos who are disabled – i.e. deaf – are in principle “*better off not being born at all*”, than being born with a disability, the Deaf community takes a radically different stance (Camporesi 2010:161). In their interpretation, deafness is not a disability, but rather a “*cultural construction*” (Hamm et al. 2008:573).

This belief, that deafness is not a disability, is strongly anchored in the argument that deafness is a social (and societal) construct which is reverberated in what we now call “the social model” of disability. The social model, which is also called the philosophical model, unlike its opponent, the medical one, is very complex, as words like “disability” and “normality” itself become objects of linguistic scrutiny. To understand this complex matrix of information, we first have to understand why the Deaf community is so adamant on referring to deafness as a cultural identity as opposed to the more widely accepted term ‘disability’. To understand the Deaf community and their arguments that can be found within the social model of disability, it is important to understand the historical background of deafness as a disability first.

CHAPTER III

The Deaf Community

3.1. A short perspective on the history of the deaf

As one of the main voices writing on the subject of cultural Deafness, the psychology Professor Harlan Lane makes a good point. He says that history cannot be written without a point of view (Lane 1984: xiv). This is an important point to keep in mind when writing about the history of the D/deaf, as this section of history will focus on a specific thing within a bigger picture. When we write about history, we can only write about it if we have a point of reference from which we can write and in this case, our point of reference will be the Deaf community. In this chapter, it is important to keep in mind that a lot more can be said about the Deaf culture and their history than the scope of this thesis allows. The focus will be to give a broad, yet thorough outline of the Deaf community and how certain key historical events shaped and altered their history and ultimately their understanding of themselves.

“A history is bound to be an interpretation because, for one thing, it makes selections at every turn among an infinity of facts. It defines its domain, excluding some periods, nations, individuals, including others. Within that domain, the documentation is incomplete, and of those facts well documented the historian will cite some and not others, according to their significance.” (Lane 1984: xiv).

In this context, it is important to remember that the fears that are associated with genetic research and enhancement technologies such as the cochlear implant are widespread amongst members of the Deaf culture primarily as the result of the gruesome way in which deaf people have been treated throughout history (Middleton et.al. 1998:1175). Before the 1970's the concepts of 'Deaf community' and 'Deaf culture' have been somewhat obscure. This was largely due to the fact that no one spoke about deafness and what being deaf really meant. There was a lack of understanding regarding deaf people and few people understood how to relate to them.

When looking back into history, one can find numerous accounts of deaf people being described as 'insane' and 'feble-minded' (Hillenbrand 2010:11). Because deaf people had trouble talking or couldn't talk at all, given that they never had the chance to acquire spoken language due to their inability to hear, most people assumed that deafness and muteness were inextricably linked. Additionally, most people during the sixteenth century believed -

although erroneously - that deaf people were unable to receive instruction (Plann 1993:6). The root of this belief can be traced back as far as ca.300 BC, when Greek philosophers such as Aristotle proved themselves as vocal proponents of this theory. Aristotle believed that hearing and reason were linked and that deaf people were thus incapable of thought and reason (Plann 1993:6). As a consequence, most people didn't believe that it was even possible to educate the deaf, let alone teaching them to speak (Plann 1993:6). Unfortunately, this belief gained a stronghold in society and was upheld through the early Middle Ages where deaf people were believed to be demon-possessed because they couldn't speak and were thus considered as strange and abnormal (Nomeland 2012:9). During the late Middle Ages, the church even forbade deaf people to enter church services because it was thought that they were unable to hear the word of God (Nomeland 2012:9). Eventually, the church concluded that the deaf lacked faith and could not be saved from eternal damnation (Nomeland 2012:9). The deaf were thus not only conceived as physically deaf, but spiritually deaf as well (Davis 1995:81).

Throughout history there were individuals, however, who recognized the rights of the deaf and who tried to integrate the deaf into society. Due to the incompleteness or even absence of proper historical documentation, it is not always known whether these individuals just felt it necessary to recognize the deaf because they simply felt it was the 'right' thing to do in a religious sense or if they were genuinely compelled by compassion for the deaf.

In any case, during the sixth century A.D, deaf people were given some form of recognition: the Byzantine Emperor Justinian I, also known as Justinian the Great or Saint Justinian, devised the *Codex Justinianus* (Justinian Code) in AD 528 which can be found in the *Corpus Juris Civilis*, a codification of Roman law, which classified deaf people into various categories according to their various degrees of 'deafness' (Nomeland 2012:9). Emperor Justinian recognized correctly, that there are indeed different degrees of deafness and that being deaf and being dumb is not necessarily the same thing. Under the *Codex Justinianus*, the Romans distinguished between 1.) deaf and mute, but literate, 2.) deaf but articulate, 3.) mute but hearing and 4.) adventitiously deaf (people that became deaf later in life) (Arnesen 1996:20). The *Codex Justinianus* explicitly states that being deaf and being dumb are two different things, even though they can sometimes be linked – but not always. The rights were only denied to those who were born deaf and therefore often mute as a direct result of their deafness. It's important to realize that this was a major step forward during that time, and it spurred an interest in and an understanding of deaf people. Fortunately, there were always individuals who were interested in understanding the deaf better. It is through their understanding that society slowly

started to change, even though this change, as we will see, is always characterized by varying levels of tolerance and compassion for the deaf. Following the creation of the *Codex Justinianus* and the recognition of basic deaf rights, it took many more years until people actively started educating the deaf by means of sign.

The first attempts at educating deaf children started in the sixteenth century AD and one of the most famous accounts of hearing individuals who acknowledged the fact that deaf people are not uneducable and dumb, as most people mistakenly believed for decades, was a monk named Pedro Ponce de León (Plann 1993:2). Even though very little is known about him personally, many people see him as the first real teacher for the deaf. Pedro Ponce de León was a Spanish Benedictine monk who lived in the Burgos province in northern Spain during the second half of the sixteenth century (Plann 1993:2). He spent a big part of his life trying to understand the deaf and teaching his deaf pupils how to speak and sign and was later credited for the establishment of the school for the deaf at the San Salvador Monastery in Oña (Plann 1993:2-3). This in itself is very significant, because he not only challenged the beliefs of his time, but he actively sought to show that they were wrong. Famously, Ponce remarked:

“I have pupils who were deaf and dumb from birth, sons of great lords and of notable people, whom I have taught to speak, read, write, and reckon; to pray to assist at the Mass, to know the doctrines of Christianity, and to confess themselves by speech. Some of them learned Latin and some, taught Latin and Greek, learned to understand Italian. One of the latter was ordained and held office and emolument in the Church, and performed the services of the Canonical Hours; he and others learned to read and understand natural philosophy and astrology...Some were able historians of Spanish and foreign history. Even better, they manifested, by using them, the intellectual faculties that Aristotle denied they could possess.” (Lane 1984:91).

There were many more monks who supported his viewpoint and often those monks were driven by compassion for the deaf as they did not want them to fail to attain salvation (Nomeland 2012:10). What is also interesting is the fact that monks understood the value of sign language. In the monasteries where they lived, they had to work in total silence and speech was used rather sparingly and only during specific times of the day (Plann 1993:7). In order to communicate without breaking the ‘obligatory silence’, monks used a series of signs to convey information to one another (Plann 1993:7). It was this signing system that enabled Ponce to realise that a lack of speech did not necessarily imply a lack of reason, as many people mistakenly believed – a belief that was heavily fuelled by Aristotle’s famous remark that speech

and reason were linked (Plann 1993:7). This realization led Ponce de León on a quest – a quest to educate the deaf. The deaf children that he taught were mainly deaf children who were born to wealthy aristocrats who could thus afford private lessons (Plann 1993:2). Ponce de León’s method consisted mainly of teaching his pupils simple sign language or rather a “gestural system”, coupled with a signing alphabet and combining these with the oralist method⁵ and his progress was often carefully recoded and documented, along with the knowledge that resulted out of this work (Plann 1993:8). Ponce de León’s main aim was to get the children he taught to speak audibly. Some also say that the development of the oralist method needs to be looked at in the context of the European Renaissance, where questioning existing ideas became somewhat of a Renaissance trademark and hence, Ponce’s work can be seen as an “*intellectual breakthrough of sorts*” (Plann 1993:7,8). Sadly, however, the oralist movement that Ponce de León began ended late in the eighteenth century, because many of its proponents died (Lane 1984:112). At least, that’s how it seemed. In reality, however, the oralist method gained popularity as the news of this method spread from city to city, challenging its proponents to develop more signs (Lane 1984:112). Subsequently, sign language was developed in different countries and modified according to the language and needs of that country (Lane 1984:112). Author Harlan Lane describes the schools for the deaf that sprouted up all over Europe as “*a planet that revolved around the sun, yet with its own satellites, for each [school] attracted not only deaf pupils, faculty and staff, but also deaf adults in the community*” (Lane 1984:112). In time, “*the nurturing atmosphere of each of these planets there evolved (...) a fully developing deaf society, lettered and cultivated through the medium of its manual language*” (Lane 1984:112).

Additionally, with the beginning of the Enlightenment, also called ‘the Age of Reason’, a cultural movement by the intellectuals of the late 17th century, people once again asked the question of what it meant to be human. The common answer, reverberating the words of the philosophers of old, notably Aristotle and Descartes, was ‘language’ (Lane 1984:77). Subsequently, the news that the deaf were made to sign and speak caused ‘*rather a stir*’ and threatened the existence of the deaf community because deaf people were described as “*an*

⁵ The oralist method refers to the education of the deaf through by means of lip reading and speech, by mimicking mouth shapes and breathing patterns of speech. One of the most famous advocates of the oralist tradition was Alexander Graham Bell, who urged against using sign language so that a spoken language could be mastered. This method stands in stark contrast to the manualist (sign language) movement, of which individuals such as Laurent Clerc were strong supporters.

embarrassment for this definition of man”, since the deaf were thought to have no proper and functional language of their own (Lane 1984:77). However, the emphasis on and commitment to the oralist method, coupled with sign language remained and, over time, the teaching of the deaf slowly changed from teaching the oralist method to teaching the deaf exclusively in sign-language, because this method seemed easier and more natural for the deaf. This ‘sign language movement’ then remained the favoured method of deaf education until the mid-1860’s, until a new generation advocated the removal of sign language in public schools – particularly spurred on by Alexander Graham Bell’s work (Baynton 1993:93).

Of course, it wasn’t only Bell’s work that fuelled the fire of scepticism regarding the oralist tradition, but also the rising popularity of scientific ideas, notably the discovery of the theory of evolution, in the heights of the Enlightenment period, made famous by the publication of Charles Darwin’s work *On the Origin of Species*, in 1859. This evolutionary theory, according to Baynton, “*fostered a perception of sign languages as inferior to spoken languages, fit only for ‘savages’ and not for civilized human beings*” (Baynton 1993:93).

While Alexander Graham Bell, whom we encountered in chapter one, was the driving voice behind the oralist method, the leading figure of the signing community - and Bell’s rival - within the United States was a man called Laurent Clerc, whom we will encounter again later in this chapter (Lane 1984:340). In the words of Harlan Lane “*Bell sought to banish the sign language; to disperse the deaf and discourage their socializing, organizing, publishing, and marriage; to have children educated in and use exclusively the majority language*” (Lane 1984:340). Basically, Bell wanted to make sure that the minority (the deaf), would be - at least in part - incorporated into a society (the majority / the norm) so that they would no longer be perceived as inferior to the hearing community.

It is important to understand this development and transition from ‘sign-only’ to the oralist method of deaf education and particularly Bell’s hostility towards sign language, because the differences in opinion created a divide that is still evident today. This is summed up by Lane, who says that “*in the one hundred and fifty years from the founding of the education of the signing community to the abandonment of that minority education (...) nothing fundamental has changed in these matters since 1900 in most of the Western world, though there have been some recent stirrings here and there*” (Lane 1984: xv). Additionally, understanding this development and the divide that exists between sign-only proponents and those individuals that believe in the oralist tradition will help us understand the moral dilemma that exists when

D/deaf individuals request Pre-implantation Genetic Diagnosis for the sake of selecting a deaf embryo.

As we can see, the discrimination against the deaf didn't end after the Middle Ages, despite the increase of understanding and reason. Deaf individuals always remained a minority group and thus had trouble being accepted by society because they were seen as a deviation from the norm. On the contrary, this stigmatization against the deaf was further aggravated by the pseudoscience of eugenics that was invented in the mid 1800's (Hillenbrand 2010:11).

3.2. Disability, deafness and eugenics

The term 'eugenics' was introduced in 1883 and its practice originates from the work of British scientist Sir Francis Galton, who, coincidentally, was also Charles Darwin's cousin. It was Galton who laid the foundation of eugenics by using his cousin's evolutionary theory of "the survival of the fittest" as a guideline (Lane 1984:353; Davis 2013:3). And, as Farrall puts it "*Eugenics was in reality applied Biology based on the central biological theory of the day, namely the Darwinian theory of evolution*" (Farrall 1985:55). In 1869, Galton published a book titled *Hereditary Genius*, in which he explained how he collected biological information from obituaries and various other sources of prominent English families that were considered to be of 'upper class'. His conclusion was that superior intelligence and abilities, which he collectively terms 'genius', are inheritable traits (Lane 1984:353; Norrgard 2008:170). He believed that the abilities of man are derived solely by inheritance; with the same limitations that govern the organic world i.e. plants. As a consequence, according to Galton, it is easy to breed a pure human species and "*produce a highly gifted race of men by judicious marriages during several consecutive generations*" (Galton 1869:1). But not only that, Darwin's ideas and ideologies placed disabled people into a box and labelled them "evolutionary defectives" which had to be surpassed by natural selection (Davis 2013:3). As a result, eugenics became obsessed with the elimination of "defectives" – which included the deaf, the blind and mentally retarded (Davis 2013:3).

At about the same time Bell began trying to get the deaf to speak, Galton theorized that humanity's gene pool could be improved by encouraging the fittest members of society to have more children and that, through selective breeding, humans could direct their own evolution (Norrgard 2008:170). This, in essence, is exactly what Alexander Graham Bell propagated in his - arguably - eugenicist speech titled *Memoir upon the Formation of a Deaf Variety of the*

Human Race which I briefly discussed in chapter one. The term ‘eugenics’ was thus born out of Galton’s work and is derived from the Greek word ‘*eugenes*’, which means ‘well-born’. Following the publication of ‘Hereditary Genius’, Galton’s work gained popularity not only in the British Empire, but also in the US.

The American eugenics movement attracted a lot of followers in the 1900’s, when people showed increasing interest in genetics regarding animal breeding. Also, the work of a German scientist, Gregor Mendel, on plant hybridization was rediscovered and seemed to confirm Galton’s ideas. In this work, which was published as ‘*Experiments on Plant Hybridization*’ in 1865, Mendel demonstrated the inheritance pattern of certain characteristics in pea plants, a demonstration which is known today as the cornerstone for basic plant and animal genetics, as it explains many of the rules of hybridization (Moore 2001:14).

Of those people who embraced Mendelian genetics, Charles Davenport, a chicken breeder and agriculturalist, probably became the most famous. Davenport conducted a series of studies in which he discovered valuable information regarding conditions that are inherited – e.g. albinism, neurofibromatosis etc. Unfortunately, Davenport’s studies also led him to an obsession with eugenics, and he used Mendelian principles to justify these convictions. His aim was to improve the quality of the human gene pool by either discouraging reproduction by people who are known to have genetic defects or by encouraging reproduction by people who are known to have desirable genetic traits. This belief inevitably led to the sterilization and institutionalization of thousands of people who were seen as genetically unfit for reproduction – including people who were deaf (Biesold 1999:1). Because this belief was echoed in Alexander Graham Bell’s speech, he was seen as a ‘eugenicist’ of sorts by his contemporaries (Lane 1984:353).

In sum, scientists believed that by carefully controlling human reproduction, institutionalizing people and sterilizing them, mental and physical disabilities could be eradicated. The eugenics movement thus led to the implementation of sterilization laws and racial restrictions on immigration for undesirables (Lane 1984:356). Without a doubt, the most famous and horrific acts of eugenics were performed by the Nazis during the 1930’s and in the course of the Second World War. Even though eugenic practices had been scientifically discredited in the US by that time, the Germans embraced it and justified eugenics on the basis that it would help Germany become a pure Aryan race – the political ideology of that time. As a result, the identities of individuals became defined by their physical qualities which could be measured. This measurable identity finds its root not only in the practice of eugenics, but also in a branch that

worked closely together and supported the eugenic ideals – namely the branch of statistics, where statistics tried to categorize society in terms of ‘norm’ and ‘deviations from the norm’. Perhaps not surprisingly, Alexander Graham Bell also took an active interest in census policy and was responsible for the collections and analysis of data on the blind and the deaf for the 1900 census, where he placed the deaf into the ‘deviation from the norm’ category (Lane 1984:356).

I will discuss the concepts of ‘norm’ and ‘normalcy’, as well as the role that the branch of statistics played in this regard in greater detail in chapter four, but for now I want to direct the spotlight onto the Deaf community itself and discuss who they are – and why.

3.3. The birth of the Deaf community

As we have seen, the history of deaf people is at the same time a history of suppression and discrimination because deafness has mostly been viewed as a physical impairment and hence as a deviation from the norm. Deafness as a community and as a discourse first appeared in the eighteenth century, through the creation of schools for the D/deaf (Davis 1995:82). Before that time, there was no discourse about deafness, no public policy and there were no educational institutions for the deaf either (Davis 1995:82). It was only during the early 1970’s, in which an additional mind shift occurred, mostly spurred on by D/deaf intellectuals who attended the deaf schools. These D/deaf intellectuals suggested that deafness should no longer be seen as a disability, but should instead form the basis for cultural identification. Subsequently, the D/deaf began constructing their own group and in the process, it can be said that they became a new ‘subgroup’, much like Jews or gypsies (Davis 1995:83). It is this ‘cultural identification with deafness’ that the Deaf community uses to justify their wish to have a deaf child.

As we have seen, it is the discrimination against the D/deaf which ultimately led to the formation of what we today call ‘the Deaf community’ or ‘Deaf culture’: A social construct that views deafness not as an impairment, but as a trait which acts as a ticket to a rich and diverse culture which share a common history, social customs and identity (Middleton et al. 1998:1175). In this sense, the D/deaf parent’s wish to have a deaf child is understandable, since having a deaf child would allow the D/deaf parents to pass their sign language, their cultural identity and their D/deaf history on to the next generation, thereby keeping the Deaf culture alive (Middleton et al. 1998:1178). Of course, deaf history has changed a lot since the 16th century and no one today would ignore the D/deaf or refuse to grant them access to the same

privileges that hearing people have or exclude them from full participation in society – thanks to legislative reforms and organizations such as the ADA (Americans with disabilities Act), amongst others.

Even though the rights of disabled people i.e. deaf people are in principle acknowledged, deafness is still seen as a disability by the majority of society. There are a handful of individuals, however, who still see deafness not as a disability, but as a culture. This statement stands in direct contradiction against what history has portrayed deafness to be – a handicap and a disabling condition that inhibits individuals from full participation and acceptance in society. Challenging the status quo, many deaf individuals now claim that deafness shouldn't be seen as a disability, but as is a subculture and a linguistic minority group.

The term 'Deaf culture' was developed in the 1970's by the Deaf community "*to give utterance to the belief that Deaf communities contained their own ways of life mediated through their sign languages*" (Ladd 2003: xvii) . In essence, creating a new (deaf) identity makes up for the loss of status in society that comes with the experience of hearing loss (Ladd 2003:33). As a linguistic minority, deaf people share common life experiences i.e. culture, which includes common attitudes and beliefs. Most importantly, however, sign language (ASL - American Sign Language or BSL - British Sign language) is the binding factor amongst culturally D/deaf people. They believe that a shared language - namely sign language – makes them share an identity. The claim that the Deaf community makes, namely that they are a linguistic minority who share the same (sign) language, and that they therefore form a culture, is an important one.

In book his "*Enforcing normalcy – disability, deafness and the body*", author and professor of English as well as professor of Disability and Human Development at the University of Illinois, Lennard J. Davis, suggests that instead of calling the Deaf a 'linguistic minority', we might as well call them a 'Deaf nation', based on a deconstruction of the term 'nation'. Quoting the German philosopher Karl Marx, Davis makes a distinction between the normal body that can be defined *an sich* (as such/ in itself) or *für sich* (for itself, where 'for' refers to 'for a purpose'), using the terms Marx himself used (Davis 1995:73). The body *an sich* (as such) is, according to Marx, a Utopian ideal or '*a vision of the pristine*', as Davis calls it (Davis 1995:73).

To understand this claim, it's important to understand what Marx means with the normal body *an sich* and *für sich*. Here, for the sake of comprehensibility, it is important to go back to the basics of Marx's capitalist theory. I will only explain the Marxian theory in passing and without much detail, as a full analysis falls outside the scope of this thesis. It's important to note,

though, that Marx was a big critic of capitalism and that he was involved with the Communist party, which, at that time, was a small group of intellectuals who sought to overthrow the concepts of ‘class system’ and the abolition of private property. Marx didn’t agree with the capitalist system, because he believed that the person operating within a capitalist system is devalued with the rise of industrialization. According to Marx, the work that we do can be one of our greatest joys, if we feel a sense of purpose and fulfilment in what we do. Taking this to an extreme, Marx believed that workers need to see themselves reflected in the objects that they have created. Work and life are seen as a unity – i.e. what you do is who you are. Unfortunately, this is not always possible in the Western world, as many people won’t directly see the contribution they have made to society. Work ‘fulfilment’ becomes abstract and distant – a process that Marx calls “*Entfremdung*” (alienation). In drawing a parallel between Marx’s theory and disability, Davis further claims that disability, as we know it, could not have existed in the ideal world that Marx portrays (where all humans are fulfilled, because they see themselves in the objects they create) (Davis 1995:73). To clarify, Davis points out that disability, as we know it, did not exist in Marx’s world, as disabilities are not seen as ‘disabling’ in that sense. Yes, impairments existed, but, according to Davis, the impaired body was part of a lived experience and because of this was also seen as functional (Davis 1995:73). The dysfunctional body was thus transformed into a functioning one by means of fulfilling labour (Davis 1995:74).

