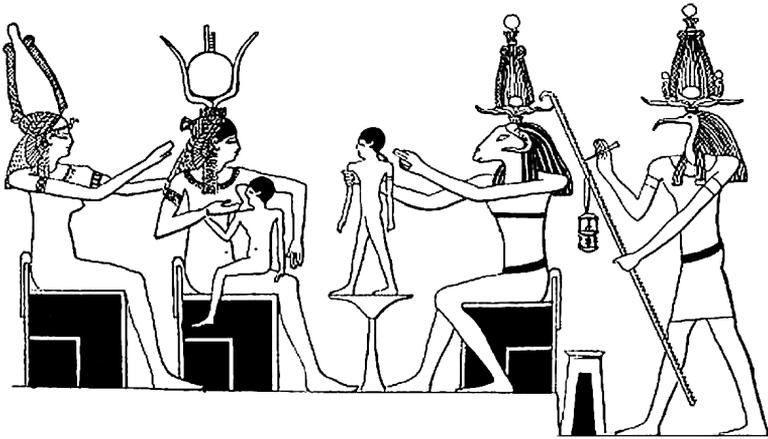


Reconstructing the Self  
Problems of Choice, Fate and Justification  
in the Eugenics Debate



*Laurens Landeweerd*

*'On Children'*

Your children are not your children.  
They are the sons and daughters of Life's longing for itself.  
They come through you but not from you,  
And though they are with you yet they belong not to you.  
You may give them your love but not your thoughts,  
For they have their own thoughts.  
You may house their bodies but not their souls,  
For their souls dwell in the house of tomorrow,  
which you cannot visit, not even in your dreams.  
You may strive to be like them,  
but seek not to make them like you.  
For life goes not backward nor carries with yesterday.  
You are the bows from which your children  
as living arrows are sent forth.  
The archer sees the mark upon the path of the infinite,  
and He bends you with His might  
that His arrows may go swift and far.  
Let our bending in the archer's hand be for gladness;  
For even as He loves the arrow that flies,  
so He loves also the bow that is stable.

*Kahlil Gibran, 'The Prophet'*

***Colofon***

*Cover illustration: Segment of the vignette of Khemnu: Khnum, the ram-god creator, creating Ptolemy on the Potter's Wheel. From: Ernest Alfred T. Wallis Budge (1885) The dwellers on the Nile, or, Chapters on the life, literature, history, and Customs of the Ancient Egyptians. Oxford: Oxford University Press, pp. 152.  
- Egyptian reads from right to left -*

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# Reconstructing the Self

## Problems of Choice, Fate and Justification in the Eugenics Debate

PROEFSCHRIFT

ter verkrijging van de graad van doctor  
aan de Universiteit Maastricht,  
op gezag van de Rector Magnificus,  
Prof. mr. G.P.M.F. Mols  
volgens het besluit van het College van Decanen,  
in het openbaar te verdedigen,  
op donderdag 19 februari 2009 om 16.00 uur

door

Laurens Landeweerd



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To  
my father, dr. Jan-Albert Landeweerd  
Kirsten and Klaas Hutschemakers, who have supported me throughout this  
ordeal more than I deserved  
And to my colleagues, friends, family, and all the people downstairs in Café ‘de  
Pieter’, who have been kind enough to provide me with their feedback



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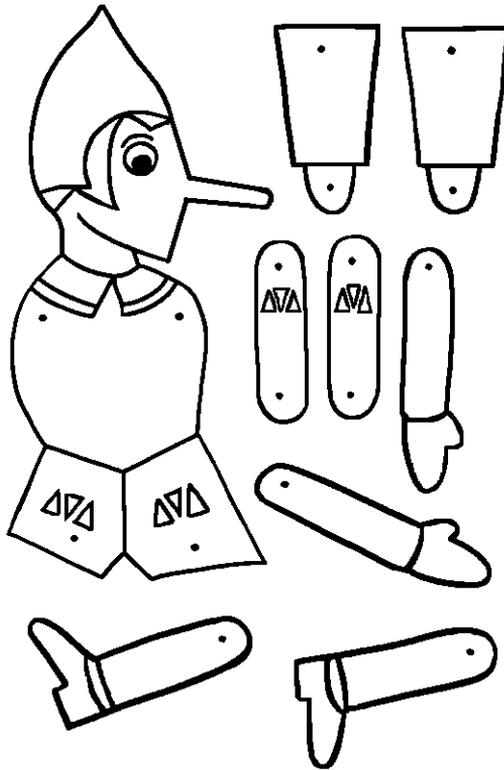
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# Preface



Archetypal accounts of man-made men such as the Golem, Frankenstein's monster but also Pinocchio are well embedded in our cultural subconscious. The idea of manmade man is seen as an attempt to be equal to the Gods: hubris therefore is a recurrent theme: man's excessive pride, self-confidence or arrogance; in creating his own simulacrum, man seeks to be equal to the Gods. Another recurrent theme throughout these myths is the problematic relation of man to his creation: Frankenstein expressing his horror over his creation, Rabbi Eliyahu of Chelm's Golem growing out of control and turning against its creator. In the case of the Golem or Frankenstein, instead of taking responsibility over his creation, the creator leaves it to its fate, taking away its chance to become truly human. Only Geppetto seems to demonstrate some concern over his creation's fate. A third recurrent theme is the created being's problematic relation to his own existential status. Frankenstein's monster in Mary Shelley's *Frankenstein* is all the more human in his pain at having been abandoned by his creator, suffering solitude, experiencing hatred and self-hatred to his unnatural origin; Pinocchio desires to become a real boy, a wish that is strangely enough granted on the condition that he behaves and is a good boy, not something typical to a real boy; in Gustav Meyrink's *der Golem*, the protagonist, Athanasius Pernath suffers from amnesia after a mental breakdown, but his inability to remember his origin and his mental breakdown refers to the fact that *he* is the Golem, illustrating man's reduction to an automaton in modern society (Spratford 2004).

In recent years these myths have resurfaced in various publications in bioethics to illustrate the ethical dilemmas brought about by the possibility to manipulate the process of reproduction by means of genetic intervention or selection. The alchemist's homunculi, servants artificially grown in a bottle, immediately bring to mind in vitro fertilisation and test tube children. The centre stage in this debate on novel human genetic technology is taken by the debate on a new eugenics. With the invention of novel technologies to intervene in the human genome, the symbolic significance of these myths has become a 'Leitmotiv' in the debate on their ethical permissibility. The debate addresses the hubris associated with such interventions. What was naturally given or made by god should not be under the mastery of man himself provoking reprehensible practices as appeared in recent history. The Nuremberger trials, for example, addressed the moral autopsy of the Nazi's eugenics programme stressing the importance of the principle of freedom and the respect for the autonomy of the patient, that is the patient's ability and right to determine its own life. Man is supposed to be unable to take responsibility over his actions with regard to those resulting from eugenics choices, which would have detrimental consequences for them and create a situation of inequality in society at large. A new eugenics programme is defended from? The idea that patient or client autonomy would not be harmed as long as one integrates the right of an autonomous choice of the individual in such a programme. On this view it would even infringe the

freedom of patients to exclude eugenics options on forehand as long as they are allowed to make autonomous choices.

This does not exclude the possibility that the individual resulting from such autonomous choices in these eugenic programmes may be harmed. If one starts discussing the possibility of designing one's own offspring, one treads on difficult philosophical grounds. The wish for one's future child to be well-equipped to deal with life by using some kind of 'enhancing' technology seems to be a just case. If a future child would become an individual equipped with traits that further his or her success in life, there seems to be no problem with such an intervention. However, a child *consisting* of certain desired traits might fall into the category of human hubris: If Man takes the position to create humans, he might risk *hubris*. Is it Man's position to decide upon such issues? A second issue with regard to eugenics may be that what is caused by Fate is less problematic with regard to human responsibility than what is created by Man. Man created by Man may necessitate an extension of the creator's responsibility over what the creator is beyond childhood. A further problem is whether a person created by another person can still think of himself as a human being, that is, as having the same existential basis as the non-created. This may possibly even take away his ability to decide and to develop his own preferences, since he cannot but embrace the circumstances that led up to who he has become. These issues necessitate an articulation of what we conceive of as a free and self-determining agent. A well-founded philosophical and anthropological conception of identity or the self would seem to be relevant for the discussion on eugenics. After all, eugenics aims at modifying or steering the genetic identity of posterity.

The claim I will defend in this thesis is that bioethics does not include a concept of the self. Bioethics shies away from implementing an explicit anthropology in the strategies to solve problems. It shies away from discussing difficult issues of a more metaphysical nature in general, focusing merely on a presupposition of rational moral agency and on fair distribution of goods and opportunities. But in this case, as I will demonstrate, one cannot rely on an ethics that deals with the equal distribution of goods, rights and responsibilities between people, since eugenics choices are constitutive of the people that are the result of them. There is no person to consent yet. Eugenics is a particular case for ethics, since it does not merely concern an internal ethical case, but also the preconditions of ethics. From an ethics-internal perspective, this preconditional layer is not visible. This necessitates a deeper analysis of the metaphysical grounds of ethics in general and the problem of personhood in specific.

There are three general conceptions of metaphysics in western philosophy (Bor 2005). The first one is the tradition that is preoccupied with 'the higher', the second one is preoccupied with issues of being and the third concerns that branch of philosophy that is preoccupied with the preconditions of knowledge. The first conception has its origin in the works of Plato, although the term in itself was not

conceived of until much later. Plato's theory of forms, the theory in which he poses that material reality is no more than a weak mirror image of an ideal world of archetypical forms, was integrated into Christian theology, most notably by St. Augustine. This gave cause to the aberration that metaphysics is no more than a side-branch of theology. The term in itself has its own peculiar history. It is said to have been derived from the fact that Aristotle's ideas on divine reality came after his treatise on nature (*μετά* (*metá*), meaning 'after' and *φυσικά* (*physiká*), meaning 'physics'). Since Aristotle's works did not appear in an edited form until well after his death, one could say that the term came into existence merely as a scribe's notation system. Aristotle's concept of a 'first philosophy' comes closer to the second conception of metaphysics<sup>1</sup>, which is the branch of philosophy preoccupied with issues of being, asking questions on the nature and status of reality, as either independent of our minds or as part of our minds. Therefore it also concerns the question of the nature of human being. The third conception of metaphysics has its origin in the philosophy of Immanuel Kant, and concerns the preconditions of knowledge. Within all three conceptions, metaphysics addresses different notions of existence (including human existence), property, space and time, causality and potentiality and objecthood. To assess the ethical permissibility or non-permissibility of a new eugenics, one will have to peel away the different paint layers that were put over the original philosophical framework of these approaches. One has to look at the status and presuppositions of contemporary medical ethics, its basis in neo-liberal philosophy and the moral autopsy of past eugenics experiments, the schism between Anglo-American and Continental (read German and French) philosophy after the First World War and the linguistic turn in philosophy, ending with the downfall of universalism in logics (which is often associated with the downfall of traditional metaphysics). The issue of eugenics necessitates, so I will argue, an analysis not only on the level of an ethics of people's rights and responsibilities, but also on the level of the preconditions of those rights and responsibilities. Furthermore, it necessitates an analysis on the level of personhood and therefore of the preconditions and status of human existence, the interrelation of human existence between humans and the relation between human existence and existence in general. If one wants to avoid king Nebuchadnezzar's mistake of assembling a giant with a head of gold, chest and arms of silver, belly and thighs of bronze and legs of iron and feet of clay, one will have to address the issue of eugenics on the level of both the second and the third conception of metaphysics, what is (human) existence, and what are the preconditions of our (moral) knowledge.

<sup>1</sup> This conception of philosophy however does not first appear in Aristotle's philosophy. The controversy between Parmenides of Elea's idea that change is impossible, and existence timeless and Heraclitus' idea of change as central to the universe is also of a metaphysical nature in this sense.

# Introduction

This critical analysis of the discussion on eugenics started out as a general criticism of bioethics: after my first introduction with this field some six years ago, it appeared to me that many debates in bioethics, medical ethics in specific, had lost their connection to the practical issues they were to be applied to, retreating instead to debates on methodology<sup>2</sup>. In this focus, bioethics appears to have lost the ability to retain a picture of human identity, or the self. I discuss this issue with a specific attention to current debates on a new liberal eugenics. Especially here it is important to uphold a proper conception of the human self. To discuss this issue it is necessary to research both genetics practices and genetics theories, both practical and theoretical (bio)ethics and both theoretical ethics and metaphysics. I first explore the current framework for ethics in reproductive medicine to demonstrate the current medical potential to and medical ethical restrictions on a new eugenics. Then I move to the wider discussion on eugenics. Proponents of such a new eugenics contest several existing rules and guidelines, or reinterpret them on the basis of their background philosophies. After this, I attempt to demonstrate how a reorientation on the subject of the self can aid in clarifying the moral limitations of, and possibilities to a new eugenics.

The Human Genome Project has significantly increased knowledge of the role of DNA in coding for human traits. The number of applications of this knowledge to genetic diagnosis has grown accordingly in the past few years. Combined with other breakthroughs in the field of genomics, this justifies it to speak of a scientific revolution. Since the start of the human genome project, the estimate of the amount of genes that make up the human genome has decreased dramatically from 100.000 to 20.000, which seems to indicate we are simpler beings than we might have thought. Still, the way genes determine our phenotype appears to be much more complex than initially thought; most traits seem to be determined not monogenetically, but by a complex of genes and non-genetic factors. Recent developments in genetics indicate that most of our traits are not simple monogenetically determined Mendelian traits, but polygenic at the least, and in most cases even multifactorial. The promise of an applicable human genetics science has been tempered by these facts. But we still overestimate the role of genes in human identity and this could lead to a wrongful application of health resources (Baird 2000). Nevertheless, we can expect a number of technologies to be developed by which one can intervene actively in the genetic make-up of posterity, be it on an individual level (through counselling) or on a population level (through large-scale genetic screening). Not all aspects of this revolution are embraced as progress. The traditional goals of medicine are often defined as providing therapy for diseases and disabilities and providing the means to prevent them from occurring in the first place. Current developments in biotechnology and medicine have created the possibility of going beyond this medical paradigm of therapy and prevention: with

<sup>2</sup> My thoughts on the issue of epistemological reductionism that is the subject of the last chapter were therefore the first thing to get entrusted to paper.

novel medical technologies, one could also enhance human capacities. Specifically in the area of reproduction an intensive debate has taken place. The application of genetic testing and selection to enhance future people's capacities has been indicated as the return of an old moral aberration of medical sciences: eugenics, with a clear negative connotation on the 'eu' in this phrase. The current debate on eugenics is to a certain extent speculative, but there are several technologies can in principle also be applied for a eugenics agenda, a preparatory discussion is not redundant. In this thesis, I do not seek to define a new criterion to delimit therapeutic forms of prenatal genetic selection from enhancement. Nor do I attempt to delineate what the limitations should be for the current applications of prenatal diagnosis. To a certain extent, the choice for these technologies as case-example are arbitrary, since this thesis deals with how the debate on a new liberal eugenics demonstrates the problems of a lack of a concept of self, not of what the potential problem may be with novel genetic technologies. After all, there are other, non-medical-technological ways to introduce eugenics such as selective partner choice. I merely take these novel technologies developed in prenatal diagnosis as an example of novel possibilities for a eugenics, and this to demonstrate that not all speculations on a new eugenics are idle fantasies and hollow speculations. In discussing these technologies, I attempt to demonstrate that the current framework of several approaches in medical ethics on prenatal selection might work for current practices, but possibly not for a new eugenics. This however does not mean that I take it to be self-evident that the process of technological developments in prenatal diagnosis is bound to head towards a new eugenics, nor that the existing framework in those approaches in medical ethics is not sufficient for these current practices.

The word eugenics is derived from the Greek and literally means 'of good birth'. Eugenics aims at steering reproduction to aim at people of good birth. Ethicists in favour of going beyond the therapeutic application of genetics in the reproductive area, that is proposing to enhance through novel reproductive technologies, articulate their arguments through principles established by the liberalist tradition in bioethics. Liberalism is the dominant approach for bioethics, although it also incorporates more pragmatist approaches as well as specific version of liberalism, such as principlism, specified principlism as well as other approaches such as hermeneutics, care ethics, narrative ethics etc. . Specifically in how it was defined, this liberalism emphasises social justice, a form of justice that relies heavily on the presupposition of autonomous choice as a self evident capacity of humans, and the principle of respect for the exertion of that capacity as a grounding ethical principle This applied form of liberal philosophy emphasises methodological issues in ethics whilst leaning heavily on utilitarianism, contractarianism (or contractualism), the analytic reception of Kantian ethics, and pragmatism. One important author who combined these four traditions was John Rawls (1921-2002). Through Rawls' philosophy the principles of bioethics, in particular the concept of patient autonomy, as formulated by Beauchamp and Childress (1979), are partially indebted

to the moral autopsy of the eugenics experiments in the beginning and middle of the 20<sup>th</sup> century.

On the basis of the principle of respect for parental autonomy – defending the best interests of the child to come-, one could also define a parental right to choose the best properties for their offspring. Therefore, the autonomy of prospective parents is not necessarily at stake if one were to aim at a reintroduction of whatever kind of liberal eugenics programme as long no external force is exerted on the prospective parents . It depends on the kind of conditions under which one would put it to practice. If everyone has equal access to genetic techniques, this would not infringe the rights of future parents, whilst it may actually result in an equalization of genetic potential, which would benefit equality in society rather than increasing inequality (Buchanan *et al.* 2000). Provided one takes certain precautions to protect the liberty of the individuals involved, eugenics might be considered permissible.

Certain standard precautionary measures are already the basis of how prenatal genetic counselling and other forms of genetic counselling are arranged in their existing applications. But then, what would be wrong if one were to offer unbiased advice and if the envisaged prenatal selection or intervention does not conflict with the interests of the future child? If no individual parental couple feels socially obliged to make eugenics choices towards its offspring, why would one only offer medically indicated forms of prenatal selection and intervention? It would be fundamentally more liberal to allow for the coming into existence of people with comparable levels of talent. The autonomy of the persons resulting from eugenics choices could also be transgressed by parental choices to define their genome. This is the issue brought to attention by Jürgen Habermas in his *The Future of Human Nature* (2003), providing a philosophical perspective which I will use later on in my thesis to strengthen my own view. As he states, someone might feel locked in by his parents' choice to have him brought into the world with a specific genome, coding for specific talents or capacities. Another problem might be that one has a right not to know one's genetic makeup. Although this right was defined predominantly as a right to remain ignorant of one's risks to develop a certain condition, this right should possibly be made to apply to one's genetic makeup in general. Still, some state that there is no categorical distinction between biology and education (Buchanan 2000). And since we do not perceive of any moral problems with parental influence on how children will become through education, why would there be a problem with such influence on a biological level? Why would there be a difference between the contingent nature of the origin of our genetic make-up now, and a chosen make-up? From this perspective, it seems that the very principles used to oppose a new eugenics can also be used to defend it. This might lead some to conclude that there is nothing wrong with reintroducing eugenics, as long as one does on the basis of the ethical principles mentioned. It would not need a change of current guidelines on prenatal genetic counselling.

Proponents of a new liberal eugenics base their defence on a similar philosophy (Buchanan 2000). They tend to circumvent the sensitive issue of who is to hold authority over which applications of genetics are beneficial to posterity. What is supposed to be an enhancement and what not is derived from a (pseudo-)scientific scale, and the boundary between the two is taken as a moral guideline. Speculations on a new eugenics that are framed in this objectivist conception of superiority are mostly dealt with in relation to questions of moral agency, freedom of choice, citizenship, and the potential one needs to develop in a liberalist society.

This picture of a new liberal eugenics is hard to retain. If one endorses a new eugenics, one would need to leave behind liberalism, since not all of the options a new genetics might offer would be in line with the concept of human enhancement. If one were to find a neutral criterion with which to describe which genotypes would be superior and which inferior, the ways in which society would want to use this distinction to 'enhance' future generations might not always coincide with parental wishes. But if one endorses liberalism (in the sense that prospective parents should be allowed open access to genetic diagnosis), one cannot hold on to the idea that this would, in all cases, constitute an enhancement of human genetic stock. Firstly, there is no clear picture of what would actually constitute an enhancement. Enhancement, as well as eugenics in general, is a normative concept, dependent on a normative idea of what is supposed to be a superior and what is supposed to be an inferior geno- or phenotype. Secondly, even if one were able to make a neutral distinction between superior and inferior genetically determined traits, this in itself does not constitute the only possible basis to choose one's children's genes. Thirdly, a truly liberalist approach to genetics beyond medical applications would not stand in the way of parental decisions on their children's genes even if it were to be based on arguments other than those derived from the scale superior-inferior. For this reason, the concept of a new and liberal eugenics is at odds with itself. Under the guise of scientific neutrality, 'eu'genics holds implicit normative judgements on what is to be seen as a good trait and what not and the word 'eu' in eugenics, especially in what it excludes, will always clash with the preferences that some prospective parents will hold for themselves or their children.

Before moving on to speculate 'beyond therapy', one historical issue needs further attention: the eugenics movements of the late nineteenth and early twentieth century. This era is often taken as the starting point of any discussion of a liberal eugenics. The history of the eugenics movement remains an important moral orientation point in the discussion on applications of prenatal diagnosis. It has had a major influence on the perception of human genetics. The eugenics movements of the past, although seemingly based on a moral good (to preserve the genetic health of the population) became derailed. The eugenics science influenced the genetic policies of the Third Reich, and can be held, if not directly, then indirectly responsible for the genetic cleansing during the Second World War (Paul 1998).

Negative eugenics, the prevention of procreation of those thought to be defective or of lesser genetic quality, was the 'scientific' backbone of the Holocaust and of forced sterilisations and compulsory euthanasia performed on tens of thousands of disabled people; estimations add up to at 250,000 (Eriksson 2000). Positive eugenics, the propagation of procreation of those thought genetically superior, led to the founding of the Lebensborn projects. Outside of Germany, throughout the western world forced sterilisations took place on the basis of traits thought hereditary such as alcoholism, epilepsy or feeble-mindedness. These eugenics policies and their history have become an absolute moral calibration for the way we want to integrate genetics in contemporary society. Policies that are aimed at the health of the general population are not introduced through a steering of reproduction, neither negatively nor positively. This is seen as an infringement on people's right to reproductive choice. There were also forms of eugenics that did not aim at state-policies. Several eugenics movements tried to create a basis for responsible reproduction on the basis of eugenics ideas through responsible citizenship. In that sense, these forms of eugenics were not coercive. Contemporary proponents of a new eugenics provide for arguments that are more similar to this approach. If one wants to clarify whether such a eugenics – i.e. one not enforced from above, but introduced in a liberal and democratic fashion from below – could be allowed for, one needs to investigate all dimensions of the nineteenth and twentieth century history of eugenics.

A major but rather unfounded suspicion on genetic selection in reproductive medicine is that it is aimed at changing the genetic make-up of posterity in a fashion similar to the historical eugenics programmes. The ends of current applications of genetics cannot be compared to the goals that old eugenics science set itself. Nevertheless, if genetic diagnostic techniques were implemented on a broad scale, the potential effects might eventually be that certain hereditary diseases would cease to exist; in the same way preventive medicine has managed to eradicate the small-pox virus through large-scale inoculation programmes (Barret 2007). The complete eradication of a specific disease is tempting for any physician. In the case of small-pox, inoculation provides the cure and the eradication of the virus, but in the case of hereditary diseases one is not just preventing a disease one is preventing a certain genotype from occurring in posterity. This has additional ethical consequences. According to Jürgen Habermas (Habermas 2003), one should not, in the interest of population health, blur the difference between the prevention of viral or bacterial diseases and the prevention of the birth of people with a disposition to develop hereditary diseases. For this reason, the genetic health of the population is not a factor that is taken into account as a prime motivation for offering prenatal diagnostic techniques. Instead the ethical considerations should remain restricted to medical necessity on an individual level; the positive medical effects on a collective level. Seen the history of eugenics, it is unwise to address issues of the genetic make-up of posterity explicitly.

In spite of the dualism mentioned with respect to liberal principles and because of this history of eugenics, the stance within the medical area as well as the (inter)national stance on the new reproductive technologies remain to date rather restrictive. Prenatal diagnosis should only be offered to (future) parents with a known, increased risk for conceiving a child with a certain hereditary disease. Parents cannot be forced to take a prenatal diagnosis; nor may one influence parental decision-making. The (future) parents cannot opt for any diagnosis that is currently technically possible, nor can they opt for just any genetic intervention. And, although there is much speculation on what could be done with reproductive genetics if one were to venture beyond its current uses, in practice there is little space for a new eugenics; whether it be a liberalist version or not.

The current problem is whether the traditional division between therapy and prevention on the one hand, and eugenics and enhancement on the other can still hold as an ethical criterion. This thesis tries to bring to the surface ethical aspects of a possible eugenics that remained underexposed due to the predominance of (neo-)liberalism in the debate, most notably, an account of personal identity. First, I will analyse the current ethical framework in their treatment of this issue of a genetic selection that apparently aims at a reconstruction of humanity's future identity. Secondly, I will attempt to develop of another kind of ethical framework, specifically with regard to the issue of the self. To this aim, I will analyse more deeply than I did above, the ethical debate on reproductive technologies (chapter I). Then, I map the differences and similarities between old-style coercive eugenics and liberal eugenics (chapter II). Subsequently, in chapter III, I will show that there are several fundamental conceptual problems in defining what would constitute a eugenics claiming that arguments for a 'eu'genics are also arguments for a 'dys'genics. . In this chapter, I provide with a series of counter-intuitive case studies (or examples), such as prenatal selection to either avoid or purposely put in the world deaf children, children with dwarfism and speculations on purposely putting in the world children with Marfan syndrome. The analysis of these examples is meant to demonstrate that one has to justify any praxis, be it conceived of as eugenics or dysgenics (choosing for a genotype considered to be a disadvantage), at least with the current vocabulary in liberal eugenics . In chapter IV, I look at the problematic features of liberalism in its approach of ethics in general and eugenics in particular. Because of the predominance of liberalism in the treatment of the subject of eugenics, it can merely be seen from one perspective. It is always regarded through the lens of a one-sided account of parental reproductive rights (presupposing the aforementioned rational moral agency) and an idealized account of individual opportunities within a state with the least possible intervention in the morals of its citizens (which is to lead to a fair distribution of goods and equality of opportunities). In chapter V I give a more in depth-analysis of the relation between autonomy and personal identity. In chapter VI, I show the problem of methodological reductionism in the application of such criteria in practical ethics. This

critical analysis demonstrates the necessity of an ontology, or attention to substantial issues in bioethics rather than merely the formal properties of ethical reasoning. It demonstrates the necessity of a reintroduction of the concept of the self in practical ethics, specifically with regard to questions of eugenics. The concept of identity or of the self was not excluded in the ethical debate without reason. The idea of an authentic self, as a core essence of one's being has become highly contestable. In Chapter VII, making use of the works of Jürgen Habermas and, particularly, his reading of Søren Kierkegaard's philosophy, I shall attempt a reconstruction of the concept of the self as not an atomistic self, not an authentic essence, not as core substance, but as process, as relational.

*Chapter I*

The Ethical Debate on the  
New Genetics Science



## 1. Introduction

In the past few years we have witnessed huge steps forwards in reproductive technology. Specifically genetic diagnosis has created a range of possibilities. This carries along benefits for prenatal care as well as carrying along unprecedented ethical dilemmas that demonstrate some more problematic sides of several basic notions in medical ethics. These new technologies also led to a widespread public ethical debate on the desirability of these technologies. Concerns are felt specifically with the potential eugenic application of these technologies. To have a correct overview of the possibilities to a new eugenics, one needs to explore the actual developments in the field of human genetics in recent years. This is important to avoid deviating from what is actually occurring into the realm of science fiction - something that happens all too quickly when talking about eugenics. In this chapter do not want to put current guidelines and regulations on prenatal diagnosis up for debate, nor do I aim at defining a new ethical criterion as a basis of such regulations. I mainly address these guidelines and regulations since cannot discuss the speculative subject of a new liberal eugenics without looking at current practices and existing technologies. This chapter will therefore give a taste of the debate on ethics in (genetics for) reproduction rather than taking a position in this field. It is important to do so since if one omits such a step, one risks venturing beyond practical discussion of a liberal eugenics in to the realm of science fiction.

