Why Use Preimplantation Genetic Diagnosis to Ensure the Birth of a Deaf Child? Or Rather, Why Not?

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Introductory chapter

Presentation of the Problem

Although new knowledge gives man new powers, it also gives him new problems. Policy-making seems to have to keep up with the advances of science, bringing up dilemmas on the prudent or even ethical use of scientific knowledge. An example of such a gap between the use of technology and policies to guide it appears in the dilemma for the ethical uses of preimplantation genetic diagnosis (PGD). Although the technology already exists and has been used since the early 1980’s, there are still at present only few policies regarding the limits of this technology and most guidelines as to its use are too general. “As with any new technology, it takes time both to figure out what is the right thing to do with it and to get it done,” affirms Alan Guttmacher, deputy director of the National Human Genome Research Institute at the National Institutes of Health about the multiplication of traits that can be screened for PGD that expands parental choice.1 How to make judgments regarding the complex (and still growing) information we now have, and how to communicate this with patients are parts of what he describes as a growing pain in the field of genetics.

One of the growing problems policy makers and ethicists need to consider is: as more gene functions are being discovered and more opportunities for PGD use are opened, who gets to choose what? That is, the more geneticists discover about which genes cause what traits, the more medical practitioners as well as ethicists will have to deal with questions such as which of the myriad of identifiable conditions could or should be allowed for PGD and subsequent implantation via in vitro fertilization. Although in theory, PGD could be used for all diseases as long as their genetic mutation is known, it is neither feasible nor practical to test for all conditions.2 The Genetics and Public Policy Center has therefore proposed that there should be a policy either on the governmental or professional level through medical provider groups to determine the acceptable uses of PGD, which at present has no legal limits in most countries in which it is offered.3 For this purpose, a delineation on what genetic traits count as dysfunctional or harmful would undoubtedly play a role. Such delineation would also be necessary as justification for those who object to certain types of intervention.

To situate, not a lot of controversy seems to be raised when it comes to performing

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1 Harmon 2004
2 Hadley 2003, p. 1017
3 Genetics and Public Policy center website
PGD for serious genetic conditions such as Tay-Sachs disease or Lesch-Nyhan syndrome—which cause unbearable pain and early death. It has been a matter of course, in fact, to add these to the list of serious diseases that PGD could screen for. Some may even call screening for such diseases commendable, if not morally obligatory. But as the list of identifiable genetic traits continue to grow, it is becoming more and more possible for parents to choose what kind of children they want to have. This issue *per se* can be considered morally problematic, but at any case, with the expansion of choices can appear more and more problematic cases on which is prudent or even ethical use of PGD, and suddenly, the answers as to which traits to screen for are not as obvious.

Consider the case of a woman who blamed the medical community for her having a deaf son. After ten diagnostic tests which confirmed that she would not have a baby with a serious disease, she felt patently disappointed when she gave birth to a child who turned out to be deaf—a condition that was not considered “life altering,” and which her doctor did not therefore test for. On the other hand, the mother argued that it was indeed life-changing for both her and her child, and blamed the medical community for their oversight. Another case was reported in Australia, where a couple—both having mutations in the gene connexin 26 linked to deafness—wanted to take advantage of PGD to ensure a birth of a child with normal hearing. Although there was little public debate about this, the case was brought to the Infertility Treatment Authority since Australian law restricts the use of PGD for the prevention of genetic diseases. The question of weather deafness was a “disease or simply an unfortunate condition” thus became the point of contention: would it be correct to use PGD to prevent the birth of children with physical impairments?

PGD, then, raises an important set questions of what constitutes a disease, when doctors should honor parental requests to screen embryos, and if embryos can be destroyed for a non-life threatening condition. Conversely—and in contrast to the examples above—we could also turn the tables and ask whether we could implant, after diagnosis by PGD, embryos with particular conditions such as those of which we normally think of as disabilities but are not life-threatening. The case is so when deaf parents want to ensure the birth of a deaf child.

The last question is asked not merely in a theoretical or rhetorical fashion, but as a

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4 Hadley 2003, p. 1017  
5 Harmon 2004  
6 Scully 2006, p. 253  
7 Hadley 2003, p.1017
reflection on a real emerging issue. In 2002, sharp criticism and debate sprung from a case of a deaf lesbian couple in the United States, who wanted to increase the chances of having a deaf child by seeking out a genetically deaf sperm donor. As a result, one of their children is profoundly deaf, while the other is deaf in one ear and has severe hearing loss in the other. Since then, the debate on the purposeful election of deaf babies has become more pronounced, especially now that prenatal testing for mutations in the gene connexin 26 has become commercially available, and a number of other deafness-related genetic tests are on its way.

Surveys have also studied the attitudes of disabled people regarding prenatal diagnosis. Of particular interest are deaf people, for having a well-established community (the term “Deaf”, spelled with an uppercase D, denotes the cultural affiliation while “deaf” with the lower case refers to individuals who lack the ability to hear), and their own language (the Deaf as a community are identified as using Sign language as their primary and preferred language of use), surveys have paid attention to the Deaf community’s potential demand. Arguably, deafness will present discomforts, if not deprive the future individual of having a so-called “normal life”. However, especially for those who have the disability congenitally, deafness may instead be a constitutive part of their personal and group identity. They may also view their condition simply as another way of being and living, and as such—as we will discuss in the fourth chapter of this thesis—Deaf couples taking advantage of PGD to ensure a birth of a deaf child does not seem too farfetched after all, nor totally unreasonable or unwarranted on their part.

The potential demand for the election of deaf babies through genetic technologies has been studied both in the United States and in the United Kingdom in surveys that studied attitudes of deaf and culturally Deaf people. The general attitude of deaf people regarding prenatal diagnosis was negative, due to the feeling that it would be a threat to the Deaf community or to disabled people. Most also said that they did not have a preference for either hearing or deaf children. However, of those who responded that they could personally consider the technology, a minority said that they would use it to have a baby deaf like them. One survey from Middleton, et. al., which surveyed deaf and hearing people alike, showed

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8 This was reported in several periodicals. The ones used here were: Blotcher, “Children by Design” (Advocate, May 28, 2002), McGovern, “Deaf to Common Sense” (Newsmagazine, April 29, 2002) and McLellan, “Controversy over Deliberate Conception of Deaf Child” (Lancet, North American edition April 13, 2002).
9 Brunger et. al. 2000, p. 1621
10 This has appeared in surveys of Anna Middleton et.al. as well as Jackie Leach Scully et.al.’s.
that a minority of culturally Deaf people they surveyed (2%) were interested in taking advantage of the technology to ensure birth of a deaf child and even consider termination of a fetus that was found to be hearing.\textsuperscript{11} An even earlier study by the same researchers in which they gave questionnaires solely to Deaf delegates of an international conference called “Deaf Nation” showed an even higher percentage: 29% of the 16% who said they would consider PGD said they would use it to ensure the birth of a deaf child.\textsuperscript{12} The percentages of Deaf parents who prefer deaf babies (but would not mind having a hearing baby) are also reported in the results of Stern et. al.’s survey, who revised Middleton’s questionnaire.\textsuperscript{13} Of the respondents whom they interviewed coming from the Deaf community (particularly those enrolled in Hard of Hearing or Deaf schools) and equal participation groups (those who are involved both in the Hearing and Deaf communities), 27% and 11% respectively had a preference for having deaf children.\textsuperscript{14}

Why this is so may at first seem baffling, as it is uncommon. The trend, as nodded on by government policies and the medical profession alike, is in fact to the opposite direction: that is, early testing for deafness in order to control or “cure” it. In 1993, a 15-member panel assembled in the United States backed up early screening for deafness in all born infants for the purposes of beginning with therapy early in life.\textsuperscript{15} Ten years later, a group of experts also urged in an article in \textit{Ear and Hearing} the need to implant deaf children as soon as possible with cochlear implants, preferably before they turn three and a half years of age.\textsuperscript{16} The aforementioned surveys by Middleton and Stern also reflected this majority thinking: more people were willing to consider the termination of a baby found to be deaf as opposed to the hearing one—which is probably the exact reason why the Deaf fears that the technology might undermine them or would be a threat to their community. Nonetheless, going the other way, i.e. choosing to render deafness to children, is obviously against the grain even among the Deaf themselves and may even seem to the hearing majority “the most perverse manifestation of creating designer babies” and a misuse of reproductive autonomy.\textsuperscript{17}

It is, however, important to put this unconventional wish into context. There are two issues to be found here, it seems. The first one has to do with the problem of what traits are ethical to screen for as the gene test pool grows. We therefore echo the Australian Infertility

\begin{itemize}
\item \textsuperscript{11} Middleton et. al. 2001, p. 121
\item \textsuperscript{12} Middleton et. al. 1998, p. 1175
\item \textsuperscript{13} Stern et. al. 2002, p. 450
\item \textsuperscript{14} Ibid.
\item \textsuperscript{15} Leary 1993
\item \textsuperscript{16} Nagourney 2003
\item \textsuperscript{17} Savulescu 2002, p.771
\end{itemize}
Treatment Authority in asking: is deafness a disease, or just an unfortunate condition? The second issue has something to do with the deaf who might see their condition as part of their identity or even social belongingness. This begets the question: are the deaf justified in purposefully implanting a baby diagnosed to be deaf, or are they dooming their children to a poor quality of life? The second and third chapters of this thesis will tackle the first question, while the fourth and fifth chapters will elaborate on the second question.

To anticipate, I will be arguing in the next two chapters that although deafness is indeed something physiological, that deafness is a “disability” cannot be the justification against implanting deaf embryos, because disability—as argued by proponents of the social model of disability—is a social state and not a physiological fact. Also, since not all disabilities are the same, and the actual abilities of the people in question must be considered. In the fourth chapter, I will then try to enumerate and explain the reasons why Deaf parents may want deaf children, and show how these wishes may be justified. In the last chapter, concluding that neither the medical model of disease nor the principle-based approach—which weighs beneficence, nonmaleficence, autonomy and justice—are sufficient in opposing the implantation of deaf babies, I propose that a different theory, model or philosophy of health should be espoused if we are still to find the implantation of deaf babies problematic.