In Davis’s own words: “*It [the human body] was not defined strictly by its relation to means of production or a productive economy*” (Davis 1995:74). By the mid-19th century, however, the body *an sich* (as such) became the body *für sich* (for a purpose) – i.e. the disabled body became disabled, because it could no longer adequately contribute towards a productive economy thanks to the Industrial Revolution and the subsequent preference of machinery over manual labour (Davis 1995:74). While this is a very abstract idea, in essence, Davis says that disability only becomes a disability when it becomes someone’s identity that is characterized by an inability to contribute significantly towards a functioning society. The impaired body as such become disabled because it was shaped and ‘made disabled’ by society. This is an important point, as we shall see, because it provides the basis for the social model of disability that we will encounter in the next chapter of this thesis.

Quoting Paul Brass, Davis makes the claim that the Deaf community’s concept of culture and their claim that they are a linguistic minority can be closely linked to the experiences of other linguistically divergent groups (Davis 1995:75). For this reason, he suggests that instead of

calling the Deaf ‘deaf’, we might as refer to them as a “deaf nation” (Davis 1995:74). In making this claim, Davis calls for a reassessment of what the term ‘nationalism’ means, so that individuals who see themselves united by a common language, a common culture and common narrative can define themselves as a ‘nation’ (Davis 1995:75). This postmodern redefinition of the term ‘nation’ “*allows for ethnic and religious minorities to claim national identity*” (Davis 1995:75). While most people would not see deafness as a culture – and much less as a nation – and would be more comfortable to refer to deafness as a disability and a medical phenomenon, Davis points out that there are similarities between the D/deaf community that shares common language as well as a complex history of oppression and other ‘*linguistically divergent groups in colonial settings*’ (Davis 1995:77). He says that we could also consider the D/deaf an ‘*ethnic group*’, because – per definition – an ethnic group is, in the words of Paul Brass, “*any group of people dissimilar from other peoples in terms of objective cultural criteria [language or dialect, distinctive dress or diet or customs, religion or race] and containing within its membership...the elements for a complete division of labour and for reproduction*” (Davis 1995:77). By these criteria, according to Davis, the Deaf can be defined as an ethnic group or a nationality, especially seeing that they have their own language (Davis 1995:77). Within a nation, then, the Deaf represent a linguistic minority (Davis 1995:78).

In this context, once again, language becomes the main focus point and it is this misunderstanding – or misinterpretation of language – that ultimately led to the Deaf community being ostracised by the majority of society. Davis summarized this in the following words:

“Because people are interpellated as subjects by language, because language itself is a congealed set of social practices, the actual dysfunctionality of the Deaf is to have another language system. That system challenges the majority assumption about the function of language, about the coherence of language and culture. Consequently, the Deaf are, in a sense, racialized through their use of sign language as a system of communication. They are seen as outside the citizenry created by a community of language users, and therefore ghettoized as outsiders” (Davis 1995:78).

As a reaction against the rejection of society, the Deaf community effectively created their own culture, or ‘nationalism’, characterized by their own [sign] language and shared history. What makes the Deaf community significant as well is that the organization as a community and their ability to raise political awareness has not been achieved by other physically disabled people in this measure (Davis 1995:79). Although perhaps a little far-fetched, the Deaf can even also

be defined as a ‘race’, because they share and carry genetic information and genetic traits for ‘deafness’ that can be passed from one generation to the next (Davis 1995:79).

What the eugenicists and statisticians back in the mid - 1800’s didn’t realize was that they, perhaps ironically, created by the Deaf community themselves by statistically and practically boxing them into one group. It is because they [the D/deaf] were constructed, institutionalized and regulated that they began perceiving themselves as a distinct group – and as a consequence they began acting as a group too, complete with their own history, culture and significantly, language. Realizing this, the State i.e. the majority, felt that it had to intervene by eradicating the D/deaf and/or incorporate the D/deaf “*back into the state and the nation*” (Davis 1995:83). They insisted that the D/deaf should “*be made people of our language*” i.e. English (Davis 1995:83). This is exactly what Bell proposed. One of the reasons why he was against deaf teachers exclusively using sign language in schools was that he wanted the D/deaf once again to be integrated into the hearing majority and he wanted the deaf ethnic groups to be abolished for their own good because he believed that “*after all, it [sign language] is not the language of the millions of people among whom his [the deaf person’s] lot is cast*” (Lane 1984:341). For Bell, deafness was always a physical handicap that should be ‘covered up by covering its stigmata’ (Lane 1984:340).

On the opposing side of this viewpoint we have Laurent Clerc, one of Bell’s biggest rivals, who is praised as “the apostle of the Deaf-mutes of the New World” (Lane 1984:203). For many years, he was a teacher for the deaf in Paris at the Institution Nationale des Sourds-Muets and later co-founded the first school for the deaf together with Thomas Hopkins Gallaudet in America, where he taught until the 1850’s (Schraer-Joiner 2014:46). He was the driving force behind the development of the signing community in America and firmly believed that the problem of the deaf in the hearing world consisted of them not being accepted by the hearing majority (Lane 1984:340). After Clerc and Gallaudet founded the first school for the deaf and even after Clerc’s death in 1869, as many as forty-six new schools for the deaf were established by Clerc’s students (Schraer-Joiner 2014:46).

In 1880, however, during the Second International Congress on Education of the Deaf in Milan, Italy, also often referred to as the Milan Conference of 1880, educators for the deaf from all over the world debated the benefits of oral educations versus manualism. At this conference, something happened that rocked the boat of sign-language proponents: The majority of hearing participants voted against sign - language as the mode of instruction for the deaf, as the oral method (i.e. the spoken word) was deemed “*more superior*” than sign language (Schraer-Joiner

2014:46; Jankowski 1997:53). The person leading most of the conference was no other than Alexander Graham Bell, who, due to his influence and wealth, presented for three days straight, placing special emphasis on the pitfalls of sign language (Jankowski 1997:53). Unfortunately, the advocates of sign language only had three hours to make counterarguments, which proved to be very little. At the end of the conference and perhaps not surprisingly, the majority of delegates voted to ban teaching in sign language from schools and endorsed oralism as the best educational method for the deaf, effectively replacing the use of sign, making Clerc's worst fear a reality (Jankowski 1997:53; Schraer-Joiner 2014:46; Lane 1984:399). Clerc has summarized the people who wouldn't understand the deaf and their needs in the following way:

“It is also a tale of destroyers: of a zealous physician who put mock science ahead of true humanity; of a haughty nobleman who imposed his will on the deaf, knowing, he believed, what was best for them but knowing, in fact, none of them; of a professional reformer who has sought to recast entire classes of society in his own image” (Lane 1984:4)

Many see this conference as the beginning of a one hundred year period in Deaf history where deaf people, especially children, weren't allowed to use sign language in schools or dormitories (Jankowski 1997:53). Even though the oralists succeeded in banning the use of sign language, there were still quite a number of deaf and hearing people who agreed with Clerc's point of view and who opposed the decision by the Milan Congress and even though D/deaf people became increasingly concerned about Alexander Graham Bell's influence and the subsequent growth of oralism, they had also come to love and cherish their deaf way of life and were not content just standing by while the movement to eradicate sign language spread (Jankowski 1997:54). As a result, the use of sign language was secretly passed on behind closed doors and a lot of those people who disagreed with the general outcome of the Milan conference began supporting the National Association of the Deaf (NAD), which marks the beginning of the Deaf social movement in the United States (Jankowski 1997:55). Its aim was to protect the Deaf heritage, language and culture (Schraer-Joiner 2014:47; Jankowski 1997:53). Additionally, with the creation of the NAD, the D/deaf people realized that they needed a political discourse to “*ward off threats to their community*” and that merely standing back was not enough (Jankowski 1997:55). They also developed strategies to “*preserve their sign language and thwart the efforts of oralist advocates. They sought to strengthen their community by adopting rhetorical strategies to symbolize self-governance and, based on these strategies, to establish a political organization as a site for discourse and networking*” (Jankowski 1997:54). Additionally, after the conference, the president of the Gallaudet University in Washington

DC, which also happens to be the biggest and most successful deaf University in the world, decided to maintain and protect sign language on campus – a decision that many today see as the reason as to why ASL (American Sign Language) has survived (Schraer-Joiner 2014:47). Mostly, however, the ‘forces of replacement’ succeeded and the majority of schools in America and Europe are still taught in the oral method today, even though a lot of work has been done by the Deaf community to undo the social oppression of the past (Lane 1984:340).

This is perhaps why the Deaf community feels so strongly about their cultural identification and is also proud to call themselves ‘culturally Deaf’, as the creation of their culture marks a triumph of sorts over cultural oppression and historic prejudice. Bell’s influence continues through the *Alexander Graham Bell Association for the Deaf and Hard-of-Hearing* whose mission is to “advance listening and talking and early intervention” for children and adults (Jankowski 1997:53). It should come as no surprise then that nowadays talking in sign language remains the favoured method of communication amongst the Deaf community and the oralist method and its proponents are largely rejected by them (Bertling 1994:33).

3.4. The Deaf community – a cultural identity

Identification with the Deaf community is completely voluntary and does not automatically include all people who are deaf or hard of hearing. Having said that, however, there seems to be some division among who is and who isn’t part of this community, but in principle the Deaf community is comprised primarily of individuals who were born deaf and who refer to themselves as ‘culturally Deaf’ too. The basic criterion for membership is what the Deaf community calls ‘attitudinal deafness’ (Ladd 2003:42). This means that members first and foremost have to see themselves as culturally Deaf and be able to identify themselves with other members of the Deaf community. According to this definition, it doesn’t matter to which degree the potential member is deaf or whether or not the member is able to speak intelligibly, all that matters is their willingness to honour and respect the Deaf community.

Apart from the most ‘obvious’ membership criteria, there are a couple of other criteria which can be applied when an individual wants to ‘sign up’ as a member of the Deaf community: those D/deaf children and adults who are born to D/deaf parents and those who have other deaf relatives i.e. those people who have a record of generational deafness in their families are eligible to become members of the Deaf community. A further membership route consists of those individuals who have graduated from a Deaf school or a Deaf university such as

Gallaudet University in Washington DC. Additionally, partial Deaf community membership can be granted to CODA's (Children of deaf adults). Sometimes, however, the CODA's membership is also based on how much knowledge they possess about the Deaf community, whether they are fluent in sign language and whether they actually make an effort to socialize in Deaf environments (Ladd 2003:42). Mostly, the membership of the Deaf community is strengthened by endogamous marriages – culturally D/deaf people marrying other D/deaf people (Ladd 2003:43).

To emphasise the fact that there is a difference between deaf people who merely see themselves as deaf from a medical point of view and those Deaf people who believe that their deafness is not a disability, the Deaf community makes a distinction based on how they write the word 'deaf' – 'Deaf' spelt with a capital 'D' refers to those individuals who see themselves as 'culturally Deaf' – i.e. those individuals that see deafness as a cultural phenomenon as opposed to deafness as a mere medical condition i.e. disability. In contrast, deafness spelt with a lower-case 'd' refers to those individuals for whom deafness is primarily an audiological experience i.e. those individuals who identify more with the hearing world and who try to remain a part of it and make adaptations to make this happen (Ladd 2003:33). While some people believe this linguistic invention to be “*a subtle method of persuasion*”, to convince others of the explicit existence of this culture, other people take pride in the fact that this Deaf culture exists at all, given the hardships deaf people had to endure throughout history (Bertling 1994:11). To those people, the formation of the Deaf culture is a form of triumph that acts as a sword against historically preconceived ideas of deafness. The linguistic invention – or demand – of spelling cultural Deafness with a capital 'D' can be interpreted to some people as a subtle method of demanding respect (Bertling 1994:11).

Additionally, for culturally Deaf people, Deaf clubs play a big role in their daily lives, as Deaf clubs embody the cultural aspect of their shared identity (Preston 1994:88). Deaf clubs take a variety of forms – from religious meetings to sport clubs. They are essentially meeting places for Deaf people in which they can partake in a wide variety of activities with other like-minded Deaf people. What they all have in common, is that they all cater for Deaf people and grant the Deaf a sense of belonging and the opportunity to communicate with other Deaf peers (Preston 1994:88). Deaf people have the opportunity to participate in a wide array of activities such as “listen” to D/deaf storytellers or watching captioned movies. This environment is vital for D/deaf individuals because it normalizes their deaf condition and offers a supportive environment where communication is the central activity (Preston 1994:88). Mostly, D/deaf

people describe the Deaf clubs as ‘safe’ and opposed to feeling as an outsider in the hearing world (Preston 1994:89). The mere fact that Deaf clubs provide a ‘normalizing environment’ proves to be attractive to many members of the Deaf community as it provides a safe refuge from social alienation (Preston 1994:94).

Also, the Deaf culture is one of separation – identification with this culture automatically separates the deaf individual from other non-deaf members of society. This identification with the Deaf community is so strong, that parents wish to rather bring a deaf child into the world than a hearing one. While a hearing parent would be devastated in learning that their child is deaf, the culturally Deaf parents cheer at the idea to have a deaf baby who shares in their “culture”. What is interesting about the Deaf community’s idea of “culture” is their firm belief that they are stigmatized on the grounds that they are different. They see technological advances like the cochlear implant as an attack on their culture, because medical treatment that is aimed at ‘curing them’ or ‘making them better’ is seen as undermining their worth as human beings. According to the Deaf culture, it is society’s role to make them ‘fit’ into society in the sense that society should accommodate their disability. This stigmatization that D/deaf people experience makes them feel that in the eyes of society, they are “*reduced in their (society’s minds) from a whole and usual person to a tainted, discounted one*” (Jones 2002:3).

According to a psychosocial study, stigma appears to play a role in group formation and seems to account for the fact that the Deaf community feels the need to hold on to their group identity (Jones 2002:3). Often those individuals who are stigmatized by society based on gender, race or disability huddle together and form a new “group”, which is used as a form of rebellion against society’s unwillingness to change for them or accommodate them. The Deaf community is no different. The basis for this new formation can be summarized like this: People want to be accepted for who they are and if they are not accepted by the majority, they will look for people who are like them and that they can identify with. These people will then form a new group, in which they feel a sense of acceptance and community. When the criterion for belonging and acceptance is not adequately fulfilled by the broader society, individuals who feel as ‘outsiders’ will form a new group that accommodates them and their gender, race or disability. Some suggest that those individuals who feel like ‘outsiders’ to the broader society create alternate groups to feel ‘normal’. Within this new group, the abnormal becomes the norm and gives its individuals a sense of belonging and identity (Jones 2002:3). Dolnick summarized the Deaf community in the following words:

“When social scientists ask people who are blind or in wheelchairs if they wish they could see or walk, they say yes instantly. Only the Deaf answer the equivalent question with ‘no’. The essence of deafness, they explain, is not the lack of hearing but the community and culture based on American Sign Language. Deaf culture represents not a denial but an affirmation.” (Dolnick 1993:3).

In sum, the historical stigmatization and discrimination that people with deafness had to endure eventually led to the formation of a new identity where stigmatization wasn't any longer an option. This form of cultural identity can be found within the Deaf community.

Chapter IV

What do we understand by “disability”?

4.1. Normality and the prejudice of difference - a view on eugenics and statistics

To most people, having a disability or even the thought of having one is either a brutal reality or a terrifying thought. No person in their right mind would voluntarily choose a life confined to a wheelchair or choose a life void of sight – or sound. Having said that, it seems that most people are drawn to a norm – we want to, in so far as that is feasible, be normal or else we would at least try to avoid a state of extreme eccentricity or difference (Davis 2013:1). But what does it mean to be normal in the first place?

We need to remember that the word ‘norm’, in the modern sense, has only been in use since around 1855, and the words ‘normalcy’ and ‘normality’ made an appearance in our vocabulary in about 1849 and 1857, respectively (Davis 2013:2). Hence, based on this lexicographical information, the common usage of the term ‘the norm’ as we know it, only became relevant within the English language around 1840 - 1860 (Davis 2013:2). This seems relatively recent, given that many people nowadays take the concept of ‘the norm’ for granted and accept it as some kind of unconscious normative standard that has always existed. Recent anthropological studies on the ancient Greek cultures and on preindustrial Europe show that disability was once very differently perceived than it is perceived today (Davis 2013:1). And, according to Davis, “...*the idea of a norm is less a condition of human nature than it is a feature of a certain kind of society*” (Davis 2013:1). Calling someone ‘disabled’ can thus historically be classified as a social process that took shape through the modernization and transformation that happened in society in the last few centuries – specifically relating to the change in ideologies that happened during the late 18th and 19th century (Davis 2013:1).

Preceding the concept of ‘the norm’ is the concept of ‘the ideal’, a concept that can be traced back to the 16th and 17th century, and that we often find expressed in art in the form of the nude Venus by the Italian master Titian or in Renaissance masterpieces such as the statue of David by Michelangelo. These ‘ideals’ are not supposed to be attainable, but should rather serve as mytho-poetic ideas that one can look at – and admire from a distance (Davis 2013:2). Much

like Plato's theory of 'The Shadows on the wall'⁶, humans are not supposed to and, in fact, cannot embody an ideal. The ideal human being would have to be composed of all the different ideal parts that we can find in various human beings. To illustrate this point, the Roman philosopher Pliny explains how a Greek artist named Zeuxis tried to paint the goddess of love, Aphrodite. To do this, he had a look at all the beautiful women of Crotona, Italy, and then combined the most beautiful features of the individual women that he saw into one whole, perfect and ideal human being – Aphrodite (Davis 2013:2). By definition, an ideal, the embodiment of absolute perfection, can never be personified by any human being and thus, there should be no pressure to be that ideal or perfect human being or conform to any norm or standard (Davis 2013:2).

Why is it, then, that in our modern society, the pressure to conform to a norm or even to embody an ideal is so strong? One answer can be found in the branch of statistics, which captured the attention of scientists around the 18th century (Davis 2013:2). One figure that stands out here is that of a Belgian-born mathematician and statistician named Adolphe Quetelet (1796 – 1847), who was one of the first individuals to apply the - then exclusively scientific - method of statistics and probability theory to the branch of the social sciences (Davis 2013:2). Quetelet observed that statistics were mainly used by the astronomers of his time and that they used what they called 'the Law of Error'⁷, to determine the frequency in which certain phenomena

⁶ According to the Philosopher Plato (born c.428 BC), the objects we see in everyday life (the table, the chair etc.) are ultimately not real. Rather, they are mere copies or reflections of the truly real objects which he calls forms. Those forms are more real than the reflections which we see and are therefore perfect (unlike the reflections). The perfect forms, according to Plato, cannot be found in this world but exist on – what he calls- a 'higher plane'. To illustrate, Plato uses an allegory which he calls 'Shadows on the wall'. According to this theory, we need to imagine some prisoners chained to the bottom of a cave. All they see are shadows that reflect off the cave wall, but because those shadows are the only 'things' the prisoners see, they take those shadows to be reality. (Plato 193 - 198; Law 2007: 24 – 25).

⁷ The 'Law of Error' has historically been associated exclusively with Astronomy. Astronomers were interested in correct measurements and how those measurements could be realized in theory. Interestingly, early Astronomers were very competitive – and indeed secretive – about their work and were thus very reluctant to share information with others. As information of various mathematical and astronomical theories and measurements became publicly available in the 18th and 19th century, scientists realized that there were a lot of errors between the various measurements and it was difficult to find the causes for these errors. As a remedy for those errors, all the observations were combined into a frequency distribution graph, which took the shape of a

occurred and the probability of an error that occurred within those phenomena (Davis 2013:2). Quetelet then sought to apply the same principal of ‘the Law of Error’ to human beings, asserting that it was possible to determine the standard of the ‘average man’ and thus determine ‘physical and intellectual features’ of a population. Quetelet himself believed that the average human being is a combination of “*l’homme moyen physique*” and “*l’homme moyen morale*” – men constructed both as physically and morally average (Davis 2013:2). It’s important to remember that, in Quetelet’s eyes, the ‘average’ human being is comprised of the sum of all human characteristics and attributes (both physical and moral) of any given country or location – a notion very similar to the story of Pliny the elder, who went to look for the ‘ideal’ women of Crotona (Davis 2013:2). It should come as no surprise then, that Quetelet’s social theory of ‘averages’ quickly became reinterpreted as ‘the ideal’.

In Quetelet’s words “*an individual who epitomized in himself, at a given time, all the qualities of the average man, would represent at once all the greatness, beauty and goodness of that being*” (Davis 2013:2). Unlike the ‘ideal’ the concept of the norm presupposes that one should somehow be part of the norm. The norm determines the extent to which society should be ‘normal’ (Davis 2013:3). Any person who deviates from the norm (which embodies the average and the majority), is thus placed into the ‘abnormal’ category. When we place this theory on physical bodies, then it quickly becomes apparent that individuals suffering from a disability are thought as being a deviant of the norm and the accepted standard of a society.