There are two important technologies with regard to the prenatal diagnosis that deserve attention: prenatal genetic diagnosis and pre-implantation genetic diagnosis. Prenatal genetic diagnosis is a sub-variant of prenatal diagnosis on the basis of genetics. With prenatal genetic diagnosis (future) parents with a severe hereditary condition in their family, such as Huntington's disease or Fanconi anaemia, can either prepare for the birth of an affected child, or opt for a termination of pregnancy the embryo or foetus is found to have the condition. Preimplantation genetic diagnosis is a diagnosis of a non-implanted embryo resulting from a fertilisation in vitro. The technique was developed in the second half of the 1970s and some anti-abortionists criticise the technique. Pre-implantation genetic diagnosis was applied for the first time in 1989 in London (Schrandt-Stumpel 2000). The technique involves testing for a certain hereditary condition, and if found, not implanting that specific pre-embryo. The major advantage of preimplantation genetic diagnosis above standard prenatal (genetic) testing is that the parents - the mother in particular - do not have to go through the difficult process of choosing to abort the foetus or not.<sup>3</sup> Pre-implantation genetic diagnosis combines in vitro

<sup>3</sup> Initially, issues concerning abortion formed the conceptual framework of the discussion on prenatal diagnostics, since providing prospective parents with information on the health status of their future child is often not where it stops when this information is negative. However, with this novel technology, one would have to criticise in vitro fertilisation as well, which until now has not raised as many objections by anti abortionist movements. By now, the discussion on both these issues has moved to the background.

fertilisation with genetic diagnosis and is applied to the embryos that are generated in vitro before implantation. It involves removing one or several cells from pre-embryos produced by fertilisation in vitro, and analysing the genetic material in the cells to test for a specific trait. The aim, of course, depends on the trait one tests for. One either implants a pre-embryo that demonstrates the trait one aims to produce, or one does not implant the pre-embryo when one wants to avoid a specific trait. The former is found to be more controversial. As prenatal genetic diagnosis, preimplantation genetic diagnosis is therefore mainly applied to prevent the birth of a child with a severe disease, but it comes at a lesser cost.

In some instances preimplantation genetic diagnosis is used to aim at a *specific* desired genotype rather than selecting against a specific genotype. This is the case in testing for a specific DNA-compatibility with a brother or sister suffering from certain genetic diseases. When a child is affected by a disease such as Fanconi anaemia or Thalassaemia, and no other sibling is found to be DNA-compatible with the affected child, one can aim at a preimplantation genetic diagnosis. This allows one not only to select away from the disease in question, but also to select the pre-embryo that is DNA-compatible (instead of leaving it to chance). One can then use blood from the umbilical cord to develop medication. The technique involved poses no risk for the newly-born child.

With the development of preimplantation genetic diagnosis, the ethical discussion on the limits of the applications of prenatal genetic testing has moved from issues surrounding abortion to areas not directly related to pregnancy and birth (de Wert 1999). The major issue in prenatal genetic diagnosis is that selection is performed through abortion. Preimplantation genetic diagnosis is less susceptible to anti-abortionist critique, since it is performed through non-implantation (de Wert 1999). The anti-abortionist would need to criticise the technique of in vitro fertilisation in general, before he could criticise this particular application of it. In criticising in vitro fertilisation, one enters the debate on when a human being starts to become a person: at conception, at birth, or somewhere in between. Therefore, the social consequences of preimplantation genetic diagnosis are more central than the nature of the technique as such.

Preimplantation genetic diagnosis has opened up a broader debate and has given rise to specific concerns with regard to human (in)equality, eugenics and disability rights. Some voice the fear that by implementing these techniques on a broad scale, the tolerance level for people with an impairment will decrease (Kristol 1993). A less than perfect child may be considered a burden to society; a burden that society is less willing to carry when there are ways to avoid disabilities. If the birth of a child with an impairment remains a question of fate or chance, society may be more willing to contribute to the costs resulting from the care that child needs throughout life. If the birth of a child with a disability is the result of a refusal

to opt for a prenatal diagnosis, the child would be the product of a choice made by individual parents. In such cases, society may be less inclined to contribute to the costs and burdens that result. This concern is voiced by representatives of disability groups and by some feminists. Pressure from the community on future parents might rise, to opt for techniques implying abortion or in vitro fertilisation when there is a risk. As voiced by B. Knoppers and R. Isasi “there is also hesitation to adopt this technique because of its eugenic potential” (Knoppers 2004; pp. 2697). This concern about prenatal genetic diagnosis and preimplantation genetic diagnosis that I take central to the discussion in this thesis is that the technique will be applied non-medically; to select preferred features rather than to avoid severe handicaps or diseases. Knoppers and Isasi state that “[w]hile often used for political expediency in the public debate, it properly remains limited to state programmes (e.g. Nazism) and has no value or place in the complex choices facing couples and their physicians.” (Knoppers 2004; pp. 269). Although this opinion is backed up by most ethicists in the area of human reproduction, there is a renewal of the eugenics debate in which this opinion is contested on the basis of the same arguments that are used against eugenics (right to autonomy, freedom of choice etc.) or by demonstrating the relativity of the distinction repro-genetics/eugenics. Therefore, a more in depth philosophical investigation of the arguments at play seems called for. The concern on eugenics referred to by Knoppers and Isasi is that if technological possibilities keep expanding, one will ultimately select genetically or modify where necessary to create more intelligent, more beautiful and stronger people. But what of future people’s autonomy? What of one’s right to have an open future? Would such a utopian approach of posterity be unnatural? Would a vocabulary of choosing children instead of having them run counter to what man’s attitude to posterity should be?

The concerns expressed by, amongst others, organisations for disabled people, centre on the following questions: does the development of new reproductive techniques stem from a eugenics background? Does the concept of prenatal selection include a particular ideal of genetic enhancement of the species? And, if such a new eugenics agenda is proposed, will we not make the same mistakes the old eugenics movements made in the early and mid twentieth century? This questions whether the development of techniques such as prenatal genetic diagnosis and preimplantation genetic diagnosis has an implicit eugenics agenda is highly sensitive. One does not want to go down a slippery slope towards an old coercive eugenics.

In this chapter, I shall provide an account of the current state of affairs on new reproductive techniques, specifically those that emerged from the recent discoveries made in the area of human genetics. First I shall give an overview of these new techniques and the way they are applied now in reproductive medicine. Here I shall focus on those issues in human genetics in the reproductive area that are relevant for the ethical debate. I shall then give an account of how these techniques are

discussed in medical ethics I shall focus on the problems that arise if one would emphasise autonomy, non-directiveness and informed consent as main ethical issues (something that can be perceived particularly in more extreme liberalist approaches in medical ethics). I shall try to demonstrate that the focus on informed consent can obscure other equally (or even more) important ethical issues to the debate. This is due mainly to the specific interpretation of the concept of autonomy that lies at the heart of the principle of informed consent. It is necessary and worthwhile to provide a painstaking analysis of this interpretation, since this will provide the basis/foundation for the subsequent chapters. In this chapter I shall conclude with the ethical questions that arise out of this analysis.

## **2. A General Overview of Genetic Testing and its ethical issues**

Genetics is often seen as Columbus' egg for twenty-first century medicine. For the past decade and more, not a week goes by without an article appearing in some journal stating that the gene for this or that trait or disease has been found. In most cases, such discoveries are used to develop a genetic test or diagnosis<sup>4</sup> (Somberg 1996). Most diseases or conditions that can now be tested for are monogenetically determined, whilst most traits, diseases and disabilities are determined multifactorially. This includes tests for cystic fibrosis, sickle cell anaemia and Huntington's disease. Until now only those conditions that are determined by one gene can be tested for easily, and only those have a useful degree of predictability (Scriver 1999), although with monogenetic diseases the chance for a phenotypic expression of the gene is not always 100% either. Most hereditary diseases are multifactorial because no single gene but several genes, and not solely the genes but also environmental factors (e.g. nutrition patterns) can play a role in whether and how these diseases develop and applications outside of diagnostics are not that manifold. Therefore, the first promising results may have led to somewhat premature conclusions. The table below lists different applications of genetic diagnosis, according to their ethical relevance to get an idea of what potential current genetics does hold (see Table 1).

<sup>4</sup> Such diagnoses can be used to test for a disease or a certain condition in a person, for example, to predict and possibly prevent the occurrence of such a disease, or on a foetus. In the latter case, the diagnosis is performed either to inform the parents of possible health problems of their future child or to terminate a pregnancy of a child that will have a severe birth defect (or to refrain from implanting that zygote if the test is performed before implantation when fertilising in vitro).

**Table 1:** Classification of applications of genetic testing<sup>5</sup>

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**I. Genetic testing on a present patient:**

Genetic diagnosis to confirm the actual occurrence of a certain disease or disability, already manifesting itself in a patient.

Genetic testing to confirm the hereditary predisposition or susceptibility to develop a disease or disability.

**II. Prenatal genetic testing:**

Genetic testing to confirm a hereditary predisposition or susceptibility to develop a certain disease or disability in utero (prenatal genetic diagnosis).

Genetic diagnosis to confirm the actual occurrence of a certain disease already manifest in a foetus in utero (prenatal genetic diagnosis).

Genetic diagnosis prior to implantation when applying a selective fertilisation in vitro (preimplantation genetic diagnosis).

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The division shown in Table 1 indicates a difference between standard (postnatal) genetic diagnosis and prenatal genetic diagnosis, although both types can either be used in a predictive way or to confirm the nature of a certain disease or disability that is already manifest. Normally a diagnosis is only used to confirm whether the patient is suffering from a certain disease or has a specific disability, or has the disposition to develop that disease or disability. The difference with prenatal diagnosis is that the outcome may influence parental decisions on whether or not to continue a pregnancy in the case of prenatal genetic diagnosis or whether or not to implant in the case of preimplantation genetic diagnosis. A further distinction running through both forms of genetic diagnosis is that diagnosis can be used to confirm the occurrence of a disease or the predisposition to develop it. In the latter case, it should be stressed that a genetic test will only show a probability, not a certainty. In this case, one often refers to the technique as genetic *testing*, rather than genetic *diagnosis* because diagnosis refers to a symptomatic, rather than a pre-symptomatic test. A test does not necessarily imply that the subject that is tested already developed the condition in question. Instead, a diagnosis only confirms a suspicion that arises from the fact that a patient already manifests certain symptoms or signs. A test rarely predicts the future occurrence of a disease with a 100% certainty. It therefore describes risks rather than actualities. Whether these techniques are applied to test for treatable or untreatable genetically-determined diseases is relevant to the ethical analysis of the application of these techniques. After all, on the one hand, providing a (possible) patient with a cure has the highest priority, whilst in the other, (fore)knowledge of having a certain disease without possible therapy causes additional ethical problems to arise. Genetic testing and genetic diagnosis both carry along an issue of steering the genetic make-up of

<sup>5</sup> Partially based on de Wert (1999)

posterity when applied in the prenatal stage (through selective abortion or selective implantation).

The International Bioethics Committee of UNESCO (IBC) divided the different types of prenatal diagnosis (preimplantation diagnosis included) into five categories when looking at the factors of early or late onset, monogenetic or multifactorial and severity<sup>6</sup> (see Table 2 (Revel 1995)). The purpose of the distinctions made in Table 2 is to help and facilitate ethical analysis.

6 Most hereditary diseases are multifactorial because no single gene but several genes, and not solely the genes but also environmental factors (e.g. nutrition patterns) can play a role in whether and how these diseases develop. Not only is it harder to determine whether someone is a carrier of these genes, but also it is difficult to establish whether being a carrier will actually lead to the disease developing in the individual. Not differentiating between these two types of hereditary disease has already led to much misunderstanding of the general character of hereditary diseases and therefore also of the ethical dimension of testing for them Carmen Sánchez Monserrate. (1996). However, it should be noted that the difference between these two classes of genetic determinacy is gradual rather than absolute.

**Table 2:** Classification of genetic alterations relevant to counselling<sup>7</sup> (examples provided)

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**I. Lethal in childhood or grave malformations**

- Tay-Sachs (GM2 ganglioside, hexaminidase deficiency, life-span 4 years)
- Mucopolysaccharidoses (Hurler, San Filipo, death in second decade)
- Gaucher Type II (betaglucosidase, lethal in childhood)
- Cystic fibrosis (respiratory disease, median life-span 25 years)
- Achondroplasia (nanism, malformations, FGF receptor I)<sup>8</sup>
- Trisomy 21 (Down's syndrome, non-hereditary)<sup>9</sup>

**II. Viable-if-treated hereditary diseases**

- Phenylketonuria (low phenylalanine diet)
- Galactosemia (exclusion of milk)
- Hemophilia (X-linked, Factor VIII or IX replacement)

**III. Late appearing genetic diseases**

- Huntington's chorea (40 years; early if CAG repeats >> 32 in HD gene)
- Myotonic dystrophy (onset in adult life, CTG repeats in DM-1 gene)
- Familial hypercholesterolemia (onset 30-40 years, responds to treatment)
- Alzheimer disease (at least 3 genes, Presenilin I, II, APO-E)

**IV. Predisposition genes**

- Spondylarthritis (HLA B27 - 600 higher chances)
- Cancer: melanoma, bladder (environment factors), breast (BRCA-1, -2 in familial cancer which are 5% of all breast cancers, so role in most cases uncertain)
- Schizophrenia (but in psychiatric diseases phenotype may be malleable)

**V. Multifactorial diseases and their genes**

- Diabetes 5% incidence but 6 genes (e.g. MODY = glucokinase gene)
  - Cardiovascular diseases 20% incidence but how many genes? (e.g. Cholesterol Receptors, angiotensin locus, coagulation factor V)
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According to Revel's report (Revel 1995), the equation between genes and diseases was still too often taken for granted. To avoid this, this table was drawn up to classify genes with relation to the clinical pathologies that are associated with them. But if one uses these same categories to demonstrate what the consequences are if extended to prenatal selection, one can immediately perceive of several important ethical issues. In class I, lethal in childhood or grave malformations, the issue at

<sup>7</sup> Based on UNESCO's international bioethics committee's report on genetic counselling.

<sup>8</sup> Whether achondroplasia constitutes a malformation or a variant is up for discussion. Only if the gene is inherited from both sides, the condition in which it will result is lethal.

<sup>9</sup> Whether Down's syndrome constitutes a malformation at all is heavily disputed. Down's is even often used to illustrate the possible socio-cultural background of definitions of a certain phenotype as a disorder.

hand is prevention. No parent would wish the kind of life described in this category for their children, so prevention seems to be justified. Of course, one would hope for a growth of class II, viable-if-treated hereditary diseases, but to do a preventive selection on the basis of diagnoses of this class does not seem self-evident. Class III, late appearing genetic diseases, offers yet more problems for genetic counselling. Even if the genetic condition has a 'high penetrance' (that the genotype determines the phenotype up to a high degree), life is often quite normal until the age of about 40. Can one justify preventive selection in this case? Class IV, predisposition genes, concentrates on the problematic nature of the genetic diagnosis. To be susceptible to a genetic disease is something other than to be certain to have or develop this disease. Although in Revel's report it is not stressed, class IV is becoming increasingly paradigmatic for (prenatal) genetic diagnosis. Most diseases and traits are multifactorial, and may have a variable degree of penetrance. Even monogenetic diseases do not have a 100% degree of penetrance. Class V, multifactorial diseases and their genes, is not entirely separable from class IV. They represent the increasing number of genes which appear to be implicated in rather commonplace diseases (cardiovascular diseases, diabetes etc.). Lifestyle and environment play a considerable role, and predictability is low. Problems related to categories III, IV and V can actually be resolved quite easily with the instrument of the right not to know one's genetic predisposition. But if extended to prenatal selection, it would be considered more problematic.

According to some (de Wert 1999; de Wert *et al.* 2001) preimplantation genetic diagnosis should be distinguished from other forms of prenatal diagnosis. Preimplantation genetic diagnosis uses in vitro fertilisation combined with genetic diagnosis to a selective implantation (selecting on a desired genotype or avoiding implantation of a non-desired genotype). Preimplantation genetic diagnosis is different from standard forms of prenatal diagnosis in that it carries an ethical advantage to select before conception. The mother is not forced to make the difficult decision whether or not to have an abortion (de Wert 1999). Normal forms of prenatal diagnosis do carry the disadvantage that in the case of a definitive outcome (a particular genetic disease or disorder) the woman in question is unavoidably confronted with the necessity to make such a choice. For those who focus on the rights and moral status of the unborn, the distinction between preimplantation genetic diagnosis and standard forms of prenatal diagnosis is often seen as relative, rather than as absolute. The argument here is that in vitro fertilisation, (a technique essentially involved in preimplantation genetic diagnosis, aims to provide parents with the possibility of having children, whereas abortion (but also selection) aims at the avoidance of the birth of a child, for whatever reason. Although in vitro fertilisation and preimplantation genetic diagnosis are quite different in purpose, both techniques involve discarding surplus embryos or foetuses. Some take the difference between (pre)-embryo and foetus to be morally relevant, since the former has no brain activity and therefore cannot experience pain, whilst the latter

can (Hope 2001). But it is equally arguable to perceive of the difference between the two as a mere difference of scale, since the one only gradually develops into the other. This position would lead to a stressing of the moral relevance of conception instead<sup>10</sup>.

Central to the prevention of the birth of children with a severe disease or handicap are on the one hand the burden it will form for the prospective parents involved to deal with raising a severely diseased or impaired child and on the other the predicted suffering of the future child. Still, even motivated from such understandable arguments, such choices also influence the genetic make-up of posterity favourably. But such reproductive choices hardly ever aim at a specific or general amelioration of human genetic potential. Because preimplantation genetic diagnosis is less invasive for the women involved, there might be less objections than in utero prenatal diagnosis since it does not come at the price of abortion. This might render applications other than preventing severe diseases in posterity more acceptable. This might lead to an acceptability of the step to avoiding less severe diseases or handicaps. In that case, the decisions made could well come down to a practice of eugenics, apart from whether they are explicitly motivated as such or not. In view of the darker sides of the history of the eugenics movements, some authors argue for a restriction of preimplantation genetic diagnosis to severe diseases (Galjaard 2003). Otherwise preimplantation genetic diagnosis could open the door to a new eugenics<sup>11</sup>.

Preventing severe diseases is one, but not allowing for the birth of people with a lesser handicap, people who can usually live worthwhile lives notwithstanding their handicap, is another matter all together. Until now medicine does not pick sides between eugenics and dysgenics, since it also keeps people alive until and beyond childbearing age with a genetic make-up that is, eugenically speaking, to be regarded as dysfunctional. Conventional prenatal genetic diagnosis is sometimes also applied to milder diseases, and the same goes for non-genetic forms of diagnosis. Some ethicists, like Wolfram Henn (2000), argue for such a restriction. Henn's particular argument is that applications of prenatal diagnosis beyond the avoidance of severe diseases could lead to an 'ethically unacceptable genetic consumerism'.

10 This is essentially a debate between Platonism and Aristotelianism. A Platonic idealist definition of foetus and embryo would see them as distinct entities, whereas an Aristotelian teleological definition of embryo and foetus would define them as phases of the same thing, whilst the embryo would be defined as already potentially being a foetus. The controversy between these two views has not aided in resolving the issue at hand.

11 In addition to the diagnostic application of genetics, one can also intervene in existing genotypes to treat certain diseases. The most common application is human germ line intervention. This aspect of genetics offers hope for a cure for various types of cancer and genetically-determined diseases such as Parkinson and Alzheimer. This technology should be differentiated from other forms of genetic therapy, like somatic genetic engineering, because the changes in the germ line made will actually become inheritable. Here, a similar ethical problem to prenatal selection arises: we seemingly take control over our own evolution (Taylor 1998; Salvi 2001).

Such a consumerism would put people and their capacities on the shelves of the supermarket just like the products which people select and buy. Some researchers therefore use the term 'therapy' when referring to preimplantation genetic diagnosis (Braude 1992) since preimplantation genetic diagnosis does not carry the risks and ethical problems associated with abortion. But preimplantation genetic diagnosis implies a *selection* of embryos that excludes non-desired traits and it might move in the direction of specific choices for desired traits. The prevention of the birth of a severely disabled child is not the same as preventing a certain disease or impairment from occurring in an individual, which is the usual goal of preventive medicine, and even preventive medicine is not therapy. This means some restrictions valid for prenatal genetic diagnosis might be valid for preimplantation genetic diagnosis as well. Prevention and selection should be distinguished, and preimplantation genetic diagnosis cannot be brought under the simple heading of preventive medicine let alone therapeutic medicine, since therapy applies to a disease already manifest and in a patient already manifest (that is, existing rather than future). The only way one might be able to refer to preimplantation genetic diagnosis as a form of preventive medicine is when one considers preimplantation genetic diagnosis on a population level. Then, one might argue that the occurrence of people with a genetic disorder in a given population is a public health problem. In that case the prevention of the birth of such people would be a public health measure and therefore it could be considered as a form of preventive medicine. Still, interpreting prenatal selection as a form of public health intervention on genetic diseases would bring us closer to eugenics than would be the case with prenatal genetic diagnosis, since prenatal genetic diagnosis still remains restricted to more severe criteria seen the harms associated with abortion.

A further argument that is often used to reject a broader implementation of preimplantation genetic diagnosis is directed towards the problematic nature of the production of surplus embryos involved in the technique. But according to some, surplus embryos can be frozen and stored until therapy for their particular defect is found (de Wert 1999). If so, the argument against preimplantation genetic diagnosis based on the idea that one has to create surplus embryos that will not be implanted, seems to be insufficient. On the other hand, the idea that in the end one has to implant all embryos (including one or more severely affected embryos) would imply a gross break of the ethical and legal rights of the mother; the fact that it is theoretically possible to conserve the surplus embryos does not constitute a refutation of the objection to their creation (de Wert 1999).

The distinction between early and late onset diseases is also considered to be morally relevant. The general stance in medical ethics is that selection – through preimplantation genetic diagnosis – in lethal or very severe diseases that develop in early childhood – is morally permissible. In contrast, selection to prevent mild diseases, whether early onset or late onset, is considered morally impermissible. This also applies to very severe or lethal diseases which develop later in life, in

adolescence or adulthood. This ethical division is reminiscent of the ethical stance on genetic testing in the context of the right to know and not to know (Chadwick 1997; Chadwick 2004). For example, in early onset diseases parents are allowed to make decisions for their children to accept genetic testing. The relevant distinction here is that in the case of diseases where therapy and other care are available it is urgent to do the (genetic) testing, whereas in those diseases where no therapy is available it is up to the parents to decide whether they want to know whether the child has a genetic disease. In case of late onset diseases the ethical view is to leave it to the children themselves to decide, that is, to wait until the child has an age in which it can make his own decision on whether he wants to know. The ethical restrictions to genetic testing have to do with its predictive nature. Often, one is not testing for an existing condition, but a condition that one might suffer from later in life. For some, knowing one's future risks is an important factor in how one plans one's life. Others will consider knowing one's future risks to be burdensome rather than helpful in planning and leading a normal life. They would prefer not to know whether they are carrier for a gene that leads to a disease or a disability later in life. This 'right not to know' (Chadwick 1997; Chadwick 2004) needs to be taken into account when one offers predictive genetic tests. This right of the patient prevails over the physician's Hippocratic duty to know as much as one can about the medical condition of their patient, especially when this knowledge does not result in a cure. It also prevails over the parental right to know about the possible condition of their child. Therefore, it is argued that predictive genetic tests should only be offered when preventive measures or an effective therapy for late onset genetic disease is actually available.

In prenatal and neo-natal care, there are further specifications of this right not to know. For example, only those diseases for which treatment needs to be started during childhood may be predictively tested for prior to the age on which the child can decide for himself; the (future) adult is to choose for a test on late onset diseases with a therapy and every other disease without a therapy. These choices all fall under the right not to know (Chadwick 1997; Chadwick 2004). Nevertheless, there are several drawbacks of the application of the right not to know to the *prenatal* area. Predictive genetic tests often form the basis for a choice for genetic selection preceding implantation or selective abortion. Apart from the ethical problems surrounding abortion and in vitro fertilisation, this means one knows about somebody's genetic background prior to birth, although there was no medical indication to know the genetic background of that specific person. After all, the *medical* indication only applied to other zygotes not implanted, or to a possible earlier pregnancy that was terminated. This means the existing criteria for the right not to know cannot be applied to the sphere of prenatal diagnosis.

Examples of non-lethal early and late onset diseases and lethal late onset diseases include haemophilia, Huntington's (qualified as late, or adult by G. de Wert (de Wert 1999; pp. 289)) and hereditary forms of breast cancer. The application of

preimplantation genetic diagnosis to avoid the birth of children that may develop such diseases is under criticism. Although some of these diseases are not lethal, or if they are, do not stand in the way of leading a fulfilled life, it is still dubitable whether this constitutes a reason to apply the same criteria on preimplantation genetic diagnosis as on issues of informed consent: After all, the child that knows it does not suffer from the disease its non-existent brother or sister might have had given another non-preimplantation genetic diagnosis-scenario seems to be less affected than the child that suffers from the condition in question. Who are we to decide what is severe or not? The distinction between mild, severe and lethal, between early and late onset are not strict. They are as much subjectively experienced states of being as objectively describable entities. In the first case, the case of haemophilia, several forms of treatment are available during childhood. Haemophilia may be a severe disease, but one expects better medication to be developed in the future. But in many cases a child with haemophilia can have a relatively normal childhood, especially in the developed countries (Chandy 2007). One might argue that the development of better or cheaper medication should be prioritised above prenatal selection. Although it is understandable that parents prefer to have a healthy child, devoid of a disease like haemophilia, the question arises whether it is permissible to select and also whether it would not be better to invest in the development of novel therapies. In the second case, the case of Huntington's disease, the person in question may live for decades in full health. Huntington's disease tends not to develop in the carrier until well into adulthood. This begs the question what is a normal age to die? And, more importantly, is it up to medicine to decide upon that? Only a few centuries ago not many people lived beyond the age of 40, now we say a man who dies at 65 dies young. From this perspective it is dubitable if preimplantation genetic diagnosis or prenatal genetic diagnosis would be justified. In the third case, the case of breast cancer, relatively successful treatments are available. Breast cancer can be treated with chemotherapy or through mastectomy. There are also harms associated with the current therapeutic availabilities. Although one may be able to reduce the risk of breast cancer with up to 90% (Sherry 2001), mastectomy remains a technique that is emotionally stressful to the woman. Although the technique can significantly reduce risks, one can still be susceptible to lymphatic cancer. In addition, there are several other preventive measures available. But even testing as such can be distressing. As Mann and Borgen state:

“Guidelines to suggest who is likely to be a mutation carrier are being clarified, but the appropriate management of someone who tests positive remains difficult. Prophylactic mastectomy and oophorectomy are likely to offer substantial gains in life expectancy to mutation carriers, especially for young women with a strong family history. Unfortunately, there are no currently available strategies to eliminate the risk of breast or ovarian cancer. The psychological impact of testing also

remains poorly understood, and the danger of various forms of discrimination remain.” (Mann & Borgen 1998; pp. 267)

Testing on a large scale (screening) might seem tempting from a medical point of view, but it might be also disruptive of people’s lives. Where does one draw a line? What hereditary disease still constitutes a legitimate reason to offer prenatal diagnosis? What is to be the age a person should reach? A question that can be raised against prenatal diagnosis is whether the implementation of such techniques would not eventually increase society’s tendency to strive for perfection in posterity.

De Wert scrutinizes and rejects several other arguments for a more restrictive stance to preimplantation genetic diagnosis (de Wert 1999). I shall mention the most important ones in this context: the techniques used for preimplantation genetic diagnosis can be burdensome for the (future) mother, preimplantation genetic diagnosis is not a technique that is 100% reliable, and preimplantation genetic diagnosis (as prenatal genetic diagnosis) might adversely affect the embryo that is implanted. This calls for close scrutiny (Adam 2005). Another ethical argument for a more restrictive stance to preimplantation genetic diagnosis might be that the number of embryos that are discarded will be higher than with common *in vitro* fertilisation. Still, although there are harms associated with preimplantation genetic diagnosis and prenatal genetic diagnosis alike, do they outweigh the benefits? Can one even weigh these issues against each other? The question whether predictive testing in general and prenatal diagnosis and selection in particular is permissible is not a clear-cut case, to be answered in black and white categories. This has been recognized in the bioethical community as well. One has to distinguish between different types of diagnosis, diseases and their causes.

The techniques developed to diagnose the genetic background of a foetus or a zygote, are focused mainly on avoiding the birth of a severely disabled child or of a child with a greater risk for diseases such as Huntington’s, Fanconi anaemia or sickle cell anaemia, and Down’s syndrome (the most commonly applied form of prenatal diagnosis). Not to have such a condition will hardly pose a moral problem for an individual who is born as a result of prenatal selection on the basis of such genetic diagnoses. There may however be societal complications in that society might grow less tolerant of those who are different. What is considered as severe and what not, however, is open to criticism. Preimplantation genetic diagnosis might also become applicable to avoid early onset Alzheimer’s, diabetes, polydactylia (to have more than ten fingers or toes) or even myopia (short-sightedness). Speculations on such applications of prenatal diagnosis have already been cause of much dispute. It is feared that if one would go from avoiding serious diseases or disabilities to avoiding minor ones, society would become less and less tolerant of those suffering from conditions deemed avoidable. One also fears a eugenics idealism to be the hidden agenda behind the proposals for a broad implementation

of prenatal genetic screening. When one only tests for one condition, and only on individual pregnancies, the influence of the technique at hand is not that far reaching, but when one decides to screen pregnancies on a population level these techniques might actually alter the genetic make-up of future generations.

If one would be prepared to venture beyond the goal of avoiding diseases, one might be inclined to mould future generations to one's own ideal. And if we actually design posterity through enhancements, will we not be subjugating future generations to what we perceive of as the good life, without leaving the future up to them? Is the future not the birthright of future generations, rather than ours to tamper with? These questions draw the attention to when one would venture beyond the goal of avoiding the birth of a severely affected child.

Liberalist approaches emphasise the principle of protecting the autonomy of the future parents whilst at the same time giving advice and information on what possible medical problems a pregnancy in their particular circumstances brings with it. This means that parental freedom of choice should be protected, by giving advice that is not affected by the opinion of the counsellor or the doctor at hand, e although most agree that the health of the child in question should not be endangered in the name of the protection of parental autonomy. Next, I shall provide an example of how new genetic technologies are dealt with within this context of genetic counselling.