That said, it is not the aim of this paper to make a definite stand for or against the implantation of embryos that screen deaf through PGD. Rather, it aims to question what might be existing biases in the philosophy of medicine, which does not take fully into account the experiences and the reasoning of those who are disabled. An understanding of those reasons, which might also be reflective and valid, is needed, especially in the realm of policy making where policymakers and ethicists alike must take not only the socially acceptable as right, but consider all the possible multitude of views in creating a prudent and ethical stand for the limits of PGD use. If policymakers were to decide that disabilities such as deafness could not be screened for in the first place, then this paper would perhaps lose its value. Given that society prefers some traits more than others, and that these conditions are considered for genetic diagnosis, the paper explores other reasoning and views about PGD, i.e. why some parents would want to choose a child that has a condition we call a disability. That is, while the mainstream may ask: “Why ensure the birth of a deaf child?”, this paper asks, “Why not?” Policymakers and ethicists must be able to tackle this question sufficiently if they would allow to screen for deafness, but only to ensure the birth of hearing children.
Chapter 2
The Medical Model of Disease

Perhaps the real problem in selecting traits for which to screen is that aside from that in really obvious and clear-cut cases (such as Tay-Sachs or spina bifida which cause much pain, dependence and early death), our commonsense intuitions about disease—when questioned as to its scope and limits—is really quite unclear. Recall the Australian case above where they had to debate on whether deafness was a disease or just an unfortunate condition. On the other hand, the disappointed mother of the deaf child herself thinks that deafness was a life-altering condition both for her and her son, and found the doctors’ explanation that deafness was neither severe nor life-altering, “hard to swallow.”\(^{18}\)

It does not help that the inclarity about what counts as disease is highlighted by socio-historical cases where what was socially accepted to be disease are now changed. Examples range from the humorous—as in Drapetomania, the disease that made slaves run away, to more significant ones, such as those political debates to take homosexuality—which, after a number of experiments on male rats was hypothesized to be caused by an “androgen deficiency during a critical hypothalamic differentiation period” during the fetus’ growth—off DSM-III (Diagnostic Statistical Manual of Mental Disorders), the official list of psychological disorders.\(^{19}\) Debates such as these are also to be found in the present, such as with ongoing discussions whether or not obesity is a disease.\(^{20}\) Moreover, what may also be considered diseases in some places—e.g. lactase deficiency in Sweden—may not even be much of an issue in others, such as those wherein milk is not a staple diet.\(^{21}\) And still, what may not be considered diseases at all in some areas—e.g. the birth of twins—could be considered so monstrous and appalling in other societies that one twin would surely be killed.\(^{22}\) As we can see, neither a layman’s definition nor the socially constructed definition of disease or disability (i.e. what a particular society agrees as undesirable for the bearer\(^{23}\)) seems to shed any light on what a debilitating condition really is.

\(^{18}\) Harmon 2004  
\(^{19}\) Nordenfelt 1945, p. 134  
\(^{20}\) Kitcher 2004, p. 234  
\(^{21}\) Nordenfelt 1945, p. 107  
\(^{22}\) Silvers 1998, p. 105  
\(^{23}\) This definition is one of the two major approaches to defining disease, according to Philip Kitcher in the article cited above. The second major approach (what he dubs the objectivist approach) will be discussed in the succeeding pages. See Kitcher 2004, p. 234.
On the other hand, it seems that stable definitions of disease and have to be found if the medical profession is to do its job at all. Yet, even the World Health Organization (WHO) doesn’t give very substantive definitions of these (in fact, to the term “disease” it gives no explicit definition; it rather describes the disease process), leaving it to philosophers of medicine, sociologists and others to fill in the nuances to their general outline of sorts. The disease process is characterized in the WHO’s *International Classification of Diseases, Injuries and Causes of Death* (ICIDH) as such:

A chain of causal circumstances, the “etiology”, gives rise to changes in the structure or functioning of the body, the “pathology”. Pathological changes may or may not make themselves evident; when they do they are described as “manifestations”, which, in medical parlance, are usually distinguished as “symptoms and signs”.

Disability is subsumed under the disease process, and—influencing the medical model as we shall see later—is described solely according to the terminology of disease:

*Diseases* causes *impairments*, which in their turn cause *disabilities*, which in their turn causes *handicaps*.  

This means that the meaning of disability being talked about here excludes injuries from accidents (e.g. amputation of a leg following a car accident), which doesn’t have its etiology in disease, described above. Nonetheless, what is important to note is that both the definition of disease and disability here do not seem to help in determining what is a disease and what is not. It also does not answer the question whether deafness—commonly considered to be a disability—is in fact a disease, as the two (according to ICIDH) relate to each other causally.

In search of a more substantive definition of disease, several thinkers have thus tried to establish its character. One possibility is to define disease simply as a breakdown in an individual’s (or his body part’s) function: an organ or system of the body is diseased if it has a condition that impairs its function. But then again, this definition only begs the question of what functionality is and what should be considered as a particular individual’s normal function, since he functions differently at different times. This definition doesn’t answer, for example, whether being constantly tired, being attracted to the same sex, or being grossly obese counts as a breakdown in one or another function. Also, not all breakdowns in bodily

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24 Nordenfelt 1992, p. 2  
26 Ibid., p. 234.
function—such as aging—can be considered a disease. Each person’s organ functions also perform differently from another’s, and these minor modifications might make them fall below the normal levels of functioning, yet not so as to be significantly or completely dysfunctional.²⁷

Perhaps what we can talk about then is not an individual body’s level of functioning, but something more universally identifiable, by pinning the definition of disease to some recognizable criteria. In this regard, others have defined disease as something “objectively” identifiable in the body according to a norm—for example, species design or statistical occurrence. In general, the thinking that diseases are objectively and exclusively identified as physiological malfunction are said to follow the medical model of disease, which deserves an elaboration in this chapter as it is the usual model to justify objections to the implantation of deaf babies. Under the medical model, aberration from definite and objectively verifiable criteria of function (e.g. deafness as a lack of the function of hearing) is a disease, and thus a pathology to be treated.

**Objectivist notions**

According to Lennart Nordenfelt who is a critic to the medical model, the clearest example of such a model of disease is one which we now call the biostatistical (BST) model of Christopher Boorse, in which the notion of health or normal function is objectively defined by the statistical norm. Nordenfelt here quotes Boorse in saying that:

Normal functioning in a member of the reference class is the performance by each internal part of all its statistically typical functions with at least statistically typical efficiency, i.e. at efficiency levels within or above some chosen central region of their population distribution.²⁸

Normal functioning of the human body, in other words, can be determined by statistically means in which the statistically normal reflect the typical functional systems that support the life of the organism. The notion of species design and a teleologically designed body (that all parts of the body are designed for a function) are thus crucial in Boorse’s model, where the statistically typical determines the empirical ideal of health, whereas the non-ability to perform a function constitutes disease.²⁹

In application, we can say that deafness, a disease afflicting a mere 0.1% of the world’s

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²⁸ Nordenfelt 1945, p. 19.
²⁹ Ibid.
population,\textsuperscript{30} is defined by the subnormal functioning of the cochlea, the cavity in the inner ear that allows most to hear by sending nerve signals in response to sound vibrations. Boorse himself would probably not agree to implant embryos diagnosed as deaf through PGD because of his description of so-called factual goals. Using Boorse’s description that organs have a factual goal, we can say for instance that the normal (that is, ideal) cochlea can be said to meet the biological goal of hearing: ears are cupped to collect sound and are found on both sides of the head in order to determine the direction of the sound. Thus, ensuring that a baby is deaf would simply be contrary to our biological and functional design as humans.

Boorse’s description of factual goals also has another implication. This means that even if the number of deaf births was reported to have increased in number, perhaps due to intermarriage by deaf couples or other reasons,\textsuperscript{31} this occurrence would not change the fact that deafness is an aberration from the norm. Instead of being the new norm, the increased statistic would reason for more alarm, as it reflects the spread of disease within a population. Thus, to go so far as to ensure a baby is deaf could in Boorse’s paradigm be seen as counter-evolutionary and even harmful: it is a deliberate breeding of defective and diseased babies who will fall short of the biological norm or will have levels of functioning directly opposed to the design of the species.

The definition of disease as seen in the aspect of aberration of normal function of body parts is shared by other thinkers, more or less similar to Boorse’s categorizations. Norman Daniels, arguing that a theory of health care needs is necessary to determine which conditions merit support under a communal health care system, support that such an objective criterion of well-being (and conversely, a criterion for the absence of well being, i.e. disease) be used to assess competing individual claims to healthcare resources. Such criterion, he claims, must both be “objectively ascribable” and “objectively important,” including course-of-life needs without which “the normal functioning of the subject of need considered as a member of the natural species” is endangered.\textsuperscript{32} At first Daniels includes under these course-of-life needs many things such as shelter, clothing, and even the need for a mate. However, in his theory of healthcare, he strongly emphasized the role of evolutionary biologists to present reinforcing evidence for the species-typical functioning of humans, in order to ascertain which occurrences are properly called deviations from the natural functional organization of a typical member of the species, and in so doing establish which ones in the population has

\textsuperscript{30} Gallaudet University Libraries Deaf-related Resources website
\textsuperscript{31} Webster 1983
\textsuperscript{32} Daniels 1985, pp. 24-26
legitimate health care needs.

Daniels’ characterization of disease was towards the goal of establishing his theory of health care. Nonetheless, if Daniels would comment on the implantation of embryos diagnosed as deaf through PGD, he would probably have the same view as Boorse’s, with an addition of insights regarding the health care system. The value of his theory of health care needs is that it “allows us to draw a fairly sharp line between the uses of health-care services to prevent and treat diseases and uses which meet other social goals.” In other words, to determine which procedures can be objectively classified (by bodily criteria) as therapeutic, and non-therapeutic, and to set out priority to the former.

It is hard to say what Daniels will say in particular about using the technology of PGD to ensure the birth of deaf babies, other than to say that it is giving a trait that is counter to species-typical functioning. It is harder to say weather he will think the “other social goals” that deaf parents see as having—such as the ability to care a child like them—is legitimate. Regardless if it were a legitimate and cause-worthy goal, however, surely the creation of such a baby will definitely not be considered a priority in the hierarchy of health care needs—at least not in comparison to the reverse situation, i.e. if a couple who is a risk of having a deaf child want to use PGD to ensure the birth of a hearing child—or in congruence with Boorse’s line of thought, a child with “normal” hearing.

A third elaboration of the meaning of disease comes from Andrew Twaddle, who defines disease as “a health problem that consists of a physiological malfunction that results in an actual potential reduction of physical capacities and/or reduced life expectancy.” Although he does not discuss statistical abnormality nor species-typical functioning, he also believes that disease can be identified by “objective means,” as they are measurable events at the organic level and therefore exist are apart from subjective experience. Under the term “disease,” Twaddle subsumes disability, injury, and defects, all of which he says fits into the definition of disease because they are likewise psychological malfunctions which are objectively verifiable by someone with sufficient knowledge (e.g. a health professional) and may lead to reduced physical capacity or life expectancy.