As the branch of statistics gained rising popularity in Britain in the 1830’s, a statistical office was set up at the Board of Trade in 1832, and the General Register Office was created in 1837 to collect vital statistics of the human population (Davis 2013:3). The goal was, of course, not only to collect data, but also to somehow make sure that individuals stay within the parameters of ‘the norm’. To achieve this goal, two things could be done: a.) one could improve human beings so that ‘the norm’ – or even ‘the ideal’ – could be attained or b.) one could reduce the number of individuals that are classified as deviations from the norm (Davis 2013:3). The proponents of the latter became known as the early eugenicists - and one of them, perhaps not surprisingly - was Sir Francis Galton.

curve – the ‘Law of Error’. This ‘Law of Error’ theory was also later taken up by Sir Francis Galton, who was a well-known eugenicist of his time.

It became clear how tightly statistics and eugenics were interlinked, mainly because statisticians believed that the human population could be normed and therefore altered to achieve this norm, which, in turn, was the goal of the early eugenicists. An important consequence of this was that through the rising popularity of the branch of statistics, the total population was divided into standard and nonstandard subpopulations and thus, ‘the disabled’ were placed into the category of ‘nonstandard’ (Davis 2013:3). In other words, the eugenicists and statisticians both decided to divide people into different boxes, where those people with undesirable traits were placed into one box, and individuals with desirable traits into another. Individuals in the ‘undesirable traits’ box, included people with mental and physical disabilities, criminals, the poor, the sick et cetera (Davis 2013:6).

Sadly, the popularity of eugenicist ideals largely prevailed in the 20th century and the concept of the norm is still the favoured ideal, an ideal which arose within a moment of time in history, but which has, in fact, not always been around. To bridge the gap between ‘normal’ and ‘abnormal’, various organisations have erected itself in the last few decades to stand against the prejudice of difference, not necessarily to place disability into the ‘normal’ box, but to show that our ideal of what it entails to be normal is perhaps flawed, thereby tentatively expanding the very definition of the word ‘normal’ and most notably, the concept of ‘disability’ itself. Depending on whose viewpoint one takes, ‘disability’ as a concept can be interpreted either as a medical disability or as a cultural difference – the latter being the view that the Deaf community wholeheartedly embraces.

For the culturally Deaf, choosing deafness isn’t a sacrifice. On the contrary, the importance of disability as a social category only increased by initiatives of disability movements such as the NAD and helped to establish civil rights for people with deafness (Wasserman et al. 2015). As with other groups that were stigmatized, the characteristics that were used as a ground for exclusion became the basis for mobilization and ‘choosing deafness’ became a favoured condition that is looked upon with pride by members of the Deaf community. It is in this choice to be deaf that the Deaf community bases its identity. To understand this choice or identity, one has to understand the premise on which this choice rests: To the culturally Deaf, deafness is not a disability, but a difference.

In essence, this means that deafness as a condition is interpreted differently by a culturally Deaf person than the norm would have it. Here, the very definition of deafness as a disability is challenged and the word ‘disability’ is deconstructed. In the process, a distinction is made between the medical and the social models of disability. Even though there are various other

“models” of disability, the medical and the social models are the two that are most frequently mentioned and that will therefore be discussed further in this thesis.

Each of these models renders a different definition to the term ‘disability’. Depending on which definition is used, deafness is either seen as an “ability” or a “disability”. While the medical model interprets a disability as being a physical and/or mental impairment that affects the individual and that, therefore, the consequences and limitations resulting out of this disability are solely to blame on the disability itself, the social model believes that disability is to be understood as a relation between an individual and his/her social environment – i.e. a disability is only a disability as far as society makes it a disability and consequently fails to accommodate the disabled individual (Wasserman et al. 2015).

4.2 Dis-ability redefined - the rise of culture & the birth of the social model

Once again, it’s important to remember that words like “disability” and “impairment” received very little attention until 19th century scientific thinking put variations on human functioning and categorized “the disabled” into a box called “the deviation from the norm” (Wasserman et al. 2015). Only once these categories were established, it became easier to talk about disability and what that meant. While the second half of the 19th century was preoccupied with eliminating and reducing the numbers of ‘the disabled’ through eugenic practices and “disability” was interpreted as an unearned disadvantage, which had to be addressed with medical correction, social philosophers slowly started to see disability as a source of discrimination, oppression and as a source of group identity formation very similar to gender and race oppression (Wasserman et al. 2015). Additionally, concepts like deafness became a source of philosophical reflection that revolved around what it means to be disabled and the connection between deafness and language (Davis 1995:61).

In the same way that women have liberated themselves from social oppression in the form of various feminist movements, the disability community has actively sought to change the common perception of what ‘disability’ entails. And not only that, many disability movements have changed our perception of what it means to live with a disability through their personal narratives (Saxton 2013:89). Spurred by frustrations of the stigmatized historical perceptions of disability and the positive effects that feminist movements and other minority groups attained in the 1960’s and 1970’s through social awareness campaigns, protests etc., various disability rights activists became united to address and subsequently rectify the injustices and

inequalities of the past (Saxton 2013:88). Saxton further explains that “*effective community organizing by blind, deaf and mobility-impaired citizen groups and disabled student groups flourished in the late 1960’s and resulted in new legislation [in America]*” (Saxton 2013:87).

Similarly, in Great Britain, various disability activist groups started forming, one of the most well-known being UPIAS – the *Union of Physically Impaired Against Segregation*, who created the social model from a combination of intellectual and politically driven arguments (Shakespeare 2013:214). This group was a small and very determined group of disabled individuals, which were inspired by Marxism, and who rejected “*the liberal and reformist campaigns of more mainstream disability organizations*” (Shakespeare 2013:214). The founder was a man named Paul Hunt, a former resident of the Lee Court Cheshire Home (Shakespeare 2013:214). In 1971, Hunt wrote a letter to “The Guardian Newspaper”, in which he proposed the creation of a consumer group of disabled residents of institutions (Shakespeare 2013:214). While Hunt was working on the formation of this institution and developing an ideology that could be used and heard by the majority, he began partnering with a South African Psychologist named Vic Finkelstein, who emigrated to Great Britain in 1968 after being expelled for his anti-Apartheid activities (Shakespeare 2013:214). Their aim was to ensure the inclusion of the disabled in society and to help them to live their lives as independently as possible because they believed that people with disabilities struggle with social exclusion because of their disabilities (Shakespeare 2013:214).

Apart from UPIAS, there were a number of other disability-led activist groups that formed in Britain such as the Liberation Network of People with Disabilities (Shakespeare 2013:215). In 1981, this specific Liberation Network published a draft Liberation Policy, in which they argued that the problems that people with disabilities face are not just of economic nature, but even more so the result of the flawed psychological beliefs and ideologies about disability that prevail in society (Shakespeare 2013:215). UPIAS remained the driving voice of the British disability movement, however, and in 1981 the British Council of Organisations of Disabled People, which was a coalition of disabled-led groups, ended up accepting their social model - approach to disability (Shakespeare 2013:215). The term ‘social model’ was coined three years later, in 1983, by one of the members of UPIAS (Shakespeare 2013:215).

What is important to understand is that these disability – led activist groups placed a lot of emphasis on connecting different types of disabled people with one another in the hope of reinforcing and strengthening their self - awareness and providing them with a support network to help them overcome social alienation. Most importantly, however, disabled individuals were

encouraged to form groups with like-minded disabled people and form communities to strengthen group identity (Shakespeare 2013:215).

4.3. The social model of disability

In contrast to the medical model of disability, the social model takes the social circumstances of the individual who has the disability into consideration and has been used to define the nature of oppression and the social construction of disability (Davis 2013:82). Since the early 1970's proponents have argued that a disability cannot be understood as a purely medical concept alone and thus they created the social model of disability (Porter et al. 2013:177).

In principle, the social model seeks to understand what it means to live with a disability and seeks to protect the rights of people with disabilities as well as enable inclusion of the disabled within society. According to this model, disability is a social construct, which means that disability is only a disability because society makes the disability a disabling condition. It thus makes a distinction between disability in the form of social exclusion and impairment in terms of physical limitation (Shakespeare 2013:215). Disability, according to the social model is defined as *“the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities”* (Shakespeare 2013:215). The priority of the social model is to *“accept impairment and remove disability”* (Shakespeare 2013:216).

This does not mean, however, that the social view denies that disabilities can be harmful per se (Häyry 2010:85). Rather, it claims that the harm isn't necessarily associated with the disability itself but inflicted by the society that labels people as disabled. This 'disabling of disability' can take place in the form of lack of inclusion of disabled people, lack of provisions such as infrastructure, lack of appropriate aids etc. In other words, according to this model, disability is only a problem in a society where disability is made a problem (Van Niekerk 2013:105).

This model sees disability *“as a form of oppression, an artefact of cultural or socio-political arrangements that devalue and exclude individuals with impairments”* (Karpin & Savell 2012: 18). The aim of the social model is to foster inclusion and advance our understanding of what it means to live with a disability, taking a more philosophical stance by analysing and extracting meaning out of a certain kind of being. In essence, the social model believes that our society is the reason that that human beings with disabilities often don't flourish in society. Social

exclusion and discrimination hinders this human flourishing, because a person is – for all practical reasons – not able to flourish as he/she would like due to socially constructed barriers. Along these lines, Alison Davis has been quoted as saying “*If I lived in a society where being in a wheelchair was no more remarkable than wearing glasses and if the community was completely accepting and accessible, my disability would be an inconvenience and not much more than that. It is society which handicaps me, far more seriously and completely than the fact that I have spina bifida*” (Harris 2000:95). The best way to alleviate this dilemma is for society to step up and create support structures that cater for people with disabilities so that they have the chance to feel as ‘normal’ as possible. And with regard to the elective deafness debate, Häyry sums this up in the following words: “*Not hearing can be simply a condition, but deafness can be a culture if allowed to be one or a disability if forced to be one*” (Häyry 2010:86).

Thanks to the social model of disability and the initiatives of members of Deaf communities in forming and creating a new ‘identity’ based on their agreed understanding that deafness is not a disability, the stereotypical notions of ‘tragedy’ and ‘suffering’ that the ‘disabled’ have to endure are now understood to be a result from the isolation of disabled people within a society (Saxton 2013:89). According to them, disabled people face challenges, but these challenges become minimal once a disabled person is able to participate in a ‘typical’ everyday life. The discriminatory attitude towards disabled individuals within a society is what makes life hard – if not unbearable – for the disabled individual (Saxton 2013:89). The disability itself is thus social in origin and not the consequence of being disabled per se. For this reason, the Deaf community is often compared to other minority groups that have been oppressed due to social exclusion – e.g. blacks are often discriminated, not because they are black, but because society discriminates against them based on stigma (Levy 2002:138).

4.4. The medical model of disability

The medical model of disability, in contrast to the social model, is most widely supported by the scientific and medical community as well as a large part of society, as it blames the disability for the individual’s lack of being able to fully participate in all ordinary day-to-day activities. According to the medical model, disability is defined purely on the basis of an individual’s physical ‘abnormality’, where ‘abnormality’ refers to any physical deformity or, in case where deafness is concerned, physical malfunction.

Or, according to a document published by the World Health Organization in 1980, disability can be described as “*any restriction of lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for a human being*” (WHO 1980 27-28). It looks at the disability from an authentic biological as well as medical standpoint where anything that isn’t ‘normal’ qualifies as a disability. ‘Normal’ in this sense refers to the biologically ideal condition a human being is ideally born into – with five fingers, five toes, eyes to see and ears to hear etc. On these grounds, the medical model identifies a disability as a condition that an individual has and assumes that this individual is thereby harmed (Häyry 2010:81). This is significant, as one of the main principles of biomedical ethics revolves around the obligation ‘not to harm’ another human being. While medicine as a practice is always concerned with preventing, relieving or curing physical ailments in humans, the deliberate infliction of harm on another human being in this case is seen counter-productive at best.

As a criticism against the medical model, some opponents argue that it disregards the social context in which a disabled person finds him/herself (Llewellyn & Hogan 2000:163). In other words, the medical model doesn’t take into consideration that there might be individuals that don’t see their disability as a disability like the medical model portrays it. The medical model emphasises that we, as human beings, need to adapt to our environment and shouldn’t expect the environment to make provision for us i.e. a deaf person should try – in as far as that is possible – to fit into society and conform to the norm. It assumes “*that the human being is flexible and ‘alterable’ whilst society is fixed and unalterable*” (Llewellyn & Hogan 2000: 158).

Additionally, the medical model neglects the fact that many “[d]isabled people themselves quite naturally reject being defined as abnormal”, as it is the case with members of the Deaf community (Llewellyn & Hogan 2000:159). Because the medical model overlooks the social and environmental circumstances in which disabled people find themselves, the medical model is termed as incomplete (Llewellyn and Hogan 2000:163). To make up for the disregard of social circumstances in which people who are labelled as ‘disabled’ find themselves, the social model was born.

In the next chapter, we will have a look at how the social model of disability shaped the Deaf community and how this model acts as a supportive structure in their argument to justify elective deafness.

Chapter V

Arguments in support of elective D/deafness

5.1. Deafness in perspective

When we talk about the arguments supporting elective D/deafness, we are mostly dealing with arguments that are intricately rooted in the social model of disability. As we have seen, the social model supports the idea that deafness is not a disability, but rather a cultural construct. Illustrating and presenting the arguments supporting elective D/deafness therefore means to navigate through a rather dense and complex linguistic patchwork, where concepts like ‘disability’ and ‘norm’ no longer apply in the traditional sense because they are given different definitions based on a cultural argument. Instead of presenting clear-cut arguments and providing straight-forward answers, the arguments supporting elective D/deafness take a bit of a different route. These arguments are more abstract in nature; as they tend to focus on the definition of words, calling into question our presupposed ideas - and ideals. In this way, the arguments supporting elective D/deafness are more philosophical and linguistic in nature, incorporating different philosophical principals and abstract ideas that only make sense when we force ourselves out of our “normal” mind-set and embrace a mind-set that is open to philosophical scrutiny and linguistic deconstruction.

In principle, if one wants to morally justify elective deafness, the idea that deafness is a disability that could cause harm to an individual needs to be challenged. This includes challenging the definition of disability itself within the larger framework of the concept of ‘normal’. Secondly, it needs to be shown that there are indeed advantages when D/deaf parents select a deaf embryo rather than a hearing one.

In building an argument for elective deafness, a lot of emphasis is placed on “lived” experiences and personal narratives, as opposed to “rational preferences” that people are presumed to have (Häyry 2010:84). In principle, the arguments supporting the parent’s wish to select a deaf baby by means of PGD are emotional arguments, as they grapple with the question of meaning behind what it means to be disabled. Additionally, it is important to realize that we cannot understand the arguments the Deaf community uses to select for deafness without taking their oppressive history into careful consideration. The arguments are deeply rooted within their cultural belief system, a belief system which has been shaped through their oppressive history and their desire to break free from the chains of discrimination.

5.2. Martha's Vineyard – normalizing what's different

To understand why the Deaf community sees deafness not as a disability but as a difference, we need to understand the concept of normality itself. As I have shown in chapter four, the concept of 'normal', as we understand it, is a relatively 'new' concept, which has changed historically. Based on this information, the Deaf community once again challenges our idea of what it means to be 'normal' and invites us to once again redefine our idea of normality. As we have seen, this 'normalizing of normalcy' has been adopted by the social model, which claims that deafness is only a disability because society makes it one.

This 'normalcy' of deafness is often explained by an analogy called 'Martha's Vineyard'. Martha's Vineyard isn't an imaginary story, but rather a bit of a strange phenomenon that has been retold from various angles by different authors. Martha's Vineyard is an island off the coast of Massachusetts which, historically, had a high rate of deafness for almost two centuries, starting with the arrival of the first deaf settlers in the 1690's (Sacks 1990:32). Mixed marriages between the deaf and hearing inhabitants eventually resulted in the occurrence of deafness to one in four by the mid-nineteenth century (Sacks 1990:32). Because there were so many deaf inhabitants, the whole island community eventually learned what is now called 'Martha's Vineyard Sign Language' (MVSL). What makes this story so significant, is the fact that the island's deaf inhabitants were never labelled as 'deaf' or 'disabled', simply because everyone made an effort to integrate them into normal, daily life. One of the lessons that can be learned from Martha's Vineyard is the fact that the social barrier of deafness can be overcome if the willingness and the correct environment exists (Levy 2002:141). Or, put differently, "*when the stigma of separateness and the communication barrier were both removed in Martha's Vineyard, deafness became insignificant as a disability*" (Glover 2006:7).

The reason I chose to mention the story of Martha's Vineyard is because it supports the social model in that it confirms the fact that deafness doesn't have to be a disability if the correct supportive structures are in place. It shows that many conditions or disabilities are not universally disabling, but only disabling in specific circumstances (Holm 2000:184). In that sense, Martha's Vineyard acts as a kind of utopic ideal for the Deaf community, an ideal world in which the barriers of communication are removed and the D/deaf are no longer stigmatized against. While it is important to acknowledge that this wish is real and understandable, it is equally important to ask whether it is feasible and whether the story of Martha's Vineyard can be used as a model on a much larger scale. I will get back to this question at the end of this

chapter. For now, it is just important to keep in mind that the Deaf community has reason to hold on to the belief that the ideal world as illustrated on Martha's Vineyard can be used as an example in their quest to normalize deafness.

5.3. Defining normalcy to claim culture

In chapter four, I touched on the subject of “the norm” and stated that the concept of “the norm” as we know it has in fact not always existed. I explained the historical background and how, through developments in the social sciences, our thinking has been challenged. I want to take this idea a step further by looking at the definition of normal within the argument of culture.

To most people, ‘the norm’ is to be able to speak, and to engage and interact with the world around us through our five senses - seeing, touching, tasting, smelling and hearing. When we look up the definition of “normal” in the dictionary, we will get something along the lines of “conforming to a standard”, and “a typical, expected state of condition”. Whenever there are standards, there must be something or someone to set the standard in the first place. This is where society and politics come into the picture. Through the eyes of the Deaf community, the “norm” is very much a man-made condition, a parameter that humans have drawn up through the ages, and then declared “this is how it should be, this is what is normal”. Could it be, then, that we blindly make assumptions on what it means to be “normal”? And in the same breath, can it be that we have misinterpreted the term ‘disability’ – and hence deafness- within the larger framework of ‘normal’?

In an attempt to answer this question, I am first going to state the most “obvious” reason as to why elective D/deafness would be acceptable: According to the Deaf community, deafness is not a disability, but a culture – the Deaf culture, which has its own language and community. And because deafness is therefore not a disability, it’s okay to choose to be deaf.

Secondly, according to the Deaf community, everyone should be able to choose which culture he/she wants to belong to. Besides, *“the Deaf do not regard their absence of hearing as a disability any more than a Spanish-speaking person would regard the inability to speak English as a disability”* (Davis 1995: xiv).

The questions that arise here are complex, because to understand the arguments the Deaf community used to justify electives deafness, we have to understand the premises on which their claims rest. Similarly, culture is a complex concept and defining culture in the first place

is not an easy task. On which grounds can the Deaf community claim their cultural identity? In an attempt to answer this question, I will explain the argument put forward by Lennard J. Davis, as illustrated in his book ‘Enforcing normalcy’.

5.4. We need disability to defend diversity

As we have seen, the Deaf reject the term ‘disability’ and instead see themselves as a linguistic subgroup, where the word ‘disabled’ becomes ‘differently-abled’. For this reason, the concept of normalcy is a big area of concern for disability studies, which seeks to challenge our existing ideas of what it means to be normal. Nowadays, the term ‘differently-abled’ is preferred by many of the Deaf community, as it implies a positive quality rather than a reduction of the person through disability (Davis 1995: xiii). Through this re-interpretation of ‘disability’, we can look at the Deaf community through a different lens – a lens that affirms and supports Deafness as a new culture with its own, unique history and most importantly – a community with their own language which has been discriminated against for way too long.

When the Deaf Community makes the claim that they are allowed to ‘choose’ to be deaf, their choice is rooted in their belief that D/deafness is not a disability, but rather an identity that they should be free to choose if they want – not only for themselves, but also for their children. This freedom of choice regarding identity is a difficult one morally speaking because respecting a person’s choice about identity falls under the broader moral requirement of respect for personal autonomy, one of the foundational principles of biomedical ethics. To them, being deaf is normal. As we have already seen, things become problematic when the term ‘normal’ needs to be linguistically defined, because the term in itself a man-made construct. In an attempt to defend the normality of disability – and hence deafness - Davis, in his book “*The End of normal – identity in a Biocultural era*”, revisits his claim that he makes in his first book ‘*Enforcing normalcy*’ and proposes the replacement of the term ‘normal’ with ‘diverse’, because ‘normal’ is, according to him, a man-made construct anyway (Davis 2013:2).

In this work, Davis echoes the work of Philosopher Michel Foucault, who was interested in understanding the relationship between power and knowledge and how knowledge can be used as a form of social control. Davis tries to show that the concept of normal is not absolute, but rather a social construction that has been created through historical events, a theory that I explained earlier in this thesis. According to Davis, the concept of normal also tried to serve a political agenda in that it categorizes people according to gender, race, and disabilities etc. to

enforce a level of control. Unfortunately, the full scope of his work cannot be discussed in this thesis, as it would include a full study of the background of his work, ranging from defining biopower and biopolitics, concepts that find their root in Foucault's work. I do, however, want to provide an overview of his ideas, as they provide an interesting take on the question of disability.