### **3. The Current Ethical Framework of Prenatal Genetic Diagnosis**

In this section I shall first provide a brief overview of the role of the concepts of non-directiveness and informed consent play in the current ethical framework for reproductive counselling. Then, I shall show that there is an ethical limit to the principle of non-directiveness, especially if one delves into the more problematic sides of medical indication as a criterion for reproductive advice. This way I shall show that the standard ethical framework in reproductive counselling is no longer sufficient in the light of new genetic technologies.

#### *i. On Non-directiveness and Informed Consent*

The recent surge in possible applications of genetics in medicine seems to change many aspects of medicine. Genetic diagnosis has increased the potential and the influence of predictive medicine. The focus is on knowing the onset of a certain disease in advance instead of dealing with the consequences when it is already too late. This focus on prediction rather than cure has changed the nature of the ethical questions in medicine. One is intervening in someone's personal life on the basis of preventing a disease he might get from occurring, rather than on the basis of curing a disease he already suffers from. One can ask oneself whether the guiding principle of respect for the patient's autonomy, informed consent in specific, still holds

in these areas. There are some aspects of the new genetics that seem to pose new questions.

For the current applications of genetics in the reproductive sphere, medical ethical discussions emphasise the principle of respect for the autonomy of the patient or client. This is considered as evenly important as how severe the condition in question may be, the risks involved and economical factors of budget and equal distribution of goods. Although ultra-liberalist approaches in medical ethics tend to overemphasise the respect of autonomy, it is mostly balanced with these other issues. The ethical principle of respecting the autonomy of the patient or client has its roots in the perception and ethical analysis of the history of eugenics. The impact of eugenics on the twentieth century has had a profound influence on contemporary ideas on prenatal diagnostics. I shall return to this issue in chapter II.

From this respect for the other person's autonomy a principle of non-directiveness has been derived. Non-directiveness implies that the counsellor informs the patient or client in as neutral a manner as possible. All information is biased to a certain extent, so there will always be some steering in medical counselling and this can also be preferable in some instances. But non-directiveness implies that the counsellor creates a climate in which patients or clients can make a choice between the options offered in as autonomous a manner as possible. If one does not respect the principle of non-directiveness when necessary, by giving unwanted advice, or by giving information in a biased manner, this can lead to ethical complications such as a restricted freedom of choice for the patient or client, an alienation between the counsellor or physician and the patient or client, a distrust of the patient or client in the physician's attention for his questions and needs or a risk for posterity. In prenatal diagnosis, a counselor's role is mainly to inform the (future) parents. The role of the counselor is different in prenatal genetic diagnosis. Since prenatal genetic diagnosis (preimplantation genetic diagnosis in specific) is more closely related to assisted reproduction (rather than standard screening), he also has to take into account risks for the wellbeing of a future person. Therefore, respect for the autonomy of (future) parents holds less strongly in this area. It is not the focus of this thesis to exactly determine what the consequences thereof are. This question is already discussed in other fields. The focus here lies on what the consequences of an overemphasis on parental autonomy may be with regard to the future person, not whom is who is to take what responsibilities over such consequences.

I shall provide an account of an approach to ethical decision making on genetic choices and reproduction, that was given by de Wert, Schrandler-Stumpel and De Nijs Bik (de Wert 2001). It demonstrates the ethical place of patient autonomy in counselling on preimplantation (genetic) diagnosis in more detail. According to de Wert, Schrandler-Stumpel and De Nijs Bik, the following issues deserve the counsellor's attention with regard to ethical decision making in genetic diagnosis (be it a genetic test in utero, before implantation (in the case of in vitro fertilisation)

or a genetic test for a certain condition in the parents themselves, before conception) (de Wert *et al* 2001; pp. 33-37):

- Accepting risks: when parents choose to undergo a prenatal diagnosis, they should be made aware that there is a risk the diagnosis for the disease one tests for might have a positive outcome, that their future child is or will have a certain hereditary condition.
- The option not to have children: when parents are tested for a specific hereditary condition, and they appear to run the risk to have a child with the condition tested for, they should also be aware that one consequence could be the choice not to have children; this is a hard decision deeply affecting one's life.
- Adoption: parents should ask themselves whether adoption is not an option, when the problem arises.
- Usage of donor-gametes and prenatal diagnosis: if one runs the risk of having an affected child, one may also consider prenatal diagnosis to be able to make sure one is not pregnant with an affected child, or consider the usage of an egg-cell from a donor who is not affected.
- Knowledge of one's own genetic predisposition: if one tests in utero, or if one has oneself tested before conception, one should also be aware that having children is not the only issue at hand; one can also appear to be affected oneself.
- Following from this, knowledge of the genetic predisposition of family members: if one appears to be affected, to have the genetic disposition to develop a certain disease, one should also be aware that such knowledge may also apply to other members of one's family. This issue further complicates the consequences of the 'right not to know'. One may consent in knowing one's own genetic background, but family members may not.

The issues listed above by the authors show that the patient or client should be made aware by the counsellor of all the possible outcomes, risks and alternatives in order to be able to make an autonomous choice. The counsellor has to provide as much information as possible and he has to respect the values and preferences of the patient. Only then is the autonomy of the patient or client respected. Since a few years, the counsellor should also be able to ask for arguments and motivations for the patient's or client's views and decisions (Emanuel 1992; Widdershoven 2000).

An indication for a termination of a pregnancy or preimplantation diagnosis is to be based on objective medical grounds. And the right to refuse an abortion, even though the pregnancy would result in the birth of a severely disabled child or with genetic defects at birth, should remain in the hands of the parents, even if the child might have a life of low quality and with a high degree of suffering. Although

doctors are not allowed to make decisions about reproduction without regard for this basic right they should offer advice, and only to the extent of the area of their profession, facilitating the process of decision making by creating the proper environment and by offering advice and counsel when called for.

The rights of the child or the future person are taken into account only as far as parental preferences are counter to the interests of the child. This is of course only relevant when such a child will actually be born, not when parents might decide for termination. If parental decisions would lead to the birth of a severely disabled child, doctors do have the right to cease treatment when they see it as no longer useful. These extreme situations, painful though they may be, are not directly relevant for the debate on prenatal selection since we already give precedence to the mother's right to carry on with a pregnancy (one cannot have a woman undergo an enforced termination).

Current medical ethical policies and guidelines aim at preventing needless harm. These policies are in the interest of future children, not primarily in the interest of the parents. But indirectly, they also benefit the genetic health of the future population as such, although in medical ethics this is hardly ever taken as a defence in favour of prenatal diagnosis, due to the possible association of policies based on this argument with the old eugenics conceptions of 'genetic hygiene'. It should be taken into consideration that if new diagnostic techniques were implemented on a broad scale, the possibly unintended side-effect would eventually be that certain hereditary diseases cease to exist, in the same way that medicine has managed to eradicate smallpox. But the genetic health of the population is not a factor that is taken as a prime motivator for offering such techniques. Medical necessity, on a more or less individual scale, is considered to be the main ethical criterion. Emphasis is put on issues surrounding the autonomy of the patient or client, the rights of the future person to an open future, the attitude and duties of the geneticist and the genetic counsellor regarding the rights of the patient or client, and the role played by guidelines in medical conduct. But the question is whether these goals, the right to an open future in particular, can be reached through the current ethical policies and guidelines of non-directiveness and respect for the autonomy of the patients or the prospective parents. Reproductive cloning, designing humans and similar issues bring in the problem that one cannot apply the principle of consent and the principle of respect for autonomy in a simple way to people who do not yet exist. Such issues might not be resolvable with the standard medical ethics approaches. It must be noted that although these issues fall partly under the scope of what the new genetics is capable of, they are not part of current medical practice.

#### *ii. Limiting the Principle of Non-directiveness*

The principle of non-directiveness is not absolute. It is based on the assumption that medical care is bound to certain limits, but it is not to be applied in all cases.

The main driver behind this principle is that medicine might want to steer procreation in a direction it deems better, without retaining the proper regard for parental autonomy. The ideal expressed by the principle of non-directiveness is that the geneticist or counsellor should not aim to steer the choices of their patients or clients in a direction they deem better. Parents can opt to continue a pregnancy of a disabled or defective child if they wish; medical perfectionism must never overrule the right to freedom of reproduction.

As the applications that are already allowed become more generally adopted as normal, the attitude regarding other applications of the technologies now considered as not permissible, might become more liberalised. This so called ‘slippery slope’ – argument (Oakley 2005) holds that if one takes a step towards a liberal implementation of prenatal diagnosis, there is no reason not to take the next one<sup>12</sup> (Burg van der 1991; de Wert 1999); if one were to allow for one exception to the moral rule that one should not apply prenatal selection to anything but very severe, or lethal, hereditary conditions, one will eventually have no ethical argument against any possible application of prenatal selection, whilst there is ample reason to remain suspicious of the quest for the perfect baby (de Wert 1999). One might opt for a very restrictive policy in which forms of prenatal selection should be offered and which forms should not. And the counsellor in question is to restrict his advice to these severe cases when offering prenatal diagnosis. In this respect, he should not direct parental decision making in any way.

The principle of non-directiveness seems a sufficient bulwark against the potential eugenics agenda of medicine and wider society. On the basis of the differentiation between disease and health, one seems to be able to define the criteria for the limit between medically-indicated interventions and cosmetic genetics. In this respect, the principle of informed consent is a defensive principle, in which it is presumed that medical knowledge is restricted to the medical professional. This definition is only relevant if one interprets eugenics or enhancement technologies as part of a project that can only be conceived of in the mind of a physician. And this is not necessarily the case.

The issue of going beyond therapy and preventive applications of prenatal diagnosis is often covered by making a clear distinction between disease or disability and normal function, and taking that distinction as a moral guideline. As long as a certain genetic disposition can still be termed normal, one is not allowed to make any decisions that would influence the genetic make-up of the future person. When a certain trait can be termed a disease or a dysfunction, there is a medical indication to allow for therapeutic or preventive measures. Nevertheless, the distinction

<sup>12</sup> There is a logical and an empirical version of the slippery slope: the logical version states either that, “we are logically committed to allow B once we have allowed A.” It also holds that since there is a grey zone between A and B, the distinction between the two can, in the end, not be tenable. The empirical version of the slippery slope argument, holds that, “the effect of accepting A will be that, as a result of psychological and social processes, we sooner or later will accept B.” (van der Burg 1991).

between disease or disability and normal function is not as clear cut as one often suggests, nor is the distinction between severe diseases and disabilities and minor defects. Since the late 1970s, the distinction between disease or disability and normal function has increasingly been seen as a normative distinction, rather than a neutral and objective distinction. The concept of a disease was heavily debated in the 1970s and 1980s, by C. Boorse and H. J. Engelhardt (amongst others). The question raised in the 1970s, was whether one should look upon a disease as an objective state of affairs or a part of a normative approach of states of affairs (for both positions see Boorse 1975 and Engelhardt 1975). Boorse argued that health could be defined as a value-free theoretical concept that can be based on a biological notion of function and statistics (Boorse 1977). Engelhardt disagreed, stating that one could not find one's conception of health and disease in (evolutionary) biology but in culture, and as such, both concepts are dependent on cultural values<sup>13</sup>. This discussion was recently elaborated by Philip Kitcher, who explored the difference between what constitutes an enhancement and what a restoration to a so called 'normal function'. Kitcher asserts that when an intervention leads to a change in our genes, such as self-chosen abstinence by people with a severe genetic defect, or it is already a form of eugenics (Kitcher 1996). After all, eugenics is a conscious and intentional intervention to adjust the genetic make-up of posterity, and many decisions we make exert such an influence. Even non-intervention influences the make-up of our genes (Kitcher 1996). Normal functioning or normality therefore becomes something we define ourselves, rather than it being an objective given.

The problematic nature of the distinction between disease, disability and health can be extended to the debate on what constitute therapeutic applications of medicine, that are indicated medically, and (genetic) enhancement. Currently, the limitation of applications of genetic diagnosis in the prenatal area hinges on the distinction between what is considered as a disease or a disability and what as normal function. Applications of prenatal genetic diagnosis and selection on the basis thereof are restricted to those instances that stem from a clear medical indication of their necessity, although there are several ways that one can distinguish between medically necessary applications, medically preferable applications and non-medical applications of prenatal diagnosis. What is perceived of as a clear medical indication for prenatal diagnosis and what not, is based on the conceptual demarcation of what is seen as disease (or abnormality) and health (or normality). Criteria for this demarcation are defined within the medical-scientific paradigm. In this paradigm, curing or preventing diseases (or abnormalities) is the central goal. Strictly speaking, all applications on humans that fall outside this goal fall outside

13 None of these researchers appeared to give sufficient attention to the mix of facts and values in the conceptualisation of diseases. In effect, drugs are developed for diseases just as much as 'diseases' are developed to fit certain drugs, as is defended by rein Vos (Vos 1991). So what counts in the definition of a disease is the 'accidental' presence of a cure.

the aims the medical geneticist must set him- or herself, and are therefore not professionally defensible. But when the medical paradigm can no longer be seen as neutral, one cannot derive the criteria for which applications prenatal diagnosis may be used and for which ones not.

The discussion on the normative or descriptive nature of disease and disability remains an important issue in this ethical debate. In relation to disabilities, John Harris, for example, does not support the idea of a clear distinction between prevention and enhancement if they both fall under the category of protecting life or health. According to Harris, health can be defined quite clearly. The basis of Harris' definition of disability should be its being perceivable as a personal tragedy or as a result of the individuals biological determinism (Harris 1993; pp. 178-187). As Harris argues, one can use health and disease or disability as the basis of a moral guideline: "there is in short no moral difference between attempts to cure dysfunction and attempts to enhance function where the enhancement protects life or health" (Harris 1993; pp. 184). Several authors challenge this position. Some argue that one cannot define in an objective and neutral way what is to be understood as a disability and what as a normal variant (Reindal 2000).

According to Harris there is no sharp division between a genetics that aims at the prevention of the birth of a child with a disease or a disability and a genetics that aims at enhancing posterity. Following Engelhardt *cum suis*, one cannot rank all existing and all potential genetic interventions from therapeutic genetics to genetic enhancement in an objective and value-free fashion. Such a ranking would be a question of intention, perspective and definition rather than a question of objective medical standards. Although the individual end results may be similar in both cases, the intention is relevant because there is an ethical difference between whether one aims to help parents at risk or to enhance the quality of the human race. The perspective is relevant, since there is a difference between looking upon avoiding diseases in posterity as a form of eugenics or as a new branch of prenatal care. This distinction may seem obvious, but it is dependent on how we look upon the practice at hand rather than being part of that practice as such. Definition is important since we would need to be able to define what constitutes a disease or disability, and what constitutes health or perfection in order to use these concepts as a basis for moral guidelines. But then, even if one would be able to set neutral and objective standards through the definition of disease and disability on the one hand and normal function on the other, one still ends up with the problem that there is no apparent reason (except for the disadvantages of having surplus embryos or performing an abortion) to restrict the use of prenatal diagnosis to what is medically indicated.

In combination with the principle of non-directiveness, this causes several problems in prenatal genetic diagnosis. If parents opt for prenatal genetic diagnosis to avoid minor hereditary dysfunctions, or to select those traits they prefer, the autonomy of the parents will not be harmed. If one were to consider the problem-

atic nature of abortion as contingent, there would seem to be no strong reasons not to allow parents to opt for specific preferred features in their children. And there are several reasons to consider these problems as contingent. The combination of genetic diagnosis and in vitro fertilisation already lessens the problematic nature of prenatal selection. After all, as much as 80 percent of the natural fertilisations end in natural abortion (Salvi 2001).

The presumed consent of the future person should also be taken into consideration. With regard to presumed consent, the ethical guidelines for prenatal genetic screening is based on genetic testing in minors. As an adult, the person in question might opt not to know his genetic risks. Genetic testing to know one's genetic disposition will therefore be translated in a postponed right to know or not to know if not knowing of the condition in question does not have negative medical consequences. Apart from testing in minors, the autonomy of the future person also plays a considerate role in how to decide on prenatal selection and on prenatal diagnosis. The right not to know is, of course, also a right retained by future people. This means prenatal genetic testing may only be allowed in cases when diagnosis offers the possibility to prevent the disease from occurring or to cure it. It may not be offered just to know the condition exists. This form of postponement of the consent of a future adult, or a future person in general, is also referred to as consent by proxy.

De Wert, states that consent by proxy should be avoided as much as possible (de Wert 1999; pp. 283). Only where one can cure, is one allowed to test. If there is an alternative to testing at an early age, one should postpone it until the child in question can choose as an adult if he wishes to know whether he has a predisposition to develop a certain disease or condition. Otherwise the autonomous right of future persons to abstain from having knowledge of their future is threatened. The exception would be tests that are in the interest of a person's health. So, when one needs to gain knowledge of a specific hereditary predisposition to provide for timely preventive or therapeutic measures, testing is allowed for. This would not be the case with many late onset diseases, nor would it be the case with diseases for which no cure is available; one would need to balance the medical interests of the child with the child's, or the future person's right not to know. Similarly, one can delineate what forms of prenatal diagnosis may be thought justifiable and which not. Prenatal diagnosis without the aim of selection should be restricted to those forms that access to foreknowledge in the interest of the medical future of the child, and that cannot be carried out later in life without postponement of diagnosis causing an additional risk. Still, when one takes into account the option of aborting a foetus that has a hereditary defect or when one applies for preimplantation genetic diagnosis to avoid abortion, why would this still be considered an ethical problem? To know that one does not have the predisposition to develop Huntington's or a milder form of haemophilia can hardly be regarded as constituting a breach of the right of a future person not to know his genetic background. The

only ethical problem arising out of such a situation might be the possible guilt a sibling could feel towards other children that were born before them in the same family, who do have the genetic disposition to develop such a disease. In the case of selections to avoid a certain disease or even a milder disease, the question of the right not to know as a restriction on the application of consent by proxy seems to be obsolete. It does not need to be posed.

If the genotype one selects for does not imply that the child will have a *specific* trait, by which he would perceive of his walk of life as different, to be informed that he does not have such a trait by no means threatens the autonomous right of future persons to abstain from having knowledge about their future. It is the specificity of a trait that might be of influence to a future person's self-observance. For example, if one were to know one was purposely created with a specific DNA-profile, since one needed a specific DNA-profile to cure an older sibling, such knowledge might damage how that person relates to his existence. In specific, there are concerns on the possible 'instrumentalisation' of a future child for the behalf of an existing child. This Kantian argument, however, is not viewed to be a valid argument in this specific case by all (Pennings 2003; pp. 402). Avoiding consent by proxy or presumed informed consent wherever possible may enhance the autonomy of the future person. This is of course only asked for when there is no medical necessity to have an early diagnosis or where the medical necessity cannot be assessed or is negligible. Another way to solve problems of the autonomy of the future adult is that one can implement an alternative and guided form of autonomy for minors. But in general, protection a future person's autonomy is considered a side-issue, since it is only relevant in creating specific traits; something that is not standard prenatal practice at present. However, if one were to venture beyond the scope of avoiding milder diseases, one treads on more difficult ground. In prenatal selection, one can think of selections that do imply knowledge of a specific trait. This would have fundamentally different implications for what is to be understood about informed consent. Such a trait will, in many cases, be co-constitutive of one's identity. And since the concept of informed consent is meant to deal with either existing people or matters that can be presumed to be the same for all people, it cannot be made to apply to cases of specific traits. Consent can only exist in a choice-framework. Examples of the selection on specific traits cannot be found easily within existing forms of genetic diagnosis on diseases and the selection following from it. However it does have implications for those applications of prenatal diagnosis that are aimed at selecting traits that are deemed preferable.

#### 4. An Old Ethics for a New Genetics? On Consent and Prenatal Selection

Until now, speculations on applications of prenatal diagnosis (or prenatal intervention for that matter) that go beyond therapy have not been taken into serious consideration in medicine and prenatal care. Current applications of prenatal diagnosis and selection are restricted to those applications that have clear medical grounds. But when what is considered a clear medical ground becomes disputed, medical indication cannot remain the only framework in which prenatal selection is discussed; be they speculative or existing practices. Discussion on both pre-adult and prenatal genetic testing was based on whether one could presume consent in cases where there was no opportunity to postpone consent. One could presume consent when the intervention (or selection) was to avoid severe diseases or disabilities. One could not presume consent when one aimed at specific traits that would be co-constitutive of one's identity. So, one is not allowed to specify a future person's genome. But this is not necessarily the case with traits that are generally present in the population.

A strong argument for this emphasis on consent is the move against medical paternalism<sup>14</sup> in the sixties and seventies. This resulted in a new conception of ethics as a dialogical relationship between the physician and the patient, instead of merely focusing on the role and obligations of the physician. There was room for nuance. Joel Feinberg defended 'weak paternalism' (Feinberg 1986 (1971)) on the basis of the idea that one may intervene in involuntary self-harming acts (or behaviour) or in human acts that are not directly associated with issues of personal identity<sup>15</sup>. Competence is taken to be the central criterion for assessing whether a paternalist act is justified, but competence should always be competence for some task (Buchanan 1989; pp. 18).

In aiming at 'general' traits one can think of aiming at an individual with a good health or an individual that is not disabled. In aiming at 'specific' traits one can think of aiming at an individual with a certain outlook, certain capacities or certain talents. In the case of general traits it concerns the standard prenatal selections that are already performed in practice; that is, cases where parents are at risk of having a child with a serious genetic disorder. Normally, this type of prenatal selection is placed under the heading of therapeutic genetics and defined as a selection away from a certain disorder, rather than a selection for a certain preferred genotype. Choosing the vocabulary of selection against certain non-preferred genotypes obscures the fact that a specific preferred genotype is implicit in the

14 Here understood as the interference of a state or an individual with another person, against their will, and justified by a claim that the person interfered with will be better off or protected from harm (Stanford Encyclopedia of Philosophy)

15 In human genetics, autonomy is defended much stronger than in other fields of medicine. This is probably connected to the moral aberrations of the eugenics movements of the past. .

practice of genetic selection, namely a genotype constituting a healthy or normal individual, although this preferred genotype can hardly be called controversial. Ultimately, one is aiming at a general genotype just as much as one is avoiding a particular genotype. But as far as these general traits such as 'good health' or 'normalness' are co-constitutive of one's identity, they would not be burdensome to the future individual, since he would only differ from other individuals whose genetic identities were created randomly, in the sense that their general traits were chosen rather than given. The other category, selecting to a specific trait that is preferred, has mainly been restricted to traits that are not co-constitutive of one's identity. An example of this category is to aim at a DNA-compatibility with an earlier sibling that is affected by a certain disease.

DNA-compatibility is, for example with Fanconi anaemia, a necessary condition in order to develop medication. The same applies to thalassaemia, a hereditary disorder of the haemoglobin. The Hashmi family in Great Britain has a son, Zain, who suffered from thalassaemia (Sheldon and Wilkinson 2004). The disease is lethal, most children die before the age of eight if no therapy is available. Zain could only be cured by a therapy derived from the cells of a relative with a blood type which matched his own. Unfortunately, none of his existing relatives matched. A genetic diagnosis before implantation of a fertilised egg, produced through in vitro fertilisation could give Mr and Mrs Hashmi not only a child free of the hereditary disease, but one who would also have cells compatible with Zain's, in order for him to be cured. These cells would be harvested from the blood of the umbilical cord, so the sibling itself would not be harmed. The Human Fertilisation and Embryology Authority (HFEA), the government organisation that regulates all applications of genetic and medical technology in reproductive medicine (including in vitro fertilisation-clinics) in the United Kingdom, granted permission to continue with the procedure.

Dr Michael Nazir-Ali, the Bishop of Rochester and chair of the HFEA's ethics committee, views the decision in the Hashmi's case as particular to that case and thinks it best to look at such situations on a case-by-case basis. In another case, namely the case of the Whitaker family, the HFEA did not grant permission. The Whitakers had a child with Diamond Blackfan Anaemia (DBA), a rare form of anaemia that results in the bone marrow producing few red blood cells. A procedure similar to that granted to the Hashmi's was asked for, but permission was not granted because the procedure did not serve the first purpose of preventing the child, whose umbilical cord blood would be used, of developing the disease. The reason is that DBA is not hereditary, it is caused by a rare spontaneous mutation: the chance of having a child that is affected cannot be estimated by studying the genetic disposition of the parents. Eventually, the Whitakers travelled to the United States in order to conceive a child which had a tissue match to the brother who suffered from the condition.

Even though in both cases the aim was to cure a diseased child, the Hashmi case was perceived of as morally different from the Whitakers, because in the Whitakers' case there was no additional goal of avoiding the birth of a second affected child. Even though these issues are only relevant within the scope of practices that are medically indicated, the answers are not always self-evident either. But would they be self-evident, the major question remains whether trying to avoid the birth of a defected child or a child with a severe disease or disability, would affect the identity of that child. For one of the main arguments against genetic selection or design is that it would affect the identity and personality of the person who would be born. Selections on a general genotype, in contrast, will not affect the individual children that come out of such selections. The individuals born without a defect, disease or disability would hardly have a distorted conception of themselves in knowing they were not disabled or diseased. After all, although we cannot interview the unborn, most non-affected people would consent in him or her being born with a non-affected genotype<sup>16</sup>.

The concept of consent can only be used in those instances in which a future person would not be selected to become an individual with specific traits (that are co-constitutive of one's identity). Consent can only be presumed in cases where one tries to *avoid* the birth of a person with specific traits (although the resulting generally occurring genotype does constitute an implicitly preferred genotype). Although closely connected to the way in which this person was conceived, this specific circumstance would, in my opinion, not constitute any additional ethical problems. Selection against Down's syndrome, for example, although possibly part of society's prejudices, would never constitute a serious problem for the way a person who does not have the syndrome would perceive of himself. His consent or autonomy would not be harmed. In that sense, one can consider this person as belonging to a certain 'general future generation' in presuming his consent by proxy. This is because in our society, having Down's syndrome is the exception. However, when a person would be the product of a selection aiming at specific traits, one cannot presume consent, for one can only consent when there are other options, not if a prenatal choice has already determined who one is in a very specific way. The precondition of someone's existence as being such and so will be of much more importance in his perception of him- or herself than in a more generalising selection, a selection away from a particular trait. Because the specific selection has been a precondition of his very existence, one cannot presume any form of choice or consent.

The fact that one cannot step out of who one already is may seem an argument that allows for any specific prenatal selection. As Parfit stated, anything we do will be conditional for who will come into existence (Parfit 1984), so they cannot

16 Although in the case of hereditary diseases that are manifest in other members of a family, there are also siblings who voice feelings of guilt that they are not affected there where their brother(s) sister(s) or parent(s) are (Evers-Kiebooms. C., E., Denayer. Decruyenaere. 2006).

rationally criticise our actions. A rationalist picture of autonomy, although standard in bioethics, has problematic features. Not all ethics is about rational free choice, and one cannot dismiss issues of identity. The restriction of ethics to questions of autonomy has major drawbacks, although these remain rather implicit in the current discourse. I shall return to this problem in chapter IV. An additional problem is raised by the fact that not all traits can be categorised as being either specifying selection (selection to create a certain trait) or general selection (selection to avoid a certain trait, or aiming at a general genotype). Selection on gender or selection on other traits that are common enough, but do specify one's identity, lies in a grey area between specific and general traits. Half of the world population is of one gender, but, however common one's gender as a trait can be found, this does not mean that it is not co-constitutive of one's identity. Being a man or a woman matters for who one is. The traits one has cannot all be fitted in the categories of general and specific. Certain general traits are also co-constitutive of who one is.

Not all traits that are genetically determined fall within an exclusively medical vocabulary. In many cases it is our cultural understanding of a certain trait rather than its medical significance that counts. So, although having blond hair is not a medical condition, our cultural understanding of it does create certain highly-specific connotations (apart from presumptions on one's IQ). And not all traits are framed either in a socio-cultural or a medical vocabulary; many have a dual significance. A medically-indicated selection on gender may also have some cultural advantages for some. This means one cannot just put a boundary between specifying and generalist forms of prenatal selection to solve the question of consent and autonomy. The current justificatory framework in medical ethics does not seem to be able to answer the question whether non-medical applications of genetics in the prenatal sphere could be allowed for. This should not lead to the conclusion that a new eugenics is permissible or ethically justified. It necessitates a deeper investigation into the issues relevant for a new eugenics. To this aim, one will have to look at the issue of eugenics from more angles, investigating the issue both from the perspective of the current justifications of a new eugenics as from the perspective of current refutations of those justifications. The discussion on eugenics however, is not merely conducted in medical ethics. It is also analysed from more theoretical approaches in the philosophy of justice and in the discourse of the theory of ethics and political philosophy. As will become apparent, even there, one encounters problems in clarifying what is at stake in the discussion on eugenics.

## **5. Conclusion**

Current standards for the ethics of new reproductive technologies are partly based on pre-existing principles, rules and guidelines such as informed consent (the right to know and not to know), patient autonomy, non-directiveness and the limits of

the goals of medicine. This framework was construed in the context of the move away from strong paternalism in medical ethics (from the sixties onwards), especially in regard to the classic Hippocratic medical ethics, that focused on well doing and not harming, without consideration for the status of the patient as an autonomous subject. Because of this application of this framework on these novel practices, several new aspects to these practices are not dealt with. This also applies to the attempts to make distinctions according to ethical relevance between different types of disease or disorder, by use of criteria such as severity, age of onset, likelihood of manifestation etc.