Twaddle, however, differentiates disease with the concepts of illness, which is the subjective feeling of malaise, and being sick, which is a judgment, made by the community—and insists on their independence from each other as concepts. For example, a person may be

33 Daniels 1985, p. 31
34 Twaddle and Nordenfelt, 1993, p. 8
35 Ibid., p. 49
considered sick (say, a woman with her menstrual period during the biblical days) by people surrounding her, regardless if she feels ill or not or does not actually have a disease. Likewise, a person may have a disease even if she herself does not feel any discomforts, nor appear sick to others. Perhaps the baby ensured to be deaf will fall in this latter case under Twaddle’s categorizations: despite integration and celebration within the Deaf community or even considering the person’s own feelings of adequacy and confidence, something “objective” in the physiological level affirms that the deaf person has a disease (or disability, since these have no distinction for Twaddle): that is, a reduction or absence of physical capacity to hear.

**Value judgments in the medical model**

Critics argue that even these attempts at pinning down the definition of disease to something objective, are themselves based on value judgments geared towards, for example, some ideal mode of being or functioning. Thus, some argue that the concept of disease is not simply descriptive after all as the medical model suggests, but rather strongly normative: it tells us what counts as a deviation from a socially-acceptable norm.

One such critique is the one made by Nordenfelt versus Boorse’s biostatistical theory. Nordenfelt’s observation lies on the fact that to Boorse, the idea of subnormal function is an unfortunate anomaly worth our attention, whereas no attention is given in the theory to another statistically rare mode of functioning, i.e. supernormal function. In everyday life, in fact, what we consider to be supernormal function (unusually high intelligence, to name one) are hardly called diseases and are in fact highly valued despite being a deviation from the statistical standard. If statistical normalcy is the basis for defining a disease (by which we normally attribute a negative connotation), then praise supernormal functioning, the theory seems to be inconsistent. Furthermore, the absent criteria for what peculiarities count as praiseworthy or not only highlights the subjective judgments on what society thinks is valuable or not. Pinning down what a disease is, is therefore not entirely a matter of “objective” identification. Boorse himself somehow admits that the thin line between “normal” and “abnormal” functioning may be a matter of convention. George Khushf, also a critic of Boorse’s theory quotes the latter as writing that:

Abnormal functioning occurs when some functions’ efficiency falls more than a certain distance below the population mean. [T]his distance can only be conventionally chosen, as in any application of statistical normality to a continuous distribution. The precise line between health and disease is usually academic, since most diseases involve functional
deficits that are unusual by any reasonable standard.36

Interestingly, for Boorse, he thinks that this conventionally agreed upon standard incidentally happens to be the species-typical norm as well.

Nordenfelt’s other critique of Boorse is the latter’s claim that the inability to perform a function counts as disease, regardless if the use of the function never arises. This is an abstraction and clearly shows a bias for particular modes of functioning a priori. That is, if one’s ability to do a function is never confirmed or denied in one’s lifetime, then it could not be judged as disease.37

A similar critique that the medical model of disease is not as objective as its supporters think it to be, is put forward by Anita Silvers, in reaction to Norman Daniels. The issue for Silvers is not that a theory of health and disease is important in the field of healthcare; rather, she worries that what the field of medicine only assent to are those things with a broader social warrant38. This social acceptability, she believes, is not there because people are concerned over species-typical functioning, as Daniels claims, but because we are expected to perform in a certain “normal function” within society. Critiquing why disability should be considered as a deviation from species-typical functioning, Anita Silvers points out that what may be important to writers like Daniels is instead “normalization.”39 That is, whereas those judged to be more effective to community are praised, those who are thought to perform sub-normally should be normalized through medicine and should be “treated” from their disability in order for them to fulfill what society expects of them. She uncovers a bias for what society thinks is inferior functioning in a similar way as Nordenfelt’s second critique to Boorse above, by showing that the positive identification of some genes are already equated with disease, even if the traits themselves are not manifest.

True to Silver’s critique, most technologies to “treat” or otherwise hide disability—including implants and prosthetics—are imposed on impaired people, without looking at their actual state of ability. For example, walking with prosthetics legs (though painfully and with a limp) is somehow deemed to more socially acceptable than wheeling vigorously, just because the former seems to be the more “normal” performance. At one time in Canada when many children were born with missing or shortened limbs because their pregnant mothers took thalidomide, the Canadian Health Care system even intervened in their “therapy” and

36 Khushf 1997, p. 156
37 Nordenfelt 1945, pp. 19, 24
38 Silvers 1998, p. 101
39 Ibid., p. 100
forbid the children to roll or crawl regardless if these offered much more functionality. Instead, the children were foisted with painful prostheses that actually decreased their mobility, in order for them to appear more normal. ⁴⁰

In the case of deafness, the justification given by those in favor of a routine newborn screening for deafness in the United States was the claim that early detection of hearing-impaired children allows a greater opportunity for them to “achieve normal language skills,” through education or cochlear implantations. ⁴¹ Normalization likewise comes into play here because the only aim of hearing-loss detection was so to make the deaf children communicate “just like the rest,” whereas the Deaf do in fact have a highly developed and elaborate system of communication in America: the American Sign Language (ASL). The lingering question then, is why it would be acceptable for PGD to work one way (i.e. to prefer hearing children) but not the other (i.e. to prefer deaf children), despite the fact that the deaf children may be well able to lead a satisfying, able, and fulfilling life with their condition as without it. As Silvers once again succinctly puts it: “The prescription is clear: although interventions that enhance a patient’s functioning so that it departs from what is normal may be advisable to the patient when they enhance the patient’s welfare, only interventions that normalize command a broader social warrant.” ⁴² Meanwhile, “Daniels thinks that the way the species typically functions constitutes a natural and therefore a neutral standard to which the public can assent.” ⁴³

In fairness to Andrew Twaddle, on the other hand, he differentiates the notion of disease (and under it, disability) with the actual experience of illness, or discomfort or unease to the bearer. This categorization accepts that not all forms of disability or dysfunction is incapacitating, or even a discomfort for the bearer. Formulated in that way, Twaddle’s categorization is also open the fact that those with physical impairments such as deafness can provide themselves an alternative mode of functioning that does not limit their personal movement in any way. However, by merely seeing disease and disability as objective notions that can be determined in what he thinks is an unprejudiced way, he discounts the contribution of society into the meaning of disease and disability. Some of these, such as the bias for which traits are praiseworthy on the one hand, and pitiable on the other, we already mentioned above. Others, such as the existence of systemic and environmental barriers that

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⁴⁰ Silvers 1998, pp. 113-4
⁴¹ Nagourney, 2003 January 14
⁴² Silvers 1998, p. 101
⁴³ Ibid., p. 99
lead to disability, and even the possible involvement of pharmaceutical companies in the creation of disease, will be discussed in the next chapter regarding what is so called the social model of disability. Under this second model, disability, as distinct from the physical status, i.e. impairment, is a social state and thus not as objectively verifiable as Twaddle may think it is.

**Conclusion**

The medical model of disease, which pins down an objective criteria by which to determine what a disease is, is usually (directly or indirectly) summoned by those who object to the implantation of embryos that are diagnosed deaf through PGD. However, it too is after all not spared from value judgments of society. Boorse’s and Daniel’s definitions of disease reveal these *a priori* value judgments about what poor function is, determined without looking at the actual ability of the affected people. Meanwhile, Twaddle’s definition, though a little better, may still be rather narrow, as it gives to little regard to the role of society in the meaning of disease and appends the cause of disability strictly as being in the body. At any case, we can say that the medical model of disease could not be the sufficient in our issue regarding the use of PGD to ensure children inherit deafness, for the very justification that it presents against deafness—the possibility of defining disease and disability objectively—already presents problems of its own.

Thus, the answer to the question of weather deafness is a disease or simply an unfortunate condition seems more problematic than when we first began. Perhaps we are only conflating the two? The social model of disability, which we will discuss in the next chapter, thus tries to make a dichotomy between the physical impairment and the disability—which are taken to be in one and the same process in the medical model. Instead of focusing on the “objective” means for determining disease (and disability), supporters of this second model instead look at it from the other end: there is nothing “objective” in the body about disability. Rather, it is a social state that is a result of a society that does not adapt to some of its citizens’ needs. This second mode will provide us with another paradigm by which to look at disability.
Chapter 3
The Social Model of Disability

From talking about the medical model of disease, we move on to the a so-called social model of disability. One may ask: why talk of disease on the one hand, and disability on the other? This calls for a clarification. Whereas the medical model of disease subsumed disability under the disease process (the best example would be the ICIDH’s definition, held by the WHO), proponents of the social model of disability think that this is exactly what is wrong with the first model. Disability, they claim, do not have their origin in disease but rather in the social environment. It is the medical model of disease that can be used by thinkers to oppose the use of PGD to ensure deaf (and as they see it, disabled) babies and instead encourage efforts into curing or ensuring against deafness. The social model of disability, on the other hand, tells us that disability is nothing that we can “cure” through medicine, since it is a social creation.