According to Davis, our culture is changing and this change brings forth a shift in attitudes towards the disabled and what he terms the start of 'the end of normal'. If we want to defend the 'normality of disability', and under disability I also include deafness, we need to move away from trying to define normal and embrace diversity. In this process, we acknowledge that "*there isn't one regnant or ideal body or culture – that all are in play concerning each other and should be equally valued*" (Davis 2013:2). In Davis' interpretation, Sir Francis Galton, whom we encountered in chapter three, wasn't promoting 'normality' through eugenic practices but instead misused the word 'normality' as a cover-up to conceal what he really wanted: "*A more dominant human being that corresponded with the putative traits of the dominant social and political classes in a racialized and sexist society*" (Davis 2013:2). He, in fact, actually promoted a form of enhanced normality which Davis calls 'hypernormality' (Davis 2013:2).

Additionally, Davis believes that the concept 'normality' only survived because it serves a political agenda: It is a powerful tool to control minority groups within society and because it makes them believe that they are not 'normal' and hence have a reason to conform to some political standard and to provide a rationale for monoculturalism (Davis 2013:2). According to Davis, it is time that we move away from enforcing normalcy towards embracing the concept of diversity in its place, as diversity is a much more democratic concept than normality, because diversity, unlike normality, encompasses a much broader spectrum of the population (Davis 2013:2). To illustrate his point, Davis links this shift of normality to diversity to the core premise of neoliberalism (Davis 2013:2).

In short, and without going into too much detail, neoliberalism is a term that seeks to give meaning to a new form of liberalism. Neoliberalism focuses on the responsibility of the individual versus governmental organization. In the eyes of the so-called neoliberals, individuals in society should take responsibility for their own well-being and not rely solely on government for support. In my interpretation, this means that instead of accepting the 'norm' that society sets, we should be free to redefine this norm into something else. In Davis' words "*neoliberalism is premised on a deregulated global economy that replaces governments with*

markets and reconfigures the citizen into the consumer. The essence of this transformation of citizen into consumer is that identity is seen as a correlate of markets, and culture becomes lifestyle. One's lifestyle is activated by consumer choice – and this kind of choice becomes the essence of one's identity" (Davis 2013:3). Unfortunately, explaining neoliberalism in more detail falls out of the scope of this thesis, but to make a point, it will suffice to say that according to neoliberalism, cultural differences should not be seen as obstacles in the establishment of a single global free market (Davis 2013:3). Within the consumerist market, consumerist principles are universally applicable because they appeal to all self-interested human beings (Davis 2013:3). In other words, people should be free to choose as to which culture they want to belong to, because ultimately people are all the same under the concept of 'diversity' and entitled to their own opinions and ideas.

In that light, diversity may be seen as the ideology that "*opens up consumerist free markets by arguing that we are all the same despite superficial differences like race, class, gender etc.*" (Davis 2013:3). The reason Davis mentions neoliberalism in the first place is because – in my interpretation – he wants to show that diversity is a global idea and hence of global interest and that there is a new interest in embracing the concept of 'diversity' over and above the disability discourse.

The reason this is so important and the reason I chose to mention this point, is because there seems to be a new interest in trying to understand where in this "big tent of diverse nationhood", to borrow Davis' term, the culture of disability – and hence deafness – fits in. In his book 'The End of Normal', Davis once again emphasizes that there is some real progress being made – both in terms of political as well as social progress in thinking of humans (including people with disabilities) as diverse rather than normal or abnormal (Davis 2013:5). There is a real shift that would take place when the disabled would no longer be regarded as abnormal but rather as another type of 'diverse'.

Yet, he also points out that – even though people make attempts at including a wider range of human beings into the pool of diversity, there are still certain kinds of people who don't feature freely within this diversity. What he means by this is that nowadays, more and more advertising agencies have started showing and celebrating diverse bodies, like for example the DOVE commercial which features women with imperfect, slightly overweight bodies etc. The point he is trying to make is that even though disabilities and 'imperfect' bodies are now celebrated more than perhaps a decade ago, there are still certain kinds of disabilities that will never

feature in commercials, simply because they are too depressing to show – e.g. people with terminal illnesses, women with disabilities etc. (Davis 2013:4).

Diversity thus becomes a kind of “cherry picked” diversity, once again borrowing Davis’ term (Davis 2013:4). To genuinely embrace diversity, we would have to embrace all forms of difference – including homeless people, the comatose etc. (Davis 2013:4).

However, if people would accept disability as an identity, as the Deaf community claims it, then it would also mean that the identity of disability can no longer be counted as ‘fixed’, because identities, per definition, should be choose-able (Davis 2013:10). This is problematic, as it is difficult to choose to adopt a disability - identity freely, because one is often born with a disability and cannot just choose it. In that sense, disability is seen as “*the state of exception that allows diversity to function*” (Davis 2013:13). In other words, Davis makes that claim that we need disability to maintain diversity, because the concept of diversity demands difference. For the concept of diversity to exist, you need to have difference and to be able to have difference, you have to have a norm. E.g. for any aspect of life, an individual may have a norm based on personal experience and anything different from their personal experience amounts to diversity in their lives. This can be of cultural or physiological nature and this applies to society as a whole as well. On a societal bases, this norm may be quantified statistically. This becomes problematic, because you need to quantify ‘norm’ in order to define diversity, creating a paradox.

For diversity to survive as a concept, then, according to Davis, we need to imagine a perfect world in which difference will disappear altogether, while at the same time living in the presence which is obsessed with difference (Davis 2013:13). If there would be no disability, i.e. no difference, we would not have to strive for diversity. Disability is different because it resists change and cure and the fantasy of a ‘perfect world’ can only be maintained because there is difference. Thus, according to Davis, “*disability is the ultimate modifier of identity, holding identity to its original meaning of being one with oneself. Which after all is the foundation of difference*” (Davis 2013:14).

Even though this claim is abstract and complex, Davis – perhaps indirectly – makes a point in support for elective deafness. What he is ultimately saying is that we need disability i.e. deafness to maintain diversity. In choosing deafness, we can maintain the diversity that is needed to maintain difference.

Admittedly, this argument seems weak. Just because we can creatively defend the concept of disability as a cultural construct by means of deconstruction does not mean that this argument is automatically reason enough to morally allow parents to select a deaf embryo. In other words: whether something is right or wrong cannot be justified by cultural ‘entitlement’ alone. Perhaps it will be easier to find some answers within the bioethics discourse itself.

5.5. Procreative autonomy

Another way to argue that elective deafness should be morally permissible is to play the ‘procreative autonomy’ card, which gives parents the right to autonomously select the desired embryo. Some pro-selectionists argue that the principle of respect for autonomy should be upheld at any cost because of the centrality of reproduction to personal identity, meaning and dignity. Because of this importance particularly with respect to identity, the right to reproduce is widely recognised as a *prima facie* moral right that cannot be limited except for very good reasons. In this case, respecting autonomous agents means not only respecting but also acknowledging the parent’s “*right to hold views, to make choices, and to take actions based on their personal values and beliefs*”, while respect in this regard refers to “*acknowledging the value and decision-making rights of persons and enabling them to act autonomously*” (Beauchamp et al. 2009:103). The right or entitlement to reproductive liberty has a variety of different sources and justifications. While some see this right as derived from the right to reproduce *per se*, others see it as a derivative of other important rights or freedoms. In any case, this is in many ways problematic, because there is such a fine line between parental self-interest and concern for the future child (Glover 2006:41). Should the right to procreative autonomy take primacy over the interests of the future child? Some people believe that reproduction is an entirely private matter which is and should remain free from moral scrutiny (Savulescu & Kahane 2009:275). According to this line of argument, parents alone have the right to decide which children they want and there is no question as to whether the child will have a ‘good’ or ‘bad’ future. The decision rests entirely on the parents.

This liberal political theory - also sometimes termed ‘liberal eugenics’ by bioethicist Nicholas Agar - provides compelling reasons as to why parents should have the right to exercise procreative autonomy (Savulescu & Kahane 2009:279). According to this view, parental choices should be “*voluntary, state-neutral and individualistic*” and their choices may be based on their own, individualistic view of the ‘good’, whether this conception of the ‘good’ has any

positive impact on the future child is irrelevant (Savulescu & Kahane 2009:279). It is not difficult to see that this makes for a very weak argument, because if it is permissible for parents to select the ‘best’ embryo possible, it may also be permissible for them to select the ‘worst’ (Savulescu & Kahane 2009:279). Savulescu suggests that parents who believe that they can select any child they want based on the principle of procreative autonomy alone, don’t distinguish between moral and legal principles (Savulescu & Kahane 2009:279). Even though it might be legally permissible to select a deaf embryo, the act itself does not make it morally right.

5.6. The ‘unbearable’ life

Perhaps the most “obvious” case for elective deafness is the fact that the ‘deaf life’ is not unbearable and therefore worth living. In comparison to some other disabilities, deafness is certainly not a condition someone would not be able to live with. This view is supported by bioethicists such as John Harris, who summarizes his stance by saying that *‘most disabilities fall far short of the high standard of awfulness required to judge a life to be not worth living’* (Harris 2007:108). What Harris is saying, in principle, is that while it is wrong to bring a child into the world that would suffer unbearably, parental autonomy should be respected as long as the resulting child will be able to live a relatively ‘good’ life without unbearable suffering, which is certainly the case in the discourse surrounding elective deafness, simply because there is no “unbearable suffering” involved if we have to linguistically apply that term i.e. no physical pain and the chance to live life by reasonable standards. In Harris’ words:

“It is difficult to believe that the mother has wronged her child. So far as her relations with the child she has engendered go, she has benefited the child. It has a life worth living because of her choice. The idea that she might have an obligation to compensate her child for benefiting him is nonsense. In such circumstances wrongful life cases are simply misconceived. Not because the life in question has been impaired, not because the individuals are not suffering, not because they have not been harmed; it has, they are, and they have: rather because it is not plausible to regard them as having been wronged.” (Harris 2000:96).

As Häyry points out, Harris is not denying the possibility that a child may be ‘wronged’ by being brought into existence, but he believes that, as long as this ‘being brought into existence’ isn’t characterized by ‘unavoidable suffering’, parents have a right to choose a child who is

deaf (Häyry 2010:86). In sum, as long as the chosen child isn't suffering unbearably, it won't be harmed by being brought into existence.

Harris does not believe, however, that this parental 'free choice' automatically means that these choices are not open to criticism and moral condemnation and agrees that if parents were to choose a *severely disabled* child, the act of choosing would become morally problematic and even morally wrong (Harris 2000:96). Additionally, he claims that just because something is termed as 'wrong' doesn't mean that we shouldn't be prevented from doing it [the act] (Harris 2000:96). Here, in my interpretation, Harris makes a distinction between an act and an assumption – i.e. just because someone thinks an act is 'wrong' doesn't automatically mean that this 'wrong' should not be committed. I believe it's important here to acknowledge that Harris is using the word 'wrong' in a broad sense. 'Wrong', in this context refers to any kind of 'harmful' act which is not necessarily based on individual opinions. E.g. A scientist who happens to be a big supporter of genetic technologies and parental rights would arguably not see the deliberate selection of a deaf embryo as 'wrong', even though the act in itself can be termed as 'wrong', depending on the point of view of the person. Similarly, a devout Christian who holds the belief that any form of tampering with genetic material is unacceptable will most likely see the same act as 'wrong'. While the term 'wrong' will mean different things to different people, the term wrong, in this context, is used as an umbrella term to incorporate different viewpoints.

Harris thus makes an important distinction between 'harming' the child and 'wronging' the child (Harris 2000:97). If a congenitally D/deaf couple would come in for a consultation to request help with the birth of a deaf child by means of PGD, Harris believes that D/deaf parents are entitled to select a deaf embryo if they wish to do so. It does not follow, however, that they have not acted wrongly (Harris 2000:96). If one only focuses on the 'harm' principle though, the parents are fully entitled to choose for deafness.

At this point, I briefly want to go back to the concept of Martha's Vineyard. Even if it can be shown that there are moral reasons for parents to select a deaf child, it seems highly unlikely that the utopic ideal of Martha's Vineyard would be implemented on a global scale. I believe that if we were to declare deafness as a cultural construct, we would still sit with the same dilemma as before – namely society's unwillingness to make provision for minority groups. Additionally, I agree with bioethicist Søren Holm, who says that the real problem lies in the fact that the severity – or disabling status – of a disability "*varies not only historically, but according to the precise social context of each affected person*" (Holm 2000:184). I am not

saying that society is completely unwilling to accommodate deafness and Deaf people into their hearing world, and I am also not saying that they shouldn't. But what I am saying is that this is difficult. People cannot automatically be expected to accommodate the wishes of a minority culture and therefore the limitation that D/deaf people face will still be the same as before.

Chapter VI

Arguments against elective D/deafness

6.1. Whose choice?

When we look at Alexander Graham Bell's speech mentioned in chapter one, it is clear that Bell regarded deafness as a medical defect that should be avoided at all costs rather than a "characteristic of a variety of humankind" (Lane 1984:361). I think it's safe to assume that if we were to ask Bell whether he'd support cases of elective deafness, he'd say no. To Bell, deafness is a physical handicap, limiting an individual's ability to partake in the world around them. It was important for him that 'hearing people of goodwill' step up and take a stand against the spread of hereditary deafness, by denying them the opportunity to further expand their [sign] language and culture (Lane 1984:340). Bell believed that to be able to function in a hearing world, deaf people should at least try to conform to the hearing world and try to 'fit in' as much as possible. He went so far as to urge us, as bystanders, and deaf people themselves to forget that they are deaf and thereby try to 'blend in'. In Bell's words: "*We should try ourselves to forget that they are deaf. We should teach them to forget that they are deaf*" (Lane 1984:340).

It becomes clear, that Bell was very focussed on integrating the deaf with the hearing majority. While Laurent Clerc, whose views were discussed in chapter 5, favoured deaf teachers and making provision for the deaf by using sign, Bell opposed this view as an obstacle to integration (Lane 1984:341). He saw the dangers in isolating the deaf as 'one community' with their own sign language, because it cut them off from the hearing world, isolating and limiting them to their own, self-constructed identity and culture. To Bell, upholding the sign language tradition represented the failure of successful integration (Lane 1984:341).

In choosing D/deafness, a person would choose deafness for him/herself for the reasons mentioned in the preceding chapters. When an individual chooses deafness for him/herself or for their child, their decision to make that choice is mostly founded on their belief that deafness is not a disability. This decision thus reflects a direct rejection of the medical model as discussed in chapter four, which states that deafness is a physical impairment that limits optimal human functioning and hence flourishing. Even though disability scholars who support the social model of disability claim that disability equals a fixed identity, much like race and gender, we encounter a completely difference perspective when we exit the disability studies camp and direct our spotlight onto the wider public opinion and the medical field. According to the medical model, disability and impairments are seen as abnormal, fixable, and medically

definable and not socially constructed (Davis 2013:7). And, according to Philosopher Lennard Davis, this may be because disability isn't seen as an identity in the same way as e.g. race. The reason for this is because disability is commonly perceived as a medical problem and not as a “*way of life involving choice*” (Davis 2013:7).

This is perhaps where deafness as a disability is different: In principle, it is possible to ‘choose’ deafness and the lifestyle that comes with it with the methods discussed in chapter two. Of course, some forms of disability cannot be freely chosen, which is probably a good thing. But where does this leave deafness? If deafness as a lifestyle can be chosen, doesn't that mean that deafness is entitled to defend its own identity exactly on the grounds that it is ‘choose-able’? Perhaps some people will claim that race e.g. blackness also doesn't involve choice, much like disability. Here it is important to understand what Lennard Davis means by ‘choice’. In my understanding, ‘choice’ refers to the ability to live life to its fullest, to be able to make decisions and do whatever is needed to function within a society. In principle, disabilities limit precisely those choices that people who embrace other identities e.g. race, gender etc. can make. In simple terms, having free choice involves being able to live a relatively ‘normal’ life. There is a paradox, however: Philosopher Dena Davis believes that, in a liberal state, it is imperative to have a wide variety of communities (including the Deaf community) to choose from because this freedom to choose increases individual autonomy, but this benefit of freely choosing which community one wants to belong to can only exist *if* there is indeed free choice (Scully 2008:62). As a consequence, Davis argues that if parents are free to choose deafness for their children, they effectively strip their potential child of his/her autonomy of being free to choose which community he/she wants to belong to (Scully 2008:62).

In making this claim, Dena Davis explains the conflicting interest of the typical state between two different concepts of liberalism: On the one hand, liberalism has a deep commitment to the principle of autonomy and on the other; liberalism strives to maintain diversity (Davis 1997:10). Only within diversity do we find choice - and hence the ability to exercise autonomy. In explaining this, she quotes William Galston who said that “*A standard liberal view [...] is that these two principles go together and complement each other: the exercise of autonomy yields diversity, while the fact of diversity protects and nourishes autonomy*” (Davis 1997:10). What Galston is saying here, is essentially that liberalism protects diversity in that it enables people to make autonomous choices and is not to be understood as a violation of choice. In other words, we should not place limits on individual autonomy because to do so would narrow the range of possibilities (of life choices) that an individual would be able to choose from within

a liberal society. When we apply this principle to the Deaf community, it becomes apparent that the Deaf community only exists because of liberalism and because of individuals who have exercised their autonomy in this regard.

This principle is closely related to the theory of John Stuart Mill, whose theory I referred to in chapter one. Mill embraces and supports freedom of choice. This becomes very clear in his writings that can be found in his work “On Liberty”, which was published in 1859. For people to make free choices, according to Mill, they should be free to choose from a wide variety of different things. To explain, Mill makes a striking analogy: “*A man cannot get a coat or pair of shoes to fit him unless they are either made to his measure, or he has a whole warehouseful to choose from: and is it easier to fit him with a life than with a coat [?]*” (Davis 1997:10).

What Mill is basically saying here, is that there are two types of people: the one type that has no issue with “fitting into a mould”, while the other type prefers choosing from a wider variety of options. Essentially, both types need to be accounted for. This also means that in supporting liberalism, “narrow-choice” communities have to be supported because they add to the diversity of choice (Davis 1997:11). I want to argue that the Deaf community is such a type of “narrow-choice” community, as Dena Davis calls it. She calls it “narrow-choice”, because within the community, there is little freedom to choose a different way of life. If you choose to be deaf, you will always be deaf, there is no easy way out. The fact that the community is there in the first place though, initially increases the diversity of choice. I want to emphasise, however, that Davis does not call them “no – choice” communities. She simply calls them “narrow – choice” communities. In other words, the choices within certain communities will be *limited*.

At this point, I want to stress the fact that the condition or *status of deafness* is – even in today’s terms – a final condition. To date, there is nothing that can be done to “take away” deafness, so to speak. Sure, there are technologies that enable individuals to hear again in spite of their deafness, e.g. by making use of cochlear implants. But even cochlear implants do not change the scientific fact that someone is – and always will be – deaf. At least until scientists come up with a way to restore the ears’ natural ability to function without the help of external or internal devices. The “status” of deafness that will be stamped onto the individual will be there even though technology is in principle able restore hearing loss. It doesn’t change the fact that an individual is deaf, however. Therefore, the Deaf community can be seen as one of those “narrow-choice” communities that Dena Davis is referring to, as options to “opt out” of deafness as a condition are limited. This of course doesn’t mean one cannot freely choose to

be part of the Deaf community. That choice does exist, but once individuals are part of the Deaf community, it's difficult to choose to exit it again due to constraints with regards to hearing abilities etc. When one is deaf, there will always be constraints in terms of "fitting into" the hearing world.

The fact that one can 'choose' to be a part of the Deaf community is – in the eyes of liberalism – a good thing, as it gives people more freedom, and hence more autonomy, to choose which life he/she may want to live. Once in the Deaf community, however, there is little space for autonomy precisely because other options are limited. And this is also where deafness (and other disabilities) differ from other "mainstream" minority group identities such as race or gender – there are limits within the choice. This is, in my interpretation, precisely what Lennard Davis refers to when he makes the statement that, within the medical field, disability is seen as "*largely perceived as a medical problem and not [as] a way of life involving choice*" (Davis 2013:7). This is also exactly where the paradox lies: On the one hand, we need "narrow-choice" communities to increase diversity, but on the other, these "narrow-choice" communities limit autonomy. This is why Dena Davis states that liberalism faces a dilemma: Because liberalism is equally committed to autonomy and diversity, "narrow-choice" communities create a problem for liberalists because the one cancels out the other.

Additionally, medical institutions and interventions are explicitly designed to restore normality or the 'normal life'- and hence, their aim is to increase personal autonomy by empowering people to make more choices based on the mere fact that a sense of normality is restored in an individual's life. Cochlear implants are designed to restore lost hearing and hence restore a sense of normality in the life of an individual in so far as individuals are more able to engage with the world around them. Braces are designed to straighten crooked teeth, aiding them to move into their 'normal' position and through it, hopefully giving those individuals more self-confidence. Prosthetic legs are given to patients who have lost a leg to allow them to walk upright 'normally' and get to places without relying on someone else. Short children are given growth hormones to help them grow into their 'normal' height so that they won't be teased by their peers.

What we see here is that there is little space for diversity within the medical definition and, in Davis's words, "*tolerance for variation*" and inclusivity (Davis 2013:8). In other words: When we look at bodies, the medical field will always embrace the 'normal': the goal is always to create or restore a body that can do everything that it was biologically designed to do. And for this reason, in the medical world, disabilities are not celebrated. If anything, they are always

seen as cases that need to be fixed and hence they are always seen as ‘abnormal’. Lennard Davis gives ‘abnormal’ another name and attempts to call it ‘*undiverse*’ (Davis 2013:8). He then goes on to explain why he calls disabilities ‘*undiverse*’: They are ‘*undiverse*’ because diversity, by definition, involves choice and – in his interpretation – also celebration, a luxury people with disabilities typically do not have (Davis 2013:8).