The focus on consent has opened the door to speculations on an application of genetics that goes beyond the original aim of medical indication, since consent does not exclude enhancement technologies, whilst the original goals of medicine (a restriction to well-doing and not-harming) would. The issue of consent presupposes a specific conception of autonomy, that has its roots in the history of bioethics in general and medical ethics in particular. This conception of autonomy is highly dependent of the idea of a general free and rational moral agent. But this conception raises several problems for an application in the design and creation of future people. It is necessary to analyse whether the defined goals of medicine are applicable to the issue of future people. One will have to address the matter of prenatal selection more broadly, looking into it from the constitution of future people as well as society at large, rather than merely through the glasses of consent. Although discussion on eugenics is kept at bay as much as possible, this discussion does bring in several issues relevant to the current discussion. In the next chapter, I shall turn to the history of eugenics, and its relevance for current decision making policies on new reproductive technologies.

*Chapter II*

Old Coercive and  
New Liberal Eugenics



## 1. Introduction

Current guidelines and policies on prenatal diagnosis (and other forms of genetic intervention in prenatal health care) are a direct result of the verdict pronounced on eugenics over time. In spite of this verdict some plea for a new liberal eugenics. Wild speculations based on the futuristic doomsday scenarios to be found in, for example, Aldous Huxley's *Brave New World*, Ira Levins' *The Boys from Brazil*, and movies like *Gattaca* will indeed probably not be the outcome of developments in human genetics. Still, the debate on the new reproductive technologies is fed by these and similar scenarios; so, apart from whether we take them seriously or not, such speculations do play an important role in public perceptions of these new technologies. And there are reasons for caution with regard to the potential of new reproductive technologies: the futuristic fictions mentioned above reflect a past scenario that left its darker imprint on twentieth-century history: the history of the eugenics movements. Nevertheless, novel scientific and technological insights might lead to new possibilities for a eugenics. Proponents of such a new eugenics try to show that the current conception of autonomy would not be harmed if a new eugenics would be introduced on the basis of the principles of liberalism. Therefore, we need to try and answer the question: what are to be the limits we will set for ourselves in the application of the new reproductive techniques.

When investigating what might be morally problematic in an application of new reproductive technologies beyond therapy or prevention, one cannot avoid a discussion on the old eugenics movements. Reference to the new reproductive technologies as scientifically more successful, and to contemporary society as giving a more prominent role to the patient's or client's autonomy, should not lead to an easy saturation of our moral concerns about a recurrence of the injustices performed by the eugenics movements. The line of thought presented in this chapter therefore not only focuses on the standard ethical analysis of that history, it will also point towards possible additional ethical problems that remain less apparent in that history.

I shall demonstrate that the focus on the prejudiced nature of the eugenics movements, as well as the focus on their blatant disregard of individual autonomy in their coercive policies has obscured related ethical problems that are implicit in the idea of steering or creating the genetic makeup of future generations. To this aim, I shall address four themes in this chapter. First, paragraph 2 provides an outline of the history of eugenics to show in what way this history has led to an ethical condemnation of eugenics. In section 3, I shall indicate in what way the objections against eugenics might be circumvented or refuted. In section 4, I give an account of a proposal for revitalising the concept of eugenics, elaborated by Allen Buchanan, Norman Daniels, Daniel Wikler and Dan Brock in *From Chance to Choice* (2000). Their proposal departs from a reflection of the American eugenics history and aims at refuting the classical objections to eugenics. In conclusion I

shall demonstrate how such refutations of eugenics-criticism fundamentally misunderstand the ‘moral autopsy’ of eugenics.

## 2. The Historical Eugenics Movements

Contemporary science has a restrictive stance towards the application of genetics. This is a direct result of the moral aberrations of the eugenics movement of the past. Genetics knowledge was speculative, the evolution theory was interpreted as socially relevant in a naïve way, and most proposals at intervention were based on societal prejudice rather than justified concern. New discoveries in genetics are in direct contrast with the ignorance and speculative nature of the historical eugenics movement. These and other arguments have opened the door to speculations on what might be done with the new techniques we now have at our disposal, rather than remain conservative.

Eugenics was a pseudoscience – as for example phrenology - that tried to apply a normative interpretation of Darwin’s evolution theory to society. The eugenics movement has its origin in the works of Francis Galton (Galton 1864-1865), a cousin of Darwin. Galton wanted to apply the principles of his uncle’s theory of evolution. The central thought was that human culture stood in the way of the principle of natural selection. If nature has a self-organising principle to select for those types that are most fit for certain circumstances, helping the weak would undo the working of that principle. This was supposed to lead to a degeneration of our genetic constitution, the symptoms of which were presumed to already be visible in society in the form of alcoholism, recidivist thievery, poverty etc.. These were all seen as the result of degeneracy in society. For this reason, according to Galton, having offspring should be regulated on the basis of the scientific principles derived from evolution theory. The creed went: if nature cannot do it by herself anymore, we had better keep an eye on the process ourselves. In his works, Galton largely aimed at a positive eugenics. Positive eugenics encourages people with desirable or preferred traits to procreate. American eugenics, under the influence of the so-called ‘degeneracy-theory’ (Micklos 2000), made the step to negative eugenics. Negative eugenics discouraged people with traits thought undesirable or abnormal to procreate, or even made it impossible to do so: sterilisation was eugenics’ main instrument in this respect. Genetic selection was only possible through propaganda encouraging the ‘fit’ to procreate, and by large-scale (often coercive) sterilisation programmes to avoid further procreation of those people deemed unfit, to avoid a spread of those properties in posterity. The scientific basis of such programmes was, to put it mildly, weak, and their ethical consequences far-reaching.

Eugenics became an important movement in the early twentieth century. Scientific positivism combined with the general idea that society was something that

could be made provided a fertile ground for eugenics, especially in the circles of well-established industrial families. Criminality and poverty were the main societal problems that were thought to be the result of hereditary degeneracy. The establishment, mainly of north-western European descent, was suspicious of the immigrants pouring into the United States in the late nineteenth and early twentieth centuries. The waves of immigrants were seen as a potential danger to the 'pure' gene pool of the nation (Micklos 2000; pp. 156). Eugenics provided these fears with a scientific excuse. As early as 1909, Charles B. Davenport, director of three institutions based at Cold Spring Harbor, applied Mendel's laws of heredity to humans (Micklos 2000). The American Breeder's Association (ABA) was founded even earlier, in 1902. Enthusiasm about eugenics led to the foundation of the American Eugenics Society in 1926 (by Harry Crampton, Harry H. Laughlin, Madison Grant and Henry Fairfield Osborn), its aim being the control over reproduction to safeguard the genetic quality of the population. Eugenics came to be well-embedded in society. Therefore it was possible for a philosopher of the stature of Bertrand Russell to support such programmes (although he later changed his views). In 1929 he stated: "(f)eebleminded women, as everyone knows, are apt to have enormous numbers of illegitimate children, all, as a rule, wholly worthless to the community." (Russell, 1965 (1929); pp. 131). He does continue to stress that a system of negative eugenics could easily be abused by the authorities to frustrate procreation of those of an unusual opinion or those opposing authority, but he sees such risks as 'worth incurring', in other words, extermination of the feeble-minded overrules the possible risk forced sterilisation of those that do not agree with the authorities<sup>17</sup>.

Eugenics was also influential in other parts of the world. In addition to the United States, the insights of the eugenics movements led to new laws in Sweden, Canada, Australia, Norway, Finland, Estonia, Switzerland, Iceland and, of course, Germany. In the United States, the eugenics policies were explicitly racist, but such views were also expressed in Britain<sup>18</sup>. Eugenics was also often regarded as an issue of public health, often appealing on civic responsibility rather than enforcing eugenics policy top-down. Later eugenics policies in Germany were an exceptional case for Europe. In Germany, Alfred Ploetz and his brother-in-law, Ernst Rüdin, laboured to spread the influence of the eugenics science. They were of the opinion that negative eugenics (in casu sterilisation) should be carried out forcefully if necessary. Ploetz' views were dominant until 1918. After the First World War,

17 The debate seems to have been governed by a postreligious liberalism with regard to sexual liberty when it came to positive eugenics (also appealing to the people's sense of civic responsibility), combined with support for coercive sterilisation programmes for those deemed mentally defective when it came to negative eugenics (as an example, also see Russell 1929 (1965); pp. 129-131).

18 Depending of the country and tradition in question, support for eugenics also intertwined with racist sentiments (e.g. again Russell 1929 (1965) with regard to Australian, New-Zealandish and North American aborigines; pp. 133: "In extreme cases, there can be no doubt of the superiority of one race to another."). Russell later came to reject these views.

more tempered eugenicists such as Hermann Muckermann and Alfred Grotjahn became more influential. They wanted to allow for a negative eugenics if conducted only on a voluntary basis. But when the Nazis came to power, Ernst Rüdin once again became politically active, participating in the forced sterilisation programme of the Nazi-government under Himmler's Ministry of the Interior's Commission (Schwartz 1995). The eugenics laws of Nazi Germany were based on the state of Virginia's eugenics law. In Germany some 350,000 to 400,000 people were sterilised during the Nazi regime. In many other countries, eugenics laws remained part of the legal system until well after the Second World War, notwithstanding the atrocities performed under the Nazi-regime in the name of eugenics. Forced and non-consented sterilisations and similar practices did not cease to exist in Europe until the 1960s and the 1970s. In Sweden forced sterilisations were endorsed by law until 1976, often on the basis of presumed low intelligence or presumed mental debility as well. Some countries continued to have eugenics laws until 1979.

In 1927 in the United States, the case *Buck vs Bell* (*Buck vs Bell* 1927) would become exemplary of how eugenics became part of the legal system as well. The case created a precedent for the whole of the United States. Carrie Buck was to be sterilised because she was diagnosed 'feeble-minded'. Mrs Buck did not consent to the procedure. The diagnosis had been based on a very short visit she made with her young daughter to sociologist Arthur Estabrook, who found her and her child to appear to be slow. Mrs Buck, 18 at the time, was diagnosed to have the mental capacities of a nine year old; she was also thought to be socially and economically inadequate and diagnosed as a feeble-minded moral delinquent. The fact that her child was illegitimate, born from a relative who raped her, probably also played a role in the diagnosis. To avoid any further offspring from her line, Estabrook advised the *Virginia State Colony for Epileptics and Feeble-minded* to have Carrie Buck sterilised. In 1927 Carrie Buck sued Superintendent James Hendren Bell of the *Virginia State Colony for Epileptics and Feeble-minded*. The case appeared before the United States Supreme Court. On the basis of several interviews, the court concluded: "She is [...] a potential parent of socially inadequate or defective offspring" (*Buck vs Bell* 1927; Lombardo 1985), and Carrie Buck lost the case. Her own lawyer, Irving Whitehead, failed to call the most important witnesses, appeared rather biased and was in direct contact with the lawyer of the *Virginia State Colony for Epileptics and Feeble-minded*, and was asked not to fight too devotedly for his client's cause.

Judge O. W. Holmes Jr. ruled:

"The commonwealth [of Virginia] is supporting in various institutions many defective persons who if now discharged would become a menace but if incapable of procreating might be discharged with safety and become self-supporting with benefit to themselves and to society;...experience has shown that heredity plays an important part in the transmission of insanity, imbecility, etc. [...] We have seen

more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. [...] Three generations of imbeciles are enough.” (Buck vs Bell, 1927; Lombardo 1985)

This ruling meant that the parties involved could proceed to an involuntary salpingectomy,<sup>19</sup> also to be performed on Mrs Buck’s infant daughter. Bodily integrity was seen as inferior to maintaining a pure and clean gene pool on a population level. Buck vs Bell became the turning point at which the United States Supreme Court took up a position in relation to Virginia’s eugenics laws. Following Virginia’s example, 33 States adopted coercive eugenics laws and policies. Eugenics led governmental institutions to forcibly sterilise people on a large scale.

In Virginia, forced sterilisations remained part of government policy until 1974. Estimates are that in the United States alone some 60,000 people were sterilised against their will or without their knowledge or consent between 1915 and 1979. Sterilisations were carried out on the basis of criminal recidivism, a low IQ, alcoholism, epilepsy and a presumed symptom of genetic degeneration called ‘feeble-mindedness’. In 2001, when Robert Hudlow, one of the victims of Virginia’s forced sterilisation programme, demanded a formal apology from the State of Virginia, Buck vs Bell was still referred to not to motivate the State’s choice to make a formal apology, but merely as a formal statement of regret. A formal apology did follow in 2002.

Eugenics became discredited because of its unscientific background and its socially, and sometimes racially, prejudiced nature. The eugenics movements and the policies they managed to implement in political programmes and legal policies proved to be an exteriorisation of the prejudices of upper middle classes of that time rather than being medically indicated or socially necessary. The history of eugenics laws and policies stands as an example of how a society can lose sight of all proportion with regard to individual justice in the name of a greater and more abstract ideal. The eugenics scientists were using their view of the world to distinguish what was considered eugenics and what as degenerate. Intelligence and morality on the one hand, and criminality, promiscuity or alcoholism on the other were considered inheritable traits that could be rooted out through coercive reproductive policies. In retrospect it appears that it was the culturally-framed opinions of the eugenicists themselves that formed the basis of eugenics policies, rather than

<sup>19</sup> The cutting and tying off of a woman's fallopian tubes to prevent her from becoming pregnant.

scientifically defensible and value-neutral predictions about the future of mankind. The measures taken in the name of eugenics not only lead to grave injustices regarding privacy, personal integrity and autonomy. A further problem was that their scientific insights were based on the prejudices of a very specific group in society. The implicit undercurrent of social prejudices, racism and fin-de-siècle anxiety about a deterioration of the human race were increasingly seen as the true Leitmotif behind the twentieth-century eugenics projects. Eugenics history has spurred the development of the principled approach to patient autonomy in medical ethics. Eugenics now stands as a paradigmatic case of what happens if medicine and society engage in strong paternalism<sup>20</sup> and disregard patient autonomy.

This very principle of autonomy that was a direct result of the moral indignation about what the eugenics movements had done is now used to justify reproductive freedom, even if the result of this reproductive freedom consists of techniques that might allow an enhancement of posterity. If these justifications are convincing, this begs the question whether we should turn back the clock on patient autonomy to avoid the birth of a new eugenics or proceed with a new liberal eugenics (Cowan 1995, pp. 262-263). If one steers away from the apparent injustices in the history of eugenics, why would one then still oppose the birth of such a new eugenics? In other words, should one restrict people's right to autonomy with respect to prenatal choice in the name of anti-eugenics, or should one retain it, and therefore allow for a rebirth of a, hopefully less morally aberrant, eugenics?

### **3. Refuting the Ban on Eugenics**

The history of the eugenics movements is often used as a backdrop for the current discussions on the new reproductive technologies. It is used as an absolute moral calibration point for these new techniques. Both proponents and opponents of the new reproductive techniques refer to the historical eugenics movements as something not to repeat. Opponents of the new reproductive technologies are concerned that if one were to apply the new reproductive technologies on a broad scale, it would lead to a revival of eugenics and the social injustices it brings with it. The German philosopher of discourse ethics Jürgen Habermas is one of the more important authors to express this opinion (Habermas 2003). Francis Fukuyama (Fukuyama 2002) also disagrees with such applications of new reproductive technologies, but takes a socio-biological determinist's picture of morality to prove his

<sup>20</sup> Here, I define the distinction between strong and weak paternalism as the Stanford Encyclopedia of Philosophy: "A weak paternalist believes that it is legitimate to interfere with the means that agents choose to achieve their ends, if those means are likely to defeat those ends. So if a person really prefers safety to convenience then it is legitimate to force them to wear seatbelts. A strong paternalist believes that people may be mistaken or confused about their ends and it is legitimate to interfere to prevent them from achieving those ends."

point that we should not meddle with our genes, since changing our genes would ultimately also change our moral principles, the basis of which he assumes to be genetic.

The notion of patient/client autonomy is currently an important notion in all debates on medicine and reproduction. As we have seen in the previous chapter, the application of the principle of respect for autonomy to reproductive choices has led to the following guidelines in reproductive medicine: the prospective parents, and especially the prospective mother, should have the absolute freedom of choice pro or contra prenatal diagnosis and termination. Even if a severe disability or disorder is discovered, the prospective parents may still decide to carry on with the pregnancy, and in such cases medicine cannot intervene. This is a definition of ethical guidelines from a negative liberalist perspective, in which not doing harm is to be the goal, rather than doing well (Vos 2009). Until now genetic testing and screening in the reproductive area must meet the following ethical demands. Firstly, the genetic diagnosis or intervention in question should have a clear medical indication. Secondly, the choice involved must be presumed to have the consent of the future person. And, thirdly, since it is impossible to predict exactly what any future person would consent to, the options offered should also be restricted to those that cannot be made in later life by the person himself. Fourthly, if a choice, pro or contra diagnosis (and the knowledge which follows from it) or intervention, can be postponed, it should be postponed until the future person can decide for himself. And finally, if such a choice cannot be postponed and if it is in the interest of medical treatment (or termination in the case of severely lessened quality of life), then prospective parents have the right to decide. On this basis, reproductive genetics has been restricted to ‘medical indication’.

An important role in the current debate is taken by the distinction between what is considered a treatment and what is considered an enhancement of human capacities. Norman Daniels offers two different objections against the treatment-enhancement distinction:

“One objection is that the treatment-enhancement distinction, even assuming we can draw a persuasive line between the treatment of disease and disability and the enhancement of otherwise normal traits, does not have the moral import that is commonly attributed to it, for example, in our insurance practices. Some nondisease conditions seem to oblige us to provide assistance to people for the very kinds of reasons that some disease or disabilities do. The treatment-enhancement distinction, then, does not map onto the boundary between morally obligatory and non-obligatory services. [...] The second objection challenges the basis on which the treatment-enhancement distinction itself is drawn. By implication, it then challenges whether we can use it to draw further moral distinctions without some kind of circularity. [...] It is our norms and values that define what counts as disease, not merely biologically based characteristics of persons, and the arbitrariness in these

hard cases comes from inconsistently applying our values. Pointing to the line between treatment and enhancement is not, then, pointing to a biologically drawn line but is an indirect way of referring to valuations we make. We cannot point to such a line as the grounds for or basis for drawing moral boundaries since we are only pointing to a value-laden boundary we have constructed.” (Daniels 2000; pp. 119).

Daniels defends that on the one hand, it is not entirely clear whether one can use the distinction treatment-enhancement as a moral criterion as such, and that on the other hand the distinction between treatment and enhancement is dependent on our definition of what counts as a disease and what does not. This definition is formed through our norms and cannot be derived objectively, that is to say, apart from our social norms. So the use of the distinction between therapy or treatment and enhancement is questionable. But as we have seen in the previous chapter, when one does away with such a difference, there seems to be no other strong framework of justification for different applications of genetics.

In the British Human Genetics Commission Report of 2004 criticism is also acknowledged:

“Some argue that such limits [the limit of medical indication to the use of prenatal diagnosis and selection on that basis] are unreasonable, suggesting that people should have the right to use developments in genetic science in the way they see fit for their circumstances.” (Human Genetics Commission 2005; pp. 24)

For some, the question is why would one stop at preventing serious diseases if one can use the same techniques to make life better for posterity? The Report continues:

“Advocates of this position argue that limiting access and the use of developments in genetics in the field of reproduction through regulatory, legislative or other means, is unacceptable unless they can be demonstrated to harm others, or society as a whole” (Human Genetics Commission 2005; pp. 24)

The pro-enhancement position, as it is exposed by the British Human Genetics Council, seems to be limited by two other provisos than medical necessity: one should not harm others, and one should not harm society as a whole. Taking this position the council bases itself on two philosophical schools that form an important undercurrent in the debate on the new reproductive technologies. Not harming others is a basic principle in John Stuart Mill jr.’s liberal philosophy. The principle of not harming society as a whole is often based on the principle of maintaining a balance of wellbeing in society as a whole. This principle can be found in utilitarianism, specifically Jeremy Bentham’s version of utilitarianism. According to the

British Human Genetics Council, such a position might actually open up the permissibility of a new eugenics. One does not necessarily seem to harm others or society as a whole when allowing for a eugenics that is implemented in society in a bottom-up fashion.

There are two reasons why eugenics is seen as morally reprehensible: firstly, eugenics was no more than social prejudice under the cover of science, and secondly, eugenics insights were put into practice on a non-voluntary basis (Buchanan *et al.* 2000). The recent insights of human genetics and the instrumental potential of human genetics appear to negate the first ethical objection against eugenics. Classic eugenics used to be based on mere speculative evolution theory and relied on breeding programmes to avoid traits presumed hereditary in posterity. Nowadays one can actually be sure of whether the traits one is dealing with are genetically determined, environmentally determined or determined by a complex of factors. We appear more able to discern cultural and societal problems from medical or genetic problems. The new genetics science seems to be more applicable than speculative human evolution theory. The second objection - the repressive nature of eugenics policies towards the reproductive freedom - can be circumvented by respecting the principle of non-directiveness. Biology has come a long way from mere speculative predictive evolution theory. Where one respects the principles of a liberal democratic society, one would not appear to make the same mistake as the old eugenics movements, namely to have social prejudice influence one's interpretation of social Darwinism and hiding these issues as prejudice by reverting to a reductionist biology. As long as one is suspicious of any such social prejudice or enforcement implicit in certain reproductive choices, one does not appear to be damaging anyone's autonomy or personal integrity. Therefore, a eugenics policy that is embedded in this framework of 'sound scientific insights' and that takes into account a respect for the autonomy of the parents appears justifiable.

One of the important publications that further explores the idea of a liberal eugenics is the aforementioned *From Chance to Choice: Genetics and Justice* by Allen Buchanan, Dan W. Brock, Norman Daniels and Daniel Wikler. They try to disprove the concerns voiced over the reintroduction of eugenics by showing that the new reproductive technologies used for eugenics purposes and the way they would be implemented in standard medical practice, have nothing to do with the old eugenics movements: according to them, eugenics can actually be supported whilst keeping the current moral guidelines intact. It is even claimed that not supporting a liberal eugenics would run counter to the very ethical basis of the current ethical guidelines of medical practice, although they partially stem from the moral autopsy of its more coercive predecessor.

This publication is an example of an approach to the possibility of a new eugenics that bases itself on a middle route between utilitarianism and the current notion of autonomy. It will therefore not be surprising that the philosophy of John

Rawls plays an important role in its philosophical foundation. *From Chance to Choice* was one of the first books outside of the area of medical ethics that dealt with eugenics in a systematic way. I shall provide an analysis of this book in the next section.

#### 4. On From Chance to Choice

*From Chance to Choice* (Buchanan *et al.* 2000) was published in the context of the debate on the new reproductive technologies, and deals with the issue of eugenics, the transition of chance in future people's genetic make-up to choice. Until now we have been dependent of chance in what the genotype of our children will be, from now on we can actually choose the better option. The four authors, all theorists in bioethics, have a general focus on the themes of harm, justice and rights with respect to the current and the future developments of human genetics. According to the authors:

“[t]he primary objective of this book [...] is to make a contribution towards answering a single question: What are the most basic moral principles that would guide public policy and individual choice concerning the use of genetic interventions in a just and humane society in which the powers of genetic intervention are much more developed than they are today?”(Buchanan *et al.* 2000; pp. 4)

This question is dealt with against the background of the errors of the eugenics movements of the late nineteenth and the first half of the twentieth century. In their analysis of the eugenics movements, the authors concentrate on the social injustices that flowed from the influence of those movements on society. The stress of the moral analysis is put on separating modern genetics, even in its non-medical application in the prenatal sphere, from the mistakes of the eugenics movements, so choosing genes instead of remaining dependent of chance in procreation becomes defensible.

By providing a historical analysis of the eugenics movements, Buchanan *et al.* hope to show that the faults of the historical eugenics movements lay principally in their giving precedence to the (perceived) interests of the *group* over *individual* rights. This was bound to lead to the injustices performed, especially in the light of the unscientific way in which the eugenics movements drew their conclusions. Buchanan *et al.*'s analysis of these eugenics movements does not lead them to dismiss with eugenics a priori. In their ethical analysis they specifically criticise the idea that the state should hold all control. But since they do not see any consistent argument against a eugenics as such, they only take a stance against any coercive eugenics or any eugenics that flows from the preferences of a certain group within society. This latter form, they refer to as communitarian eugenics: eugenics performed by a

sub-community, or even some sect within society. They see this kind of eugenics as another form of coercive eugenics, since it is coercive to the offspring of such a community, although it is not necessarily coercive to the members of that community. Most importantly, a eugenics based on the principles of liberalism is not dismissed with a priori. By aiming at this separation from the historical eugenics movements and with the proposal of their own concept of a liberal eugenics, the door is opened to a new eugenics.

Buchanan and his colleagues adhere to an emphasis on the protection of free individual choice. This does not lead them to a dismissal with the idea of a genetic experimentation on society as such. According to them, it is a question of taking the right ethical precautions rather than entirely moving away from human genetics. The authors identify the following four practical issues (Buchanan *et al.* 2000; pp. 15-16) that emerge when one envisages a society in which one would apply the new reproductive technologies in ways that stand outside of the traditional scope of medicine:

- Disabilities rights and genetic therapy
- The tension between reproductive freedom and prevention of harm
- Genetic therapy and genetic enhancement in the light of the history of eugenics
- The role of the state in regulating individual freedom of the choices in genetic technology

By taking these issues in consideration, free choice is to be protected and a coercive eugenics can be avoided.

The discussion on the first issue, disability rights, has been triggered by disability rights movements that oppose existing prenatal diagnostic means to avoid offspring with the disability in question. Some consider these types of prenatal selection as a form of discrimination against their group. Their concern is that a broad implementation of the new reproductive technologies would actually be discriminatory toward their group. The kernel of Buchanan *et al.*'s position on this matter is that society's prejudices and negative attitudes towards disability are much more problematic than the actual disability (Asch 1988; Asch 1993; Blumberg 1994; Ward 2002; Raz 2005) So, according to some, it is not just the disability but also the disabled that are discriminated against. They argue that we should be very careful to implement new reproductive selection methods in standard pre- and neonatal care. Buchanan *et al.* disagree, since in their view, it is the disability, not the disabled, that is discriminated against (Buchanan *et al.* 2000; pp 278). A negative judgment on the people that have a disability is not implicitly present in a stance pro avoiding handicaps.

The second issue is the problem of reproductive freedom and the prevention of harm. There is a tension between the prevention of harm for people's offspring

and their reproductive freedom to choose not to have genetic tests in spite of the fact they know they are at risk of having a child with a severe genetic disease or impairment. Can one say that parents are morally required to prevent harm to their offspring if they are able to do so through prenatal selection or intervention? In most cases, Buchanan *et al.* do not expect problems to arise, since most parents would agree to creating the best chances for their child<sup>21</sup>.

The third issue, the supposed moral significance of the difference that is taken to exist between genetic therapy and genetic enhancement technologies in the light of the history of eugenics, has probably been the most dominant issue in the current debate on a new eugenics. The history of the eugenics movements necessitates prudence on the subject of eugenics. A question that needs to be asked is whether the difference between a liberal eugenics and a coercive eugenics would be categorical or gradual. If the difference is categorical, then the old eugenics and a new eugenics would not need to be associated with each other ethically. There would be no danger of regressing to the same mistakes as the old, coercive eugenics. But if the difference between the two is merely gradual, then one should be cautious in applying it.

The fourth issue that deserves attention according to Buchanan *et al.*, concerns the question who should be responsible for genetic decisions. Should genetic interventions be steered by the government through the public health system, or should these decisions remain entirely within the domain of personal choices and private decision-making? In the first case, this would mean an infringement on individuals' freedom to make their own reproductive choices. In the second, there is less of a check and balance on the risk of allowing people to make reproductive choices that are counter to the interest of the future child, or to the general conception of what constitutes an enhancement and what constitutes a 'dysgenetics'. Therefore, one should steer between the two options of complete state control and absolute genetic freedom.

The two moral problems Buchanan *et al.* stress as the most important are the problems of governmental paternalism and prejudice, which have already been discussed. However, the authors do note a third important moral issue: "Even if an individual is no more locked in by the effects of a parental choice than he or she would have been by unmodified nature, most of us might feel differently about accepting the results of a natural lottery versus the imposed values of our parents.

21 Some disability organisations have gone further than simply stating their concerns about the potentially discriminatory background of reproductive choices on the basis of genetic diagnoses. They also expressed their wish to have the right to select posterity on the trait in question. Prenatal selection on hereditary forms of deafness and dwarfism are striking examples which have preoccupied the media in recent years. The main argument of these disability organisations is as follows: if the 'normal' or the 'average' in society have the right to avoid offspring with their genetic traits (e.g. deafness), and this trait does not constitute a severe form of physical suffering, why would the exceptional not have the right to select on their offspring and avoid an average child? I shall discuss this more in depth in chapter III.

The force of feeling locked in may well be different.” (Buchanan *et al.* 2000; pp. 177). Even though certain genotypes might occur naturally as well as artificially (through human intervention or selection), the way in which such a trait plays a role in individual life might be very different for both cases. This problematic nature of the chosen versus the contingent, does not lead the authors to dismiss all possible forms of ‘going beyond therapy’. It merely leads them to search for conditions under which such a step may prove justifiable. In the authors’ opinion, there could be ways to implement eugenics in society without falling into the social injustices of the eugenics projects of the nineteenth and twentieth century. As long as the conditions of the liberal society are met, Buchanan *et al.* pose that nothing would be wrong with eugenics.