Indeed, from the previous part of this paper, we realized that the medical model, though hoping to pin the definition of disease on neutral and objective grounds, is likewise value-laden. The factor in defining disease and disability is not after all to be based on purely physiological criteria; the definition is also normative in that it involves an implementation of value—in particular, values that would gain the approval of the majority. Critics of the medical model have recognized this, and thus took that into account in looking for a more nuanced definition of disability—that which recognizes the effect of environment and society in the creation or perhaps perpetuation of disability. The seeds for such a theory were expressed in 1975 by a group of disabled people called the Union of Physically Impaired Against Segregation (UPAIS) in a book *Fundamental Principles of Disability*, which was later elaborated on by Mike Oliver who christened it as what is today called the social model of disability.\(^44\)

The UPAIS defined disability as:

Disability is the disadvantage or restriction caused by a contemporary social organization which takes no or little account of people who have [physical] impairments and thus

\(^44\) Mike Oliver discusses this in a book called *The Politics of Disablement* published in 1990 by Basingstroke Macmillans. I was not able to find a copy of the book, but it is mentioned in another article by Oliver, “Individual and Social Models of Disability” that I cite.
excludes them from the mainstream of social activities.45

This means that under the social model, it is recognized that some people indeed have impairments that affect their physical or mental function, but adds that their disability exists because of the barriers in society and the lack of structures that support their needs. Such barriers may be environmental (e.g. buildings without lifts and busses without ramps), systemic (that they are segregated from the rest of community through, for example, depictions in media), and negative attitudes towards them by the public, who see them as expensive, useless, or needy.46 There is thus a difference between the terms impairment—the physiological state of the person—and disability—the state of handicap and incapacity—in the social model. To borrow an example from Scully, “the presence of impaired hearing is one thing, while the absence of subtitling on TV is quite another.”47 This delineation does not exist in the medical model, where the handicap is conflated with the physical condition seen as a defect. In the social model, it is rather the refusal of society to make accommodations that is “the real site of disability.”48 Thus, the problem lies not on individual limitations, but on what they see as the institutionalized discrimination that exists in society.49

That the locus of disability lies not on physiology has led Mike Oliver to call the term “medical model of disability” (which others are led to call it) a misnomer. He rather thinks that the so-called medical model is simply a medicalization of what he terms the individual model of disability: that is an unfortunate personal tragedy ever to befall a person.50 The medicalization enters the scene when this “unfortunate condition” becomes viewed as a medical problem to be solved. Doctors are asked to use their skills in locating the source of, and “cure” disability, as in the case of identifying etiological factors for deafness, and implantation of cochlear implants to deaf children in order to normalize them. However, the inappropriateness of this medicalization appears when one becomes aware that disability is not a medical condition but a social state incurable by medical intervention.51 What “doctoring” disability achieves is to pinpoint the fault somewhere in the impaired individual, perpetuating the cycle of oppression towards impaired individuals and the disabled community by giving it an “objective” basis. Oliver has thus two critiques against the

45 The Open University website
46 British Council of Disabled People website
47 Scully 2004, p. 651
48 Ibid., 651
49 Oliver 1990, p. 3
50 Ibid.
51 Ibid., pp. 3-5
medical model:

Firstly, it locates the “problem” of disability within the individual and secondly it sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability. These two points are underpinned by what might be called “the personal tragedy theory of disability” which suggests that disability is some terrible chance event which occurs at random to unfortunate individuals.\(^\text{52}\)

**Environmental and systemic barriers throughout history**

Perhaps Oliver and other proponents of the social model have a point in blaming society as the locus of disability. To find support such a theory, however, we may have to look into the history of how impairment was viewed. As impairment may not necessarily mean handicap if facilities exist (say, in a society with lifts and ramps and cars operational by impaired people in wheelchairs), the thinking that impairment is an unfortunate condition must have come from a society that—perhaps at first—was not able to accommodate these other needs and thus saw the people in question in an unfortunate light.

In the case of deaf people, Per Eriksson believes that the strong sense that deafness is a pitiable defect was institutionalized by none other than Aristotle.\(^\text{53}\) Not to mention that the handicapped were not given education in Greek society during Aristotle’s time, the philosopher-scientist attempted to explain the deaf’s inability to be taught as a lack of the faculty of reason, as he regarded hearing as an important channel of learning. He is quoted to have said that “if one of the senses is lacking, it necessarily follows that a certain type of understanding is also lacking, an understanding impossible to acquire,”\(^\text{54}\) giving rise to the opinion that the deaf were impossible to educate. Galen, perhaps in view of medicalization, even attempted to locate the hearing defect in one of the nerves of the brain, which he believed was the same nerve that controlled speech.\(^\text{55}\)

Eriksson believes that it is because of this Aristotelian legacy that schools for the deaf had not been established until the 16\(^\text{th}\) century—and only because intermarriage between the elite bore many deaf children, leading to a crisis in inheritance to unschooled nobility. Nevertheless, in concurrence with Oliver’s thought, the inability of the deaf to be taught was attributed to the individual’s own lack rather than, for example, a creation of a school system in which it was possible for the deaf to be integrated in society and schooled like the rest. Indeed, the early schools for the deaf were also designed to “fix” the impaired bodies—most

\(^{52}\) Oliver 1990, p. 3  
\(^{53}\) Eriksson 1998, p. 15  
\(^{54}\) Ibid., p. 15  
\(^{55}\) Ibid., p. 14
teachers for the deaf until the 18\textsuperscript{th} century were physicians, if not priests.\textsuperscript{56}

Perhaps one of the best examples of how the “personal tragedy” model of disability has become systematized was in the 1930’s in the United States, at the time when the eugenics movement—the idea that undesirable traits could be eliminated by selective breeding—gained hold there. Eugenicists bifurcated into two camps regarding what to do with the deaf. While “negative eugenicists” insisted on institutional sterilization for deaf people, “positive eugenicists”—or Oralists, as they were called—lobbied that they instead be taught to speak like “normal” people, and discourage the deaf from intermarrying.\textsuperscript{57} Alexander Graham Bell, who was an Oralist, had even addressed the problem the “propagation” of deafness by Deaf people in a \textit{Memoir upon the Formation of a Deaf Variety of the Human Race}, calling the increasing number of deaf people a “calamity to the world” and suggesting that the deaf be discouraged to use Sign language and disallow the deaf from becoming teachers to deaf children.\textsuperscript{58}

A comprehensive history of deaf people is not the goal here; nevertheless, from a few examples we can already see how, according to Oliver, the creator of disability may not so much the physiological state—the deaf have been known to use a “finger language” to enable them to communicate as early as the antiquity and before Aristotle.\textsuperscript{59} For the social model, disability is a social state created by educational and societal systems and the attitudes of others, which later on try to find “rational” justification in scientific and medical terms. This may also have a strong political effect: the medical community, by blaming the inability to cope within society on the impaired bodies, can then claim control on what and what not impaired people should and should not do. It is the social system, externalized in the medical model, that can tell the Deaf: “Yes, you must get implants, because you are defective,” or “No, you may not have deaf babies since you are condemning them to an abnormality!”

\textbf{Medicalization: A prescription for every disease}

Also, in a community where we rely more and more on scientific and medical expertise to tell us what to do, what to eat, and how to live our lives, the medical community’s hand in the institutionalizing the “personal tragedy” view of disability becomes more obvious. This gives us an insight on the systemic barriers that create disability. It is not only the lack of

\textsuperscript{56} Ibid., p. 48
\textsuperscript{57} Marin and Arnos 2006, pp. 30-31
\textsuperscript{58} Padden and Humphries 2005, p. 174
\textsuperscript{59} Plato even mentions it in a book \textit{Cratylus}. Per Eriksson says this is the oldest known mention of sign language. See Eriksson 1998, p. 13.
technological facilities or the need for educational methods, which when recognized, must be—excuse the pun—remedied to reduce disability. Systems like health care and the pharmaceutical industries may also perpetuate the social state of disability in their own ways, by continuing to “doctor” disability as if it were primarily a physical problem and not a social one. After all, the medical model in which the pharmaceutical companies work relies on an unproblematic definition of disease and disability. Yet, Scully echoes Oliver in asking weather the so-called pathology is a social or even a pharmaceutical creation. This question must be asked, she says, not only because (in agreement with Daniels), our definitions of disease and disability is important in health care allocation and in determining which ones are diseases and not. More importantly, the crispness of these definitions must be examined because of contemporary biomedicine’s power to intervene in domains that are beyond health, where moral and economic problems might emerge.60

In a part of her essay What is a Disease?, Scully discusses the controversial role pharmaceutical industries may play in the creation of disability. She cites how ADHD (Attention Deficit Hyperactivity Disorder) diagnoses—which previously was merely considered as children’s bad behavior—skyrocketed as have prescriptions to control it, and how pharmaceuticals are now considering research on whether a female equivalent of erectile dysfunction exists, in order to make drugs for the hypothetical disease which at present does not even exist. Hypermobility—or being ultra-flexible—has also turned from an enviable childhood talent (and even a musical asset) into a “pathology” in Scully’s lifetime, though her personal experience of hypermobility had not changed at all.

Others have also discussed medicalization and the role of pharmaceuticals in defining disease. Lynn Payer, for example, had written a book describing how pharmaceuticals broaden the definitions of disease in order to increase demand for pharmaceutical products.61 A recent publication on the journal Psychotherapy and Psychosomatics also divulged that at least 95 of the 170-member panel responsible for the revisions in DSM-IV had financial ties with one or more drug companies.62

It is not a wonder then, that the thought of ensuring babies are born deaf are met with such negativity, in light of medical technologies made to “correct” or normalize their bodies.

60 Scully 2004, p.650
62 Cosgrove et. al. 2006, pp. 154-160
such as new and improved cochlear implants that are said reduce the risk of complications. But in agreement with Silvers’ critique of normalization, even these implants are risky and their effectiveness questionable. Studies show that deaf children are more prone to meningitis—an infection of the fluid surrounding the brain and spinal cord—to begin with, but cochlear implants, which require surgery expose children to risk of infections, apparently increase the risk for developing meningitis up to four years following the operation. Because of this life-threatening risk (which arises because of the desire to eliminate a non-life-threatening condition), the children have to be vaccinated against infections and monitored for fever and stiff neck, symptoms of meningitis. Aside from this and contrary to popular thinking, implants do not actually allow children to actually “hear” after all, but only allows them to sense small vibrations; not all cochlear implants are successful in that they actually allow correct sound recognition, for example. Thus, after implantation, these children will still need technological and human assistance such as captioning and interpreters in order to communicate.—All this for the cost of around $60,000 as of March 2006, including expenses for the device, surgery and therapy. Some in the Deaf community find the increasing number of children being implanted—and the vigorous promotion of it by healthcare workers—worrisome, as other channels of communication such as Sign or captioning are available to deaf children, if only their parents have a positive attitude towards the Deaf community.

Attitudinal barriers: projected vs. experienced disability

The “personal tragedy” thinking towards disability seems to be so deeply entrenched in our culture that, according to Michie and Marteau, studies found that people usually attribute negative feelings towards disabled people even if that person is shown in a happy context: subjects presented with pictures of children with Down syndrome felt sorry for their condition, regardless whether the picture showed a positive or negative image. Likewise, when we hear the words “deaf baby,” we suppose that it has a negative state of being, regardless of whether we actually do know what the baby’s situation is, nor how its is being brought up by its parents. If having a deaf baby of deaf parents were cherished and allowed to

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63 Duenwald 2006
64 Duenwald 2006
65 Deaf.com website
66 Duenwald 2006
67 Deaf.com website
68 Michie and Marteau 1999, p. 1206
be given all the opportunities open to it, then the words “deaf baby” would actually entail something positive.