If we assume that Davis is right and that disabilities, and hence deafness, are abnormal and therefore in need to be fixed, doesn’t it then also mean that choosing this abnormality, a lifestyle of deafness, would amount to the infliction of harm on the individual either choosing deafness or on the individual for whom deafness is chosen?

In an attempt to answer this question, I choose to only comment and refer to cases in which D/deaf parents choose deafness for their child by making use of the biotechnological methods currently available as discussed in Chapter two. The reason for this is simply, because there is a stark difference between an autonomous individual choosing deafness for him/herself versus parents making autonomous reproductive choices which ultimately affect the embryo’s future. The ethical dilemmas arising out of these two case scenarios are of a different nature and thus cannot both be addressed here.

When I talk about the possible harm that can be caused by choosing D/deafness, I build my argument on the assumption that an embryo deserves respect and, arguably, has some form of moral status at the four - or - eight week - cell stage and that it is therefore important to consider the possible harm that can be caused in choosing deafness for this developing human being. Also, I am focusing on parents deliberately choosing a deaf embryo over a hearing one and the question of harm that arises in this context. I am not looking at cases in which there is a deliberate intervention made at, say, the fetal stage, to make a hearing child deaf. This would pose a different moral problem altogether and cannot be discussed in this paper. It’s important to be aware of the fact that the question of ‘harm’ is a very broad one which is addressed by different philosophers and bioethicists in different ways and by using different definitions and theories. Similarly, the bioethical principles of nonmaleficence, beneficence and autonomy are applied differently to the same case by different authors, which we will see.

Even though ‘choosing deafness’ might not affect the embryo before the time of birth, I intend to show that it is possible to argue that the embryo is harmed by being selected as a ‘deaf’ embryo because this choice will have far-reaching consequences after the baby is born.

While this statement seems controversial initially, especially because it seems almost strange to suggest that an embryo will be “harmed by being selected”, some people also ask whether the ethical question isn’t rather “which embryo should be chosen to carry to term?” In the following section, I will explain these approaches in more detail and will show that it is indeed possible to argue that an embryo is “harmed by being selected” and that people should thus be careful when choosing which embryo they want to have implanted.

In this context, I want to argue that this form of harm would result in an infringement on the bioethical principle of nonmaleficence and that parents therefore have a moral obligation to practice the principle of procreative beneficence, as put forward by Savulescu, and therefore have the moral obligation to refrain from ‘choosing deafness’ for their child in the first place.

6.2 Nonmaleficence and beneficence

In its most basic definition, the principle of nonmaleficence imposes an obligation not to inflict unnecessary harm on others and echoes John Stuart Mills’ opinion that we shouldn’t harm others by the actions we take. Because we have so much genetic knowledge available nowadays and because it is possible to select for a certain kind of embryo - as is the case with the elective deafness case scenario we are looking at - selecting for deafness may result in an infringement upon the principle of nonmaleficence, often proclaimed as the fundamental principle in the Hippocratic oath (Beauchamp & Childress 2009:149). Sometimes, what is seen as ‘good’ by one person may actually result in the harm of another. As a consequence, there needs to be some kind of responsibility on the part of the parents selecting a deaf child if it can be shown that selecting a deaf child causes harm. I will discuss the nature of this harm in due cause.

In this regard, two bioethical principles are often confused: The principle of nonmaleficence and the principle of beneficence (Beauchamp & Childress 2009:149). While the principle of nonmaleficence states that we “only” have an obligation not to harm, the principle of beneficence goes a step further and states that we have an obligation to ‘do good’ and in the process help others (Beauchamp & Childress 2009:150). Depending on the context, the principle of beneficence can take priority over the principle of nonmaleficence and vice versa. In other words: If I choose to insert an intravenous line into a patient, then I am causing him/her some degree of pain and possible discomfort even though I have an obligation not to harm (by i.e. not inflicting pain), however, it will be beneficial for the patient to have this intravenous line inserted for e.g. life support. In this context, the principle of beneficence takes precedence

over the principle of nonmaleficence because the benefits outweigh the momentary discomfort (Beauchamp & Childress 2009:150). In some cases, however, the bioethical principle of nonmaleficence takes precedence, especially in cases where there is no foreseeable benefit. While the principle of beneficence always focuses on an action by helping i.e. preventing harm, removing harm and promoting the ‘good’, the principle of nonmaleficence requires only intentionally refraining from actions that cause harm in the first place (Beauchamp & Childress 2009:151).

I want to argue that in the case of elective deafness, this bioethical principle of nonmaleficence is a fundamental one, and should be upheld at all costs by the potential parents. When we look at the principle of nonmaleficence, we look at the possible harm that can be caused resulting out of the parents’ decision to have a deaf child. I once again want to mention that in this case, we are not talking about harm in the sense of physical pain or biological damage, but harm in the sense of robbing the child of opportunities in life, which I think is a legitimate interpretation of the word “harm”. Additionally, Beauchamp and Childress state that the principle of nonmaleficence can also be understood by a set of more specific moral rules that need to be upheld in any given situation (Beauchamp & Childress 2009:153). These moral rules include the following statements:

- 1.) Do not kill.
- 2.) Do not cause pain or suffering.
- 3.) Do not incapacitate.
- 4.) Do not cause offense.
- 5.) Do not deprive others of the goods in life.

I think that the focus in the context of elective deafness is most notably on number 5, which states that we have an obligation to not deprive others of the goods in life (Beauchamp & Childress 2009:153). This principle of honouring the principle of nonmaleficence and our obligation as parents to ‘not deprive others [our children] of the goods in life’ and what that means will be further discussed later in this chapter by taking a look at Joel Feinberg’s ‘Open Future’ argument. It’s also important to remember that the principle of nonmaleficence not only imposes an obligation not to inflict harm, but also that we have an obligation not to impose risks of harm (Beauchamp & Childress 2009:153). In other words, there is a focus on the future as opposed to “only” focussing on the “here and now”. Parents can impose harm on the unborn (deaf) child without any explicit harmful intent, but the consequences of their actions would impose harming the child in the sense that their choices withhold life opportunities from their

children. In showing that the principle of nonmaleficence indeed takes priority over the principle of beneficence, it needs to be shown that the potential child is indeed harmed by being selected as deaf.

Parents that would choose a deaf embryo would argue, on the other hand, that the principle of beneficence should take precedence because in their eyes, their decision to have a deaf child would be beneficial to the future child and indeed the best decision possible. The question as to what constitutes ‘the best decision’ possible is an important one to address, however. I believe that this decision ultimately doesn’t rest on the parents alone, but that we should decide whether or not this decision is also the ‘best possible decision’ for the unborn child itself. If this decision is only beneficial to the parents, then the act of choosing a deaf embryo remains questionable and the principle of autonomy is violated. In other words, the act of choosing a deaf embryo would only be beneficial to the parents and consequently, they would be “using” the child for their own benefit i.e. because they want the child to be like them and partake in the Deaf culture. By choosing the deaf embryo, the future child’s autonomy is disrespected and ‘devalued’. I believe that the focus should also be on the well-being of the child and not only on the demands or the wishes of the potential parents and that the autonomy of the potential child should be respected at all times if possible. Of course, parents don’t only choose to have children for their children’s sake, but also for theirs. But does this necessarily mean that the child’s future quality of life should be disregarded? I don’t think so. For parents to choose a deaf child for their benefit might be wonderful and even beneficial for them, because it would enable them to ‘bond’ with their child on their level and enable them to share their cultural identify with them, but at the end, it will be the child who will have to live with the condition of deafness and the child who will have to try to live with deafness even after he/she leaves their parent’s home.

Having said that, I also believe that parents have a moral obligation to take the principle of procreative beneficence into careful consideration when the decision for elective deafness is made. I will explain what I mean by that in the next section.

6.3 The harm principle

The harm principle is an interesting principle to discuss because intuitively, most people feel that choosing a deaf embryo is a perversion of the PGD technique, which was developed to prevent parents from having to abort an embryo in cases where the embryo is found to be a

carrier of a life-threatening or disabling condition. Some individuals feel that by purposely selecting a deaf embryo over a hearing one, the deaf embryo is harmed. The definition as to what this ‘harm’ entails differs widely, however. According to Søren Holm and Jonathan Glover, no embryo is harmed by simply being selected. In making this statement, Holm summarizes the classic argument, which Dan Brock calls the “wrongful handicap conundrum” (Davis 1997:12; Glover 2006:25).

This argument seeks to show that no harm is done by selecting a deaf embryo over a hearing one and it runs as follows: If a woman falls pregnant this month, the child conceived through this pregnancy will be different to the one conceived next month. This also means that the genetic makeup of the embryo conceived this month will be different to the genetic makeup of the embryo conceived next month. This is due to the fact that in both cases different gametes are being used for conception (Holm 1998:186-187). If we apply this principle to the PGD debate surrounding the selection of a deaf embryo, it becomes apparent that we cannot look at one embryo and say “oh, this embryo is harmed, because it’s been made deaf”. In fact, the deaf embryo could not have been harmed, because it wasn’t ‘made deaf’, it was chosen like it was – i.e. deaf.

We therefore cannot compare the welfare of a deaf embryo to a hearing one in this case, because this specific deaf embryo will always be deaf, it could not have been different. In other words, for this selected deaf child, the “deaf life” is the only life this child could have. So, if the choice is between allowing the deaf child to live or not allowing it to be born at all, then we would have to show that the life of the deaf child is so bad that it would in fact be better for the child not to live this kind of deaf-life at all (Holm 1998:187).

Opponents of this argument remark, however, that it is not enough to simply say that the deaf embryo would not have been harmed and that the potential deaf child is better off not being born at all. Instead, most commentators agree we can still morally question the parent’s decision, despite the fact that the above argument logically leads us into a one-way street. Of course, no child is harmed by merely being selected, if one applies Holm’s notion of harm. Unfortunately, Holm’s argument still doesn’t solve the ethical dilemma, because the question still remains: what is meant by the word ‘harm’?

If harm in this context simply means ‘no child has been harmed *physically*’ - i.e. in the sense of pain, then the statement is correct: no child has been harmed. Also, “proving that the life of the potential child is so bad that it would in fact be better for the child not to live this kind of

deaf-life at all” is also problematic, because this statement assumes that the life of a deaf child is naturally horrible and not worth being lived. Of course, this is not the case as there are many deaf and happy children alive today, who all have different stories to tell about how pleasant their life is.

If arguments lead us into a one-way street, without any feasible conclusions, perhaps it would help asking another question: Even if it can be shown that no child is harmed in the ‘traditional’ sense, could it be that ‘harm’ in this case can be explained in other terms? And, even more importantly, do parents perhaps have a moral obligation to choose to bring ‘the best possible’ child into the world? In other words, do parents have the moral obligation to uphold the principle of procreative beneficence, a term coined by bioethicist Julian Savulescu? (Holm 1998:187; Savulescu 2001:414). If the parents could have chosen to bring a ‘better’ i.e. impairment-free child into the world, should they not have the ethical obligation, for the sake of the child, to do so, as doing so would result in the child having more options (e.g. jobs, relationships) to choose from in life and would possibly be a better addition to society as a whole?

At this point, I briefly want to return to a question I asked in my introduction, where I quoted Erik Parens who asks whether “better is always good”. If it can be shown that this ‘good’ should be actively pursued, wouldn’t failing to pursue this good amount to the infliction of harm? (Hall 2012:6). This statement would suggest a strong argument in support of the parental obligation to honour the bioethical principle of beneficence, which - as discussed elsewhere in this thesis - states that we have an obligation to do good. The obligation to do ‘good’ in this sense would refer to parents having an ethical obligation to bring an impairment-free child into the world as opposed to a disabled one. Here, the focus shifts to the ethical responsibility and the future implications of the actions by the parents as opposed to only commenting on their initial decision to choose. In this context, the ‘harm argument’ is being taken a step further, because the question transcends over and above the parent’s initial act or decision. It shows that simply asking “to choose or not to choose a deaf embryo” isn’t enough and challenges us to look a little further. Harm doesn’t only refer to the initial decision by the parents but transcends this decision and calls into question the type of life the future child might have and whether this (deaf) life would harm the child in any way.

In an attempt to answer the question as to whether a child is harmed by being selected as ‘deaf’, I first want to turn to Joel Feinberg’s “Open Future” argument. Here, Feinberg argues that children have definitive rights that should be upheld and honoured at any cost. While

Feinberg's argument sounds similar to that of Savulescu's argument of procreative beneficence that will be discussed later in this thesis, there is a slight difference: While Feinberg simply argues that parents have a moral obligations to keep the child's future open, Savulescu argues that we have a moral obligation to choose the child who will have the best possible life. In principle, Savulescu's argument is taking Feinberg's argument a step further, as we shall see.

6.4 Robbing the child of an 'Open Future'

When we go back to our original question and ask whether it is morally permissible for parents to select a deaf embryo, we need to ask ourselves why it would not or would be permissible to select for deafness. As I have shown above, it is very difficult to simply reply with "because the child will be harmed", because the definition of what "harm" entails is very narrow. In bioethical terms, this would mean that defending the permissibility of this act (parents choosing a deaf embryo) by using the principle of nonmaleficence as justification is problematic, as applying this bioethical principal in this context would just be too vague. We need to be more specific in explaining what harm would refer to in this context. Surely harm cannot mean 'physical pain', because the child is not physically harmed, it is merely selected as it is – deaf. Perhaps there is another question that needs to be asked: If parents decide to select a deaf embryo, is that child perhaps harmed by the direct choices of their parents regarding their future and the life that they will live? In this case, harm would consist in condemning the unborn child to a life with a disability that could have - in principle - been avoided (Scully 2008:61). Of course, in this case "avoiding" would mean not to select a deaf child and rather selecting a hearing one, but this would also mean 'selecting' a totally different child. Either way, supporters of this argument feel that the child is harmed by being selected with a disability. This line of argument directly questions parental autonomy, parental rights and obligations as well as societal obligations towards the unborn child. In other words, it asks the question as to whether parents have the right to make these kinds of decisions for their children that carry far-reaching consequences at all. It also asks if we, as the broader society, have an obligation to protect the child's rights in this regard.

Understandably, most parents want what is best and 'good' for their children. Let's assume the D/deaf parents who want a deaf child base their decision on the genuine wish to give their child the 'best possible' future. This decision is probably based on their belief that they can only provide adequate care and a safe environment for their child when the child is deaf like them.

They believe that the child is cared for best when it can grow up within the supportive structure of the D/deaf community and feel a sense of belonging by growing up in the safety of that culture, adopting a positive sense of identity while learning sign language et cetera. If we only look at the child's *upbringing*, the D/deaf parents make a seemingly valid point: the environment of the child must be of such a nature that he/she can feel safe and grows up with a sense of belonging, which often hearing children within the D/deaf community don't feel they have. Parents mostly want their children to lead 'good' lives – but what does this mean in this context?

When children are still young, they just need the basic physical and non-physical things to live 'good' lives: nourishment, shelter, warmth, clothing, medical care, love and security, the chance to build friendships and relationships, being talked to and listened to and the chance to develop their talents and themselves (Glover 2006:51). It is important here to point out that the needs a child has in childhood and adolescence and those needs the child will have in adulthood are of equal importance. What I mean by this is that the decisions that are important now and the decisions that will be important later in the child's life should be taken into consideration equally, especially because the decisions that are made now have far-reaching consequences for the child's life at a later stage. In other words, parents that only choose a deaf embryo without considering the full impact of that choice on their child's life are not considering the needs that the child will have in adulthood. To be good parents means that parents should make good choices now, so that the child can benefit from those choices later in life. For this reason, Jonathan Glover states that we don't only owe 'these things' to our children when they are still children, we also owe these physical and non-physical things to our children so that they can later lead 'good lives' as adults (Glover 2006:52). If they are deprived of any of these things, their lives will be 'severely limited' (Glover 2006:52). Here, one has to ask the question whether parents have a moral obligation, over and above these 'basic childhood needs' that consists in honouring and thus upholding the child's future options and choices in life. In other words, do parents perhaps have the moral obligation to respect their child's future autonomy as well as providing basic needs now so that the child can have a successful and fulfilled life in their adult years as well? In bioethical terms, the question is asked whether parents have an obligation to respect the autonomy of future persons (Savulescu & Kahane 2009:282). According to the principle of autonomy of future persons, parents have significant moral reason to not only maximise the child's expected well-being, but also to maximize the child's *expected autonomy* (Savulescu & Kahane 2009:282).

In an attempt to answer the above question, a paper titled “A Child’s Right to an Open Future”, written by American legal philosopher Joel Feinberg is often quoted. In this paper, Feinberg argues that every child has the right to make decisions about his/her own future, especially if it concerns decisions that are as pivotal as e.g. to hear or not to hear. Even though Feinberg does not specifically refer to deafness, he does question parental autonomy in cases where parents make choices for their children that carry significant consequences. In principle, Feinberg touches on an ethical view which Glover calls ‘procreative perfectionism’ – the view that parents should aim to have children who will have “the best chance of a good human life” (Glover 2006:53). Similarly, this version of procreative perfectionism is echoed by Australian bioethicist Julian Savulescu, who raises strong arguments for a consequentialist view which he calls ‘the principle of procreative beneficence’. He summarizes ‘procreative beneficence’ in the following words: “*Couples (or single reproducers that i.e. make use of sperm donors) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information*” (Savulescu 2001:413).

When we talk about any form of genetic counselling, the respect for patient autonomy is strongly emphasised – perhaps even more so than in any other area of medicine (Davis 1997:7). Philosopher and bioethicist Dena Davis summarizes this patient autonomy dilemma as follows: “*When moral challenges arise in the clinical practice of genetics, they tend to be understood as conflicts between the obligation to respect patient autonomy and other ethical norms, such as doing good and avoiding harm*” (Davis 1997:7).

Because patient autonomy is given such emphasis and value in the medical field in general and in genetic counselling specifically, it becomes very easy to blur other areas that should – morally – be given equal status, such as discussions surrounding human suffering or the moral claims of the embryo in question (Davis 1997:7). This becomes especially clear in cases where parents (i.e. the patient) want a child with a certain disability. The focus thus shifts from the deaf embryo to the responsibility of the parents that make the choices for the embryo in the first place.

In his paper, Feinberg argues that parents have certain rights, but some of these rights are, in fact, children’s rights that are possessed by adults until the child is old enough to make his/her own autonomous decisions (Feinberg 2007:112).

Feinberg believes that a child's autonomy is threatened when parents have the freedom to decide what kind of life a child should have. If this autonomy is abused, the child is harmed. In making his argument, Feinberg distinguishes between two different classes of rights that children have, but which are possessed by the parents on behalf of the child until the child is mature enough to make his/her own autonomous and informed decisions. Essentially, these rights are in place to 'safeguard' the child's future. These rights Feinberg calls C-rights (Children's-rights), which he divides into two subclasses: The first class of rights Feinberg calls 'dependency rights' and the second class of rights he calls 'rights-in-trust' (Feinberg 2007:112). The 'dependency rights' are basic rights that encompass things like shelter, food and (parental) protection (Feinberg 2007:112). The second class of rights are the rights on which I want to place specific emphasis for the purpose of this chapter: The so-called 'C-rights-in-trust'. These 'C-rights-in-trust' are significant, because these rights must be protected and preserved for exercise by the adult the child is expected to become (Feinberg 2007:112). Feinberg argues that these rights-in-trust are violated when parents take 'key options' away from their children before that child is an autonomous individual. I will argue that one of these key - options include the child's ability to hear.

The 'rights-in-trust' that Feinberg refers to are unique in that they pose an obligation and a duty on potential parents in advance of the right being able to be exercised (Lotz 2006:539). In other words, according to Feinberg, parents are obligated to protect their child's autonomy before the legal age for decision - making is reached. For this reason, Feinberg also calls the right to an 'open future' an "anticipatory autonomy right" (Feinberg 2007:113). He believes that every child should have these 'anticipatory autonomy rights', in the form of future options, kept open until one (the child) is a "fully formed self-determining adult capable of choosing among them [the options]" (Feinberg 2007:113). Applying Feinberg's principle to the elective deafness debate, we can see that if parents 'choose deafness' for their child, they are closing the future options their child should, according to Feinberg, be able to choose from. These future options could include e.g. opportunities in the hearing world, ranging from University education options to job opportunities that are limited if the child is born deaf. Applied to this context, it would mean that a child should be allowed to choose whether he/she wants to be deaf or not and whether he/she wants to be part of the Deaf community at all. If this choice does not exist, the child is robbed of the right to autonomously decide what kind of life he/she will want to live. In other words, when parents choose a deaf embryo, they autonomously decide about the type of life their child will live – a deaf life. According to this argument, the future child should

be given the option to stop hearing later in life, thereby “choosing deafness”. The status of deafness will then be irreversible.

Here some people will probably argue that a deaf life is not necessarily a bad life and that this kind of life is certainly worth living. I think it’s important to keep in mind that Feinberg is not saying that a life void of choices is not worth living. I also don’t think that Feinberg would say that a deaf life is not worth living, but I think that he would strongly object to parents deliberately choosing a life of deafness for their child simply because it closes options and possibilities in life. He is talking about real choices and real opportunities that parents would take away from their child when the ‘C-rights-in-trust’ are not exercised as they should be.