The authors do acknowledge the following five serious concerns that were problematic in the old eugenics, and might still be in a liberal eugenics (Buchanan *et al.* 2000; pp. 46-50). They need to be dealt with in the implementation of a new liberal eugenics:

1. Replacement, not therapy: eugenics decided for a replacement of certain types rather than providing them with the necessary therapy. This is morally problematic to many.
2. Value pluralism: guided by government policy as well as criteria provided within a medical paradigm of disease/disability – health – enhancement resulted in a universalistic conception of the ideal person. This might also be valid for a liberal eugenics. One can imagine this might run counter to the pluralistic nature of our current society.
3. Violations of reproductive freedom: eugenics put a restraint on the basic right to reproductive freedom. The historical, coercive eugenics already proved that the attempt to enhance posterity actually led to an infringement of individual reproductive freedom. What if societal preferences and economical burdens prove to be as coercive as state policies?
4. Statism: the state was to be the locus for decisions on eugenics policies (which options to allow for and which not). If this happens again, state influence on individual lives would again become too extensive.
5. Justice: eugenics has turned out, and can again turn out to lead to injustices, especially in the distribution of burdens and benefits.

Buchanan *et al.* do not see a principled problem in issue one, the replacement of types of people taking the place of provision of therapy. This is a question of distributive justice, rather than of genetic enhancement technologies per se. Similarly, on the second issue of pluralism, they do not perceive any obstacle that cannot be overcome. Eugenics might propagate genetic diversity as much as the reverse. There is nothing inherent in what eugenics is that would lead to a homog-

enisation of our genetic quality. Buchanan *et al.* don not see a problem in issue three either. They assume that although indirect coercion might be of influence, it does not necessarily result from eugenics, nor is it unavoidable. State coercion, the fourth potential problem, can be avoided too. Indeed, the authors only see a problem specifically concerning eugenics on the fifth point (Buchanan *et al.* 2000, pp. 46). All others they see as circumstantial, following from poor science and prejudice rather than from the concept of eugenics in itself. However, even this potentially unjust distribution of means can in the authors' opinion be circumvented by giving the state some control on how access to eugenics could be organised in a fair way. But a further analysis of how such a control is to be exerted would likely lead to several moral implications that are not directly visible. In chapter IV, I shall show whether the analysis of Buchanan *et al.* is sufficient by elucidating the philosophical tradition from which this analysis emanates. Here, I will restrict myself to sketching their basic arguments.

The conditions under which certain eugenics choices can be justified are constituted on the basis of the concept of a distributive justice in the tradition of John Rawls (Rawls 1992 (1971)). Rawls aimed at a distributive justice to compensate for the differences in fortune between individuals in society. Justice is seen as being dependent on a reduction of luck in favour of a more equal distribution; one should attempt to distribute capacities equally. To be able to grasp this concept of an equality of capabilities better, the authors of *From Chance to Choice* also adhere to a so called morality of inclusion, a concept developed by Dan Wikler; our world has been designed for the average human being. This means people with a disability cannot participate in society as fully as they should according to the principle of a distributive justice. By redesigning the world around us we can make it accessible for the disabled as well as for the abled. For example, we have already made adjustments to render museums and theatres accessible for people in wheelchairs. To a certain extent, they are now included and can participate in these important social domains. However, as the authors defend in a charged fashion, if it were possible to include these same people by adjusting *them*, with the help of genetic technologies, would we not be including them in a more profound fashion? Buchanan *et al.* state:

“[...] a theory of the morality of inclusion would articulate criteria for membership in what might be called the primary moral community, specifying the characteristics that individuals must have in order to qualify as worthy of equal consideration and respect. Such a theory would also delineate the scope and limits of our obligations to include other individuals or groups in various mutually beneficial cooperative arrangements and hence make them eligible not only for the concrete benefits of participation in those arrangements but for the status of equality that is accorded to

those who stand in relations of reciprocity with one another.”(Buchanan *et al.* 2000; pp. 258)

In order to participate in the world in a satisfactory way, an adjustment of the world to all its subjects is not what should be aimed at, if there is the alternative of adjusting these subjects to that world. If one has an impairment, it is better to cure or treat the impairment than to provide for the means to live with it in a way that compensates for the disadvantage. Cure or treatment would be in the individual’s advantage, because they would be able to participate in a much more satisfactory way than if one adjusted the world to their needs. In this fashion, Rawls’ concept of a distributive justice and his ideas of equality of opportunity can be defined for genetic enhancement as well. This way, such enhancements would lead to a society in which more people are included to participate, with an equality of capabilities.

Several disability rights movements are of the opinion that by prenatal diagnosis to avoid that disability, one discriminates against them. Eugenics history demonstrates that cultural racial and societal prejudice is a risk implied in eugenics. But according to Buchanan *et al.*, it should be noted that it is not the disabled person, but the disability that is devalued (Buchanan *et al.*; pp. 278). Similarly, one can also ask oneself what would be the problem of going beyond the goal of avoiding disabilities. The more one can offer someone the possibility to develop him within society, the better. Not offering our offspring the best chances to develop in a meaningful way would seem to constitute a similar injustice as not offering parents the chance to have healthy offspring whilst the technology to do so is at our disposal. As long as one manages to differentiate between the disability and the person suffering from it, one can make a very clear distinction between attempts to rid our offspring of impairments and attempts to devalue the people with such disabilities. Still, to be able to make such a distinction, one needs to discern between discriminatory selections or interventions and truly enhancing selections or interventions in the human genome. One will even need to address the question whether it is possible to find a neutral ground that would not be disputed on the basis of which one can make such distinctions. Can one rely on a Rawlsian picture of distributive justice and a morality of inclusion as an undisputable and neutral ground for just decisions, or would such a basis also hide a discriminatory basis? Whether a new eugenics would be discriminatory or not is also rather dependent of what definition one takes for eugenics or genetic enhancement. Motomu Shimoda gives the following definition of eugenics:

“The core of eugenics lies in intervention in the genetic qualities of human beings based on specific values of being superior/inferior, whether at population level or at individual level, by government policy or by individual voluntary choice. As far as such interventions are concerned, both negative-eliminative and positive-enhancive interventions are eugenic practices. This is a broad definition of eugen-

ics. It is often said that eugenics is intervention in heredity traits only by governmental policy at the population level, so genetic intervention by individual voluntary choice with the aid of biomedical technologies is not eugenics. However, depending on our interpretation, we could miss the commonality and continuity of both types of intervention. Governmental policy and individual voluntary choice and are not necessarily opposed, but rather, complement each other as factors promoting eugenic practices. Eugenics must be understood as a theoretical/practical movement that is changing as technologies advance.” (Shimoda 2004; pp. 4)

As Shimoda righteously points out, although one might differentiate between old and new eugenics by differentiating between state coercion and individual free choice, states sometimes provide free choice, and individuals might also be coerced by something different from states. And one could assert that every intervention in the human genome is in some way based on what we perceive of as superior or inferior. Perhaps we need to incorporate more examples of what we see as eugenics for that reason. In any case, the discussion on ‘going beyond therapy’ would benefit from a clear analysis of the normative relevance as well as the possibility of a demarcation between severe, less severe, normal and enhanced. In some ways *From Chance to Choice* seems to offer such an analysis, but Buchanan *et al.*’s analysis remains highly dependent of a medical paradigm. Jonathan Glover defends deafness is a disability, but he would not frame it as incompatible with leading a normal life (Glover 2006). On the basis of a medical paradigm, one can regard deafness as a disability, even though many deaf people disagree with this analysis. One cannot answer the question what constitutes an enhancement in a neutral way, which is in itself a prerequisite to answering the question what would actually constitute eugenics. This poses a moral problem for the nature of selections and interventions in posterity. Will they actually be ‘enhanced’ or will their genetic make-up merely be subjugated to the preferences of contemporary society (or certain groups within contemporary society)?

To embark upon a mission that aims at adjusting the genotype of posterity, be it on an individual or on a collective, generational level could only be justified if one were sure that these adjustments would be based on a neutral criterion. It is not altogether certain whether we can find a *neutral* criterion with which we can measure and rank our properties and traits. This might lead us to unintentionally express our cultural and societal preferences in the genetic makeup of our posterity, under the guise of what would be termed an enhancement. Society would instrumentalise future generations to what we perceive of as the perfect life or as the perfect society. One cannot assume that this is the case; that the values of our group, our nation, our generation are the values of all groups, all nations and all generations (although one cannot assume the opposite without losing the ability to justify claims and courses of actions either). If anything, the opposite is more likely. The

analysis of the moral issues concerning genetic technology in *From Chance to Choice* only appears in the perspective of freedom of choice on the one hand and safeguarding social equality on the other. This, however, is not the only morally relevant structure in the analysis of genetic technology. As Buchanan *et al.* themselves mention, an important issue might be that how someone who is designed genetically or selected on the basis of genetic criteria, considers himself to be. Would the idea of having been designed by one's parents influence the way one would look upon oneself in a negative way? Would one consider one's identity to be the same as other people's? As mentioned, the authors only bring this to bear upon a communitarian eugenics, and they do not provide a reason why the same argument does not apply to their own 'justifiable' form of eugenics as well. Similarly, functionalising human lives in the name of an enhancement of human nature, begs the question of the inherent value of human life at the least. One cannot dismiss this problem by referring to our conception of the good life as its justification. This last problem raises another question which sheds a shadow on the justifications for a liberal eugenics put forward in *From Chance to Choice*. Is it society or the individual that should have precedence? Should we adjust future people to the ideals of Rawls' liberal society, take his ideas as a supposedly neutral basis of a criterion for what counts as an enhancement, or would the idea of such an adjustment in itself run counter to those ideals?

## 5. Conclusion

The old eugenics movements are considered morally aberrant, especially because of the prejudiced nature of their ideas and the way they used coercive medical interventions to act upon those prejudices. These prejudices reflected the ideology of the social class that was enthusiastic about eugenics in that day and age. But history's moral autopsy of eugenics stresses the coercive way in which eugenics was put to the practice in society, rather than its risky cocktail of social prejudice and biological misconception. This moral autopsy only regards problems of eugenics for the conditions of a liberal society rather than issues of the dubious role science sometimes plays in influencing society under the guise of scientific neutrality or issues of Man's relation to his biological and existential identity. The current debate on going beyond the traditional scope of medicine does not touch upon this core problem of the old eugenics. Although much work has been conducted to demonstrate where the old eugenics was at fault, these studies do not necessarily demonstrate whether eugenics was principally at fault or not. The benefits and the potential injustices that could come from a new eugenics are sketched out, with a focus on parental rights to access to medical care, even when going beyond the traditional goals of medicine, and a focus on the rights of future generations to the best possible starting position in our society. In the past, the sole means of steering

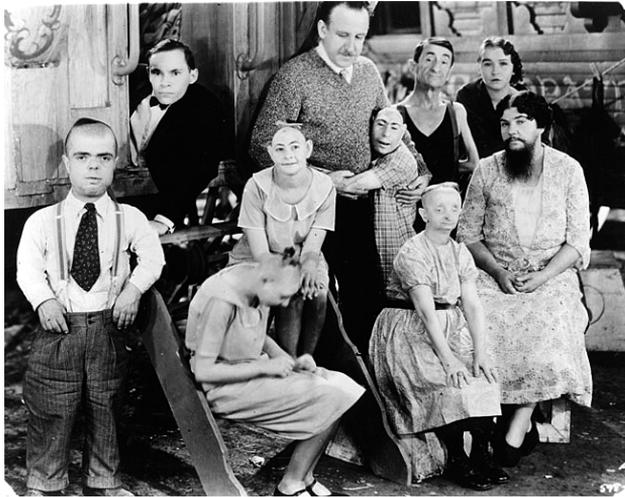
posterity consisted of making use of restrictive reproductive policies. In most cases, those traits that were meant to be rooted out in posterity were non-hereditary or even only existent in the eye of the eugenicist himself. This has changed with the development of the new reproductive techniques. It is claimed that a eugenics based on the new scientific insights at least has one advantage above the old eugenics movement: now, we can actually steer the traits of posterity through selective abortion or implantation, and, perhaps in the future, even through germline intervention. Next to this, science has overcome old prejudices and society is now more liberal. Since genetics has come a long way in the past 100 years, and since society is now less prejudiced, the door to a new liberal eugenics seems to be opened.

One needs to show why our ideas about what is to be considered an enhancement and what not, are less naive than the scientific claims of the mid twentieth century. If not, one could be making a similar mistake, even though one is not directly harming prospective parents, or infringing on autonomy liberty and integrity. In bioethics, the focus is on social justice and rationality in a communicative field that is populated by free agents. In this sense, autonomy is seen as the ability that is constituted by freedom of choice. This communicative field is mostly defined as something that takes place in a normative space of reasons. Choice, freedom and autonomy also appear within this space. There is a blind spot within such an approach: there is no room for any feature of human identity or the self, since such features are to be discarded with as contingent issues that should not play a role in the debate, and could even be seen as obstructing autonomy, rather than being part of it. This has important ethical consequences for the debate on prenatal diagnosis. Within the framework of a liberal eugenics as elaborated by Buchanan *et al.*, individual human existence is functionalised in an all-encompassing goal of a fair distribution of opportunity and wellbeing. The quest for a fair distribution of wellbeing and opportunity should always remain instrumental to individual human life, and not the other way around. It might be possible to give an account of how the new reproductive technologies can be used for goals that go beyond the scope of medicine without making such mistakes. But this would only be possible if we leave behind the idea of a universal standard for the enhancement of posterity. I shall go into this issue in succeeding chapters.



## *Chapter III*

# Tampering with Genetics; Improvement or Personal Design?





## 1. Introduction

As argued in the previous chapters, a proposal for a revival of eugenics cannot be dismissed with by merely referring to the injustices of the past. The ideology behind the old eugenics movements and their blatant disregard of the individual's rights was the main reason for history to judge it to be immoral. It might seem that if one can propose a liberal framework for individual people's reproductive choices on enhancement technology, one would not be able to raise any different objections to it than to, say, cosmetic surgery. The only restrictions might be that one should prevent possible harm to the client and that one should not exert any direct coercion. However, if these aspects are not proven to be an inherent part of eugenics, we cannot dismiss every non-medical usage of the new genetic technology.

There are many authors who use this right to an open future as an argument to oppose any form of genetic selection or genetic design that goes beyond obvious preventive medical goals. As is stated in a report for the United States' President's Council on Bioethics:

“Selecting and designing children under the guise of ‘parental choice’ instrumentalizes children as a means to the parents’ ends and places limits on a child’s right to an open future. This becomes increasingly worrisome as the intent of these techniques moves away from arguably ‘medical’ purposes to those that are clearly non-medical. The psychological impacts to children selected to have particular traits, desires, talents could be immense.” (Simoncelli 2003; pp. 4)

Moving beyond the scope of medicine might render having children into a commodity for the parents, whilst restricting the future child's basic rights to choose its own path in life. In this respect eugenics choices are often restricted to those applications that also seem to maintain the openness of the prospective person's personal future (Feinberg 1992; Davis 1997). And there are those that state it is not the quality of the genes that are chosen but the fact that they were chosen at all where the right to an open future is threatened (Habermas 2003). But why would one be more restricted in one's future if one's genes are the result of parental choice rather than of the genetic lottery? Could genetic technologies not be used just as easily for broadening the options one has in life? For the eugenicist, this would restrict the options to ‘general traits’ rather than traits or talents that a priori lay down a certain life plan. Some traits, such as a higher intelligence, do not seem to lay down a specific life plan, others, such as being taller than two metres (with a basket ball player in mind) or having a better musical talent do. These issues led proponents of a new eugenics (Buchanan *et al.* 2000) to defend their position on the basis of the right to an open future. On this basis one can derive the following definition for the ethics of eugenics choices: choices on the genetic constellation of our offspring that aim at a specific life plan should not be allowed for, whilst

choices that broaden and strengthen one's general options in life, that give a person a better initial position should be allowed for. In that case, a higher intelligence or physical fitness seems to enhance one's options in life, whilst having a specific talent for music does not (Buchanan *et al.* 2000). This seems to defuse the argument against eugenics on the basis of the right to an open future.

If one chooses to define what constitutes a better initial position, one could pose the question why such a restriction on the reproductive choices parents may want to make would still be called liberal? Furthermore, one cannot specify what would constitute eugenics, and what would merely constitute a form of genetic design according to some people's subjective preferences without prioritizing some type of biological perspective with a notion of what counts as species-typical. Without, there seems to be no clear demarcation between what we would perceive of as an enhancement and what as merely a form of designing posterity (be it collectively or on an individual scale), but with it, it appears that choices cannot be offered in a liberal fashion. One can support or refute the idea of a liberal eugenics, but in either case it will be necessary to have a clear definition of what is seen as eugenics, and whether such a practice can be combined with the idea of a liberal society.

The main issue appears to be on a deeper level than the question 'how can we ameliorate posterity?' The question is not merely 'what are we able to do?' but also 'can we find a neutral criterion on which we can decide what we should do?' The latter question goes well beyond fantasising about the amplification of human potential or finding new capacities to add to the existing ones. Proponents of enhancement technologies and eugenics perceive of new technologies such as pharmacologically-induced cognitive enhancement, genetic selection and intervention, or cybernetics as a means to ameliorate human potential or add upon our existing capacities. Opponents are either distrustful of the technological potential to enhance humankind, or distrustful of the human ability to discern what should count as an enhancement or as eugenics and what not. It is dubitable whether we can presume to know what constitutes gene-fit and what not.

If we cannot find a neutral scale on which to base our ideas about what counts as 'better' and what counts as 'less', we should tread with caution. For some, the positivist's account of scientific facts provides for a sufficiently sophisticated framework to answer this question. For others, the criticism on the neutrality of scientific facts as it was offered by philosophers such as Foucault or Kuhn, makes it a much more complex question to answer. On the basis of that criticism one is forced to admit that if science cannot provide us with a neutral framework on which to place features such as the level of intelligence or our physical abilities, we should not tamper with our make-up so readily. In order to answer the question where the boundaries should be placed for non-treatment applications of genetics in the prenatal sphere, one will also need to examine whether the ethico-political discourse of liberalism is sufficient to cover the ethical issues involved in such a

practice. The question of whether there can be clear definitions of what can be seen as genetically better must be examined. Another important question seems to be whether the distinction between better and less can be drawn in a neutral fashion. It is not clear whether it can be taken to be relevant for the ethical debate on the new reproductive technologies at all.

## **2. Different Options in Reproductive Genetics**

The debate on the new reproductive technologies has suffered from a rather one-dimensional view on what eugenics is supposed to be and how the difference between 'normal' applications of genetics (i.e. those that fall within the medical paradigm) and eugenics applications of genetics (i.e. those that fall outside of the medical paradigm) is to be used as an ethical criterion. But in a sense, existing forms of advice and counselling in the reproductive area can already be considered eugenics: they influence parental reproductive decision-making, and therefore influence the genetic make-up of posterity. Extrapolating from this, any decision made by a couple at risk of any genetic disorder, be it thalassaemia, fanconi anaemia, diabetes, manic depressive disorder, polydactyilia, or myopia, would be a eugenics decision. Choosing pro- or contra-selective termination or selective implantation, and even choosing not to have a child will have an impact on the genetic make-up of posterity. However, with such an all-inclusive definition of eugenics, something becomes obscured. Eugenics is not merely the steering of the genetic make-up of posterity, but the steering of the genetic make-up of posterity towards a certain ideal. Eugenics always has an implicit or explicit conception of what is genetically better and what is genetically defective. In abandoning one-dimensional views on what counts as eugenics, and calling any decision that affects the genetic make-up of posterity eugenics, one would ignore this genetic idealism implicit in the term 'eugenics', signified by the prefix 'eu'.

The majority of existing examples of prenatal (genetic) diagnosis are neither treated as eugenics nor as a form of cosmetic genetics. They are not treated from the perspective of designing or selecting persons, but rather from the dichotomy handicap/disease - normal variant. Prenatal selection to avoid a certain serious disease or impairment is already an accepted medical practice. It is motivated on the basis of health issues and quality of life for the future child. A standard example is testing for Down's syndrome by obtaining foetal tissue samples by amniocentesis or chorionic villus sampling. Another practice, which takes place in the context of reproductive counselling, is advising parents against offspring in the case of a shared genetic defect. Neither of these examples is seen as a form of eugenics or as a form of designing our posterity. Still, they could also be interpreted as at least in part, a form of eugenics. In the first case, although not changing the risk of having a child with Down's syndrome, the large scale implementation of such tests do

result in a reduction in the number of people with Down's syndrome in the population. In the case of advising parents against offspring with shared genetic defect, this would change the genetic make-up of the population in the long run.

Looking at existing and possible future practices as a form of eugenics can be helpful in deciding where medical interventions cross over in eugenics, and whether there is an ethical argument of justification for or against such practices to be found in this difference. It may be helpful to discern the following eight categories of genetic steering of the offspring, some of which are seen as eugenics and others are not<sup>22</sup> (see table 3).

**Table 3:** Different applications of prenatal selection in a eugenics context (with a few examples)

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Avoiding the birth of a child with a very severe to lethal defect (like anencephaly<sup>23</sup> or other grave malformations).

Avoiding the birth of a child with a disposition to develop a severe disease later in life, either during or after childhood (like Huntington's or Fanconi Anaemia).

Avoiding the birth of a child with a severe disability (cerebral palsy, Down's syndrome with severe complications).

Avoiding the birth of a child with a disposition to develop a less severe disease (either during or after childhood), or only at risk of developing such a disease (diabetes or breast cancer, for example).

Avoiding the birth of a child with a lesser disability or with a trait of which its status as impairment is disputed (deafness, dwarfism, polydactyly).

Aiming at the birth of a child with a lesser disability or with a trait of which its status as impairment is disputed (e.g. deafness or dwarfism).

Selection on other properties in a child that have a neutral character (hair or skin colour, gender)<sup>24</sup>

Selection on other properties in a child generally thought of as positive (intelligence, muscle growth, fitness, disease resistance).

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Prenatal diagnosis and selection on the basis thereof, as they are exemplified in the first four cases, are, I would presume, hardly ever induced by eugenics motives. It is the self-evident parental wish to have normal, healthy children and the predicament of the future person if one would have a child with defective genes to be born which is given as a reason for a choice to reproduce selectively. This means parents that are in a situation in which they know they are going to have a child with a disease or impairment or a grave malformation, and are in a position to avoid pregnancy or birth of such a child cannot be called eugenicists for expressing a

22 Apart from secondary genetic selection (such as selection on DNA compatibility with an earlier sibling to develop medication)

23 "Anencephaly is characterized by the absence of scalp, calvarium and normal brain, which is replaced by an angiomatic mass. The typical appearance of the face (batracian phenotype) is due to absent frontal bones and shallow orbits causing protrusion of the eyeballs." Gilbert-Barnes Mosby, E., Ed. (1996).

24 Although such properties might be constitutive for the individuals and groups concerned.

wish to have a normal and healthy child. They are not aiming at an enhancement of posterity, nor are they taking advantage of the luxury to express their preferences for a specific child. They only want what is natural for any parent to want: a normal, healthy baby. Creating the perfect society or rooting out hereditary diseases altogether in posterity is not the secret agenda behind such practices. At the most they might be an accidental side-effect. The ethical difficulties of these practices are not 'when to say no' to genetic techniques, but 'how to accept no' if parents do not want to use them. Each of these first four categories exposes some specific ethical problems.

With regard the avoidance of the birth of a child with a very severe to lethal defect, most would agree that it is understandable that parents would want to use genetic diagnosis and prenatal selection to avoid the birth of children with a severe impairment or (genetic) disease. Only anti-abortionists who have extended their argument to the practice of in vitro fertilisation might oppose the application of our knowledge of the human genome to avoid the birth of such children. Even they would agree that not having children could be an appropriate alternative, if the risk is too high. Choosing not to have a child is also a way to steer the genetic makeup of posterity, and hoping for the best when alternatives exist will also result in different genes for posterity than if we were to allow for intervention or selection. Still, avoiding the birth of a child with a very severe to lethal defect through genetic technology does not seem to lead to coercive or forced eugenics.

With regard to the avoidance of the birth of a child with a disposition to develop a severe disease later in life, either during or after childhood, most parents will obviously wish to avoid having a child that has a risk of developing for example Huntington's. The ethical problem lies in those cases in which parents do not want to make use of medical techniques to avoid a severe disease or disability for their child. Is society willing to accept the moral implications of parental choices against prenatal diagnosis, or selective termination, when the birth of a diseased or impaired child can be avoided? Are insurance companies be willing to continue bearing the costs involved if a parent chooses against prenatal diagnosis when alternatives exist? Avoiding the birth of a child with a disposition to develop a severe disease later in life does come with additional ethical problems: it might indeed lead to an indirect coercive eugenics, although side conditions might be defined to avoid such a scenario.

With regard to the avoidance of the birth of a child with a severe disability, the prevention of the birth of people with for example Down's syndrome or similar genetic defects also poses difficult question, although prenatal diagnosis on such genetic defects has become rather normalised. Are we still trying to prevent human suffering, or are we actually taking the stance that we may decide on which types of people deserve to live and which do not? For most parents, having a child with Down's syndrome is not what they had wished for. And, one could say, why would individuals with Down's syndrome suffer from the fact that less of them are born?

The difficulty, similar to examples from the second category, seems to be that society might become less tolerant of those who decide against prenatal diagnosis, or those who decide against selective termination or implantation. Prevention of the birth of people with Down's syndrome or similar genetic defects therefore might also come at the price of an indirect, societal, coercion.

With regard the avoidance of the birth of a child with a disposition to develop a less severe disease, the reason for most people to opt for a selection to avoid having a child with a slight impairment hardly ever stems from biomedical idealism. As with category three, parents will opt for a child without such traits because they want the healthiest child they can have, for themselves as well as for the child itself and its starting position in life. Still, as in the former cases, avoiding the birth of a child with a disposition to develop a less severe disease might lead to a society that is less open to bear the burdens of those diseases.

Things change with regard to examples from the categories five to six. If society decides to go as far as to allow parents to make reproductive choices on traits the status of which as an impairment can reasonably be disputed, one enters the area of personal preferences rather than neutral and objective medical goals. Will such choices be in the best interest of the future person or not? With the avoidance of the birth of a child with a less severe impairment, we tread on more difficult ground. In this case, humaneness, or avoiding (severe) harm cannot be held to be the sole reason behind a choice for controlled reproduction. Although the traits in question are generally looked upon as an impairment, one should bear in mind that a trait which is considered an impairment by some may be regarded as a mere variant by others. We consider it to be natural for hearing parents not to want to have a deaf child, when offered an alternative. They will not be choosing the child they want as if they were selecting a Christmas present. This option offered within medical contexts gave rise to speculations on the applications of genetic selection mentioned in category six, aiming at the birth of a child with a lesser disability or with a trait of which its status as impairment is disputed. Some see their condition as something that adds to their life rather than diminishing their life's happiness. For them, being deaf, being a dwarf, even being in a wheelchair is not solely seen as a restriction on how they can live their life but also as a trait that is constitutive of whom they are. It marks them as being part of a particular group with its own right to existence, and in some cases its own history and culture. They look upon the new means to selective reproduction with suspicion, since it seems to be a form of discrimination towards their group. As A. E. Raz states: "Prenatal testing is morally problematic because it expresses negative or discriminatory attitudes about both impairments and those who carry them" (Raz 2005). Obviously, those who would accept category five as a viable option, would disagree with those who find category six a worthwhile choice. Problematic is that the reasons given by those accepting category five can just as easily be used to defend category six. For, when one thinks of specifically choosing a trait that is considered a disability by some and a mere

variant by others, the definition of what is improvement is under fire. What constitutes impairment for one person, constitutes a trait by which they are part of a certain group, a positive building stone of their identity and culture for another. Deaf and dwarfs do not regard themselves as being impaired. They therefore look upon the development of new techniques that make the birth of a child that is deaf or has a hereditary form of dwarfism optional, with suspicion. When the status of deafness or dwarfism as impairment can genuinely be contested, one can also wonder why they do not have the same reproductive rights as 'normal' people. Still, society might indeed not want to bear the burdens that come with the creation of people with a trait the status of which as a handicap can be disputed.

The reproductive choices in category seven, selection on other properties in a child that have a neutral character, can be differentiated from the choices exemplified in the preceding categories, since they do not have the connotation of disease, disability and impairment (contested or not) as in the former categories. The complications do not emerge from the difficult nature of aiming at the birth of a child with a trait that is generally looked upon as a medically-defined disadvantage in life. On the contrary, a selection on gender or skin colour cannot be put in biomedical terms (except if it is conducted to avoid a gender or ethnic related hereditary disease). Some ideal of social perfectionism must underlie any justification of this category. Whether or not seen through the glasses of a prejudiced interpretation of the evolution theory, selection on other properties in a child that have a neutral character might indeed lead us to a path of a eugenics that is steered by social prejudice, whether coerced by the state or not.