Also, a large body of psychological literature shows that people affected by a condition have more positive attitudes towards it than do others, and experience their condition as being less serious than how others perceive it. Michie and Marteau say that it is perhaps because those living with the condition have many more examples of it not being serious than those who simply observe it from a distance. There is no evidence that the differences in perception result from differences in knowledge about the condition itself.69

Still, in recent years, there had been an advance towards adopting the social model, for example, in legislation. These may slowly change society’s perception of disability for a more nuanced one. For example, the Disability Discrimination Act in the United Kingdom defines disabled people from the medical model as those who have a “physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.”70 Yet, the Act requires employers to make adjustments through “provision of goods, facilities and services or the disposal or management of premises; to make provision about the employment of disabled persons”71—the latter leaning more to the social model of disability.

**Critiques against the social model of disability**

The social model of disability, although rightly pointing out that the medical model is one-dimensional, is not itself free from criticism. Tom Shakespeare, for example, hold that changes in society such as those which the model proposes can be had even without adhering to the social model itself, for such a “strong social model” of disability where disability is considered solely a social state as depicted by Oliver, is untenable. Shakespeare juxtaposes the slogans of disabled people, i.e. that they are not “people with disabilities” but “disabled people”, with the truth that even most disabled activists feel in pain while in their own homes.72 Not only does he think that the impairment-disability dichotomy is impossible because impairment results from a plurality of different factors—including, but not limited to physiology—he also holds that a barrier-free utopia is truly untenable, since a removal of barrier may be the cause of another’s, and that not all barriers (such as chronic pain) have

69 Michie and Marteau 1999, p. 1205
70 Disability Discrimination Act 1995, electronic copy
71 Ibid.
72 Shakespeare 2002, pp. 9-10
Admittedly, most of Shakespeare’s critique is true. After all, no model is flawless and can account for all factors in the lived world. It is also true that sometimes, there is little or nothing environmental factors can do to eliminate disabling conditions. Pain caused a physical condition can prevent one from even getting up from bed at all, and there is little that the society can do about that. Shakespeare also asks how society can ever equalize the playing field to accommodate, for instance, mentally-handicapped persons. Thus, it is true that some environmental barriers can be improved or eased, but some physical conditions may always make some more or less “disabled” than others. Besides, Shakespeare says, saying that people aren’t disabled in their bodies might send the message that there is nothing wrong with wanting to avoid such conditions. What is wrong, Shakespeare asks, in medicalizing terminal and unpleasant conditions such as Tay-Sachs and anencephaly, which most people would in fact want to avoid at all costs?\(^{74}\)

But this is exactly where we diverge from Shakespeare, since what may apply to some of his examples may not apply to all conditions. For example, being deaf, in contrast to those suffering from anencephaly or Tay-Sachs in Shakespeare’s examples, still allows the bearer to fulfill the minimum of what Kitcher describes as essentials for the quality of life: that they are independent, can form a theme for their lives, and can see to the fulfillment or revision of the life-themes that they own for themselves.\(^{75}\) As for the deaf, not only is their condition absent from pain and discomfort, they can also be in charge of their lives and activate themselves like most “normal” people. In fact within their communities, some would even claim that they do not feel disabled at all. Besides the lack of hearing, the Deaf themselves can testify that they can do most things that hearing people can. They can communicate, either in Sign or in spoken language; can educate themselves; they can do all motor skills and therefore do not need special attention for their everyday needs; they can read road signs and TV subtitles, etcetera. This is exactly what makes this example of Deaf very interesting: in all aspects except their hearing, they can actually be quite normal, and most of their needs can easily be remedied by environmental changes, even if they remain physically impaired.

In fairness, even Shakespeare grants that analytically, disabilities are different from one another, and this is exactly what Scully refers to when she says that the concept of disability needs to be studied more, since what we call “disabilities” are usually lumped together in one

\(^{73}\) Ibid., pp. 16-18  
\(^{74}\) Shakespeare 2002, p. 13  
\(^{75}\) Kitcher 2004, p.236
conceptual category—i.e. deviations from the standard—even though the conditions vary from one another, and so also the experiences of the affected people.\textsuperscript{76}

Others may say that the Deaf might only be minimizing their pain and suffering in order to console themselves, while in truth they are “people with disabilities”—the fault being something objective in their bodies, as in the medical model—rather than “disabled people” as a result of an unaccommodating society. In Nussbaum’s Aristotelian discussion that political institutions should provide its citizens the material, institutional, and educational circumstances for good human functioning, for example, she lists “being able to use the five senses” as one of the basic human functional capabilities which, if one lacked any “no matter what else [one] has, [he] will be regarded as seriously lacking in humanness.”\textsuperscript{77} Surely, what Nussbaum meant wasn’t that the deaf weren’t human, but that their humanity lacked something that could still be wanted. Hearing, for example, opens one up to generations of grandiose music that flourishes in human cultures; without hearing, one’s access to music—and thus to one of the possible potentials of human flourishing—remains closed. Should we instead say that society, through subsidizing implants for example, or preventing the deliberate inception of deaf babies, has instead the obligation to prevent such a “disability” from hearing music, from occurring?

Nevertheless, though the deaf are unable to hear music or listen to announcements over the P.A., it remains that if they are given resources and opportunity in society, they are capable of achieving goals that they set for themselves which they might consider to be important in their own evaluation of their lives. Such is Nordenfelt’s description of vital goals, or those goals necessary for a minimal degree of happiness.\textsuperscript{78} Parallel to Nussbaum’s elaboration that political institutions should promote human welfare, Nordenfelt’s idea is that health care is to provide people with the ability to fulfill their vital goals. Yet, Nordenfelt’s elaboration of vital goals, as compared to Nussbaum’s item-per-item enumeration of human functional capabilities, take into consideration that what makes one individual feel fulfilled (e.g. generations of grandiose music) may not necessarily count as a vital goal for another. Indeed, nothing disallows us to think that the Deaf may not be able to pursue their vital goals—or what they need for a truly human happiness. This is especially so if the society can make accommodations to their needs or if they are raised by loving people who expose them to opportunities for his growth. The quality of life we are talking about here therefore—that

\textsuperscript{76} Scully 2006, p. 248
\textsuperscript{77} Nussbaum 1990, p. 225
\textsuperscript{78} Nordenfelt 1945, p. 78
which is available for deaf people—does not only lie on the bare minimum level described by Kitcher (and in the way we contrasted deafness to Tay-Sachs or anencephaly). With support from the society he lives in—which goes by the social model—there can be nothing preventing the overall happiness of a deaf person, including the social, relational, psychological, aesthetic, and even emotional aspects of his life.

**Conclusion**

As we have seen, environmental factors, systemic considerations, and attitude shape the meaning of disability, even if until recently, the predominant and the only coherent model for thinking about disability was in reference to a biomedical norm. The social model of disability blames the medical model of locating the problem of disability to the individual, and that by conflating disease with disability, the medical model overlooks that there are in fact societal contributions that lead to the creation of disability.

For sure, there are also genetic and biological markers for disability. This was pointed out by Shakespeare’s critique, who rightly pointed out that disability is caused by a pluralism of factors and not solely one or the other. But the deaf is an interesting example, as in contrast to Shakespeare’s other examples of disabled people who feel pain, discomfort or are at risk of early death, the deaf can in fact function much like “ordinary” people. This makes us realize that is it is important to also look at the condition itself, as disabilities—though a very general and broad category—actually describes conditions that can be different from one another.

Nevertheless, if there is anything that the social model contributes to us, it is that the medical model does not, and cannot be the sufficient model from which to justify opposition of implantation of embryos that are diagnosed deaf via PGD since their “disability” may have more to do with the societal and attitudinal barriers rather than an actual investigation on what their abilities, in literal terms as well as their ability to perform vital goals necessary for happiness and a full human life, are.

I borrow from Scully, who succinctly puts in a paragraph what has been said in so many words in this chapter:

Ironically, just at a time when genetic intervention is becoming feasible, the cultural climate is beginning to shift as well. Although the change is slow there is a growing recognition of the rights of disabled people, that not all disabilities are the same, that disablement is environmentally contingent, and that not all variations from the biomedical norm are tragedies to be eradicated or overcome. The combination of genetic medicine
with a changing cultural understanding confronts us with what we really think about embodiments that differ from the norm. When little direct intervention was possible, and when the meaning of disability was theologically or socially defined, the need to be clear about this was less acute. Being able to diagnose genetically before birth, and in the future perhaps to intervene genetically after birth, makes it imperative to evaluate whether such interventions are morally right or not; and this will not be possible while we remain so unclear about the meaning in contemporary culture of bodily variation or disability.⁷⁹

⁷⁹ Scully 2006, p. 250
Chapter 4

Disabled Embodiment and Moral Reasoning

We have seen from the introductory chapter that the increasing opportunities for the use of PDG present problems both to ethicists as well as policy makers. Since it is not possible to screen embryos for every identifiable trait, there is a question of which traits are ethically acceptable to screen for. Questioning the limits of PGD also becomes more relevant as the expansion of parental autonomy increases and problems emerge. Some parents may wish to implant an embryo with a gene expressing a trait that we normally would consider a disease or a disability, in this case deafness.

In search for a definition of disease, and as a possible discourse to prohibit implantation of deaf babies, we might want to define the condition of deafness in objective terms based on species-typical function. Under this so-called medical model, an impairment such as deafness is not only an aberration of normal species function but is also a pathology to be treated. Yet, as we have also seen, the medical model of disease is not itself independent of social values, and it might even conflate disease with behavior or traits which society simply finds disturbing. The medical model also equates impairment with disability, pointing the site of disability as the individual’s own unfortunate defect.

As a reaction to the medical model that saw disability as a disease to be cured, a group of disabled people sowed the seeds of what is now known as the social model of disability, arguing that the site of disability did not lie in the bodies of the impaired but in the barriers that exist in society. Thus, they argue that the existing (and expanding) medicalization of their disability was improper, as disability is a social state and not something to be “doctored”. This calls into question again the meaning of disease, and deafness presents itself as a good example. Despite the fact that physiologically speaking, deafness may be an impairment, the bearers do not feel any discomfort and may—as we shall see in this chapter—even link their deafness to a positive aspect of their identity, rather than to their health status. This brings us back to the issue at hand: we are questioning further whether deaf parents are justified in taking advantage of PGD to ensure the birth of deaf babies, knowing now that the excuse for it being a “disease” does not stand after scrutiny, and that it is different from other disabilities that give significant discomforts to the bearer.