To give an example, suppose a deaf child grows up and expresses the wish to become a musician or a pilot. For both jobs, good hearing is required – the ability to distinguish between notes and the ability to be able to hear via a microphone. Of course there are deaf and partially deaf musicians and singers, but those musicians and singers typically only lost their hearing later in life, as a result of an illness or due to environmental circumstances such a burst eardrum etc. Also, those musicians are not classified as ‘profoundly deaf’ from birth. Individuals who are born deaf will never be able to acquire the audiological knowledge that is needed to play an instrument or sing a song correctly because they either cannot listen to music or won’t be able to hear notes correctly, even with the help of a cochlear implant.

When deaf individuals sing songs that they learnt before they became deaf, they are able to sing these songs correctly from memory. The point I am making here is that deaf individuals lead lives that are characterized by real limitations and that their choices are limited in terms of decisions they can make in certain areas of life. The same applies to their relationships – deaf people are limited to their sign language and cannot communicate freely with hearing people. Of course there are exceptions, but generally speaking, the majority of deaf individuals will have difficulties communicating with people that cannot speak in sign language themselves. All these limitations would amount to the closure of ‘key - options’, that Feinberg believes are vital to have access to.

Feinberg believes that a child’s capacity for self-governance requires that “basic options are kept open and growth kept ‘natural’ or unforced”, that “the making of serious and final commitments are postponed until the child grows to maturity and is legally capable of making them [the decisions] himself” and that “the child should be permitted to reach maturity with as many options, opportunities and advantages as possible” (Feinberg 2007:114; Lotz 2006:539).

Feinberg ultimately believes that granting the child ‘as many options as possible’ will maximize the child’s chances of self - fulfilment (Lotz 2006:539).

The same kind of view is also expressed by various other writers. One of them is philosopher Kenneth Henley, who wrote a paper called “The Authority to Educate”, in which he argues that children’s rights to have open options – and in fact to have as many options as possible – is more important than their parents’ wishes to raise them according to their own personal interests (Henley 1979:254; Mills 2003:1). He takes it a step further and says that the State has the duty to protect the child from the tendency of parents wanting to enforce their way of life unto their children or their views on how the child should live his/her life. According to Henley, parents have a moral duty to “*foster the unfolding liberties of their child*” (Mills 2003:1). This view is also supported by Dena Davis, who believes that it is important that ‘the liberal State’ protects an individual’s right to choose which kind of community he/she wants to belong to and leave from if he/she could choose (Davis 1997:11). Quoting Even Galston, she says that a society must “*defend (...) the liberty not to be coerced into, or trapped within, ways of life. Accordingly, the state must safeguard the ability of individuals to shift allegiances and cross boundaries*” (Davis 1997:11).

In her view, autonomy of the individual is ethically more important than the autonomy of the group, provided group autonomy doesn’t overpower the individual to make his/her own life choices. If group autonomy threatens individual autonomy, then the State has the duty to protect individual autonomy – especially if the individual in question is still a child (Davis 1997:11). In other words: When Deaf parents want to choose deafness for their child on the grounds that they want their child to be part of the Deaf community and partake in their way of life, the State has the duty to protect the unborn child from his/her parents making such a choice, as the choice would mean that the child would have fewer ‘options’ open in life and would be doomed to live life in a certain way without having the choice to ‘opt out’. The child, according to Davis, should be able to freely choose the life he/she wants to be able to live. When “choosing” deafness means to “*radically narrowing the range of choices available to the child when he/she grows up [and] when it impinges substantially on the child’s right to an open future, then liberalism requires us to intervene to support the child’s future ability to make his/her own choices about which of the many diverse visions of life he/she wishes to embrace*” (Davis 1997:11).

While Deaf activists argue that the Deaf are only constrained in so far as society doesn’t want to make provision for them in the sense of inclusion in form of e.g. making the general

population learn signs language, we need to remember that the Deaf community is a minority group and it will be very difficult - especially logistically - for the majority to bow down to their wishes. I want to reemphasize that we are working with real problems and real limitations that cannot be romanticised or simply 'wished away'. While it is true that Deaf children have access to language in the form of sign, there are comparatively few Deaf children who can read and speak properly (Davis 1997:13). For this reason, it can be argued that things like 'mainstream' literature e.g. Shakespeare's dramas or poetry will never really be in the Deaf child's reach given the language deficit. Davis even argues that access to 'mainstream' literature can be considered a child's "birth right" (Davis 1997:13). Additionally, while Deaf activists argue that the D/deaf have access to a variety of jobs; the reality is that the available options on the job market for the D/deaf will always be limited (Davis 1997:13). A prelingually deaf person not only cannot hear, but in most instances cannot even speak well enough for a hearing person to understand him/her. Consequently, Dena Davis argues that – given the narrow options of choice – the child is harmed. And not only that, she also argues that the narrow range of options available to the child will likely lead to "lower standards of living", because for most well – paid jobs, hearing is essential (Davis 1997:13). As I mentioned earlier, deafness also limits the kinds of friendships and relationships D/deaf individuals are able to enter into. When we look at the mere facts, it should be easy to see that deafness, in whichever way one wants to look at it, limits possibilities in real terms.

Deafness narrows a child's future choices regarding occupation, relationships, cultural options and even marriage options. Based on this alone, I think it's safe to say that deliberately choosing a deaf child and thus closing possible life options available and forever confining a child to a culture without his/her free will, will morally count as "harming" the child.

In sum, if the child's right to an 'open future' and thus his/her right to make autonomous choices is violated, parents should be discouraged from choosing deafness for their child on grounds that it narrows the choices and options an autonomous individual should be able to make and because narrowing the child's choices would inflict harm on the unborn child, thus threatening his/her right to autonomy. Additionally, it's equally important to keep in mind that a hearing child can, in principle, freely leave the Deaf community should this be his/her wish, but not vice versa. A D/deaf child will always have difficulties functioning and flourishing in a hearing society based on real limitations.

6.5. Procreative beneficence and making better people

In this section, want to go back to Savulescu and Kahane's statement mentioned earlier, where they state that we don't only have a duty not to harm, but that potential parents have, in fact, a moral obligation to "*select a child, of the possible children they could have, who is expected to have the best life as the others, based on the relevant, available information*" (Häyry 2010:65). According to Savulescu and Kahane, potential parents have a moral obligation to practice procreative beneficence, which states that we should make it our priority to always create "better" human beings, because better human beings logically would make up a better world (Häyry 2010:82). Savulescu and Kahane summarize the principle of procreative beneficence in the following way:

"If couples (or single reproducers) have decided to have a child, and selection is possible, then they have a significant moral reason to select the child, of the possible children they could have, whose life can be expected, in light of the relevant available information, to go best or at least not worse than any of the others" (Savulescu & Kahane 2009:274).

According to this principle, parents have a moral obligation to select the child which will be able to enjoy "most well-being" in life, or, as Savulescu and Kahane put it: the parents have an obligation to select *the most advantaged child* out of the possible children that could be chosen (Savulescu & Kahane 2009:275). They point out, however, that this doesn't mean the child will have a perfect life, or that it will enjoy more advantages than other children.

Intuitively, a lot of people have problems with this theory, because it sounds like Savulescu and Kahane are suggesting that parents have a moral obligation to use genetic technologies to genetically select a *perfect* child, including choosing a child with non-disease related conditions e.g. a child with blue eyes etc. For this reason, the principle of procreative beneficence is highly controversial (Savulescu & Kahane 2009:276). My view is that the opponents who make the claim that Savulescu and Kahane are suggesting that parents should pick a 'perfect child' are misunderstanding the point that Savulescu and Kahane make. They are not saying that parents have a moral obligation to pick a 'perfect child', but they are merely saying that parents have a moral obligation to choose the child with the best chance of the best possible life – and that doesn't imply that the child that will be chosen will be perfect.

Some cases are definitely more straightforward and less morally controversial than others. If a mother had to select between conceiving a brain damaged child and selecting a healthy one, the choice would be clear and there would be no question as to whether she made the right

choice. Intuitively, it is generally accepted that parents have the moral duty to make sure that their child will have the best possible *future*, because that's just what parents have to do. This is an important point within the elective deafness debate, because it once again raises the question as to whether the parents who select a deaf embryo indeed offer the child the 'best possible future' the child could have. Savulescu and Kahane state that mostly, parents will always intuitively 'choose for the best' and criticize those ethicists that oppose genetic selection to 'choose for the best', because in doing so, they ignore the norms, attitudes and intuitions that are natural for parents anyway (Savulescu & Kahane 2009:277). Simply stated, Savulescu and Kahane believe that parents have a moral obligation to choose the child that will benefit most from the reproductive choice made.

Procreative beneficence is not an absolute obligation, but rather the claim that there is a significant moral *reason* to choose the best child possible, which, according to Savulescu and Kahane, warrants an obligation to procreative beneficence in any case (Savulescu & Kahane 2009:278). But what do Savulescu and Kahane mean when they claim that parents have a moral reason to select the "best possible" child? In my understanding, it means that parents have a strong moral *reason* – and arguably a strong moral obligation – to choose that child which will benefit most from the choice made. I don't believe that Savulescu and Kahane are specifically talking about "superficial" characteristics such as choosing whether the child will have blue or brown eyes, but that they rather refer to those characteristics that would foreseeably impact the child's life significantly. While a child's life probably wouldn't be significantly different if it had blue or brown eyes, the choice as to whether a child will be born with Dwarfism or deafness will have far greater consequences.

In this case, moral reason and moral obligation is the same thing, as moral reason presumes moral obligation. "*When the obligation to have the most advantaged child is not overridden by sufficiently strong opposing moral reasons, it will be true that parents ought, all things considered, to select the most advantaged child. Procreative Beneficence is not just the claim that parents are permitted to choose the most advantaged child. If the competing reasons are stronger, then it is not permissible to choose the most advantaged child. And if there aren't any such reasons, or they are weaker, then it is not morally permissible to choose anything less than the best*" (Savulescu & Kahane 2009:278). Applying this to the elective deafness debate, Savulescu and Kahane would probably state that if there is no good reason to select a deaf child, then we have a moral duty to select a hearing child, as that hearing child would arguably have a better life than a deaf one.

Opponents of this argument have claimed that there is no such thing as a ‘best life’ and that it is difficult to determine what a ‘good life’ or the ‘best life’ consists of, because ultimately each life is different (Savulescu & Kahane 2009:278). According to hedonistic viewpoints, the ‘best life’ would consist of that life which enables us to experience most happiness and pleasure and according to desire fulfilment theories, the ‘best life’ would consist of that life in which our preferences are fulfilled et cetera (Savulescu & Kahane 2009:278). It’s not difficult to see why a lot of people have problems with the procreative beneficence theory, because it’s so difficult to define what exactly a ‘good life’ should consist of. Savulescu and Kahane do note, however, that it should be possible at least to get to some kind of broader agreement as to which states or traits would make life better or worse (Savulescu & Kahane 2009:279).

Most, if not all, people would at least agree on the point that a life filled with joy is more worth living than a life filled with sadness. Therefore, what the principle of procreative beneficence seeks to do, is simply to challenge people to apply the concepts and ideas they have of a ‘good life’ which they already have intuitively (Savulescu & Kahane 2009:279). Here I want to stress, once again, that the question here is whether parents perhaps have a moral obligation to choose the “best possible” child in the sense of characteristics that are *immediately foreseeable*. Of course, we won’t know with hundred percent certainty what kind of child will be brought into existence. In other words: While there will always be an element of “not knowing” exactly what kind of child will be brought into existence, there are options (e.g. by making use of PGD) to at least rule out the possibility of the child being born with deafness or other conditions that would impact the child’s future life significantly.

Another objection to this argument would be the misapplication of procreative beneficence i.e. parents erroneously thinking that their choice is indeed the best, while in fact it isn’t (Savulescu & Kahane 2009:279). The principle of procreative beneficence leaves open the possibility that sometimes parental choices fall below a ‘minimal threshold’, because the parents believe that their choice is good or ‘the best’ (Savulescu & Kahane 2009:280). Perhaps it can also be argued that the choice of D/deaf parents wanting to select a deaf embryo over a hearing one falls into this ‘minimal threshold’ category. They believe that their choice is good and in the best interest of the future child, when in fact it isn’t.

What makes the principle of procreative beneficence so strong in comparison to other views, is the fact that it provides strong *reasons*, rather than an absolute obligation, to choose the ‘best possible child’ out of the possible children that could be chosen for implantation, even if those children would have a “high overall level of well-being” (Savulescu & Kahane 2009:281). In

other words, if D/deaf parents argue that they would prefer having a deaf child rather than a hearing one, and that this deaf child would have a high level of well - being and would be free from unbearable suffering, the principle of procreative beneficence would stop them from making this selection if it can be shown that the reasons to choose against a deaf embryo outweigh the reasons to select for a hearing one, which I believe is easy to show.

There are a couple of arguments that run along the same lines as the principle of procreative beneficence, but they are weaker. For example, the Minimal Threshold view states that parents have a moral reason to select one of the possible children they could have who is expected to have a life worth living over any child that does not, but they have no reason to select one such possible child over another (Savulescu & Kahane 2009:280). Instead of having a moral reason to choose ‘the best child possible’, this principle simply states that parents should choose a child that will have a life worth living – a weak argument to make in the elective deafness case, as deaf children definitely have a life worth living. These views would only hold if we would be able to argue that a deaf child’s life isn’t worth living, which is difficult – if not impossible.

The Satisficing view, in contrast, argues that parents have moral reason to select “*one of the possible children they could have who is expected to have a ‘good enough life’ over any that does not*” (Savulescu & Kahane 2009:280). According to this principle, it doesn’t matter which child the parents choose, as long as the child will have a ‘good enough life’. This is another problematic view, as it – in principle – supports parents choosing a deaf child rather than a hearing one, as a deaf child would certainly be able to live a ‘good enough life’. When taking this procreative view into consideration, there is simply not enough reason to not select for a child with deafness.

Savulescu and Kahane claim that the principle of procreative beneficence is the strongest principle with regard to reproductive choices, because “*we have reason to choose what is good, but more reason to prefer what is better*” (Savulescu & Kahane 2009:280). While the principle of procreative beneficence is able to acknowledge that often, the lives of deaf individuals range from good to very good; it does state that parents have good reason to choose the embryo that will have a chance of a better life. In other words, a deaf life is good, but a hearing life will be better, therefore there is reason to choose the hearing life above the deaf one (Savulescu & Kahane 2009:288).

This is perhaps where the law plays an even stronger role in making sure that parental choices are informed rather than based on mere emotional choices. Additionally, it highlights the need for a legal framework which sets reasonable procreative boundaries.

6.6. Children and the principle of autonomy

In biomedical ethics, the principle of respect for autonomy, according to its most basic definition, refers to “*self-rule that is free from both controlling interferences by others and from certain limitations such as an inadequate understanding that prevents meaningful choice*” (Beauchamp & Childress 2009:99). And a person who does not have full authority is described as someone who “*is in some respect controlled by others or incapable of deliberating or acting on the basis of his/her desires and plans*” (Beauchamp & Childress 2009:99). For autonomy to be exercised, two conditions need to be in place: liberty (refers to the independence from controlling influences) and agency (refers to the capacity of intentional action) (Beauchamp & Childress 2009:100). Once again, I want to refer back to the ‘choosing deafness’ scenario where parents make deliberate choices for their children.

In this case, it becomes clear that the second condition for autonomy to be exercised, namely agency, is not met based on the fact that an embryo is incapable of autonomous decision - making. I want to argue though, in agreement with Feinberg, that a child has the right to exercise his/her autonomy when he/she is old enough to make informed and individual choices and that the child’s right-in-trust therefore needs to be protected by the state until the moment arrives when the child can start exercising that right. It must be said though, that these rights-in-trust only apply to a handful of case - scenarios in which the child’s life would be significantly altered by the decisions of the parents. Additionally, I believe that these rights – in - trust and therefore the right to make autonomous choices should be available and protected in cases where the child’s ability to live a relatively “normal life” is in jeopardy. With “normal life” I mean that kind of life that a “typical” child should be able to live in a biological sense – with intact hearing, intact sight etc. I refer to the child’s right to have at least the biological functions available to live life the way he/she chooses.

Similarly, the philosopher Immanuel Kant argues that “*respect for autonomy flows from the recognition that all persons have unconditional worth, each having the capacity to determine his/her own moral destiny*” (Beauchamp & Childress 2009:103). Similarly, Kant states that “*...autonomy is the ground of the dignity of human nature and of every rational nature*” (Kant

1994:41). Moral destiny here is an important point, as it reaches further than merely looking at the ‘now’ of the child’s life. It directs the spotlight into the future, arguing that autonomy is a right that doesn’t only encompass the ‘now’, but also the future. And not only that, it also emphasises the fact that embryo - selection is a public practice, as choosing ‘disabled’ children would place a burden on society and not just on the parents (Häyry 2010:57). Also, Kant links autonomy to the worth of a person (1994:41). If there is no autonomy, the person doesn’t have worth, as he believed that all humans have “intrinsic worth”, which makes them valuable (Kant 1994:40). What Kant was trying to say with this, is simply that he believed that humans should never be used as a ‘means to an end’ because of their worth. “(...) *A rational being himself, must be made the ground for all maxims of actions and must thus be used never merely as means but as the supreme limiting condition in the use of all means, i.e., always at the same time as an end*” (Kant 1994:36). According to the Kantian principle, then, all humans should be free to make autonomous choices, because they are worthy ‘rational agents’ who have the ability to reason for themselves (Rachels 1998:130). Applied to the elective deafness dilemma, this would mean that by parents deliberately selecting a deaf child, they would ‘use’ the child as a means to an end – the end being the fulfilment of their (arguably) selfish wish to have a deaf child for reasons discussed in Chapter three, thereby refuting the Kantian principle.

To respect autonomous agents thus would mean to acknowledge the fact that all human beings have the right to make choices based on their personal beliefs and convictions. Additionally, respecting their autonomy means displaying respectful action and not only a respectful attitude (Beauchamp & Childress 2009:103). It requires more than the non-interference in the parent’s personal affairs (Beauchamp & Childress 2009:103). Instead, it requires the State, genetic counsellors or medical practitioners to actively oppose parental procreative choices where the autonomy of the embryo is under potential threat. Respecting the autonomy of an embryo would thus mean taking his/her rights into consideration *before* making life-changing decisions in e.g. genetic counselling sessions. Once again I want to emphasise that I am basing this argument on the assumption that an embryo and its future life should be respected and therefore given some form of moral status – if only hypothetically. In this case, the (future) autonomy of the child should take precedence over the reproductive autonomy of the parents, as this choice has heavier consequences for the life of the child as opposed to the lives of the parents. Or, as Feinberg would put it: the C-rights-in-trust should be honoured and upheld by the parents, thereby respecting the future child’s autonomy.

6.7. Parents and the limits of reproductive autonomy

At first glance, it seems that the right to procreative autonomy or procreative liberty is - at least in most countries - a right guaranteed by the State that is protected within the individual's constitutional right to freedom of religion and freedom of expression (Mills 2011:41). Even though this right sounds compelling and even convincing, it is flawed on the grounds that it can easily become a form of self-expression as opposed to an obligation not to harm. The individuals that support reproductive autonomy as a right to freedom of expression see this reproductive autonomy as a benefit that allows them to express their deeply - held beliefs and attitudes (Mills 2011:41). In essence, it is this 'freedom of expression' that D/deaf parents use to justify their decision to choose a deaf embryo rather than a hearing one, as choosing the deaf embryo will enable them to honour their cultural identity. Supporters of this argument include bioethicists such as John Harris, who states that we should respect other people's right to procreate and thus respect the underlying values that people have when they make the decision to procreate in the first place (Harris 2000: 34; Mills 2011:42). He believes that the right to freedom of expression i.e. the right to procreative autonomy, protects the "*freedom to choose one's own lifestyle and express through actions as well as through words, the deeply held beliefs and the morality which families share and seek to pass on to future generations*" (Harris 2007:76). With this statement, Harris insists that reproductive autonomy is right to a negative liberty i.e. free from interference by other people with regard to reproductive decision - making (Mills 2011:42). Of course, this notion of procreative autonomy is welcomed by the members of the Deaf community, as it supports their cultural viewpoint on deafness and supports their right to make autonomous choices based on what they perceive as the best decision for their child, i.e. deafness.

In essence, Harris believes that a right to self - expression implies a right to procreative autonomy. In making this argument, Harris relies heavily on a book titled "Life's Dominion", by philosopher Ronald Dworkin, who argues that the right to autonomy derives from our right to make our own decisions and our right to "*shape our lives according to the values, commitments, convictions and interests that are important to us*" (Mills 2011:42). However, Dworkin also states that the right to procreative freedom is "*a right [of people] to control their own role in procreation unless the State has a compelling reason for denying them that control*" (Dworkin 1993:148). This 'compelling reason' to deny potential parents the control to freely select an embryo for implantation is an important point.

Often, procreative autonomy is in conflict with procreative beneficence, in that procreative autonomy in principle should *prima facie* allow prospective parents to choose any kind of embryo for implantation, even those embryos that would, according to conventional standards, have a 'bad life' (Savulescu & Kahane 2009:279)

Pre-implantation Genetic Diagnosis thus supports procreative autonomy in that parents can - in principle - choose the kind of child they want based on their own beliefs and convictions, provided their choice is accepted within the legal framework. In other words, PGD could *in principle* enable parents to choose a child with blue eyes instead of brown eyes or let them choose a child with brown hair instead of blonde hair. Within the abilities of PGD, a lot of options for choice are possible and therefore the *practice* of PGD supports procreative autonomy. The question here is though whether this parental autonomy should be absolute or whether there is perhaps a way in which we can argue that even parental autonomy has its limits, contrary to theories of legal permissiveness.