In the eighth category, selection on other properties in a child generally thought of as positive, some ideal of social perfectionism also reigns, but now it is conceived of in a non-discriminatory sense. For example, selection on intelligence, if possible, would certainly constitute an enhancement in most people's eyes. This is different from the discriminatory choice as argued for by those who accept category six or seven, (*aiming at the birth of a child with a lesser disability or with a trait of which its status as impairment is disputed or selection on other properties in a child that have a neutral character*). The difference is less fundamental than on first sight. One is still selective in one's preferences for a certain genotype, and therefore against others. But the preferred genotype is to be to the benefit of all future people, rather than being exclusive of certain groups. Still, selection on other properties in a child generally thought of as positive would bring us the closest to the original definition of eugenics, although direct state coercion is not necessarily part of such a selection. Coercion would only be present if dysgenics choices would be excluded.

Examples from category eight, especially when aiming at a presumed improvement of genetic traits, can be compared with the historical genetics most easily, and it therefore forms the core of the current discussion on a liberal eugenics. We would specifically associate the last two categories with eugenics. The

difference between the two is gradual, and would differ from time to time. This in itself already begs a difficult question to the justification of eugenics: can one define neutral or objective criteria for the justification of positive prenatal selection on certain genotypes at all? But it even appears that, depending of the definition one holds of eugenics, any of these eight categories can be seen as eugenics. Still, we will probably have very different moral intuitions with these different categories of genetic selection. It might be better to look at the existing practices and discussions on these practices themselves, rather than restricting ourselves to the abstract and speculative discussion on classical conceptions of eugenics.

### **3. Traits in Context: Problematic Issues in Defining ‘Good Traits’**

In order to see what is at stake in the discussion on the more problematic aspects of prenatal selection, it is necessary to look closer to the actual situations people who wish to have a child are confronted with. Much energy has been spent on constructing new abstract principles for future societies, either opposing or embracing new utopias. Instead of delving in abstract and speculative utopias, it is worthwhile to spend more energy on looking at the concrete prenatal practice, the situation in which parents find themselves, and the ethical dilemmas that go way beyond the oversimplified idea of specifying one’s order for the perfect child. Before doing that, I want to demonstrate how such new utopias remain implicit in the many versions of liberal eugenics, since it proclaimed developing supposedly neutral criteria of justification for the application of new reproductive techniques.

The core argument that has been used to decide upon the limitations of genetic interference is built up from a distinction between what is considered to be normal or natural and what is considered to be deviant or unnatural. If one looks closer at the categories discussed above, there is one issue covering all examples that has played an important role in the discussions of the past 15 years. This is the possibility of finding a neutral definition of normality. To cite from a note on Norman Daniels’ conception of the distinction between therapy and enhancement in the 7<sup>th</sup> Staff Working Paper of the President’s Council on Bioethics:

“Norman Daniels has written that ‘disease and disability are seen as departures from species-typical normal functional organization or functioning,’ so that health is defined by species-typical capacities. Daniels draws from this definition a rough sense of what the purpose of therapy or healing is: ‘to maintain, restore, or compensate for the restricted opportunity and loss of function caused by disease and disability.’ Successful therapy, therefore, ‘restores people to the range of opportunities they would have had without the pathological condition or prevents further deterioration.’ In this sense, therapy makes people whole, while enhancement alters the whole.” (President’s Council on Bioethics 2002)

This notion of species-typical functioning is used a lot in discussions on the permissibility of eugenics. Strangely enough, elsewhere Daniels himself states that it is not biology that separates treatment from enhancement, but our norms and values (Daniels 2000). From that perspective, having a lower than average IQ is not something that can be defined biologically. But with his notion of species-typical functioning, one might consider an IQ lower than the average as a disability. Of course this is not what Daniels was aiming at, and of course his view on what is acceptable and what is not does not constitute an eccentric view. Nevertheless, the basis of the argument is not as self-evident as it seems because although the ideas and definitions of normal function and disease or disability often seem clear, they are in fact disputable. To quote Stephen Toulmin:

“The nature of *health* is, at one and the same time, a matter for empirical discovery and a matter of evaluative decision. We refine our sense of how the human body *ought* to work, and ought to be *helped* to work, in the course of and in the light of our empirical studies of how it *does in fact* work.” (Toulmin 1975; pp. 65)

In Toulmin’s terms, health and disease have a dual significance: descriptive and evaluative. What is considered to be normal or natural and what is considered to be deviant or unnatural is therefore also not ‘given’, it is construed through societal needs and preferences.

The problem for liberalism in this context is that if one were to enhance the traits needed to function optimally in a liberal society, one takes liberal society as a universal standard, according to which even the genetic make-up of people should be evaluated. In many societies, it is harder to be a woman or to be black than to be a man or to be white. This also applies to traits that have nothing to do with genetics, such as being from a Catholic family, being rich, speaking a specific language. For example, if one were to find the genetic base for dyslexia, one might start speculating on the prevention of the birth of people living with it. However, as Paulescu *et al.* found out in their research:

“The recognition of dyslexia as a neurodevelopmental disorder has been hampered by the belief that it is not a specific diagnostic entity because it has variable and culture-specific manifestations. In line with this belief, we found that Italian dyslexics, using a shallow orthography which facilitates reading, performed better on reading tasks than did English and French dyslexics. However, all dyslexics were equally impaired relative to their controls on reading and phonological tasks.” (Paulesu *et al.* 2001; pp. 2165)

It might be that in contemporary Italy, it is much harder to diagnose dyslexia, since written Italian does not differ that much from spoken Italian. Maybe the academic

world should turn back to Latin, or its contemporary variant, to solve dyslexia, rather than adjusting posterity to the complex and various demands of written English, German or Spanish. It also means that someone who is identified with dyslexia in England might not have been identified with it if he had been raised in Italy, therefore leading another life not only qua potential, but also in its development of a different attitude towards himself and others. Following that same liberalism as mentioned above, one could also say that within a just society people should not be made to follow the verdict of societal ideals. Whatever that ideal is, when the subjects of a society are made to follow its structure in such a way, even when not directly coerced but indirectly 'grown', liberalism might lose all just intentions implied in its structure.

If one tries to define the proper ethical framework for ethical reflection, judgment and decision making on a possible eugenics, the principles of liberalism alone cannot provide us with a sufficiently worked out notion on what is personal identity. This is because liberalism, although emphasising a principle of respect for the autonomy of the individual, has no image of human identity nor of how this constitutes a certain form of ethical obligation in itself, without the necessity of referring to societal consequences alone. The individual person in liberalism remains of necessity without identity, liberalism cannot hold a different image of individuals than as free and equal autonomous agents. There is a principal lack of an explicit philosophical anthropological notion of the self in liberalism. But it is this notion of a self that constitutes a distinguishing factor between individuals, which could obstruct the idea of their functioning as similar agents in a space of rationality. The problem of the self, of what constitutes the self, and in what way the self relates to itself, still appears to be a necessary issue in the discussion on the shaping of the self.

To be able to understand these notions sufficiently, it is necessary to take into account more practical descriptions of what would constitute (genetic) design of people, and to show in what way different notions of identity constitute different motives to intervene in a future person's genetic makeup. It is the focus of the next section whether these differing motives based on differing conceptions of personal identity lead to different criteria of justification should play an important part in such an analysis.

#### **4. Designing Deaf and Dwarfs**

The ideal of genetically healthy or even perfect man takes different guises in different times, cultures and in different people's imaginations. Even if one could sketch out a single medical ideal of the healthy or improved human, the ideals held by individual parents or by society are often not merely based on medical grounds, and on occasion even held in direct contrast to medical grounds. Most preferences have

a socio-cultural rather than a medical background. And more often than not, it is not 'preferences within a range of options' that forms the discursive framework in which people make decisions, but rather their way of life, their backgrounds and their identities.

The knife of a liberal eugenics seems to cut on both sides, if liberalism is followed consistently. Enhanced muscle growth through genetic adjustments or hormone therapy, enhanced resistance to diseases or cognitive enhancements form the paradigmatic cases within the discussion on a new liberal eugenics. But they are not the only, and maybe not even the first, applications that people will decide upon when offered the opportunity to influence the genotype of their offspring. In practice, traits that fall outside the biomedical paradigm, such as gender or skin colour, will be adapted sooner. Even traits that are medically-speaking seen as negative, such as deafness or hereditary forms of dwarfism, are seen as desirable by specific groups or specific couples. If one follows liberalism consistently, one should allow for selections usually perceived of as eugenics as well as selections usually perceived of as dysgenics. In the following subsections, I shall discuss several examples of non-medical forms of eugenics, as well as some medical applications of genetic diagnosis that have a secondary eugenics consequence.

#### *i. Gender Selection*

Parents who wish to choose the gender of their child can undergo a preimplantation selection after an in vitro fertilisation (IVF) on the basis of the gender of the fertilised egg. Selection on the gender of the future child was developed to avoid a child with a certain gender-related hereditary disease. Of course, before the technique was sophisticated enough to apply before implantation with in vitro fertilisation, it was only used when the benefit of not having a diseased child was weighed against the cost of undergoing termination. With the development of preimplantation diagnosis, things changed. Not implanting certain fertilised eggs (pre-embryos) is a matter that is generally treated in a very different way to termination. The ethical complications of termination are seen as much more severe than those of non-implantation. This is the reason why in vitro fertilisation is generally not looked upon as ethically problematic: when parents already had five boys but wanted a girl, the technique could be used to make sure the parents would have a girl. Would there be ethical complications when parents were to be allowed to choose the child they would want the most in this case? After all, in the example above, allowing for choice on the gender of one's child would only benefit the balance within the family, and knowing one's gender was chosen does not seem to be ethically problematic. Still, for some gender would play a different role in life than for those 'accidentally' born with the gender they were born with, although this may not be as problematic as other cases of prenatal diagnosis. But there are reasons to suggest that an imbalance might be the more likely outcome of non-medical gender selections.

In India and China boys are preferred above girls; and China's one-child policy adds to the pressure caused by this preference. Infanticide traditionally is a result. Gender-selection before implantation when applying in vitro fertilisation would actually grant parents the possibility to choose a boy rather than a girl. Facilitating access to such techniques on a broad scale would prevent such infanticide (Savulescu 2000),<sup>25</sup> Even though many would wish for an India or China in which gender was not seen as an issue, to strive for such a situation on a short-term basis would not be realistic. One can ponder on whether gender-selection with the help of a specifying technique of in vitro fertilisation would be better than to allow for a wide practice of infanticide. However, the boy-girl ratio would fundamentally change if these techniques were easily accessible in China and India. The most feared effects of the imbalance that would inevitably be the result of such cultural prejudices, are that enforced celibacy would lead to an increase in sex-crimes, an increase of prostitution, polyandry, etc. (Boer 2004). On the other hand, the sociological and societal problems that could follow from an imbalance in the male-female ratio might also resolve itself, simply because of the fact that a society that does not have sufficient women will in the end value the birth of a girl equally to that of a boy.

Perhaps one should not analyse the ethics of gender selection on the level of the sociological problems that might follow from an imbalance in the male-female ratio. There are other societal issues involved. We allow people to make decisions on individual level without reference to societal outcomes in many cases. And the perceived negative social outcome of an imbalance in gender-ratio in this case is not certain. The possible problematic nature of choosing the gender of one's child might rather lie in the question whether medicine should let itself be used for purposes in which a gender, the female, is discriminated. To cooperate with such choices might indeed lead to a reinforcement of societal prejudice, apart from the possible problematic sociological problems following from an imbalance in the male-female ratio.

## *ii. Ethnicity and Egg Cell Donation*

Ex-utero fertilization of an egg-cell of another woman was developed to help women with fertility problems or severe genetic disorders to become pregnant and have a child. When a woman chooses an anonymous donor, during the selection procedure, attention is paid to ensuring that the child looks like the mother: white women will get an egg cell harvested from a white woman, black women from a black woman, Porto Rican women, from a Porto Rican looking woman and so on.

<sup>25</sup> Ethics Committee of the American Society of Reproductive Medicine, Sex Selection and Preimplantation Genetic Diagnosis, 72-4 Fertility & Sterility 595 (1999), cited in: Duke, L. (2002). "Customizing Conception: A Survey of Preimplantation Genetic Diagnosis and the Resulting Social, Ethical and Legal Dilemmas.." Law & Technology Review 12.

Still, not all prefer to have a child of their own ethnical phenotype when offered the choice through ex-utero fertilization of an egg-cell of another woman.

Several infertile woman of African descent already applied for a pregnancy of an egg-cell fertilised by her husband's sperm (Lowry, 1987). They deliberately applied for a donation from a white donor for secondary discriminatory reasons; having encountered many instances of discrimination in their personal life, they believed a white child would have an easier life. Ex-utero fertilisation of an egg-cell of another woman in itself does not constitute a genetic intervention in the explicit sense of the word. Still, the child's genes were chosen on the basis of societal prejudice, rather than chance or parents' personal preferences for each other. It has been selected on the trait to be white, even though both parents would probably have loved a black child as much as a white child. Should we allow societal prejudice to have such severe outcomes for the genetic make-up of posterity?

### *iii. Selection on Hereditary Forms of Deafness*

In 2002, an Australian lesbian couple opted for a sperm donor with the same hereditary form of deafness as they had themselves, to have a reasonably good chance to have a child with that form of deafness. Normally sperm donors are selected on the grounds of not being deaf, as with other hereditary 'deficiencies'. This couple therefore contacted a friend with the same form of deafness (Spriggs 2002). They contacted a doctor to be able to get the necessary medical assistance, but this was initially refused. They therefore stepped to court, and the judge ruled that they were allowed to make use of preimplantation genetic diagnosis to make sure the child they would be pregnant of would indeed have the desired trait.

Deafness is a trait that would count as dysfunctional from a medical perspective. One can also perceive of it as socially-construed to be dysfunctional. As a deaf person, one encounters deafness as a disability in the context of the hearing world and in the context of a society which is directed at the hearing. On the island of Martha's Vineyard in the USA, a hereditary form of deafness was quite common: in parts of the island one in every four people was deaf. Until the twentieth century the majority of the population used sign language as a result. Within this context deafness was not a trait that was as decisive for one's life history as it usually is. Having a dark skin is normal in Africa; predominantly, it is not in Italy. Being an Afro-American is a social disadvantage in contemporary American society, being of English-Anglican descent an advantage. It is the cultural context of a certain trait that gives it a specific meaning, turns it into an advantage or a disadvantage, rather than the trait itself. Should we then still allow for people to avoid having a deaf child? And if yes, can we still maintain deaf people cannot preselect on a deaf child if we cannot maintain that deafness is a medical dysfunction?

#### *iv. Selection on Hereditary Forms of Dwarfism*

Even though there is no actual patient to be ‘treated’, we view prenatal selection to avoid the birth of a child with a hereditary form of dwarfism as ‘treatment’. But genetic interventions to enhance the height of a future child because the parents have a height less than average would not receive general support. But even prenatal selection to avoid the birth of a child with a hereditary form of dwarfism (such as achondroplasia) is criticised. The community of people of restricted growth, whose voice includes (amongst others) the ‘Little People of America’, have expressed their concern about techniques such as prenatal genetic diagnosis or pre-implantation genetic diagnosis (Gooding 2002). They fear that if techniques to test for hereditary forms of dwarfism were to be offered on a broad scale, their community would disappear within a few centuries. Nevertheless, the risk of avoiding a pregnancy of a child that inherits the trait from both sides, almost always ending fatally for the child, can be circumvented by the same technique. In addition, many parents with dwarfism would not wish their child to encounter the same prejudices and difficulties they have encountered and are relieved that there is now a technique that can be used to avoid the pregnancy of a child with the same condition. There have also been parents who applied for the technique to purposely have a child with their form of dwarfism. They believe that if they had a child of normal stature, their family life would encounter problems of a more mundane nature, the practical problems a normal child will bring within an adjusted house and wider societal problems. If one were to reject application of preimplantation genetic diagnosis to select for a child with dwarfism, such a rejection could be motivated by the medical argument that the most common forms of dwarfism also imply secondary complaints such as rheumatism and spinal problems. But not all forms of dwarfism are accompanied by such secondary medical problems. The medical profession is not allowed to intervene in instances where two people with the same hereditary form of dwarfism decide to have a child without medical problems even though there is a 50% chance of the child having that form of dwarfism (and a 25% chance of the child inheriting the gene twice, and having a life expectancy of less than a year). So, why would we presume to have the right to stop similar couples from making sure they do have a child with a similar form of dwarfism, at the same time preventing the birth of a child with a low life expectancy?

The core issue in the discussion in this case is where to put the boundary between what is a disability and what not. In his article “Normal Functioning and the Treatment-Enhancement Distinction” (Daniels 2000) Norman Daniels poses the question whether one can make a clear distinction between treatment of a child with growth hormone deficiency that is the result of a brain tumour, and an enhancement of one’s child’s height because of a normal hereditary shortness. In the first case, it is quite clear that the problem has a medical background. In the second, the child’s (future) shortness is part of normal variance in human length. Although the distinction between the two is treated as morally relevant to whether

one allows for treatment or not; they are completely similar in their phenotypical appearance. Both children can have exactly the same height problems. This would necessitate us to discard with the boundary between disability and normal functioning as an ethical demarcation criterion in the case of height.

*v. Preventing and Aiming at the Birth of Polydactylous Children and Children with Marfan*

In the United States a woman opted for termination twice after the embryo having been diagnosed, through ultra sound scan, to be polydactylous. Having more than ten fingers can hardly be seen as a serious impairment. The public reactions to this issue were mostly negative. If this same woman had more than ten fingers herself and would have opted for abortion if the ultrasound scan showed the child to have only ten fingers, indignation about this decision would probably be even greater. But the difference between normalness and deviancy in this case seems so arbitrary that one can wonder why one would offer a prenatal diagnosis on the condition at all, let alone allowing parental choices during pregnancy to avoid either. Being deaf or being a dwarf, plays an important role in one's perception of one's identity. The deaf community, as well as the community of people of restricted growth appear to have a strong argument in saying they do not consider themselves to be disabled but rather to have different traits, which also constitute their identity in a profound way (similar to people of African descent having a dark skin constitutes their identity in a profound way). They are not saying that they would want to see a world consisting only of people with the same traits, but they do consider the *general* tone in the discussion to go in such a direction, with those traits considered as average or normal. From this criticism they position themselves to belong to a community with an existence on its own right (Chadwick and Levitt 1998). Still, having more than ten fingers will probably not be seen as an important constitutive of an individual's identity.

The composer Rachmaninov is known to have had a genetic condition known as Marfan syndrome (Pyeritz 2000). The symptoms of the Marfan syndrome (also known as arachnodactyly, meaning 'spider fingers') are extreme height, myopia, heart problems and so on. A striking feature of people with Marfan syndrome is that they can bend their thumbs back completely: a trait that can be rather convenient for a composer or a pianist. Rachmaninov's music therefore seems to have been influenced by his genetic condition. Suppose one could prevent or cure all other symptoms of Marfan relatively easily, should one than allow parents that want their child to develop in classical music to select for Marfan syndrome? One can also imagine certain compositions or styles of music to be easier for a twelve-fingered pianist than for a ten-fingered pianist. Polydactylia would be convenient for Bach-performers or Ragtime pianists. It would be an enhancement of human capacities rather than a cosmetic impairment. If one allows women that are pregnant with a child with polydactylia to have an elected termination, why would one

deny other parents to opt for polydactylia through in vitro fertilisation and selective implantation, or, if possible, through prenatal germ-line intervention?

*vi. Discussion*

How are we to deal with the instances listed above in a just way? The authors of *From Chance to Choice*<sup>26</sup> express several concerns about eugenics, although they deem these surmountable as long as one retains the principles of liberalism. Their main concern is described as follows:

“One concern is that those who would better humankind by bringing about the conception of ‘better’ humans would make faulty judgments on what kinds of people should be conceived and born. The eugenic authorities might favour the wrong traits, and they might not appreciate the value of diversity and differences in points of view over what makes life valuable and worthwhile. A related concern is that any scale of human excellences which eugenicists might use to ‘improve’ the population would automatically stigmatize those people, both living and those yet to be conceived, whose traits put them at the bottom of the eugenicists rankings.” (Buchanan *et al.* 2000; pp. 47)

The concern is that allowing for certain forms of genetic selection or intervention and banning others, one makes certain normative choices that are implemented in society from above, possibly leading to stigmatization and discrimination. More often than not, the restriction to specific forms of selection is an expression of a reduction of the average to the normal, combined with what counts as best within these traits considered normal. To be a hearing person is normal, to have better hearing is an enhancement of capacities; therefore prenatal selection on such capacities should be allowed for. To be a dwarf is abnormal, therefore prenatal selection on dwarfism should not be allowed for. This restriction to specific cases poses a severe problem to the so called liberal eugenics that the authors of *From Chance to Choice* aim at. However, they see a solution to this problem in the ‘disease and cure’ paradigm:

“In theory, eugenicists could heed concerns over diversity. Objections to the choices eugenicists made [...] do not necessarily argue against any attempt to choose. And some of the same concerns about stigmatization could be raised in opposition to programs which seek to ameliorate conditions, such as deafness, among existing people: for why try to ‘cure’ a person of deafness unless it is undesirable to be deaf?” (Buchanan *et al.* 2000; pp. 47)

The objection raised to certain types of enhancement that are put in the service of a liberal eugenics can also be raised against existing therapeutic forms of eugenics:

“As a general argument, it [the concern in question] would condemn genetic screening even for very serious conditions, which disabilities rights organizations themselves support. The gene for achondroplasia, for example, a single copy of which produces a (usually) healthy dwarf, is dreadful in combination, and, according to Ruth Ricker (1995), former President of Little People of America, the dwarf community looks forward to the day when dwarf parents can be spared the fear of giving birth to a child with two of these genes. Advocates among the deaf have asked to appreciate the quality of life achievable with hereditary deafness (Wernimont 1997); but the argument we are considering would also condemn any interest in ‘preventing lives’ marked by disabilities which do not permit such a high quality of life. .” (Buchanan *et al.* 2000; pp. 47)

Applications of genetics beyond treatment, and thus beyond what is understood as curing or preventing diseases or disabilities, are often supported by reference to the societal advantages for future generations. These are then defined along the lines of an ethics of inclusion and equality, principles that may seem to be universal, but when tested against the background of specific cases it appears more difficult to tell which traits would benefit people in their quest for life in future society. Furthermore, allowing for the one type of genetic selection or intervention whilst banning other forms seems to run counter to the ideal of a *liberal* eugenics. Often the importance of a so-called species-normal standard for functioning is taken as a basis for a criterion of which forms of enhancement should be allowed for, which ones even seem morally obligatory (Harris 2007 (II)), and which ones should be excluded. But in defining such a criterion on that basis, one implicitly accepts a specific definition of what is to be considered normal, and takes it to be not merely logically but also morally valid. The logical validity of such concepts is already contestable, as I defend elsewhere (Landeweerd 2009), the moral validity is even more controversial. Such a definition of normalness cannot be held to be fundamentally different from the treatment-enhancement distinction, a distinction which, for various reasons, can also be criticised as a moral criterion. And, if the main reason to discard the treatment-enhancement distinction is that it runs counter to the liberal principle of equal access to the means provided by the biomedical sciences, this argument can also be brought against the usage of a species-normal definition as an ethical criterion. If one ventures into the discursive framework of societal benefits and liberal freedoms to find an ethical discourse in which one can differentiate between just and unjust forms of human enhancements, one begs the question whether one should give access to the possibilities offered by those sciences without restriction. Nevertheless, this might lead to a practice within pre- and neonatal care that would bring grave injustices with it; choices that no physi-

cian would endorse or co-operate with. Currently there are already guidelines that frame the possibility for a medical expert to refrain the rights and autonomy of future parents. To defend a eugenics solely on the basis of parental autonomy appears to be insufficient. But how to restrict these parental rights, on what basis to discern between different forms of selective reproduction is not sufficiently clarified. A different approach seems to be called for.

## 5. Conclusion

It is questionable whether we can derive a criterion to distinguish between genetic selection on the basis of sex-preferences, ethnicity, deafness or height that is both neutral and morally relevant. However, discerning between traits that are genetically defined and traits that are socio-culturally defined does not provide us with a sufficient justificatory criterion for the different choices parents want to make. Does it matter whether parents hope for a certain trait in their offspring and trust in the genetic lottery to get what they want, or whether they knock on the door of the medical science to make sure they get what they hope for? Is there a categorical difference between parents who specifically choose for a black or a white child through adoption or through prenatal selection? After all, in both cases, whether the genotype of the child in question is determinative for the outcome or not, the parents desire to make sure they end up with what they want. This, however, should not lead us to allow the injustices in society to dictate non-medically indicated forms of prenatal selection and intervention. The discussion on where to put the limit of applications of prenatal diagnosis often becomes mixed up with questions of ethnicity, emancipation movements, disability organisations etc. . And when a certain diagnosis or intervention is already found to be indicated in such a case, it becomes hard to justify proper criteria to say no to such a more cosmetic intervention. The neutral criterion of species-typical or normal functioning, traditionally used as complementary to states that ask for medical intervention (Daniels, 2000), is a criterion induced by a predominantly medico- or bio-statistical framework. This criterion does not seem to hold as a basis for the distinction treatment-enhancement, since one cannot uphold such a picture of ‘normal functioning’ as ethically relevant in this discussion. It does not seem to be the right ethically-relevant criterion for a liberal eugenics either.

The idea of a liberal eugenics is often closely associated with the concept of an enhancement of human genetic stock, or an enhancement of posterity. ‘Enhancement’ is a problematic term. It is not self-evident what constitutes a progress and what constitutes a regress of genetic quality. The distinction between normal and enhanced would therefore also be subjective or normative rather than objective or universally valid. This has several implications for the way one discusses a speculative liberal eugenics. It might necessitate a more pragmatic definition of eugenics,

one that would also encompass applications of genetics which would intuitively be perceived of as dysgenics.

Choices made by future parents seem to be induced by personal preferences and cultural backgrounds rather than by medical factors. However, the discussion on the permissibility of non-medically indicated forms of prenatal selection or intervention is often restricted to a medical perspective on either avoiding diseases and deficiencies or opting for a medically-defined enhancement. My claim is that such a perspective takes one's genetic features to be seen as traits possessed by an individual rather than traits making up an individual, which I will defend in the later chapters of this thesis. Traits are seen as commodities owned by an individual, helping him or her to get along in society, instead of as constituents of one's identity and personhood. Taking such a position frames one's view by excluding certain ethically relevant issues. I shall deal with this issue of the relation between issues of identity, culture and preference with respect to free choice in the next chapter.



# Chapter IV

## On the Limits of a Social-liberalist Ethics



## 1. Introduction

Liberalism perceives of the injustices of eugenics in a predominantly vertical fashion: as an injustice between a coercive state and the individual. For liberalists, the most important ethical argument would therefore have to be the blunt disregard of the basic rights of the individual in the interest of preservation or improvement of human stock. Buchanan *et al.* tried to show that eugenics does not necessarily intervene with parental reproductive freedom, and that not all ideas about what would be better for mankind are a dangerous form of idealism. Why would one not be able to use genetics to go 'beyond therapy', whilst maintaining a respect for the basic rights of the individual? After all, it seems to be justifiable to allow for eugenics 'from below', as long as the parents, as well as the future person, retain the right to choose freely. In that case, a medical science that, in its advisory role, does not direct its clients should be able to provide for a justification of a liberalized eugenics. And since not being directive towards one's clients is already the central guiding principle in medically-indicated forms of genetics in reproduction,<sup>27</sup> it might just as easily be used to justify non-medically indicated forms of prenatal diagnosis.

Another danger perceived by some is that such eugenics would lead to a generation of people that all possess the same traits and talents. However, as Glenn McGee defends in his *The Perfect Baby* (McGee 2000), and as I defended elsewhere, (ter Meulen, Nielsen and Landeweerd 2007) this is not necessarily the case. There are many different traits that can be called advantageous. If one would not give precedence to one common conception of 'enhancement', but allow for more forms of genetic selection that would reduce the likelihood of the birth of a severely impaired child (by existing medical standards), there would not necessarily be a hidden utopian agenda behind the implementation of such techniques. If one allows for choices for a child with traits that are generally accepted as advantageous as well as traits only accepted as advantageous by a smaller group in society, no parent would be harmed in his or her autonomy, nor would one need to fear for a homogenization of posterity.

However, the position that a future person would be better off with advantageous traits than without them hides several problematic presuppositions. In liberalism, autonomy is predominantly defined as freedom of choice. Liberalism embraces a conception of the person as a free and rational agent, stripped of any contingent trait that would define his identity. Liberalist approaches in bioethics take this type of choice to be a self-evident ability. Choice can therefore only be restricted on either the level of options offered or on the level of the competences an individual has. Because of this implicit presupposition of the liberalist framework, not all aspects of freedom and autonomy are taken into account. A person's

<sup>27</sup> Situations such as genetic diagnosis for parents who are at risk of conceiving a child with a severe hereditary disease.

autonomy is not just determined by being provided with as wide as possible a list of options and an initial position that is as little restricted as possible. The relation between the traits one has and the person one is, is more complicated. If one only focuses on a choice-perspective of human autonomy, fundamental ethical issues are left out from the discussion about the new eugenics. The relationship between the traits one has and the person one is, should be applied to the discussion of a genetics that goes beyond therapy; whether it is termed enhancement or design. This issue does not appear within a conception of choice, autonomy and moral responsibility that is restricted to the artificially-reduced notion of a self as an abstract core with certain traits that are at his disposal within his choices in his life history. Such a picture does not allow for a conception of autonomy as constituted by the relation one has to oneself, or moral responsibility as also constituted by how one perceives of the other.