In this chapter, we move from the theories of health and try rather to account for why
some deaf parents may opt for deaf children in the first place. This serves to contextualize the discussion of the uses of PGD. Also, it shows that in contrast to the discussion in the last two chapters, deaf parents may reason in lines not connected to the debate whether deafness is a disease. It would be beneficial to explore these other existing lines of reasoning, and in so doing show how professional evaluation of deafness—according to the medical model, or based on an Aristotelian view of the quality of life—are not enough to justify opposition to implantation of deaf embryos. Simply, this chapter will aim to show that deaf parents who want deaf babies are not simply “deaf to common sense” after all, but may just be judging the moral situation different from professionals.

**Professional vs. patient evaluation**

Jackie Leach Scully had examined this difference between professional and non-professional moral evaluation in an article tellingly called *Non-professionals’ Evaluation of Gene Therapy Ethics*, in which she reveals the results of a study that she did with Rippberger and others regarding patients’ moral evaluations of somatic gene therapy.\(^{80}\) She starts the study with the fact that “the new genetics” has raised a number of ethical issues discussed by medical professionals and ethicists alike, but that little or no attention has been paid to how potential patients—the ill or disabled themselves—reflect on the said issues. During the course of the study, they gave questionnaires to 35 patients with four different conditions, and interviewed 17 of them in depth. The results of the study indeed highlight that there are significant differences between how professionals and patients evaluate the moral problems in the case.\(^{81}\)

Scully’s claim is that there are factors and values affecting the patients’ reasoning that are overlooked in debates by professionals.\(^{82}\) For one thing, the lived experience of being disabled (in the case of Deaf people and individuals with achondroplasia (dwarfism) in the study)\(^{83}\) or ill (in the case of multiple sclerosis (MS) and cystic fibrosis (CF) patients) gives a particular insight to the patients that in turn contributes to their moral evaluation. For another thing, the different life experiences rendered by these different conditions (be it chronic or congenital) also shades their insights regarding their condition. Thus, as Scully—a deaf

\(^{80}\) Scully et. al. 2004, pp. 1415-1425
\(^{81}\) Ibid., p. 1415
\(^{82}\) Ibid.
\(^{83}\) All the deaf patients associated themselves with the Deaf community, thus the ascription with a capital D. On another note, according to Scully, achondroplasia (also known as dwarfism, a hereditary condition where the limbs are short, though the person has a normal skull size) is commonly categorized as disability.
scholar herself—sees it, there is an undeniable relationship between the lived experience of having a disease and disability, and one’s attitudes towards (in the case of the survey,) gene therapy. Thus, the approach taken by Scully, Rippberger and others in this study was phenomenological, i.e. based on the experiences of the potential patients rather than making attempts at objective (and disembodied) description. ⁸⁴

Among the four patient groups, those with the chronic and progressive illnesses (CF and MS) were more positive in their evaluation of gene therapy than the deaf and achondroplastic participants, who judged the therapy more negatively. Besides the fact that their conditions were more stable over time, this is perhaps because the Deaf and achondroplastic, although aware that their conditions were genetic, were also less likely to think of their condition as a “disease” to be fixed. In fact, both groups reported that they saw their condition as “an integral and inescapable part of their identity, as something without which they would no longer be the person they now felt themselves to be.” ⁸⁵ This strong link between the condition and identity was strongest with the Deaf who participated in this study, all of which reported their condition as something positive, regardless whether they had the condition since birth or at a later age. ⁸⁶ Interestingly, more than one Deaf participant also gave their ethnic group as “Deaf culture” although their nationalities were Swiss, illustrating that they primarily saw their belongingness and identity not with their nationality, but with their disability.

In contrast to the patient response, medical professionals had positive evaluations of somatic gene therapy, seeing such a therapy as an extension of other medical interventions. The professionals were more likely to base their moral evaluations around medical principles (in particular, the principles of biomedical ethics attributed to Beauchamp and Childress, which we will discuss more in detail in the next chapter). Professionals evaluated their moral decisions using language such as risk-benefit balance, informed consent, confidentiality and the therapeutic imperative that seemed to be the over-riding, positive value in their ethical evaluation. ⁸⁷ One doctor is quoted as saying: “I think there is no major concern in the public… as long as we are trying to cure diseases, it’s fine.” ⁸⁸ On the other hand, this is exactly the issue that disturbs the Deaf and achondroplastic patients: although doctors saw somatic gene therapy as not ethically different from other interventions, these patients surely

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⁸⁴ Scully et al. 2004, p. 1416
⁸⁵ Ibid., p. 1419.
⁸⁶ Ibid., pp. 1419-1420
⁸⁷ Ibid., pp. 1416-1418
⁸⁸ Ibid., p. 1418
did, as they saw a special significance between their condition, their genes, and their personal identity. Notably, none of the medical professionals in the study thought that disability or illness could be part of a person’s concept of selfhood.

**PGD and disabled moral evaluation**

That said, we can return to the issue of the ethical use of PGD. The results of Scully et.al.’s survey is significant to this thesis as the insights could be used to shed light on why Deaf parents may want to use PGD to ensure having deaf offspring. That is, there may be some values or factors that affect the deaf parents’ decision to have a deaf child—reasons which are for the most part overlooked by medical professionals, who rely on an unproblematic definition of disease and evaluate the moral problems surrounding PGD according to the therapeutic imperative and medical principles.

PGD is in fact the core example in another article by Scully, *Disabled Embodiment and an Ethic of Care*. Here she again argues the lived experience of disability, which she coins as disabled embodiment—i.e. having experiences not shared by non-disabled people—affects structures of interpretation and imagination in disabled people, allowing those who are affected to see their condition in a different way.\(^89\) This not only means that they may see their condition as a source of pride, identity and belongingness; more importantly (and in accordance to Scully et.al.’s study mentioned above), this implies that even the way the disabled see themselves as moral agents can be radically different from that of non-disabled people.

Let us go back to the example of the deaf American couple who enlisted a deaf sperm donor in order to increase the chances of having deaf children. Amidst opposition by various groups who were scandalized and outraged by the couple’s action, the couple claimed that they considered having a hearing child “a blessing,” but that a deaf child would be “a special blessing.”\(^90\) After the birth of their second child Gauvin and before he was tested by an audiologist for deafness, the couple affirmed that it was important for them if Gauvin were deaf like the rest of the family. Otherwise, “he would be the only hearing member of the family, other than the cats.”\(^91\) It was apparently significant for the American couple to make their child feels like he belongs with the family by becoming deaf like them. The belief that parents could better care for a child like them is also noted by Scully. Parents feel that they

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89 Scully 2006, p. 247
90 Pyeatt 2002
91 Ibid.
are able to better anticipate the needs of their children, communicate with them more deeply, and provide better guidance if they live in the same world, so to speak. For the Deaf, they might not see electing a deaf child as handing it a disease or disability, but rather a way of allowing their children to grow up in the same culture where they belong.

The American couple even likened it to raising their children in a particular religion, or preferring a black sperm donor if both parents are black. It is of course true that being members of a religion or being black are not disabilities, but perhaps that is the point: the Deaf do not consider themselves disabled within their own community. Thus, being black and being Deaf can be similar in that both characteristics are part of one’s culture, upbringing and personal identity. In societies where the Deaf establish themselves as a culture, there are indeed wide areas for personal and community development. For some Deaf parents even, to have a deaf child is like opening the child to encounters he would have otherwise missed on if he were a hearing child in a Deaf world. Though this reasoning is peculiar to some, notably, it is also the justification used by hearing parents (at risk of having deaf children) who want to opt for cochlear implants or prefer hearing babies. Such is a unique evaluation, i.e. a positive attitude towards deafness as a form of membership into the Deaf community, is afforded to the Deaf by their embodied experience: they see their condition not as qualifying disability, but as a source of self-concept, togetherness, and even pride.

The Deaf community

Such a claim is perhaps better established if we were to know a bit more about this community which we call “Deaf”. Partly mentioned in the introduction, “deaf” with a small d refer to individuals with severe-to-profound deafness, while “Deaf” with a capital D refer to deaf or hard-of-hearing individuals who identify themselves with the Deaf culture. Again, we are taken back to the models of disability through Middleton’s elucidation: “People who refer to themselves as being culturally Deaf view deafness from the cultural or sociological perspective—that deafness is a condition to be understood and preserved—as opposed to the medical perspective—that deafness is a pathology to be treated or cured.”

But why, one may ask, should we append the word “culture” to the sense of identity and belongingness afforded by being deaf? True, the term “Deaf” is used to emphasize cultural affiliation, but to talk of “culture” presupposes other things. In Deaf.com, a site

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92 Scully 2006, p. 256
93 Scully et. al. 2004, p. 1418
94 Middleton et. al 1998, p. 1175
managed by the Deaf for the Deaf and hearing people who are interested in learning about them, this cultural membership (among other things), is said to be determined by the use of Sign language, for example the American Sign Language or ASL (or other native sign languages, as some countries have developed their own, e.g. British Sign Language, BSL) as the everyday means, and primary mode of communication. Meanwhile, a deaf person (with lowercase d) can be any person with impaired hearing, irrespective of his or her mode of communication.95

For sure, culture denotes other things than a mere shared language—the neighborhood children’s group with a secret set of words could hardly be called a culture. Other factors, such as intellectual and special training, beliefs, aesthetics, and socially transmitted codes and patterns of conduct may be part of a definition of a culture and should also be applicable to the Deaf culture. It is true that unlike other cultures (e.g. Yiddish, etc.), the Deaf cannot claim to have a particular way of dress or food, but upon reading accounts of the Deaf, there does indeed appear characteristics of culture such that we cannot simply call the Deaf community a “deaf club”.