In most cases, genetic information limits the damage done to the individual autonomy of those who would have to care for a severely disabled child (O'Neill 2002:72). In other words, in most cases, people using PGD do not see this type of genetic screening for the purposes of enhancing their own autonomy or even as a form of self-expression. Rather, they use their procreative autonomy to safeguard the birth of a healthy child, as can be seen in cases where PGD is used to prevent the birth of a severely disabled child or a child born with a terrible genetic condition that would, without PGD, be unavoidable. It can be argued, however, that in cases where parents select a deaf embryo over a hearing one, they are abusing their procreative autonomy because in this case autonomy may be used (and abused) as a form of self-expression.

Some people would argue that there is no difference between selecting for or against deafness and that both could be understood as a form of self-expression. I don't believe this to be same thing though, because in selecting for deafness, we choose a child with a disability, while when we choose against deafness, we select a perfectly healthy child. In my mind, selecting a healthy, disease-free, disability-free child cannot be regarded only as a luxurious form of self-expression, especially in cases where both parents are carriers of life-threatening genetic diseases and simply want to make sure their child won't suffer from a life-threatening disease that would, in all probability, shorten and impair the child's life. Rather, in cases where parents makes use of PGD to select an impairment-free child, it should be seen as a natural choice that respects the child's future autonomy and enables the child to live a 'normal' life. In contrast,

the wish to have a deaf child can easily be seen as a form of self – expression because there is - arguably - little benefit for the future child in being deaf.

When we talk about procreative autonomy, we need to realize that this type of autonomy is constrained for good reasons, most notably to prevent possible harm done to future children (O’Neill 2002:66). Here, Philosopher Onora O’Neill argues, contrary to Harris, that just because freedom of expression is a right, it doesn’t automatically mean that procreative liberty is a right as well (Mills 2006:41). Also, in agreement with Feinberg, O’Neill argues that the prevention of harm is not enough reason to constrain individual autonomy in procreative decisions. The question is rather whether reproductive autonomy should extend to decisions about what kind of child should be born (Glover 2006:38). It is not enough to simply ask whether harm is done or not, but rather “*whether there are reasonable grounds to think that any child brought into existence can expect to have at least an adequate future, cared for by a ‘good enough’ family (biological or not) who will be present and active for the child across the long run*” (O’Neill 2002:67).

Jonathan Glover seems to agree when he says that “*the interests of the child should set limits to what parents can do*” (Glover 2006:43). Taking this a step further, O’Neill states that instead these limits need to be grounded on a more convincing argument than merely stating that ‘choosing a deaf child causes harm’. In her opinion, we need a convincing account of ‘the good’ in the form of “*the good for man or of human interests, from which derives an account of human rights*” (O’Neill 2002:76). She admits, however, that this view is difficult, as we can never really arrive at a satisfactory conclusion of what this ‘good’ entails, because we all have a different idea of what is ‘good’ (O’Neill 2002:77). Instead, she argues that it is more important and perhaps easier to take a look at our *obligations* as human beings as opposed to trying to identify what ‘the good’ would entail (O’Neill 2002:77). In her opinion, we should “*anchor an account of human rights in an account of human obligations (or human duties), rather than in an account of the human good*” (O’Neill 2002:78).

In placing the focus more on (parental) obligation, O’Neill makes a compelling claim: She says that obligations are more fundamental than ‘goods’, as obligations can more readily be seen as a requirement rather than a choice (O’Neill 2002:78). In other words, O’Neill states that human rights are fundamentally rooted in some kind of obligation i.e. if the embryo has the right to an ‘open future’, then parents have the obligation to respect that right, otherwise it wouldn’t be a right at all. While Harris claims that the freedom of expression is a human right which includes the freedom of reproductive autonomy, O’Neill argues that human rights include the duty of

obligation. While Harris focuses on the rights of the individual i.e. the rights of the parents to self-expression and hence procreative autonomy, O'Neill focuses on a more utilitarian notion of this right. In my understanding, O'Neill supports procreative autonomy in so far as this autonomy focuses on an individual's (i.e. the embryo's) quality of life as opposed to the mere option to 'choose' what kind of child one wants to have. If there are no obligations, there are no rights, because rights require obligation and for a right to be implemented, it must be attainable (O'Neill 2002:80). Therefore, it can be argued that the "rights" of the embryo - assuming the human zygote is given some form of moral status or respect at the four or eight week cell-stage - the obligation of the parents cannot be separated. They are, in O'Neill's words "*the same requirement from two perspectives*" (O'Neill 2002:80).

While I agree that "giving the embryo moral rights" or even "respect" is problematic because in most countries children don't have rights until they are actually born, it might still be beneficial to ask "what if?" In other words, if – in a hypothetical situation - a child had rights before birth, should the parents not honour those rights?

Rights can only be secured, however, when there are people who are willing to take action i.e. implement the right by acting in a specific way. Also, obligations focus not only on the individual, but also on the people around us, taking into account the lives of others. This is echoed in Kant's work, where he stated that autonomy is never supposed to be used for the benefit of self-expression, but is rather to be understood as an obligation to act according to moral principles (O'Neill 2002:84). In Kant's words "*autonomy is the ground of the dignity of human nature and of every rational nature*" (Kant 1994:41).

Other proponents also argue that a deaf child should not be preferred over a hearing one, as the deaf child would be well able to learn sign and hear at the same time and thus live in both 'cultures'.

6.8. The two cultures argument

While a lot of the debate regarding the moral question of elective deafness focuses on the developing embryo and the possible harm that can be caused when deafness is selected and on parental responsibilities in this regard, it is equally important to consider the views of hearing children to deaf parents and hear their opinion on the matter. This is important, because their stories might help us to understand to which extent – and if – it is really necessary and even "better" for D/deaf parents to have deaf children, as they claim, because the protective

environment of the Deaf community would offer the child the ‘vital benefit of a positive sense of self’ (Blume 2010:81).

We need to remember that, ultimately, parents choose deafness for their child because they believe their decision for their child to be deaf to be in the best interest of their child on the one hand, and on the other, they sometimes choose deafness as a sign of loyalty and commitment towards the Deaf community. Deeply entrenched in this loyalty to the Deaf community lies their belief that deafness is not a disability, as we have seen in preceding chapters. According to the D/deaf parents, only by being deaf can the child be fully immersed in and participate in their Deaf culture and partake in their way of life and be able to communicate using sign language. As we have also seen in the preceding chapters, being able to communicate efficiently within the Deaf culture, one has to master sign language. Here, sign language acts as the access point to the Deaf culture. But, if sign language is really the gateway to proper communication with the D/deaf community, then how come are D/deaf parents so adamant to get a deaf child, if a hearing child would also be able to master sign language and learn how to communicate with his/her D/deaf parents? If sign language can be learned and mastered just like any other language, doesn't it then follow that parents should rather choose a hearing child, as that child would be just as able to partake in the Deaf culture as would a D/deaf child? Of course, this argument will only hold if language and hence communication is indeed the big area of concern for parents. Either way, the question arises whether it wouldn't make more sense not to select a deaf embryo and rather have a hearing child who is able to live in both “cultures”?

It is estimated that ninety percent of children born to D/deaf parents are born with normal hearing (Preston 1994:13). These children are often known to call themselves CODA's (Children of Deaf Adults) in the USA or are referred to as HMFd (Hearing, Mother-Father Deaf) in the UK by members of the Deaf community (Mand et al. 2009:722; Ladd 2003:42). The reason why their insight is so valuable is because they can provide an insightful narrative of both the Deaf and hearing world as they can operate in both. This also makes CODA children ideal candidates to add to the academic discourse concerning the use of genetic selection for or against deafness (Mand et al. 2009:722).

In a ‘first of its kind’ survey conducted on sixty-six CODA participants, the participants were asked a variety of questions regarding the PGD procedure (Mand et al. 2009:724). The majority of participants (77.2%) said that they would not use the PGD procedure at all – not for or

against deafness, thus showing a general aversion against genetic screening (Mand et al. 2009:724). One respondent expressed her views in the following way:

“I think that life brings us many things. The same thing can be good and can be bad. I think that wishing to be Deaf or having Deaf children on purpose is egoistic and unnatural. If you’re Deaf or you have Deaf children you adapt yourself...but being Deaf on purpose just because you want to preserve your culture or give continuity to the Deaf family is as strange as seeing a doctor or musician and forcing your children to choose the same career even if they’d prefer to be an actor or a writer...being different is ok...even if being different means being hearing...or deaf.” (Mand et al. 2009:724).

Most participants felt it was inappropriate to purposely select a deaf child by making use of the PGD method to preserve the legacy of the Deaf culture and instead rather preferred nature to ‘run its course’ - i.e. not to use any screening methods available at all (Mand et al. 2009:725). Of those few hearing participants that felt that it was acceptable to make use of the PGD method, there were only a small number of participants who leaned towards wanting a hearing child (12%) and those who rather wanted a deaf child (9%) (Mand et al. 2009:725). Additionally, participants were asked about their experiences while growing up as a CODA in the D/deaf community. Four broad themes were identified in this study: 1.) CODA’s had negative experiences growing up because of identity confusion or because they often acted as interpreters between the deaf and hearing worlds for their parents, resulting in an associated loss of childhood; 2.) CODA’s had positive experiences; 3.) CODA’s had mixed feelings towards their lives as CODA’s and 4.) CODA’s had a neutral attitude towards their experiences (Mand et al. 2009:725).

The experiences resulting in identity confusion are often due to society’s lack of understanding regarding D/deaf people and specifically society’s presumption that deaf means dumb (Mand et al. 2009:725). Often, participants felt confused and didn’t know where they wanted to belong. On the one hand, they felt at home amongst the deaf and speaking in sign, but on the other, they didn’t want to lose their hearing either (Mand et al. 2009:725). Some participants also stated that they felt that they had an ‘incomplete childhood’, because they were constantly used as mediators between two worlds, causing confusion about ‘their place in the world’ (Mand et al. 2009:726). According to many participants, these negative experiences had repercussions that spread into their adulthood, resulting in emotional problems (Mand et al. 2009:726).

On the opposite side of the spectrum, there were also a lot of participants who shared the positive experiences of growing up as a CODA in the form of feeling proud to be able to associate with the Deaf community, describing it as an ‘enrichment’ (Mand et al. 2009:726). Others had mixed feelings growing up as a CODA, as they had trouble ‘fitting in’, but later learned to navigate the hearing world. Mostly, deaf children of hearing parents learn to speak properly only when their parents make a concerted effort to regularly expose their child to speech and sound. This can happen in the form of using audio tapes, and by regularly exposing and allowing the child to interact with hearing peers in e.g. day care centres, making use of a hearing nanny, allowing the child to spend time with other hearing family members etc. Interestingly, all the CODA participants recognized Deafness as having a distinct cultural identity and status, probably because most of them grew up within the Deaf community themselves (Mand et al. 2009:726).

Lastly, participants were asked whether they ever had a personal desire to deaf themselves. Almost half (36.4%) the participants responded that they – at some stage in their lives – expressed the wish to be deaf themselves, mostly to be able to identify with their other D/deaf family members (Mand et al. 2009:726). Most of the participants also stated, however, that this wish to be deaf was most prevalent in their childhood and adolescent years and that this wish to become deaf disappeared completely in adulthood (Mand et al. 2009:726). In its place appeared a new appreciation and gratefulness for the fact that they can hear and are thus able to ‘move freely’ within both the deaf and hearing communities. One participant was quoted as saying *“I like being hearing with the ability to move within the D/deaf community if I wish to do so. I feel life is easier for me”* (Mand et al. 2009:726).

All participants in this study agreed that D/deafness as a culture and as an identity is often utterly misunderstood by the broader society – or more specifically, by the hearing majority and that allowing individuals to screen for or against deafness by using PGD would threaten the existence of the D/deaf community. This is understandable, because these CODA’s grew up with D/deaf parents are thus very much immersed in the Deaf culture and thus have a better understanding as to why anyone would want to use PGD to select for deafness. The Deaf community provided them with a sense of belonging while growing up, which they didn’t experience in the hearing world – simply because they were torn between ‘two worlds and cultures’. Most of the participants highlighted the importance of parent-child relationships when growing up and could thus understand why there are sometimes D/deaf couples who express the wish to have a deaf child, so that the child can have the same hearing status as their

parents and thus won't experience the identity confusion often associated with 'living in both worlds'. What is especially interesting though is that it seems that none of the participants in the study would want to be deaf if they had had the choice. Even though participants indicated that they wished they were deaf during their childhood and adolescent years, mainly resulting out of the need to belong, none expressed the desire to be deaf as an adult.

Having said this, I believe it's important to take the results of this study into careful consideration when developing future policies for PNG. While the need for belonging would be a major argument for elective D/deafness, it is equally important to take the views of the CODA's into consideration – and especially their explicit wish not to be deaf in adulthood. Perhaps this also supports Feinberg's 'Open Future' argument, as discussed earlier in this chapter, as it supports the importance of respect for the child's autonomy. It is important to keep future options open for the child, so that he/she can make autonomous choices about his/her future. I believe this is something that the CODA adults have come to appreciate later in life – they realized that having the ability to hear presented them with more opportunities than they would have if they were deaf. Even though all the CODA's in the study viewed and acknowledged D/deafness as a difference and a distinct culture because they grew up in this culture themselves, they mostly expressed no preference as to having deaf or hearing children – presumably because they understand the D/deaf. They also state that they would not want to be deaf themselves, making a strong case against elective D/deafness and confirming the argument that parents have a moral obligation to “*choose a child with maximum potential for human flourishing*” (Glover 2006:50).

6.9. Medical intervention

The next question which is important to answer, is which role medical interventions play in this whole elective deafness debate. According to Allen Buchanan, biomedical enhancements can be defined as “*applying biomedical science, which aim to improve existing capacities that most or all human beings typically have, or to create a new capacity, by acting directly on the body of the brain*” (as quoted in Van Niekerk 2013:107). Even though Buchanan's notion of enhancement is aimed more at making people 'better' over and above normal functioning, enhancements also include those enhancements that restore – in as much as that is feasible – normal human functioning. When enhancements are looked at within that definition i.e. aimed at restoring normal human functioning, then it becomes clear that the question of enhancement

e.g. in the form of medical intervention, is applicable to the deaf as well, because the aim would be to restore hearing loss as well as - hopefully - increasing the potential for human flourishing in the process. The question here would be if there isn't, at least prima facie, a strong moral case to be made that to be able to function within both the Deaf and the hearing world is more in the interest of the child - and perhaps even more beneficial - than being confined to the Deaf community, thereby limiting the child's opportunity of broaden his/her options.

According to van Niekerk, the possibility of a cochlear implant complicates the Deaf parent's right to elect deafness, assuming that such a right exists in the first place (Van Niekerk 2013: 113). He believes that the possibility of a cochlear implant threatens to complicate the right of parents to choose a deaf embryo, because parental moral obligation requires them [the parents] to make a decision based on what is in the best interest of the child (Van Niekerk 2013:113). Quoting Glover, he concludes that "*the view that deafness is a disability supports the view that parents who can give their child hearing should do so. If that is accepted, the choice of a deaf child becomes self-defeating*" (Van Niekerk 2013:113; Glover 2006:26).

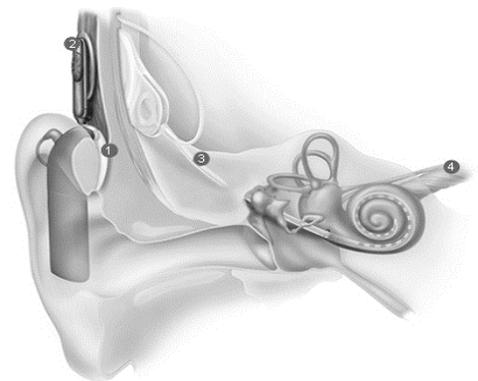
While this sounds really good in principle, most people who support the Deaf community believe that any form of medical intervention that aims to treat or cure deafness undermines the worth of the Deaf community (Levy 2002:141). Similarly, people who support the concept of deafness as difference view medical interventions such as cochlear implants as an example of an objectionable imposition of 'normality', similar to treating black people as white people with a skin disease (Glover 2006:26). A snippet in the Deaf Life magazine summarizes this in the following way: *Parents who choose to have their children implanted are in effect saying, 'I don't respect the Deaf community, and I certainly don't want my child to be part of it. I want him/her to be part of the hearing world not the Deaf world'* (Levy 2002:141). The message that is being conveyed here is that the Deaf community opposes cochlear implantation on the grounds that it discriminates against them on the basis of their disability – i.e. we want to implant people, because we somehow think that living in the hearing world has more value than living in the Deaf world and that is discrimination. Also, when we take a look at deaf history, as summarised in preceding chapters, it isn't surprising and almost understandable that the Deaf community for the most part raises their voice against cochlear implantation. They just achieved so much – a form of recognition within the law in the form of disability rights, the right to practice sign language and a sense of cultural community and general acceptance. Within Deaf circles, the use of the cochlear implant is certainly frowned upon and deaf individuals using this device are sometimes even shunned from their own community and

pressured to remove the device, as a reporter explained after spending some time at Gallaudet University: “As anyone at Gallaudet knows, a student with a [cochlear implant] device...runs the risk of being shunned” (Tucker 1998:9). What we have also seen, however, is that historically, there have been strong voices speaking out against the Deaf community, just like Alexander Graham Bell when he opposed sign language in residential schools to force the D/deaf to blend into the hearing world. Now, this oppressive voice speaking against the Deaf community has taken a different form: This time, the voice is that of medical intervention. Before I go on discussing the above, I want to explain what the cochlear implant is in the first place and provide a brief overview of the background of cochlear implantation in the hope of providing a clearer picture of the complexity of the cochlear implant dilemma.

6.10. What is a cochlear implant?

A cochlear implant is a small electronic device that is surgically implanted to restore hearing loss in profoundly deaf and severely hard of hearing people. Essentially, it replaces the function of the damaged inner ear which sends sound signals to the brain. The cochlear device itself consists of two parts: The outer part and the inner part. The outer part consists of an external sound processor which is worn behind the ear. Its function is to pick up the sounds from the outer environment and convert it into a digital code. The sound processor then transmits this digital code through a coil on the outside of the head to the inner part. The inner part comprises of the actual implant that converts incoming sound waves into electrical impulses and then sends those impulses along an electrode array which is surgically placed in the inner ear (cochlea). The electrodes then stimulate the cochlea’s hearing nerve which, in turn, sends impulses to the brain where they are interpreted as sound.

- 1.) Sound processor
- 2.) The coil
- 3.) The implant
- 4.) The area where the implant’s electrodes stimulate the hearing nerve ⁸



⁸ Image credit: <http://www.cochlear.com/wps/wcm/connect/au/home/understand/hearing-and-hl/hl-treatments/cochlear-implant>

6.11. The cochlear implant – a historic breakthrough

While UPIAS and various other supporters of the disability liberation group were fighting for disability rights and the re-acceptance of sign language into the education system, the medical world was busy developing the cochlear implant and over the course of the 1980's, the implants was gradually accepted within the medical and industrial circles (Blume 2010:67). As information about the nature of the cochlear implant spread through the media and through international medical journals, so the news also spread to the members of the Deaf community. While the media praised the scientific community for their technological genius and congratulated them on their achievement of this outstanding scientific breakthrough, the news of the development of the cochlear implant evoked a completely different response from the members of the Deaf community (Blume 2010:69). Some were angry, others disappointed and many especially appalled by the idea of children being implanted with the device, fearing them becoming “*guinea pigs in experimentation*” (Blume 2010:69). Understandably, children became the focus point in cochlear implant studies as people believed that the earlier medical intervention took place, the better the chances of the child being able to hear ‘normally’, an idea that was later scientifically proven. In 1979, Michel Portmann, a Professor in France and son of an eminent ENT (Ear, Nose and Throat) surgeon, ended up writing to the French newspaper, the L’Aurore and stated: “*It’s scandalous. To spread by a book, by interviews resounding in the mass media, the hope that the deaf – the deafened and even the born-deaf – can now hear, is unacceptable*” (Blume 2010:70). His claim wasn’t completely unjustified – despite the unknown risks and long- term effects of the implant surgery the media sold the cochlear implant as a medical and virtually risk-free procedure, which was far from the truth. Additionally, media publicity served as an invaluable tool for publicity to attract potential implantees, and most importantly: funds (Blume 2010:68). Despite the initial scepticism, however, most people bought into the idea and were convinced that the cochlear implant would prove invaluable in enriching the lives of the deaf and a few years later, in 1978, thanks to a series of fortunate events, the first cochlear implant patient underwent surgery performed by an Australian doctor named Graeme Clark, who was the driving force behind the research and development of the cochlear implant. The operation proved a success and marked the triumph and technological breakthrough within the scientific community.

The indifference towards cochlear implants as experienced by the Deaf community was the direct result of a perceived attack on their identity and their world, a world that they fought so hard for and that most people knew little about. As I have mentioned in Chapter three, most

people didn't understand the deaf and what deafness and especially cultural Deafness entailed and thus couldn't understand the initial reaction by the Deaf community either. If you can make a deaf person hearing, why not do so? What the medical world – used in a broad sense here, because I realize that not every medical practitioner supports cochlear implantation, let alone paediatric implantation – perceived as a scientific breakthrough, the Deaf community perceived as a real threat to their culture. Paddy Ladd, one of the founders of the radical National Union of the Deaf argued that “*the Deaf community has a responsibility towards deaf children and must mobilize to protect and preserve their rights to grow up as members of the Deaf community*” (Blume 2010:79). On the same note, other opponents of cochlear implants referred to the device as “*one of many technologies of normalization*” (Blume 2010:80).