This chapter is devoted to an analysis of the philosophical structure of the discussion on a liberal eugenics. In order to investigate the concepts used in the debate, it is necessary to undertake a thorough survey of them, so that we can see where they stem from and what the consequences are of using them in the way they have been used up to the present time. First, I shall describe the discursive problems of the concepts of ‘enhancement’ and ‘eu’genics. Next, I shall go somewhat deeper into the ethics of John Rawls because his work has been of paramount importance to the early development of bioethics and has laid the foundation for the current discussion on political liberalism. I shall demonstrate in what ways certain basic concepts of Rawls’ work are used in the current bioethical debate in general and in the debate on eugenics in particular. After this analysis, I shall go deeper into the ongoing discussion on the rights and status of ‘future people’, a debate initiated by Derek Parfit. Next, I shall discuss a specific problem implicit in liberalist political and ethical thought, namely the problematic nature of the self in relation to the predominance of the concept of choice in liberal philosophy. A different sketch of choice and autonomy is presented by the American legal philosopher Meir Dan-Cohen, author of *Harmful Thoughts*, who saw the way choice and autonomy are dealt with within the area of legal philosophy as insufficient. Dan-Cohen tries to provide an alternative conception, which can cover the subject of legal and moral responsibility in a better way. His ideas can also be made to apply to the application of concepts of choice and autonomy in bioethics and medical ethics.

## **2. The Implicit Normativity of Enhancement**

Old eugenics perceived of various problems in society as being genetic in nature, and thought they were the symptoms of a slow degeneration of human genetic stock. Proponents of this historical eugenics also supposed that this could be

countered by selective reproduction. In most speculations on eugenics in present time, the idea of degeneration is not taken seriously. In our society we already try to prevent the birth of severely disabled or diseased children, but not on the basis of explicit eugenics arguments. We aim at such prevention to avoid harm to parents as well as future children. We offer prenatal and preimplantation genetic tests to parents who are known to be at risk of having a child with a severe birth defect, a severe impairment or a severe to lethal childhood disease. In addition, some countries allow for testing on 'less severe' diseases such as hereditary forms of breast cancer. A new negative eugenics *would* hold such an argument explicitly and might not merely aim at the prevention of the birth of severely disabled children, but also the prevention of the birth of children with a minor impairment or genetic defect. Even though new eugenics does not attach much scientific value to the idea of a degeneration of human genetic stock, things start to get more controversial, since it is not always clear what should count as impairment or disability.

As I have demonstrated, our conception of the normal medical functioning of human beings contains many implicit presuppositions that stem from either societal values or a bio-statistical and evolutionary view on normality. To use this latter view to develop explicit guidelines would result in several rather strange practices. From a Darwinist picture for example, successful reproduction is a key notion for survival. Within this perspective, homosexuality can only be seen as an abnormality, whilst, as Kitcher states, compulsive sperm donors should be considered as being on the peak of "normal functioning" (Kitcher 1996; p 212). Compulsive sperm donors are not seen as 'normal' in our society, and homosexuals are now no longer regarded as 'defective' (although homosexuality was regarded as a psychological aberrance until the late 1960s). Only those genetic traits that carry a risk factor to severe diseases or disabilities are relatively unproblematic in this sense. When one moves to traits such as myopia or polydactylia, it is not entirely clear if we are still speaking about genetic defects or normal variants. These traits do not solely have a medical definition. Wearing glasses has many connotations apart from the ophthalmological definition. And, as we have seen in chapter III, even the concepts used in medicine can be seen as socially construed; not all of the genetic choices one can make with regard to posterity can be put in an exclusively bio-statistical framework.

People's conceptions of what constitutes an enhancement are widely differing, but in the human enhancement and transhumanist discussion (e.g. Bostrom 2005; Sevalescu 2001; Stock 2002; Harris 1993; 2007 (I); Pence 1998; Parens 1998), it is often supposed that we can know what would benefit humankind and what not. The possibility and value of cognitive enhancement, height enhancement, muscle growth enhancement and even the enhancement of moral sensitivity is taken for granted. But not all proponents of going beyond preventive uses of prenatal genetic diagnosis embrace this assumption to have a neutral criterion for good and bad traits. Glenn McGee, author of *The Perfect Baby*, embraces a more pragmatic view

on what such a step beyond prevention would look like in a pluralistic society (McGee 2000). He moves beyond from the concept of a neutral criterion for enhancement, and states that people should be allowed to define such criteria for themselves. Most proponents of going beyond prevention – including Buchanan et al. (2000), Kitcher (1996), Agar (2004) - have a more concrete and narrow image of the potential of a new eugenics. They all presume that one can determine in a neutral manner what are good and bad traits. In these aspects, current proposals for a liberal eugenics bear an important similarity to the old eugenics. They also both presume that there is just one continuous line going from imperfection through normal state to perfection. And they both embrace a mixture of speculative evolution biology and controlled reproduction for their goals. New style eugenicists will presume one can mould the scale from non-preferable to preferable to fit with bio-statistical and medical standards in a very similar way to old eugenicists. This narrowing down of what constitutes an enhancement has consequences for the moral assessment of a liberal eugenics.

In most proposals for a new liberal eugenics, one finds a certain concept of what sets of choices we should allow for with regard to selecting posterity (with the potential of the new genetics, possibly with the exception of McGee's *The Perfect Baby* (2000)). And when one has a concept of what is a good way to steer the genetic make-up of posterity, there will be a converse concept of what should not be done. The liberal eugenicist presupposes that one can form a neutral and universally valid criterion for what are good traits and what are not; ergo what is a good way to steer the genetic make-up of posterity. But if this claim can be disproved, if one cannot determine objectively what is a good way to design posterity and what not, then one is not justified in excluding certain ways of steering the genetic make-up of posterity. In that case, it is not that self-evident which traits would be beneficial to a future person and which traits would not. The ethical question is no longer whether one can enforce a certain eugenics policy or not, but whether a eugenics that only poses a specific set of choices and excludes other possibilities can still count as liberal.

There seems to be a contradiction implicit in the very idea of a liberal eugenics if one looks upon notions of normal functioning, impairment, disease, disability as normative terms rather than universally-given neutral standards. If a liberal eugenics were to aim at genetic selections for posterity based on medical criteria, it would cease to be a *liberal* eugenics. After all, not all possible options would actually be offered, only those options deemed preferable by this one dominant interpretation. In such a case, one is placing one's own values upon society and denying people the right to make genetic reproductive decisions on the basis of their own values of what are good traits, be it dwarfism, gigantism, intelligence, etc.. Either one opts for a eugenics that is, one way or another, coercive, or for a liberal, non-medically defined, reproductive genetics. In the latter case, one needs to abandon the idea of *enhancing* traits or maintaining or ameliorating the human genetic condition. One

would need to leave it up to the prospective parents themselves what inheritable traits they want to see expressed in their future children. Leaving out certain options that some parents may want to have is after all a form of coercion; and liberalising access to all possibilities that could be available to the public would not lead to realising a certain vision of 'better humans'. The idea of a 'liberal' 'eu'genics is somewhat contradictory.

No one would wish to return to a coercive eugenics. History has already proven that such eugenics is reprehensible. Although the coercion in a new 'liberal' eugenics would take place on another plane, it still runs counter to the basic principles of liberalism to respect parental reproductive freedom. To leave it up to parents to make whatever decision they want with respect to the genetic make-up of their children does not seem to be the ideal solution either. Although the genetic identity of people born with a set of genes that is more or less determined by contingency, is as much (or just as less) laid down by those genes as the identity of people that would be the result of parental choices before their birth, the idea of 'leaving it up to the parents' to make whatever eccentric choice with regard to their children they want does not seem to be justified either. Liberalist ethics can be termed a negative ethics. It states 'do nothing unless the individual's freedom is harmed or restricted'. With respect to the problematic nature of the disease-normality distinction as discussed in chapter III and the problematic nature of sketching a neutral scale that runs from therapy to enhancement, it is questionable whether a negative ethics will still be able to deal with the ethics of genetics choices that have an impact on posterity.

I shall now turn to the contemporarily most dominant interpretation of liberalism to see whether the abovementioned problems of liberalism with regard to eugenics, also contains flaws on a more fundamental level.

### **3. Rawlsian Liberalism and Eugenics**

In the 1970s, John Rawls (amongst others) contributed to a revival of liberalist political philosophy. Thinkers who worked in a similar direction and who were sometimes directly influenced by Rawls include Isaiah Berlin, David Gauthier, Thomas Scanlon, Ronald Dworkin, Norman Daniels and James Buchanan. As well as Rawls' general influence on political and ethical philosophy, he also had an extensive influence on bioethics. Rawls most important contribution to juridical and political philosophy was the publication of *A Theory of Justice* (Rawls 1992 (1971)). In this book Rawls set out to find a more rational basis for the contractarian tradition in political and ethical theory.

In Anglo-American bioethics, the horizon within which the debate takes place is, next to the aforementioned Lockean contract-philosophical perspective on state and individual, very much defined by three other mainstreams in ethics: utilitarian-

ism, (Kantian) analytic philosophy, and pragmatism. John Rawls tried to merge these four different approaches in ethics in his theory of justice. In his contractarian philosophy, the position of the citizen is delineated against the power of the state. In contractarianism, the state is considered as a result of a social contract that is reached by mutual agreement to circumvent the problem of man's fundamental egoism in his pre-societal state. Within this approach, the Lockean idea of a need for protection of the individual's rights against state interference is also taken to be central. From Kantian philosophy, Rawls took the Kantian concept of a maxim, in which one is to embrace a certain considered course of action by looking at its potential to form a general law for an envisaged society. Rawls combines Kant and Locke on a pragmatist basis rather than seeing them as universally valid. He further incorporates utilitarianism, also to show that the morality of a course of action can eventually be reduced to a matter of measuring whether the vectors of pleasure or happiness and avoidance of pain or harm, would lead to a better society with happier citizens.

Rational agreement was to be the basis of Rawls' philosophical system. To this aim he developed two principles of justice on the basis of rational agreement, and the concept of an original position to ensure the justness of this rationality. Rawls stated:

“[the principles of justice] are the principles that free and rational persons concerned to further their own interests would accept in an initial position of equality as defining the fundamental terms of their association. These principles are to regulate all further agreements; they specify the kinds of social cooperation that can be entered into and the forms of government that can be established.” (Rawls 1992 (1971); pp. 11).

In Rawlsian philosophy the basic principles of justice should balance individual liberty with an equal distribution of liberty. This should be combined with a provision of the greatest benefit for the least advantaged:

“Social and economic inequalities are to be arranged so that they are (a) to the greatest benefit of the least advantaged, consistent with the just savings principle, and (b) attached to offices and positions open to all under conditions of fair equality of opportunity.” (Rawls 1992 (1971); pp. 302)

People should come to this agreement through rational reflection, envisaging themselves not to have a specific place or background in society; what Rawls called 'original position'. Rawls' conception of an 'original position' forms the rationale behind these basic principles of justice. The concept of an original position also has its origin in the contractarian tradition in political theory. The original position was usually posed as the beginning state from which the social contract was formulated,

from within a 'state of nature'. In Rawls' work, this construction of an original position should be regarded as a hypothetical position rather than a true historical occurrence. It functions as a maxim; it is the basic position one should take to come to the principles for a just society. In Rawls' original position, one is supposed to wear a 'veil of ignorance', meaning that one should regard oneself as not knowing what position one would have in society, whilst one is envisaging what society would be a just one. To summarise, in Rawls' vision, "those who are at the same level of talent and ability, and have the same willingness to use them, should have the same prospects of success regardless of their initial place in the social system" (Rawls 1992 (1971); pp 43-44). Social class, gender or any other contingency should not have a negative influence on the liberty someone is to have, to pursue his goals in life. With this construction, Rawls tried to find a tool that could balance freedom, or liberty, and equality and omit any prejudices stemming from one's class or one's ethnic, linguistic, religious or cultural background. However, social and economic inequalities should be distributed in such a way that they can reasonably be expected to be advantageous to all those who are the worst off in the first place.

Rawls' influence permeated bioethics through the publication of *Principles of Biomedical Ethics* (Beauchamps & Childress 1979). The impact of *Principles of Biomedical Ethics* on the early development of bioethics can hardly be overestimated. The book is sometimes said to have saved the discipline of ethics from becoming a mere historical footnote, only taught in the curricula of faculties of philosophy. The principle-based approach to ethical problems in medicine presented in this publication was to become the dominant approach in bioethics at least until the end of the 1980s.

The authors of *Principles of Biomedical Ethics* proposed a set of four ethical principles that should guide decision-making. These four principles are roughly based on Rawls' two principles of justice, and were similarly taken to be universally valid. Although they have been over-paraphrased in the past two decades, I shall summarise them for reasons of clarity. They are: a principle of respect for other people's autonomy, a principle of beneficence, a principle of non-maleficence and a principle of justice. According to Beauchamps and Childress, these principles are universally valid and would probably be endorsed by anyone, if motivated from an original position. Since these principles can prove to be in conflict with each other in certain practical situations, they need to be weighed in relation to each other.

One problem with this approach to ethics is that it puts such a strong emphasis on individual freedom of choice in defining autonomy. Next to this, one cannot take into account questions of the self because everything that has to do with self and identity is to be regarded as contingent. In the Rawlsian argumentation leading up to the principles of justice, these influences should be discarded with when one takes on the veil of ignorance in the original position. But how can one actually reflect on how the world should be if one has to discard with every specific notion

of the self? How is one to envisage autonomy if one does not take into account the fact that it is always a specific person who chooses? No choice is made in an interpretative void. Who we are always influences the way we make choices. If one strives for a type of abstract universality in ethics, one is bound to lose the ability to deal with problems in the practical world. This issue is important for the discussion on a new eugenics.

Liberal eugenicists such as Buchanan and Daniels picked up again the Rawlsian conception of justice. They pose that Rawls' system should not be made to compensate for only social injustices, but also for natural inequalities (Buchanan *et al.* 2000, Chapter 3): since we can now steer the genetic make-up of our children (although our ability to do so may well remain rather limited), it becomes questionable whether we should still accept the distinction between the naturally given genetic lottery, and socially construable compensations for those who lose out on that lottery. With the conception of justice as equality of opportunity combined with protection of the liberty of the individual, Buchanan *et al.* set out to define the ethical goals and limits of a new eugenics, thus extending Rawls to include the natural next to the societal. One's nature was still treated as chance in Rawls' time, necessitating a fair compensation of accidental restrictions through a just distribution of social goods. Now that this 'chance' has become subject to our influence as well, we should allow for choice in the genetic make-up of posterity, so we can reduce these natural inequalities alongside social inequalities.

As soon as one tries to develop a criterion to justify applications of genetics that are supposed to enhance the human gene pool, one automatically has to exclude certain applications that run counter to that goal. Otherwise one ends up with a genetics that, although going beyond therapeutic applications, does not constitute a eugenics but possibly even a dysgenics. Most ethicists would agree that a complete liberalisation of the means provided by the biomedical sciences would run counter to the basic rights of future people, since it would amount to a sanctioning of the most eccentric genetics choices conceivable, such as creating future people with an abnormal length so they can compete better in baseball. If one were to hold on to the liberalism implied in a liberal eugenics, one would not be able to define an argument against such a libertarian eugenics. A liberalist approach to the ethical questions raised by the new reproductive technologies therefore does not appear to be sufficient.

Brian Barry (2001) defends the Rawlsian approach to liberalism, specifically in its being at a par with the multiculturalist's approach. If one respects a plurality of cultures, one has to make space for other communities to uphold their identity. An approach to justice that aims to abolish such differences, or at least, make them redundant for the ethico-political arena, is in itself a (post-) colonial form of oppression. But protecting multiculturalism can indeed be oppressive of specific individuals, specific groups of individuals or even basic notions of justice in themselves. Even if, for example, one were to embrace the idea that westerns society

cannot disapprove of African practices of female circumcision, one cannot uphold the idea of a society that allows for one community to practice female circumcision, whilst denying it for others. Therefore, liberalism necessitates the creation of institutions that decide in a top-down manner what types of genetic selections and interventions would be advantageous to future subjects in an open and liberal society and which ones would not. With regard to the argument of free choice, each and every proposal for a new eugenics holds certain applications of genetics to be more beneficial than others, and some to be counterproductive in the light of the goal of an enhancement of posterity. However, if access to genetics is opened up to the public not all preferences held by the public will fit into these categories; some will not be permitted to make use of genetics to steer posterity in a direction they see as beneficial. This means there is an indirect top-down coercion to be found in these proposals of a new 'liberal' eugenics; the exclusion of a series of possible applications of genetics seems to run counter to the type of liberalism Rawls departed from.

From within the current liberalist Rawlsian bioethical paradigm, there is a tendency to treat the subject of eugenics merely in relation to questions of moral agency, freedom of choice or citizenship in a liberal society. But there is a lot more to human decision making processes. People do not choose on the basis of an *a priori* rationality. An agent is always placed in context, which triggers questions regarding the individual's relation to himself and to others. The question of identity seems to be an underdeveloped theme in liberal philosophy. This is also the criticism the legal philosopher Meir Dan-Cohen developed towards liberalism in legal philosophy<sup>28</sup>. I will discuss his ideas in this context in the following paragraph.

#### **4. A Different Liberalist Cuisine: Meir Dan-Cohen on Choice and Autonomy**

According to the legal philosopher Meir Dan-Cohen, responsibility and autonomy are dealt with on a predominantly liberalist philosophical level, and within what he calls a paradigm of free will (Dan-Cohen 2002). Within this paradigm, autonomy is seen as intrinsically linked with freedom of choice, and freedom of choice is seen as conditioned by not being restricted in one's options in one's life history. Within such a paradigm, several important features of choice and autonomy - such as the will to choose something or the link between autonomy and identity - are inher-

<sup>28</sup> Although he aims his criticism to the Kantian basis of this ethics, it should be noted that this is a criticism to one specific interpretative tradition in Kantian philosophy (the universalistic reading of his moral philosophy). There are other readings of Kant, in particular in continental philosophy (but also in recent analytic philosophy), that interpret Kant's moral philosophy as evaluative rather than prescriptive. In these approaches of Kant's moral philosophy, as well as in other areas in philosophy, the subject of human identity is not merely regarded as a contingent side issue.

ently left out. To provide for an alternative, Dan-Cohen deconstructs the link between autonomy, rationality and (freedom of) choice, especially in regard to questions of (legal) responsibility. Alongside this, Dan-Cohen provides for an alternative approach of autonomy and responsibility, through the concept of *willing* rather than the concept of *choosing*.

Meir Dan-Cohen addressed the subject of autonomy in the existing legal definition framework for issues of responsibility. Within this context he contended that ethical values were often defined in a discourse of preference-based choice on the one hand and a narrow picture of experiential harm on the other. Dan-Cohen sees this conception of choice as faulty. He perceives this standard conception of values regarding choice and harm as an over-rationalistic and overly simplified picture of choice (Dan-Cohen 2002). In Dan-Cohen's view this standard way of dealing with choice is not sufficient for certain legal questions because it has a distorted view on choice. The view of choice resulting from it leaves no room for ethical questions that are connected with the self, in relation to oneself as well as to others, whilst this is often a fundamental factor in the choices one makes. Within the context of medical ethics, autonomy is implicitly conceived of as linked to such an idea of choice too. And therefore, this approach of autonomy might not be sufficient for medical ethics either.

According to Dan-Cohen there are four dimensions to the standard conception of choice in law (Dan-Cohen 2002; pp. 126). Firstly, choosing involves a *set of options*. Secondly, the agent in question will have his personal *preferences*, upon which he will base his choice. Thirdly, there is a process of *valuing* the options offered in order to make a proper selection. And, fourthly, choosing involves *costs*, specifically the costs suffered by not choosing the options that the agent did not evaluate as the proper one. Within this standard conception of choice, freedom is seen as a non-restraint on the person who makes choices whilst the emphasis is put on autonomy as the ability to select from a list of given options.

There are some problems with this concept of choosing. The choice set is seen as exclusively ranked by the agent's preferences. In reality, the fact that one does not get to choose one's own set of options may frustrate the chooser, and this can play a role in what one chooses. Furthermore, the only valuation that can be made is a valuation relative to other choices one could have made. In reality, one often does not look upon the value of one option in such a relative way; one merely likes or wants what one chooses. Finally, within the free choice paradigm, a picture is sketched of the individual as someone who loses in any choice he makes, because in choosing, he excludes all other options. This, according to Dan-Cohen, renders the current concept of choosing impotent to solve issues of rights and responsibilities.

I shall illustrate this with an example: in the free-choice picture of autonomy, one would have to state that in having a restaurant menu that does not offer most

of the world's cuisines and most dishes of those cuisines, one is frustrated, since there are so many options that do not appear on the menu. One's set of choice is therefore already limited by going to, for example, a French restaurant that specialises in Normandic sea cuisine instead of a Chinese restaurant that specialises in the Cantonese cuisine, and within this model, one has to see this narrowing down as frustrating. In having a preference for oysters à la Normandie, one is supposed to be frustrated even further, and even more so after one has ordered, since then one cannot choose the New England lobster anymore. But in reality, at least for most people, the smaller the menu the less frustrated one gets in a restaurant, and ordering according to one's preferences is actually quite satisfactory. Next to this, most people would be rather glad with having ordered, rather than getting locked into a state of regret over all other meals on the menu that were not ordered.

The option-based conception of choice holds a concept of choice as a way in which one can cope with the limitations of the world, rather than as the source of the individual's frustration in his life history. One can come to terms with the lack of diversity on the menu because it teaches one to live with these shortcomings, and to cope with it by accepting the meagre nature of choice in our society. But such a conception of choice as a way of coping does not show in what way all these supposed shortcomings constitute ourselves and the world we live in, rather than being limitations thereof. But the origin of this gloomy image of human existence might be found in the paradigm of free choice, rather than in what actually happens when one goes to a restaurant (Dan-Cohen 2002; pp. 130). Choice often involves other aspects than rational ranking or listing one's options. Not all choices in life can be compared to choosing one's dishes from a restaurant menu. To treat them as such presents a gross caricature of the role of choice in life. The problem that arises in using the concept of choosing in autonomy is that it presupposes a certain picture of identity. It presupposes the self as something that stands apart from someone's life history (Dan-Cohen 2002; pp. 139). In many cases one needs to look upon the self as constituted by one's life history, and because of this, inseparable from it. The idea that the identity of the (moral) agent is irrelevant or even frustrating for the choices he makes apart from 'personal preferences' is flawed. One's identity constitutes part of one's actions, and one's actions constitute one's identity. Therefore, one has to broaden the picture of autonomy beyond choice and give a sketch of autonomy beyond man's limitations and frustrations.

The structure of the concept of 'willing' seems more adequate to describe what happens when one chooses than the concept of rational choice, since with willing one also takes into account one's preferences and one's self. If one has a relationship, one does not choose the other persons from within a set of other potential partners, but one 'wills' a relationship with that specific person, apart from other options. Willing (Dan-Cohen 2002; pp. 131) does not imply a choice set, rather it involves a merging of 'the object of attention' and the act of valuation; the valuation is not a ranking of options in relation to each other, but is specific to the

object one 'wills' (in this example, the relationship with one's partner). Furthermore, 'willing' is not preference-based but value-based. This means willing excludes a comparative valuation (or a relative valuation), it takes the value of its object in itself. In this respect the object of 'willing' does not seek a degree of satisfaction in a quantitative sense, but just satisfaction (or dissatisfaction) as such. The concept of willing implies eliciting something rather than selecting something, which means it does not come with any costs since no other options get to be lost<sup>29</sup>.

The idea of an inner necessity as a basis for moral action is not new. In Immanuel Kant's work, one also encounters a concept of moral action, which is built on inner necessity; willing rather than rational choice between different options. Moral choice, in that sense, is "non-optional", (Dan-Cohen 2002; pp. 136) as are many other forms of choosing. Dan-Cohen explicitly names love, morality and creativity as areas in which willing provides for a better model for choice than choosing. In love, one does not rank one's loved one in comparison with others one did not start a relationship with; in morality, one acts according to the goodness of that act, not according to comparisons to other possibilities; and in creativity one wills one's creation. Willing allows us to claim authorship over our moral actions, our relationships and our creative products, something that cannot be accounted for with the model of choosing.

Willing, as defined above, is a constituent of autonomy that takes into account the issue of the self. One cannot choose from a void. One is always situated in a specific history, a certain moment of time, and having had a specific past that directs the way one chooses through one's experience, environment and education, and one will always choose in a way that is consistent with whom one is. In the paradigm of free choice, these influences would need to be regarded as infringements on one's range of options. These are not restrictions to one's range of options, they form the very precondition that enable one to choose. One always chooses as a self and not from within an exclusive focus on freedom of choice. And an exclusive focus on 'freedom of choice' with regard to autonomy does not cover moral problems that involve this self. The self cannot even be perceived of as a potential element of ethical deliberation within a free choice paradigm. What it should be perceived of is another matter, to which I shall return in chapter VIII.

## **5. The Limitations of the Current Debate**

Too little attention has been given to more individual sides of eugenics, such as the problem of personhood or identity in designing people. If one does not address these subjects too, one feature of the concept of a eugenics, liberal or coercive, is

<sup>29</sup> For the remainder of this chapter, I will make use of this meaning of 'willing' as proposed by Dan-Cohen.

being omitted: the connection between (created) identity and autonomy. On the one side, the discussion on a genetics in the reproductive area that goes beyond the scope of a medical indication<sup>30</sup> concentrates too much on new genetic knowledge and ignores the fact that several means of shaping the biology of our posterity have already been normalised. On the other, the ethical analysis is too restricted to issues of the ethical limits of the shaping of *society*, without regard for the consequences of other people's choices for one's identity, and one's own ability to see oneself as author of one's own actions.

To indicate this omission, one needs to define what eugenics consists of more clearly. Buchanan *et al.* consider eugenics to be that type of genetic intervention (or selection) that aims at enhancing certain genetic features in posterity which are deemed positive within society. Positive is then defined along two lines: the medical line of what features are medically seen as constituting the healthy body, and the line of the liberal society, in which the enhancement of individual opportunity (through selection on intelligence for example) is seen as a means to a better starting position in society. Genetic equality, which is not the same as genetic similarity, should then form the main focus of a new liberal eugenics. Both these lines of definition can be disputed. The medical ideal of the healthy person is not necessarily the only model for one's perfect baby. And the idea of a genetic equality to provide everyone with similar chances in reality is also based on a view on what is ideal and what is not, and such views cannot be taken to be universal either. One still adjusts a new generation to the demands of contemporary society, rather than creating a society that provides enough room for all. One can wonder whether this in itself does not already constitute a precedence of the way society looks and is built now, above the existence of the individuals living in it. By implicitly accepting the liberal democratic society as the only possible just society, one runs the risk of giving precedence of this society over its (future) citizens, who should be created to comply with its structure. This risk is greater if one regards individuals merely as abstract rational agents with the ability to choose, rather than as people with a specific identity that is constituted by their actions.

What has become subject to discussion in this debate, instead of being self-evident, is the most important criterion of admissibility of prenatal diagnosis and intervention: the boundary between the medically-induced concept of normalness and illness/disability/deviancy. This criterion seems to remain self-evident only in cases such as Huntington's sickle cell anaemia or Franconia anaemia, but this appears not to be the case for dwarfism, deafness or other similar hereditary features. Taking the examples of either dwarfism or deafness, one needs to ask where the differences lie between the next four situations:

30 Going beyond the principle of avoiding severe harm

- Two parents hoping to have a child with the same traits as themselves, and although being dependent on the genetic lottery, they do get the child they wanted.
- Two parents making sure they get a child with the same traits they have by choosing a specific sperm donor, and/or through prenatal selection on the basis of a preimplantation or an in utero (genetic) diagnosis.
- Two parents adopting a child with the same traits they have.
- Two parents creating a child with the same traits they have, post-natally.

Although all these categories result in the same thing – two parents raising a child with the same traits they have – we would probably feel very differently about each of these instances. If two people have a deaf child and they hoped for it or have a deaf child by making sure, most people would agree that the second case is more problematic. In the first case, people will have a child that is like they are, but do not rank the quality of possible future children in a list of options, whereas in the second they do. Two people adopting a child that is deaf or has a form of dwarfism, like they themselves, would probably not be looked upon as making a wrong decision. They have not ranked their options, the child already exists and they *will* this specific child, because of their own dwarf or deaf identity. Therefore, it is not created to fit their preferences. In such a case we would probably agree because of the advantages for the child. Not only will he have parents, but they will also understand his condition from an interior position, as well as being better equipped to be parents of the child than a hearing couple would. But two parents opting for an operation on their newly born child's legs to make it fit their own reduced stature and the adjusted furniture they furnished their house with, or on his ears to deprive him from his sense of hearing, would seem abhorrent to all - even proponents of genetic selection on dwarfism or deafness. This is not just because a 'healthy' child, or a child that already has a specific phenotype is changed, but because it is changed according to a ranking of options that are taken to be available to the parents. The child is not willed, elicited, or desired for what it is. Its parents love it merely conditionally.