Let us take the U.S. Deaf culture today as an example, starting from the use of ASL as a primary mode of communication. It is estimated that between 100,000 to 300,000 individuals in the U.S. and Canada use ASL as their primary language, which makes the Deaf community larger than primarily French-speaking communities.96 A group called Society of ASL Guardians also seeks to preserve Sign language, and is the authoritative body in the creation of new “words,” and the preservation of correct syntaxes in ASL. Thus, as like any other language that fulfills Wittgenstein’s criteria of being a community possession and where correct use can be verifiable by community (in contrast to the neighborhood kids’ secret codes), ASL too evolves and has grammatical rules and even etiquette for usage just like any other language.97 True to Wittgenstein’s definition of language-games, Sign can be utilized to express anything from pun and jokes to plays and prayer. Proof that ASL can also possesses cultural, and even aesthetic nuances is the possibilities of expressing sophisticated and complicated thought. Deaf theater propagated in the U.S. during the 60’s, for example—some of them original and some remade from existing plays. Some Deaf individuals had even made poetry in ASL, expressing complex thought both in the use of the “words” as well as

95 Deaf.com website
96 Padden and Humphries 2005, p. 9
97 Society of ASL Guardians website
through the visual imagery afforded to them by the gesticulated sign.\textsuperscript{98}

In aspects of education and special training, complexity and creativity is reflected in schools and universities of the Deaf, which had long moved from controlling schools established by hearing people and have found their own creative spirit. Gallaudet, a liberal arts university for the deaf where the Deaf intelligentsia thrive, even resisted the seating of a hearing president by marching to the White House in 1988. Today, institutions of higher education for the deaf and hard-of-hearing such as Gallaudet and NTID (National Technical Institute for the Deaf), the world’s largest technical college for the deaf—prove not only that Aristotle was wrong in judging the deaf as incapable of reason; they are able to produce qualified professionals in different fields.

Nonetheless, this does not mean that the Deaf community is a local hermit group or social club masquerading isolation and special education as culture. Their voice is heard even in the political and multicultural sphere. The European Union for the Deaf, for example, which comprises national associations for the Deaf around Europe, holds regular meetings and represents the interests of the Deaf at the European Union to be able to use their local sign languages and have equal access to opportunities. In all of the above, the Deaf show themselves not merely as audiological patients who are too stubborn to avail of their cure, but a social, communal, and creative force.

Opponents of the idea that the Deaf compare themselves with ethnic or linguistic communities—those who may see the Deaf community as a self-conscious, artificial attempt at posturing themselves—perhaps take this lightly. For sure, there are psychosocial bases of the culture: the Deaf may prefer to mingle and communicate with their own kind out of a sense of belongingness, and adopt it as an attitude. On the other hand, the roots of Deaf culture are also to be found historically and politically, as it established itself through resistance—for example, against the attempts by Oralists to eradicate the use of Sign language and turn the deaf into hearing mainstream; against paternalism from hearing school administrators; and by lobbying for equal opportunities and recognition.

The link between impairment and the belongingness in community should not be taken lightly, as illustrated by some in the Deaf community who primarily see their association with that culture rather than their nationality. Being Deaf can be a source of positive attitudes of belongingness to something that is indeed more than a mere “social club”. That they see their condition as opening them up to a culture rather than as a pathology makes it easier for

\textsuperscript{98} Padden and Humphries 2005, pp.133-140
us to understand why the American couple linked their decision with that of raising a child to a particular religion, or opting for a black sperm donor.

“Deaf of Deaf” and the Ethics of Care

Aside from the belongingness and pride of community, being a deaf child of deaf parents may also afford the individual a sense of personal pride and self-esteem, as well as a feeling of being “connected” with their parents. This is illustrated in an empirical study by John Obrzut and others, which concluded that deaf children of deaf parents (who may not necessarily be culturally Deaf) had a better self-concept than did deaf children of hearing parents. That is, deaf children of deaf parents had a stronger and clearer sense of identity and a higher self-esteem or self-regard, a critical index for mental health and influential in the child’s education and relationship-formation.99 These self-attitudes, Obrzut, et.al. conclude, are closely tied to social interaction and the feedback the children receive from parents, friends and significant people. The study goes that since deaf or hard-of-hearing parents were quicker to accept their child’s hearing loss and communicated earlier with their deaf children than did hearing parents—who are the ones usually taught by their children Sign language if they haven’t learned it at all—the deaf child fosters a closer social-emotional relationship with their deaf parents who reflect the accepting self-image to the child.100

This empirical study echoes precisely what Scully is talking about when she discusses the Ethics of Care with regards to disabled embodiment. Originally a Feminist critique of justice-based morality, the Ethics of Care takes into account relationships, context, and care—aspects of moral consideration that are traditionally ascribed to females but are rendered meaningless in the ahistorical and impersonal justice-based morality, which is traditionally regarded as masculine (and as noted above, commonly used in professional moral evaluation). Scully believes that care ethics is also in an advantageous position in elucidating moral issues regarding disabilities, by paying attention to the particular condition of the moral agent.101 Not only do the biological peculiarities shape moral reasoning—something we have already seen at the start of this chapter—also, by considering the social relation as morally relevant (i.e. situation of both the cared for and the carer), it sheds light on the conditions that make certain moral judgments justifiable.102

99 Obrzut et. al. 1999, pp. 239-241
100 Obrzut et. al. 1999, p. 241
101 Scully 2006, p. 251
102 Ibid., pp. 251-254
In the case of Deaf parents wanting deaf children, the parents’ concern to be better able to take care of their child apparently plays a huge role in their decision making. Parents want to feel that they are able to communicate with their child, anticipate his needs and provide appropriate guidance that they feel they can give if they share the same language and are not alienated from one another’s experience of the world. Some deaf parents even fear that they would not be able to know how to communicate with a hearing child, as was the case of one who worried that she and her hearing child would never connect, and that they would drift apart. As we have seen, it can indeed be the case that children cared for by parents like them (if they are from the Deaf culture, coined as “Deaf of Deaf,” reflecting pride in one’s heritage) have higher self esteem, perhaps giving credence to the fact that both the capabilities of the carer and cared for should be taken into account.

True, the belief that the child-parent relationship is better if parent and child share the same world is not unique to the Deaf. Hearing parents, according to Scully, use the same justification to secure cochlear implants on their children. However—perhaps because we are used to thinking in terms of the medical model—what is used as a justification by hearing parents is usually considered morally acceptable, while Deaf parents who use the same motivation, such as the American couple, are condemned as egotistical or selfish. In terms of health care, Daniels would probably say yes to implants but no to implantation of deaf embryos: the first one he would classify as “therapy” and the other he would lump together with “other social reasons” though the justification by parents are in fact one and the same. This double standard cannot be shown to be right now that we have seen that the medical model has its biases, that not all disabilities stand the same, and that there are other legitimate reasons why parents opt for deaf babies.

Conclusion

We have seen two things in this chapter. First, that deafness can be, as opposed to evaluations by professionals, a source of positive attitudes, personal identity, and even belongingness in a community. Such is the case for the Deaf community, who liken themselves to an ethnic culture or a linguistic minority. Thus, paying attention to the lived experience of the disabled is important, since this affects their moral evaluations, which can differ from the professional evaluation of their condition. Disabled embodiment and moral reasoning are connected. Secondly, aside from the particular embodiment, looking at the

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103 Scully 2006, p. 256
104 Ibid., p. 256
social relations of the Deaf likewise sheds light on how they make moral evaluations. The
Ethics of Care, which gives importance to the capabilities of the carer, thus shed light on why
some Deaf parents prefer deaf babies. Looking at both the lived experience and social
relations of the Deaf can help us understand why Deaf parents may decide the way they do—
which is not irrational after all, but which the medical model, or the principle-based approach
(which involves weighing the principles of autonomy, beneficence, nonmaleficence and
justice) render meaningless.
Concluding chapter

Beyond the principles-based approach

In the previous chapters, we saw how the medical model of disease that is commonly invoked to oppose selecting deaf babies by PGD, cannot after all live up to its standard of objectively identifying what a disease and a disabling condition is. We have seen also in the chapters regarding the social model of disability as well as the account of the Deaf themselves that disabilities are different from each other, and that some may even attach to it very positive values. Thus, what may be cause for alarm under the lenses of one moral evaluator (e.g. one who sees the therapeutic imperative as a priority, based on the medical model), can after all be justified or even praiseworthy for another person with a different set of factors that affect his moral evaluation.

In this concluding chapter, we examine what is proposed to be a “universalizable” way of dealing with such moral dilemmas, and see what it can or cannot contribute to the issue at hand. We will discuss here shortly the principle-based approach elaborated by Tom Beauchamp and James Childress. Concluding that this approach cannot lead to definite answers since the principles can be interpreted in different ways can actually work both for and against implantation of deaf babies, we then question why only one interpretation of the principles is being used predominantly to evaluate the ethical use of PGD. At the very end then, we conclude that because of the limits of the principle-based approach, we may need to look for a different framework for thinking if we still find the implantation of deaf babies problematic. This is especially so if we are thinking of making a policy for it that should be acceptable for all.

Beneficence, nonmaleficence, and the medical model

The principle-based approach elaborated by Tom Beauchamp and James Childress in the book *Principles of Biomedical Ethics* espouse four principles, namely autonomy (which refers to respecting or not interfering in the voluntary decisions of an informed and competent patient), beneficence and nonmaleficence (nonmaleficence means avoiding causing harm to the patient while beneficence means positively contributing to his welfare) and justice, the distribution of “benefits, risks and costs fairly.”\(^\text{105}\)

In the previous chapter when professional and patient moral evaluation had been

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\(^{105}\) Beauchamp and Childress 2001, p. 12
compared, we had already seen some influence of the so-called principle-based approach on how professionals make evaluations. For example, they take the therapeutic imperative, translated as the principle of beneficence, as a priority, and evaluated somatic gene therapy as preventing harm, translated as the principle of nonmaleficence. They were also more interested in the risk-benefit analysis of gene therapy.

Indeed, Beauchamp and Childress’ principles-approach have become influential in moral evaluations of bioethical dilemmas. A possible reason for this is that according to Beauchamp and Childress, the principles are grounded on common morality—or norms that they claim all morally serious persons accept as authoritative—which therefore make the approach universalizable. The principles are also mid-level principles, i.e. between ethical theories and rules, though they derived from neither of these. In fact, Beauchamp and Childress hold that since these principles are grounded on common morality, they are pre-ethical, or prior to moral reflection found in systematized ethical theories. As the principles are taken to be authoritative by all morally serious persons, these four principles are prima facie obligatory: one ought to act according to the principle unless it conflicts with another. In the case of a dilemma, the moral agent should resolved such a dilemma through specifically stating the contents of our moral principle and balancing the conflicting principles with one another.

As we have seen in the medical model, the opposition to implant deaf embryos is not only because the supporters of the model find it counter-evolutionary; they also hold that the statistical anomaly which we call deafness can objectively be called a disease, and therefore something that should be cured and prevented. We can perhaps say that the principles of nonmaleficence and beneficence morally require us not to implant embryos that screen positive for deafness; that it causes harm to the future individual to deliberately elect deafness.