What becomes important here though, going back to the elective deafness debate, is that deafness, when perceived as a disability and hence viewed through the eyes of the medical model, supports the view that parents who can give their child hearing i.e. a cochlear implant, should do so, whether they are part of the Deaf community or not (Glover 2006:26). This proves to be yet another moral dilemma and one which I want to discuss briefly.

6.12. The cochlear implant dilemma

In Chapter five, I have shown that it is possible to argue that a deaf child isn't necessarily harmed by being brought into existence and that the parent's autonomy and hence their wish to bring a deaf child into the world should be respected. There is a complication, however. As we have seen in chapter five, bioethicists place a lot of emphasis on the principle of nonmaleficence, which is closely associated with the harm principle (Beauchamp & Childress 2009:149). In that case, if it can be shown that no child is harmed by being selected, then surely the act of parents choosing a deaf embryo instead of a hearing one is permissible, simply because no harm is done and the only other option would be for the embryo not to exist at all. At first, this seems like a sound argument, provided one chooses to ignore Savulescu's argument that parents have a moral obligation to choose the child with the maximum potential for human flourishing. Either way, even if we were to ignore Savulescu's argument and pretend not to agree with Feinberg and go ahead and let the potential parents choose the deaf embryo, a new complication arises as soon as the child is born.

If the child is born and would then be identified as an ideal candidate for a cochlear implant, won't the parents in that case not have a moral obligation to choose to allow him/her to undergo

surgery to get a cochlear implant, because not doing so would amount to the infliction of harm on the basis that not implanting the cochlear implant would result in reduced human flourishing? If this is indeed the case, then the argument of harming the embryo becomes self-defeating, as Glover mentioned (Glover 2006:26). We need to remember that this harm - argument can only be applied in cases where individuals decide to play the ‘no child is harmed and therefore it is okay to choose a deaf embryo’ – card.

In his later writings, John Harris argues along the same lines. Even though he believes that parents are – in principle – free to choose the child they want, provided that this choice doesn’t cause the child ‘unbearable suffering’, he asks whether the child would perhaps be wronged (note, not harmed) if “*a cure for congenital deafness be made available and parents withhold this cure from their child*” (Harris 2000:97). It’s important to note though that Harris refers to this cure as ‘risk free’ and without ‘side effects’ (Harris 2000:97). Of course, cochlear implants cannot with a clear conscience be called ‘risk and side - effect free’, and they can also not be termed as a ‘cure’, but I do believe that Harris’ question is still relevant in this context because he asks if the child would have “*any legitimate complaint if they [the parents] did not remove deafness*” (Harris 2000:97).

In this regard, I want to quote Harris again, who asks how we should answer if the child would say his/her parents: “*I could have enjoyed Mozart and Beethoven and I could have danced to music and listened to the sound of the wind in the trees and the waves on the shore, I could have heard the beauty of the spoken word and in my turn could have spoken fluently if it wasn’t for your deliberate denial to grant me the opportunity to hear*” (Harris 2000:97). I have taken the liberty to change Harris’ sentence a little bit, just to make a point that this is really a legitimate question the child could ask his/her parents when they chose to deny their ‘unharmed’ child the opportunity to hear.

In Harris’ opinion, there is no moral difference between choosing a deaf embryo by using PGD and the parent’s refusal to cure a newborn baby (Harris 2000:97). Similarly, it can be said that there is no moral difference between choosing a deaf embryo and refusing to restore hearing loss in a newborn baby by fitting it with a cochlear implant. I can imagine that there will be individuals that will differ on the grounds that a.) the cochlear implant surgery carries considerable risks and thus cannot be equated with the moral standards of parents choosing a deaf child and b.) because they believe that acts and omissions have the same moral value, which is problematic.

In this regard, it probably makes sense to mention that, essentially, no procedure is completely and foreseeably risk-free and even the PGD procedure itself carries risks with it. The point is though, that Harris clearly asks whether the parents are not perhaps wronging the child by refusing to grant him/her access to a cure (Harris 2000:97). Granted, nowhere does Harris explicitly refer to cochlear implants, but even so, I believe Harris would agree that the parent's deliberate refusal to fit their child with a cochlear implant would mean that a wrong act has been committed by the parents. Whether the child has been 'harmed' or 'wronged' is, at least in my opinion, in this case irrelevant, as arguing which word is more appropriate will just lead us into a linguistic one - way street. Either way, I believe parents have a moral obligation to make sure their child receives the adequate aids in life to function as normally as possible to be able to flourish in a hearing society, and that the child should not be harmed – or wronged.

Chapter VII

Conclusion

In this conclusion, I want to tie the threads together that have been left untied by providing a summary of this thesis as well as suggesting some recommendations regarding the elective deafness debate.

The aim of this thesis has been to give an overview of the moral perspectives on the problem of elective D/deafness by a.) providing a brief overview of the legislative frameworks that govern the modern reproductive technologies that enable prenatal screening, b.) presenting a historical overview on the history of the deaf and how their history shaped their thinking and finally, c.) by providing an overview of the arguments put forward by proponents of both the social and medical models of disability.

In Chapter 1, I tried to set the scene for the ethical problem of elective D/deafness by quoting Alexander Graham Bell, who was a big opponent of deaf intermarriage and a big proponent of oralism who believed that deafness is a disabling condition that should be eradicated. Next, I explained the concept of elective deafness by taking a look at the paper of psychologist Dr Veale, who explained how one of his patients chose to “make herself deaf” by taking matters into her own hands. The reason for mentioning this case was simply to show that the choice for elective deafness can be twofold: Either one can choose deafness individually i.e. by choosing deafness for oneself by either using self-mutilation techniques or by seeking the help of medical practitioners to “make oneself deaf”. Alternatively, one can choose deafness for one’s offspring by purposely selecting a deaf embryo by making use of the reproductive biotechnologies that are currently available. To explain the latter, I have chosen to mention the Duchesneau/McCullough case scenario, where a lesbian couple chose to use a deaf sperm donor to safeguard the birth of a deaf child. I used this case scenario to illustrate that the wish for elective deafness is in fact a reality. I have suggested that the moral problems underpinning both case scenarios are different in nature, and that the question of elective deafness for oneself cannot be discussed in this thesis and stressed that I would focus solely on cases where parents deliberately choose to implant a deaf embryo in the hope of conceiving a deaf child.

Finally, I showed that the moral problem of elective deafness lies in the fact that a divide exists in terms of the opinion as to which bioethical principle should take precedence when the

decision for or against elective deafness is made and whether the child is harmed in the process of being selected.

In Chapter 2, I provided an overview on the current reproductive technologies that are available to make the wish to select for deafness a reality. These technologies include procedures such as PGD and PND, which were discussed in some detail. Additionally, I showed that different countries have different laws and regulations that govern the PGD procedure and I specifically had a look at the South African National Health Act 61 of 2003 to highlight the fact that a comprehensive framework for PGD within South Africa is lacking and in need of further development and implementation to provide a more comprehensive framework that would clearly state for which conditions and under which exact circumstances PGD should be or should not be performed. I suggested that it would be beneficial for South African legislators to team up with their overseas partners, most notably those in Great Britain, to help with the review and implementation of a more thorough legislative framework surrounding PGD to safeguard against the misapplication of current reproductive biotechnologies. Finally, I stressed that the right to reproductive freedom is a right that is protected by the South African Constitution, but that this does not mean that a proper framework for PGD should not be implemented.

In Chapter 3, I introduced the Deaf community by providing a brief historical overview of deafness and how the concept of ‘being deaf’ changed over the centuries by focusing specifically on eugenic practices as well as the branch of statistics, which tried to categorize people according to a normative standard. I then explained how this inevitably led to the formation of the Deaf community and how historical stigmatization contributed towards their formation of deafness as an identity, which, in turn led to their reinterpretation of the word ‘disability’.

In Chapter 4, I then tried to define the concept of ‘disability’ by once again turning to historical events that shaped our perception of the ‘norm’. In this chapter, I draw heavily on Lennard Davis’ work, where he talks about this concept. Further, I explained how this concept of ‘normality’ led to and ultimately paved the way for the social model of disability which states that deafness is not a disability, but a difference that should be embraced rather than fought. I explained the social model in some detail and then explained the other side of the coin in form of the medical model, which sees disability not as a social construct, but as a medical disability that results in real limitations and diminished quality of life and a condition that should therefore be fixed.

Chapter 5 explains the arguments that pro-selectionists use to justify the wish for elective deafness. I started off by putting deafness into context again by explaining the relevance of deafness from a social model perspective. Then I used the analogy of Martha's Vineyard to explain the wish of the Deaf community to incorporate deafness into our sense of the 'normal'. I went on to explain the concept of normality to illustrate the Deaf community's argument that deafness is not a disability and that deafness should thus be seen as 'normal'. Subsequently, I presented Davis' argument that we need deafness to defend diversity within a democratic environment. Afterwards, I explained the concept of procreative autonomy and how this argument can be used as a way to defend elective deafness. Lastly, I stated that deafness is not a condition that can be justified as 'not worth living' and thus it should be permissible for parents to choose deafness for their child as a way of life.

In Chapter 6, I presented the arguments against elective deafness by explaining various bioethical principals such as the principle of nonmaleficence, the principle of beneficence and the principle of harm. Further, I explained Feinberg's Open Future argument to illustrate the value of procreative beneficence, an argument put forward by Julian Savulescu. I then went on to explain the value of child autonomy and how there should be limits on parental autonomy in order to honour the child's future autonomy. I then also presented the 'two cultures' argument which states that children would be able to benefit from the Deaf and the hearing world / community and do not have to be deaf to enjoy both equally. Lastly, I explained the cochlear implant dilemma and how this form of medical intervention complicates the elective deafness debate.

As a concluding remark, I want to point out that I believe that it is crucial for everyone, most notably those individuals working within the medical field as medical practitioners or genetic counsellors, to have a solid and unbiased understanding of the historical struggle and stigmatization that deaf people experienced over the course of the last centuries. This would help them to get a better understanding of the thought processes that govern the decision of those D/deaf patients who request to either "be made deaf" and those patients who express the wish to choose a deaf embryo over a hearing one. Similarly, it is important to understand the historical context behind the social model of disability and how key figures such as Alexander Graham Bell and his opponent, Laurent Clerk, both contributed towards the formation of what we now call the social and the medical model of disability and how history shaped our understanding of what we perceive as 'normal'.

While I do not agree with the general principle behind eugenics, I do recognize that statistics and therefore the bell - curve that was used to categorize people according to standard and non-standard is a powerful tool in aiding governments and legislators to understand a problem at hand and make a positive impact in the lives of those individuals who cannot help themselves in a society where its people categorize people into either a ‘normal’ or an ‘abnormal’ category. Ironically, only by categorizing people and recognizing that they are different and that they have different needs are we actually able to help them in the first place. I also believe that we will always have - even if only intuitively - an idea of what ‘normal’ should look like, simply because we need some standard of ‘normal’ to be able to define what ‘different’ means in the first place. I also think that we can, in fact, give a definition to explain ‘normality’ based on pure, functional biological properties and principles. Like I said in this thesis – normal should be defined in such a way that it will be seen as functional in its most basic form, i.e. a ‘normal’ human being is that human being that is born with ten fingers, two pairs of feet, ears to hear, eyes that see etc. I don’t think there is anything inherently wrong with describing normal in such a way. ‘Normal’ in this sense, would simply mean ‘natural’.

Additionally, I believe that the social argument put forward by the Deaf community is very weak on the grounds that it is difficult to ethically justify a linguistic argument. Just because the Deaf community sees deafness is a culture and because deafness could – in principle – linguistically be described as such, it doesn’t follow that the *morality* behind selecting a deaf embryo is on par with the underlying bioethical principals that govern the act of selecting a deaf embryo. While I do admit that the Deaf community makes a compelling claim on culture, I do not believe it proves helpful in deciding whether elective deafness should be permitted or not. Also, I do not believe that the argument of culture can be used as a justification for elective deafness because cultural preservation alone cannot be reason enough to select a deaf child. Similarly, whether something is right or wrong cannot be judged by culture but should rather be determined by some standard of objective moral judgment and justice.

In this regard, I admit that the arguments presented in Chapter 5 are weak and I agree with John Harris, who states that “*I (Harris) don’t believe that it is social factors that make blindness and lameness and deafness into a disability. Social factors may exacerbate the problem of having such disabilities but they are disabilities because they are important options and experiences that are foreclosed by lameness, blindness and deafness*” (Harris 2000:98). While some members of the Deaf community would like to change this mainstream definition of “disability” to the term “differently abled”, there should be little doubt that deafness is and will

remain a disabling condition, doesn't matter how one wants to frame it linguistically. No amount of re-description or deconstruction would be able to change the real limitation of a hearing disability within a hearing world.

While I do believe we have reason to celebrate cultural diversity, and can appreciate the fact that the Deaf community sees themselves as a community with their own identity, we need to realize that this identity also becomes a source of pride which can potentially have negative effects. The Deaf community prides itself in the fact that they have their own sign language and with that, their Deaf culture. Here, it is important to recognise that this pride in cultural identity led the Deaf community to demand that their language be accepted as a national language in the first place and demanded for their (sign) language to be adopted into the education system. Not only that, they also started demanding societal accommodations e.g. in the form of sign language interpreters and now demand the right to have deaf children. One could even argue that these actions are more a form rebellion against society as a whole for placing deaf people into boxes in the past. But again, cultural justification and even retaliation does not provide reason enough for allowing D/deaf parents to select a deaf embryo.

Unfortunately, the social model proves to be a weak tool for explaining social exclusion, as deafness is – however one wants to put it – a real limitation that simply warrants social exclusion because of its limitation. While I do believe that it is important to integrate the deaf into society as far as that is feasible, I think it is equally important for both the deaf and the hearing parties to make an effort to accommodate one another without pointing fingers. While society can do a lot to help D/deaf people cope in a hearing environment, it is also important for D/deaf people to realize that their deafness is a real condition and hence a real limitation that cannot be fully accommodated within a hearing world, because the hearing world is not deaf. Expecting preferential or entitled treatment because of historical social discrimination or stigma is unwarranted, because deafness, at least in my eyes, is a very real and limiting condition that has real effects on individuals. Once again I want to stress that I am fully supporting initiatives that aim to include the D/deaf into society and I can appreciate the efforts made by disability right's movements to make provision for them [the disabled], to help them cope and flourish, I strongly disagree with the extremity of Alexander Graham Bell's elimination tactics and I also do not agree with the principles behind eugenics. But I do believe, agreeing with Feinberg, that when parents seek to select 'a deaf embryo over a hearing one', they are closing the many opportunities that their child would have in a hearing world. Granted, one can argue that the chosen child cannot be compared to a hearing one, as the only life the

deaf child would be able to live is a deaf life, but even this argument does not morally justify the action of selecting a deaf child, because the deaf child that is selected will still not be able to enjoy all the benefits that a hearing life has to offer, doesn't matter how one chooses to frame it. And then why select a deaf embryo in the first place?

Ultimately, I think that honest genetic counselling cannot and should not favour either the medical or the social model of disability, but should rather apply some standard of objective moral judgement and justice. It is dangerous to rely on the standpoint and beliefs of the individuals of the Deaf community alone, as many support the view that deafness is a cultural enrichment as opposed to a real disability because many do not know what they are missing out on. If you have never heard, how can you speak for those who do or should?

Here, I think it's important to move away from theoretical debate and instead place more focus on lived experiences to find out who really has the chance at a better life. While I fully agree that deaf individuals have a chance to live lives that are worth living, I still think that parents should be prevented from selecting a deaf child, because this selection has far-reaching consequences on the deaf child's future. It is important to realize that the majority of the members of the Deaf community have either been born deaf or have grown up in a supportive environment where D/deafness was celebrated rather than looked down upon or have been deaf for most of their lives and thus don't have the desire anymore to hear. As we have seen, there are very few individuals who have become deaf post-lingually and then embraced the Deaf culture, but for exactly this reason the Deaf community itself cannot be a good gauge as to whether the choice for deafness is morally right or wrong. This is where I think CODA's play an important role in helping us understand the Deaf community a little better and enable us to see both sides of the argument through their personal narratives. The study that was conducted on the sixty-six CODA participants as discussed in Chapter 6 proves vital in this regard.

It's significant that most of the participants stated that their desire to become deaf disappeared completely in adulthood and that they were grateful that they were able to move feely within both the deaf and hearing communities. Personally, I think that these claims alone should make people think and re-evaluate whether selecting a deaf embryo is really such a good idea, esp. because these claims are made by individuals who understand the Deaf community. The question, as to whether a child would choose deafness for him/herself is so important, because in asking this question, we honour the child's future autonomy. Asking CODA's how they feel about living in the Deaf community is probably the best way to get an idea on how life in the Deaf community would be. Their opinions and especially the fact that many answer that they

are grateful to be able to hear should not be taken lightly. It's also important to remember that one of the arguments that the D/deaf parents use to justify their selection of a deaf embryo is that they feel that a deaf child would be happier being deaf while growing up with D/deaf parents and while growing up in the Deaf community. And not only that, they believe their decision to be in the best interest of the future child. Contrary to their opinion, I believe that CODA's could prove them to be wrong.

If D/deaf parents indeed have the potential child's best interest at heart, then they should take the opinions of CODA's into careful consideration while making a decision. Even though I would suggest that another study would be needed to get more data on this matter, i.e. more CODA's need to be interviewed to confirm their views on not wanting to be deaf if they had the choice, I still think this is something that should be thought about before a decision is made. If the parents indeed have the potential child's best interest in mind, then it only follows that they should ask the question as to what the potential child would want. Would the child also choose deafness for him/herself? If the answer to this is no, then choosing a deaf embryo isn't morally justified. CODA's often say that they wouldn't want to be deaf – a statement that carries a lot of weight in this regard.

Similarly, as we have seen, D/deaf parents also argue that choosing a deaf child would allow the child to grow up feeling that it is part of a community and that choosing a hearing child would somehow influence the psychological development of that child negatively because it wouldn't feel included in e.g. social situations etc. Again, the CODA's that have been questioned in the study that I mentioned in Chapter 6 commented that feelings of isolation and the feeling of 'not belonging' were definitely present in childhood, but that those feelings disappeared in adulthood – probably because the horizons and options that the CODA's had available were vast and opened up new possibilities, which the CODA's were thankful for. While I can understand that a small child needs the feeling of belonging somewhere, I still don't think that this statement represents a compelling argument. D/deaf parents of small children and adolescents can do a lot on their part to include their children in their "deaf world", by teaching them to speak in sign etc. A failure to provide them with a sense of belonging and acceptance simply cannot be attributed to the child's "hearing abilities". It depends on the D/deaf parents to make a hearing child feel included. Also, parents should not just choose a child based on their personal preferences and use their reproductive autonomy as an "excuse" for making the choice they make. Agreeing with O'Neill, I think autonomy is never supposed

to be used as a form of self-expression. Parental autonomy should rather be understood as an obligation to act according to moral principles.

The strongest argument against elective deafness, I believe, is the argument of procreative beneficence put forward by Savulescu and Kahane, where they argue that, bioethically, we have strong moral reasons not to select a child with a disability, because, according to the bioethical principle of beneficence, we have strong *moral reasons* to choose the child who will have the best chance at life. Of course, we can never really know what exactly a ‘good life’ should consist of but ultimately, we need something to guide procreative choices, and in this case ethics provides that moral framework for those procreative choices. I think it’s feasible to at least say that parents have a moral obligation to choose the best kind of life for the child and logically this would mean choosing a child who is not disabled i.e. a child who is most likely to have the most possibilities in life by being given the natural capacities such as sight, sound, taste etc. If the parents can help it and not select for deafness, then they shouldn’t. Similarly, if the principle of procreative beneficence take precedence over parental autonomy, the question whether parents can choose a deaf child will become irrelevant altogether.

As a last concluding remark I also want to point out that this elective deafness debate should be pursued with a strong future – outlook. Even though there are currently only a handful of people who have requested PGD for the purpose of selecting a deaf embryo, it shows that the request for PGD is “out there” and that it might just be that these requests - and perhaps requests of similar nature - will increase as the knowledge surrounding these reproductive procedures increases. In the process it is important to look further than the “now” and recognize that similar issues might surface in the years to come. Additionally, I believe that embryo – selection will always be a public practice, because ultimately choosing disabled children would not only place a burden on the parents, but also on society as a whole, simply because society is expected and sometimes even demanded to make provision for the disabled i.e. the deaf.

For this reason I feel that it’s important for the general public and medical practitioners to start engaging in this debate in more detail and come up with possible conclusions as to how we can go about these dilemmas in the future.

As far as South Africa is concerned, I have mentioned that genetic screening tests are already offered in the academic as well as in the public domain at the major Universities throughout South Africa and that smaller, private laboratories such as MEDFEM and Genesis Genetics offer a whole variety of genetic screening tests to their patients as well. The concerning factor

is though that South African legislation – and more specifically the National Health Act - nowhere lists under which circumstances or for which conditions PGD may be used. It might just be that these genetic screening tests are carried out without legal consultation and because there is no concrete legal framework, there won't be consequences either in cases of misapplication. Additionally, there is often no data available that shows what is screened for, which means that there is little or no legal control – a concerning thought. South African legislation should urgently be revised and updated in terms of the guidelines that underpin genetic screening and implantation.

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