Yet, as we have seen, the medical model relies on an “objective” and therefore unproblematic definition of what a disease (and thus, a harm), is—an assumption that is after all not solely objectively determined as the model’s proponents claim. The medical model assumes that disease and disability can be determined solely on biological factors, disregarding social elements—the medicalization of disturbing behavior, the value judgments

that make color our opinion on which traits are valued or disvalued, the possible engagement of pharmaceutical companies in broadening the definition of disease, and the barriers the environmental and systemic factors that exist in society that may contribute to, if not create disability.

Thus, that deafness is argued to be a harm is not even a solid refutation now that we have uncovered that the definitions of disease also bear biases towards a value, where everything that diverges from the socially acceptable becomes a pathology, without looking at the actual situation of the disabled. The fact is that different conditions of disability—though they are lumped under one conceptual category—yield different experiences and thus different ways of looking at their condition. Deafness, as we said, is a particularly good example, for not only are they able to do most things; their condition does not give any substantial discomfort and on the contrary can even be positive feature of their identities and a feature of their culture.

Besides, how can we really say that the principle of nonmaleficence holds in the case of implantation after PGD? The principle of nonmaleficence only warns against doing harm to a person, but we are not doing harm to a person by selecting him as an embryo unless his future life would be so bad that it is not worth living. This is certainly not the case for deafness. Not only are the deaf independent and can form and follow through their own life themes—the bare minimum of a good quality of life according to Kitcher; nothing, not even their lack of hearing, prevents them from meeting their vital goals which they themselves consider as important to their own fulfillment and human happiness.

This can also hold true not just for deafness but for other conditions that happen to be just lumped up in the broad categorization called “disability”. The Little People of America, for example, a group of people with achondroplasia, have also expressed enthusiasm over genetic technologies such as PGD. They expressed excitement over the possibility of not enduring a pregnancy resulting in the infants’ death, which happens to some achondroplastic couples who bear a fetus homozygous for achondroplasia. Though their condition is listed as disability despite otherwise being “normal,” some of them likewise express wishes of having children like themselves. Shouldn’t this then invoke a new meaning for “beneficence” in PGD use? Recalling the chapter in which the experience of the Deaf were discussed, shouldn’t we on the other hand call the caring aspect of the parent-child relationship a “beneficence,” since the aim of electing a child at all is to be able to choose a child which has

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110 Scully 2006, p. 249
the best future? The studies on the psychological health of deaf children of Deaf parents perhaps show that such a choice is indeed for the better.

**Autonomy and Justice: double meanings**

Beauchamp’s and Childress’ principles are also open to many interpretations—and this indeed seems to be one of the potential weak points of the principle-based approach aside from being its supposed strength (i.e. that it is applicable to many cases). For example, the principles, which have yet to be substantiated as what they mean to each case, can mean many different things in different contexts, which is probably exactly why they are present in all cultures. However, it can be argued that the principles may not mean the same for different cultures. If substantiated in different ways, the weight of each principle will also vary according to the interpretation of the moral agent. This is so because, true to the critique put forward by proponents the Ethics of Care, moral agents are not ahistorical and disembodied, but belong in a context and are colored by their own position, relations, and embodiment. How then do we attempt to resolve moral dilemmas where two types of moral agents use the same principles to justify contrary positions? In the case of the Deaf, as we see above, “beneficence” that for the medical model meant “not to inflict a disease” would be meaningless to people who do not see deafness as a disease. Instead, to “beneficence” can be attributed: the best way to raise the offspring, which is exactly to choose that they are deaf like them.

Once more, the principle-based approach can also be summoned by proponents of implanting deaf embryos as well as opponents, by appealing to the same principles of autonomy, and justice. Julian Savulescu, for example, describes for us what reproductive autonomy for the deaf who want deaf babies could mean. The goal of reproductive autonomy after all, according to him, is to select a child with the best life prospects. Prospective parents may be engaged in dialogue regarding their decisions and can be persuaded with reason to think another way, but at the end of the day, the parents themselves must make the free decision to choose what it is they think counts as “best prospects” for their future child. No doctor or politician should be able to impose on those who will bear and rear the child what they think those best prospects are, either by being paternalistic or by refusing services.\(^\text{111}\) Such an imposition by authority would not only deny the parents of their reproductive autonomy, but is tantamount to declaring the life of the future child not worth living—an

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\(^{111}\) Savulescu 2002, p. 772
inherent judgment that already bothers the disabled community with regards to genetic technology, as we have seen with the surveys of Middleton, et. al.

This also brings us to the question of justice. If the social model is right in comparing disabled groups to other oppressed minorities, then the principle of justice asks of us to make available for them the same services that are available to others. If it can work one way (implanting hearing babies to parents who are at risk of having a deaf child) but not the other, only because the former is more socially acceptable, then why not correct it in the name of justice, and grant the disabled their reproductive autonomy as long as they are not harming their child? In the case of deafness, as we have seen, the condition is not only not so bad as it seems—if one only paid attention to the lived experience and narratives of the Deaf.

“Universalizing” the socially acceptable

To conclude, what we mean to say here it this: that in opposing for the implantation of deaf embryos after screening via PGD, we use only one interpretation of the principle-based approach, that is: the approach that is most congruent with the medical model and most congruent with that which has the biggest societal warrant. This overlooks that there may be other, equally reasonable interpretations that may be less common or even hard to understand, but nevertheless not lacking in reasonability or soundness.

No wonder the promoters of the social model of disability compare the disabled with other oppressed groups. They struggle to have the same rights and interests as the majority, because the society espouses only those systems and theoretical frameworks that promote the status quo. On the other hand, if we are aware that such systems are at work, and that it is not the only way by which to do moral evaluations; if we accept that some moral evaluations are also valid within their own frameworks, how do then do we justify the opposition implanting deaf embryos without committing ourselves to some ideal sort of the human body? That we choose only one predominant way of interpreting the principles only reveals that our biases run deep. Yet, it cannot be acceptable that we would allow other non-therapeutic uses of technology simply because we praise them, and shun others simply because we find them difficult to understand.

Of course, one can always say that implanting deaf embryos is an abuse, rather than a use, of reproductive autonomy; that freedom should not be abused such as to justify “inherently”—though they themselves cannot point what this inherent wrong is without falling into contradiction—wrong decisions in the name of justice. Yet, as Savulescu rightly
points out, it is very easy to grant people the freedom to do what is agreeable to them. Freedom, on the other hand, is only true freedom if people are allowed to do what is disagreeable to others.\textsuperscript{112}

\textbf{Postscript: “Boxing with shadows”?}

The case of whether or not to use PGD to opt for children with traits such as deafness is interesting. It is interesting because people usually feel wary about genetic technologies for fear of eugenics—for being able to choose “better” traits to improve or perfect population—or at least, the portion of it that can afford it. Muin Khoury, et. al. even proposed that constrained by justice, “the prospect of healthier and more able generations of human beings in the years to come is an appropriate and defensible goal of public policy on genetics.”\textsuperscript{113}

Yet, less attention has been paid to another possibility: those who may want to go the other way around, who may want to choose traits that we usually associate with undesirability, for reasons that—after some examination, also seem justified. We take for granted that these traits are undesirable; we commend the choosing of “desirable” traits and the avoidance of “undesirable” ones, and at the same time but look down upon the justification of parents who choose differently. Could it be that we are being as eugenic today just by simply upholding the status quo, if we prefer some characteristics more than others even if we cannot sufficiently show why those other traits should not be passed on? Besides, medicine has long since moved from simply providing what it thinks is therapy: abortion, plastic surgery, and hand transplants following hefty doses of life-threatening steroids aren’t exactly therapy the last one looked, yet are condoned and even routinely offered by medical professionals.

There is the possibility that medical professionals and the patients themselves are just not meeting on the same level when it came to their moral evaluations. Recall Scully’s study that shows that the two groups can have different moral evaluations over the same case of somatic gene therapy. Then, responding to each other’s justifications and trying to put forward one’s own would just like be punching a shadow, with each party wondering why the other party would not fall down. Such was the analogy given by Jonathan Haidt, when he explains in the Social Intuitionist approach to moral judgment. Personal moral judgments, according to this approach, are already pre-made in an automatic way, in congruence to a

\textsuperscript{112} Savulescu 2002, p. 772
\textsuperscript{113} Khoury et. al. 2002, p. 483
certain set of virtues that are praised or are obligatory in the cultures where we belong.\textsuperscript{114} Simply put, social intuitions—on the one hand, that deafness is a disability and is undesirable; and on the other hand, that it is an integral part of one’s cultural affiliation and personal identity—remain what they are, despite reasoned persuasion from the other party to see things like they do. To a social intuitionist, this is simply because the intuition comes first and more directly, and justification comes later—by means of theory, principle, or rational explanation—in order to defend the intuition which may not have a rational ground in itself.

For instance, Shakespeare says that despite the persuasive testimonies given by disabled people regarding their own abilities, and their passionate campaign for reproductive autonomy, some people simply dismiss these by saying that the disabled are too personally attached to their conditions to make objective judgments.\textsuperscript{115} This is also why it is easy for some to dismiss the Deaf community as artificially posturing themselves as a culture, and to discount their wishes of having deaf babies as being selfish and harmful, even when shown that it is not necessarily so. Surely, not all will be convinced by the Deaf’s reasoned defense. Yet, if policies in the governmental or institutional level should be made regarding the use of PGD to such conditions as deafness, then we must consider not only the society’s strongest intuition but also the arguments of the disabled themselves regarding the value of disability, and their views which are also likely to be reflective and meaningful. If the voices of these people remain unheard in debates in public issues, and the double-standard that pervades the status quo remains unexamined, then we are at risk of undermining the disabled people’s own capacity to reflect upon their situation, and snatch from them terms such as “autonomy” and “justice” which we otherwise proudly claim to defend.

Nonetheless, if we are still to justify why implanting embryos that screen positive for deafness (and similar situations) should not be allowed, then we must think of categories and reasons that are beyond the principles-based approach. Perhaps we need to review the meaning of disease and disability, as Scully suggests. Perhaps we need to overcome both the medical model of disease and the social model of disability, like Shakespeare seems to indicate. Perhaps we have to rethink our philosophy of medicine. Or perhaps, whatever we do and how hard we try, we end up just boxing with shadows. If the latter is so, then, the discipline of ethics may just another word game.

\textsuperscript{114} Haidt 2001, p. 817
\textsuperscript{115} Shakespeare 2002, p. 647
References