The distinctions between these cases are felt by most intuitively, but within a paradigm of free choice they cannot be accounted for. This, added to the tendency of (neo-)liberalism to reason in a consequentialist fashion leads to a distorted picture of morality. Since the result is the same, the road that offers the widest set of options would appear to be the more justified one. Will parents who hope for a certain particular child, and act accordingly, love their child less than parents who participate in the genetic lottery in the traditional way? Everyone has certain wishes and preferences about their children before they are born, and everyone hopes their child will not come into the world with a severe impairment or disease. But acting according to those wishes in a specific way, in how one's child should look and

what traits he/she should have, is more than wishing a healthy and normal child. Even if the child would be loved in all other respects, this choice seems to be predominant to how the parents look upon having children. If one would define the picture people have of the good life as something outside of their own parental wish, would there not be some basis to claim that not all applications of prenatal selection are condonable?

If one would take society as a whole, a eugenics policy or any genetic policy towards posterity, no matter what the backgrounds of its contents are, would design posterity to fit the ideals of contemporary society. One could also say that having children is in itself a form of commodification, even if only partly. One could state that having children is something parents do to commodify their wish to have children (even if only in its preference of that time and place in the individual couple's life-history; something not possible before the development of a proper birth control). Should we allow for prenatal selection and/or intervention to create a deaf child, or a child with a form of dwarfism? Should we allow for any prenatal testing and/or intervention for those hereditary conditions, which are seen as deviant from a medical perspective? From what background should we define our criteria of justification, and perhaps more importantly, on what basis can we reject some of the possibilities offered by the development of genetic technology?

## 6. Conclusion

In this chapter I first investigated the discursive problems of the concepts of 'enhancement' and 'eugenics'. The main problem in this respect appeared to be that one cannot formulate an objective, neutral, non-monist scale from diseased or disabled through normal functioning to enhanced functioning. This means that the mixture between biostatistics and idealism that is the supported view of the liberalist's form of eugenics is not as neutral and liberal as it is presented to be. Next, I discussed the ethics of John Rawls to show in what way certain ground concepts of his work have pre-structured a specific conception of autonomy that does not apply to the problem of the self in decisions on future people's genetic make-up. The self is a necessary constituent of autonomy but it is traditionally left apart, since the way one views autonomy is predominantly through a form of free rational agency. In more theoretical philosophical discussions on human autonomy, responsibility and freedom of choice, this view has its merits. But when one looks at how people actually act in their lives, such a form of free rational agency not only appears to be rare but also irrelevant. Next, I went into a specific problem implicit in liberalist political and ethical thought; namely the problematic nature of the self in relation to the predominance of the concept of choice in liberal philosophy. A different sketch of choice and autonomy is presented by the American legal philosopher Meir Dan-Cohen., author of *Harmful Thoughts*. He saw the way choice and

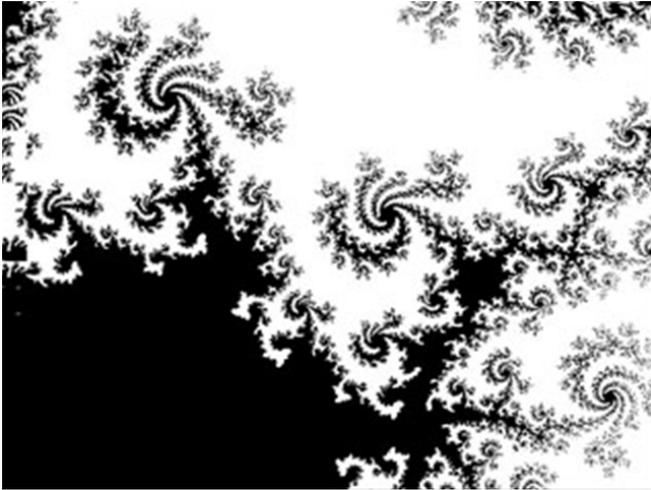
autonomy were usually dealt with within the area of legal philosophy as insufficient. He tried to provide an alternative conception that can cover the subject of legal and moral responsibility in a better way.

A further problem lies in the question whether a child, or the person he will become, will be burdened by the knowledge of such a supposed commodification. Can a person who has come into existence not only because of his parents wish to have children, but also to have a child with or without specific traits feel he would be better off not being born? Can he think him away and give his right to existence speculatively to his unborn brother or sister who would have been born if he had not been chosen? In the next chapter I shall go into the issue of the interrelation of autonomy and the self, by discussing the role of contingency and choice. I shall sketch where and in what way reproductive choices might influence future generations' sense of self, by referring to the philosophy of Derek Parfit. Next I shall go into choices that intend to change future generations, and choices that change future generations without intent.



## *Chapter V*

# Conditionality, Contingency and the Consequences of Choice



## 1. Introduction

In the current discussion on applications of genetics in reproductive technology that go beyond, or outside of medical purposes (treatment or prevention of diseases or disabilities), the focus has been on the wrong discursive framework. The ruling framework remains the medical paradigm of what counts as a disease or a disability and what counts as normal functioning. The derived criteria of prevention and cure count as the true goals of medicine, and any action that goes beyond that is to be seen as a matter for the person at hand - be it cosmetic surgery to enhance one's appearance or taking ritalin to enhance one's ability to concentrate. With respect to future people it is not a question of finding the right conceptual tool to differentiate between what should count as a disadvantage and what as a disability, and what as an advantage or an enhancement. Instead, one should be asking the question of whether it is ethically justifiable to make decisions for future people. This is something that sets choices that affect future people apart from choices that affect existing people.

Our choices constantly affect the world in which future generations will live, but they also decide on who will exist and who will not. One can ask oneself how we could possibly owe something to future people, if a choice for one course of action will create another future generation than a choice for another. With every choice we make we create one potential world whilst destroying another. And, unintentionally, with every breath we take we appear to be creating millions in the far future whilst destroying others. How come we do not feel any ethical problem towards those people and the worlds they could inhabit? Is it mere pragmatism that drives us to forget what the implications of our choices are, or is it something else?

An important logical problem must be taken into account: how can one perceive of a type of autonomy for future people at all? If they do not exist yet, how could they have rights where they cannot have duties? Can we have obligations to future people, and can they be perceived to have personhood, autonomy etc. in respect to the choices we make in our day and age? Derek Parfit addressed this question with regard to certain problematic aspects of utilitarianism. To consider this I shall now turn to the discussion on the rights and status of 'future people', a debate initiated by Parfit.

## 2. Derek Parfit on Future People

Respect for the other person's autonomy is often seen as the most important principle in bioethics. The principle of respect for autonomy is sometimes referred to as a *prima facie* principle, although often defended from deeper lying ethical theories such as liberalism, Kantian deontology etc. When interpreted as a *prima facie* principle, it cannot be based on deeper ethical principles or argumentations.

Because autonomy has been taken as a *prima facie* value in such a strong way, an analysis of the preconditions that constitute people's autonomy has not been part of the debate on autonomy and 'genetic design'. The complicated nature of a respect for the autonomy of future persons necessitates a further investigation into what is meant by autonomy and what the preconditions are of the ability to be autonomous and to act autonomously. Although the idea is that one cannot deduce this principle to deeper ethical principles, this does not necessarily mean that it cannot be deduced to other, non-ethical concepts and conditions which might be relevant for an ethical analysis. For this reason it is necessary to look at the way autonomy and the right to an open future have been interpreted within the discussion.

In bioethics, the 'right not to know' is considered as a fundamental right. When one knows what risks one has in life, one will lead one's life differently. Wherever possible, the right to decide for oneself whether one wants to know one's genetic risks should be retained. The right not to know was initially used in the 1980s as an ethical principle on the newly-arisen genetic tests in order to defend a person's right not to know his genetic risks. Initially, a physician would provide information on genetic risks automatically to the patient even if they were discovered by accident. But one came to see that when no treatment or preventive measures were available, the patient should retain the right to be ignorant of his risks to develop a specific condition.

One of the arguments against genetic selection that specifies the genetic make-up of a future person is based on this right not to know. The reason why people should have a right not to know the risks they might have in developing a specific condition is that this knowledge might fundamentally narrow their future plans and expectations. If one were to know one had a high risk of developing Huntington's chorea, a disease for which hardly any preventive or therapeutic measures are available, this would change one's perception of one's future, the plans one is making, the studies one would want to follow, the relationships one might want to enter into and whether one would want to have children or not. For some, such knowledge might offer a reassurance that provides clarity in an otherwise uncertain future, or even a feeling of being part of one's family, or to rid oneself of a dormant feeling of guilt, should other siblings already suffer from the condition. For others, not to know one's genetic risks might be constitutive to leading a normal life, in spite of feelings of uncertainty. One is still in a sense 'the same' as those that are potentially ignorant of a condition that is not hereditary or accidentally did not get to be expressed for a number of generations and therefore went undiscovered.

The quality of life one might experience and the life expectancy one might have are the main issues in wanting or not wanting to know one's genetic risks. One's options in life are heavily dependent on these two issues. But one's quality of life is not just dependent on whether one is restricted by the pain and disabilities a disease brings with it, but also by other traits that are genetically induced. Whether I

am talented in different areas, what physical appearance I have and what type of life I am able to lead are all at least in part genetically induced. In the case of a specification for a certain genotype prior to birth, one's future is laid down similar to knowing one's risks and feeling restricted by them. Although no sane parent would opt for a genetic selection to specify his child to purposely be at risk of a certain hereditary disease, hereditary traits that are not a symptom of a disease or disability could be experienced as narrowing down one's future in a similar way. The idea behind this right not to know when applied to prenatal genetic selection is that a genetic choice of parents for specific traits in their offspring would narrow their future, whilst the non-genetically designed would still be able to look upon their individual future as something which has not yet been filled in. But since for the genetically designed, being designed is a precondition for his own existence, on a logical level, he can only wish himself not to have been born at all were he to wish he had not been designed.

The rights and responsibilities we have towards existing people can be dealt with in a rather straightforward manner. We have a relationship of interdependence with other people and the consequences of our actions for them and for their actions towards us, create the necessity to define certain rights and duties. This is different for our responsibilities towards people that do not exist yet. Since anything we do will be conditional to their very existence, it is the question whether one can have any moral obligations to future people at all. This complicates the debate on genetic selection too. Our choices, one way or the other, dictate whether a person will exist. Deciding against genetic selection is also a decision that affects the genetic make-up of posterity. The argument against designing people genetically on the basis of some kind of right to an open future appears to be problematic. The person resulting from a specifying genetic selection will be unable to trade in being designed without trading in himself completely. The American philosopher Derek Parfit elaborated this problem, terming it the 'non-identity-problem'.

Parfit's *Reasons and Persons* offers an analysis of the relation between what someone's identity is and how this constitutes justifications for their moral actions. What determines the continuity of someone's identity? Some claim that a physical continuity of existence is necessary for such a mental continuity. Others claim that a psychological continuity is necessary for a continuity of identity, for example through memory. Parfit's view on human identity is built on a reduction to genetic identity. He states that we are at least partly dependent of the fact that we came into existence when an ovum met a spermatozoon. This, according to Parfit, also means we are dependent of the way this fact came to pass. So the contingencies of when ovum and spermatozoon met, what oocyte, what spermatozoon etc., are decisive for whom we are.<sup>31</sup> If the life standard of future generations will be less in choosing A than in choosing B, that future generation in A still cannot prefer B

31 He therefore does not embrace a traditional genetic reductionism.

over A. Neither can we, since A will not exist if anything other than A were to be chosen. The comparison itself cannot be made on a moral basis. The same goes for blaming former generations for what they did, whatever they did, since their choices are the preconditions of our willed existence: to put it bluntly, without the Second World War, there would not have been a 'Wirtschaftswunder' in Western Germany, and those that, in their coming into existence have been dependent on that miracle of economical recovery could therefore, in principle, not be opposed to the Second World War.

Following Parfit's arguments has a number of consequences. If parents failed to opt for a prenatal genetic diagnosis to avoid pregnancy of a child that is known to be at risk of developing a severe hereditary condition, one might hold that this constitutes an injustice performed to that future child. However, one cannot state that unassisted reproduction resulting in the birth of such a child was an injustice performed on that child. The case is similar to the generation having come into existence in the abovementioned option A. If the parents would have opted for an assisted reproduction, selecting a healthy pre-embryo to implant through in vitro fertilisation, would have result in that specific child not existing. And opting against reproduction would result in no child being born at all. The child that is or is not going to be born when one does or does not opt for prenatal genetic diagnosis, has no identity yet, there is no circumstantial situation to determine it yet (be it the moment of conception, or the specific genes involved). This means not all questions on prenatal diagnosis can be solved through a debate on presumed consent and presumed non-consent. Within the concept of choosing, one necessarily takes the self as separate from one's life history (because it has not been lived yet). By doing this, one steps outside of the field of questions which would arise in a self-inclusive approach of choice and autonomy. Historically speaking a person could have made choices that would have led him to another route in life. Counterfactually speaking, he would not be able to make such statements, since choices made in the past are co-constitutive of who he is at the moment they make such a statement. This applies to choices on future persons too.

This so-called non-identity problem outlines the problematic nature on a conceptual level of our responsibilities to future people. Future people do not have an identity as yet and cannot be seen as specific persons, so in what way can their non-existence constitute a claim to our moral responsibility? The number as well as the identity of future people will be influenced by our decisions in the present. With every single choice we make now, the number of people in the future as well as who they will be, is decided. An ethical standpoint against designing humans on, for example, the principle of autonomy and beneficence will be problematic in this light. On a logical level, future people will be dependent on our choices in their existence, whatever our choices are. But then, however eccentric the choice of certain individual parents may be, any other choice would have retrospectively led

to another person, so the person in question, whatever non-useful or even negative traits he may have, will always be better off.

We therefore need to take into account another value-criterion than what people in the future would think of our decisions, since their existence depends on what we do, whatever we do. But if we embrace a view on the community in which the net welfare is the most important value to set for whatever type of policy making, we would arrive at a rather counter-intuitive conclusion. This is termed the repugnant conclusion by Parfit:

*“The Repugnant Conclusion:* For any outcome where everybody enjoys very high positive welfare, there is an outcome where people have very low positive welfare which is better, other things being equal.” (Parfit 1984; pp. 388)

The repugnant conclusion, a conclusion one does not want to draw in spite of being forced to by having used the proper arguments, implies the following: it would be better to create as many future people as possible, even if the individual degree of welfare would be lower because of it, since creating less people with a higher degree of welfare would amount less net welfare. This is a standard argument against total utilitarianism. One appears to be obliged merely to add numbers to the expected future population to arrive at a net welfare that would be equally acceptable. One would have a total amount of utility that is greater than with fewer, but happier people. An average form utilitarianism that aims at a maximisation of average utility, regardless of population size, would also lead us to this repugnant conclusion (Chan 2003). In this case, we would already be doing well if we would bring about the birth of slightly less unhappy people, since it would already heighten the average level of welfare and wellbeing. In both cases, the conclusion is repugnant. In both cases, one has to look for other means to define justificatory criteria for prenatal selection. With choices in the present, the amount of future people will change. This phenomenon cannot be taken as the basis for such criteria. It cannot be taken as a basis either that with choices in the present, the identity of future people will also change.

Utilitarianism takes a benefit-harm calculus as the basis of ethical justification. Not harming others constitutes a much better principle that would guide further demarcations of what one is allowed to do with the new reproductive technologies. But what constitutes harm? Intuitively, one may think of examples in which the person that would emerge from a certain prenatal selection is disadvantaged by the type of trait he has been selected on. But it may not only be the trait in question but also the fact that it has been selected to be part of one’s genotype, or the fact that it was conditional to one’s existence that may be experienced as harmful by the person in question. To harm society as a whole forms an even broader issue. When is society as a whole harmed? How does one describe ‘society as a whole’? Intuitively, the idea of harming society as a whole may lead us to scenarios in which the

‘gene-poor’ do not have the means to shape their offspring, and the ‘gene-rich’ do (Fukuyama 2003). In such a situation, an imbalance would come into existence at the level of our biological make-up. It seems that the focus on not harming others or society has overruled specifying which harm is meant, therefore implicitly leading the focus to medical harm.

### 3. The Relevance of Contingency

One cannot substitute a future person’s genetic make-up for another without substituting that one future person for another. This forms the core of the non-identity problem. There is a distinction to be made here between the role of the person that chooses posterity and the person that will be posterity. This is the problem of first person’s perspective versus third person’s perspective (Harvey 2004). From a first person’s perspective, a person that has certain traits that have been conditional to his existence will not be able to change those conditions in retrospect, since he would not have existed at all were he not in possession of those traits. He can therefore never value those traits as a wrong on an ontic level. From a third person’s perspective, any choice for a trait that lays down one’s future, be it a disability or a talent, would constitute a harm for a future person. Still, that person himself will not be able to question the choice for those traits, since they will have been conditional for his existence. This, however, also goes for traits that are not genetically determined, such as the language one speaks. The language with which we grow up contributes to the way we have been formed. It is difficult to speak languages other than one’s native language, and it is even harder to ‘feel at home’ in another language. Similarly, the language my parents ‘chose’ to raise me in has been decisive for who I am, and what possibilities as well as what restrictions I have in the world. In what way would the language in which I was raised be any different from my genetic traits?

If I were to have met my wife in a local cinema and we wound up marrying and having three children, the movie playing that night will be conditional for me marrying her, and therefore the existence of my children. However, my going to that movie was not an intentional act with regard to our three children; although our choice to stop using contraception was. Though both occurrences, and many others, were conditional to the existence of my children, our choice to have children was meaningful in another way. Since it was an intentional act with regard to having children, it created a bond of responsibility between our choice and our children.

Now, something awkward seems to occur when we apply Parfit’s arguments to my case. Sometimes, our children might express the desire we had not met at that specific movie. They say we talk about it too much, and always want to see it when it is on television. According to Parfit, our children’s line of thought is absurd,

since me and my wife not having gone to that movie would undo their existence. This conclusion is flawed. For example, it is in no way impossible to wish one did not have a certain genetic condition. On a logical level, one might be able to state that such a wish would imply, by consequence, a wish not to have existed at all. One can easily create further fictional circumstances in which one could have been born as one is, but without the impairment. As can our children easily imagine having come in existence even if my wife and I had not met at that specific movie.

Although there are countless situations in which taking responsibility over someone else is the right thing to do, in the case of genetics choices according to personal preferences it is not (Harvey 2004). One is putting oneself above the other, and creating a situation in which this, quite literally, can never be overcome by that person. One is assuming a position of responsibility towards another person's identity, not merely the values he should have or the way he should lead his life. One is making conditions on whom that person should be in choosing a person to come into existence. The more cultural the contextual meaning of the traits (or genotypes) in question are, the more compelling the reason not to pursue them because of this issue of unjust intergenerational responsibility.

#### **4. Choosing Children for the Right Reasons: Means and Ends**

To consider the other person as merely an extension of one's own goals is considered unethical, even if the other person might benefit from being treated as such. This concept of the non-instrumentality of the other person was derived from Kantian moral philosophy. In the *Metaphysics of Morals*, he states that another person "must be treated never as a mere means but as the supreme limiting condition in the use of all means, i.e., as an end at the same time" (Kant 2002 (1785)). One should never reduce the other person to merely a means to another end, although he may also be a means to an end. So, if one were to aim for pre-selection on traits that are preferred by parents, this would compromise the future person because he will have been treated as a means to the ends parents set themselves, rather than as an end in itself. He will not only be treated as such, he will even be created as such. In one respect, the child is treated as a commodity. This is supposed to violate the principle of a respect for the autonomy of that future person. However, although the birth of a child might have been a means to an end of the parents in question, this does not necessarily imply that they will keep on treating it as such. In many cases, parents will choose to have a child as a means to some other goal, rather than as an end in itself

I shall sketch a parallel. There are parents that plan their children, and there are parents that become parent by accident. Many children are born unintentionally. People forget to take contraceptives, or just happen to end up in the same bed after a late night party. In the past, when society did not approve of contraceptives and

abortion was still illegal (and in some countries still is), the number of children born in such an unintentional fashion was much larger; and it is still quite considerable. Although an unwanted pregnancy often led to personal distress, society was not tempted to legalise abortion or contraceptives in the interest of the future child. We still do not necessarily perceive of unintentional childbirth as a moral problem, as long as the parents embrace the fact that they have a child post-factually. Apparently we accept it when parents want and plan a child just as easily as when parents have children unintentionally. Even though we would prefer people to think things through before they have a child, we accept it, albeit reluctantly, that children are sometimes born although they were not wanted. If we do see a difference between the wanted and the unwanted child, why would there be a problem with parents pre-selecting children they want, if we already accept a possibly worse case in which the child was not wanted at all?

The idea however is that if the child is born unintentionally, its status as a goal in itself is not directly affected. The child can still be a goal in itself rather than being a means to something else. Although it was not chosen to be born as a being in himself, it was not put on the earth for other instrumental purposes either. And one of the main arguments against eugenics was that it supposedly instrumentalises the child. In the very veins of his existence, he will be instrumental to what the parents' desires, preferences, wishes and dreams were. However, one can imagine that a child whose traits were pre-selected or predetermined by its parents would grow up under better circumstances precisely because it was what the parents preferred it to be. Would a child with traits that were wished for be loved more than a child whose traits were not wished for? After all, one might say it is part of the parents' reproductive rights to make use of available reproductive technologies; yet it would probably be better for a child to be preferred by its parents than not to be. We already accept many instances in which the child is instrumentalised. We accept it when parents choose a second child as a playmate for the first one, even though one might say this formally constitutes an instrumentalisation of the child. In David Heyd's words, parents have chosen children for "emotional satisfaction, to provide extra work force for the family, to have someone to transmit the family name [...] to guarantee support in old age, to obey God's commandments, to gain self-esteem or reputation for virility, and so forth"(Mills 2005).<sup>32</sup>

When the emotional satisfaction a child can offer is the main reason parents have a child, we do not perceive this as a harm to the future child at all. And although we might perceive of "prolongation of the name and the ancestral genes" as an anachronism, it will not be regarded as an injustice performed upon the future child if he is conceived for that reason. It appears children have been known to be chosen for a variety of reasons, all of them deemed acceptable, but none of them for the sake of the child itself. The argument that eugenics is to be dismissed

<sup>32</sup> David Heyd, as cited in Mills, C.

on the basis that it turns the child into a means rather than an end hardly holds up if we consider that many of the reasons for having a child are not in that child's interest. All these issues do not imply that the child cannot also be looked upon as an end upon itself.

There is another problem with the idea that a child must be born as a goal in itself rather than a means to other purposes. If a child is to be a goal in itself, this is supposed to be in the child's interest, rather than in the interest of the parents, that it was born. But the idea that the birth of a child would be in the child's interest is rather contradictory. To cite C Mills on this issue: "Before conception, as Heyd and Jecker have argued, there is no child there to be valued, for whatever reason, intrinsic or extrinsic. I can not value you for who you are if you do not exist yet" (Mills 2005; pp. 21-22). As there is no child yet to have an interest, how can conception, of whatever type, be in the interest of a child at all? How can the circumstances of conception be either good or bad for a child if with the one choice the one child will be born and with the other choice another?

## 5. Conclusion

Most approaches to ethical questions in medicine concentrate on the potential benefits and potential harms that follow from certain actions. In this sense, bioethics is still highly influenced by utilitarianism. Utilitarianism is an approach in ethics that is mainly preoccupied with questions of welfare on a societal level. Many ethical problems can be accounted for within this approach. However, not all actions can be measured solely along a continuum of harms and benefits. It is not just the direct consequences but also the intentions of a certain act are ethically relevant. In the case of prenatal selection, we are not talking about actual persons. Therefore we cannot talk about harms and benefits. These only apply to existing persons. However, this does not mean that there is no ethics that is relevant for future persons at all.

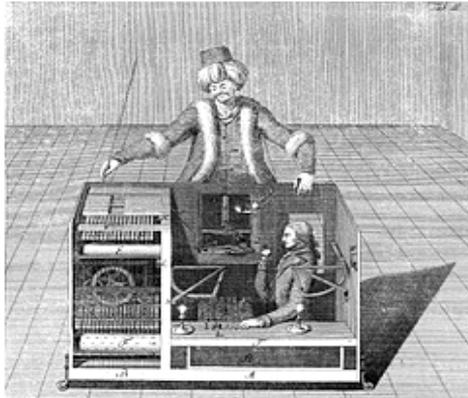
The problem with genetics choices that affect posterity and are intentionally aimed at affecting posterity; is that one is always born with a certain genetic makeup, that determines certain features of who one is - be it a genetic make-up that is the result of chance or of choice. However, in the case of chance, one's genetic makeup is only a side-effect of other occurrences, some will be choices aimed at something else (one's parents marrying each other because they love each other, rather than consciously choosing each other as genetic partner because they expect a certain genotype in their offspring), some will be mere accidental. And in the case of choice, certain genetic features that are fundamental to who one is, will be the result of another person's plan. But since they are fundamental to one's very coming into existence, they cannot be denied. Another person's choices form the very fabric of one's identity.

The act of choosing a specific genetic makeup for one's children that is aimed at creating a specific type is different from the act of choosing a child as such. In the one, the desire to have children is turned into the factual circumstance to actually have one, and in doing so one is morally obliged to assume responsibility over the child's welfare. However, in choosing the specific genetic make-up for one's child, one is assuming responsibility over something that should never be the responsibility of anyone but oneself. One is assuming responsibility over the identity of that person. One can only be responsible for one's own self, one can not take the right to assume responsibility over the self of another person. Just because a person may not be capable of doing this himself, the state or society will do so (for example, in psychiatry). If one thinks it is justified to take that position towards one's children, one is *de facto* embracing a relationship with that other person as if he were not another person in his own right. It will rarely be the explicit motivation a parent who makes such choices will assume, but that one has taken such a position of responsibility follows necessarily from such choices. This is all the more relevant if the choices in question have a cultural rather than a medical character. In the remaining two chapters, I shall first investigate issues of methodology in bioethics. This possibly somewhat eccentric chapter is necessary to show in what way the tendency in neo-liberalism to focus on issues of method rather than content, issues of process rather than substance, or issues of epistemology rather than ontology has obscured the central moral issue of a new liberal eugenics. Specifically with regard to the debate on eugenics, this approach cannot suffice. One needs a conception of the person if one wants to discuss the problem of the eugenically designed. In the last chapter I shall elaborate such a conception, partially through a criticism on the debate on humanism, partially by reference to Jürgen Habermas' account of eugenics in *The future of Human Nature* (2003).



## *Chapter VI*

# Philosophical Monstrosities and Dilemmas of Methodological Ethics



“A chess-playing automaton, the Turk was a sensation in Europe in the 1770s. The Turk was a wooden cabinet on wheels, atop which sat a chessboard and a life-sized wooden mannequin dressed in Turkish style. This mysterious contraption would play against, and often defeat, human opponents. In truth the Turk was a clever illusion: the cabinet concealed a human chess expert who moved the Turk’s arm and played the games. [...] Ownership of the Turk eventually passed to Johann Maelzel, who took it to America where it toured anew. The Turk finally passed out of fashion and ended up in Philadelphia, where it was destroyed in a fire in 1854”  
[www.answers.com/topic/the-turk](http://www.answers.com/topic/the-turk)

*“All universal moral principles are idle fantasies”*  
Donatien Alphonse Louis de Sade (1740-1814)

## 1. Methodological Problems of Bioethics

Anglo-American philosophy emphasises methodological issues in ethics, leaning heavily on utilitarianism, contractarianism, the analytic reception of Kantian ethics and pragmatism. The four were combined by John Rawls and much of the (bio-)ethical debate is still confined to the conceptual horizon of his philosophy of justice. The emphasis on method rather than content is a side-effect of the desire to provide for a universally valid ethics: if one aims at the creation of a universally valid ethics, the subjects at hand are more easily disregarded in favour of issues of the internal mechanism of the approach. It led to an ongoing discussion on the status of moral justification, addressing the question of the function of rules, practices and social behaviour in ethics. The concept of the person as a free and rational moral agent is often the hidden presupposition of methodological approaches in bioethics. The combination between a focus on methodology and a presupposed conception of the self as a free and rational (and trait-less) moral agent has hampered a deeper understanding of the moral issues at stake in the discussion on eugenics. To show that an approach in bioethics that merely looks at issues of methodology cannot account for these issues, I shall devote this chapter to the problem of reductionism, both with regard to the epistemology of bioethics in general and with regard to the issue of nature in the discussion on eugenics.

The literature of bioethics has been the stage of a fierce discussion between ethicists who prefer a top-down approach and those who prefer to approach ethics bottom-up. The basic question, which is asked in many guises, is: should ethics be about setting rules on the basis of theory, which should then be applied downwards within social practice (actions and speech utterances) or about this social practice itself, from whence ethically justified courses of action would emerge self-evidently (or through some communicative process)? In other words, should communicative and behavioural *practice* or reflective *theory* be taken as a starting point? The arena is filled by principlists, specificationists, supporters of the concept of a reflective equilibrium, supporters of casuistry, neo-pragmatists and other strands in applied ethics. Bioethics has had a close relationship with linguistic philosophy from the outset, and a similar issue was also noted when linguistic philosophy turned away from the representationalist theory of meaning, at which time the status of rules and practices in the theory of meaning became problematic. In applied ethics this epistemological issue is also often referred to as the controversy between top-down and bottom-up approaches. Principlists tend towards the top-down approach. Casuistry and neo-pragmatists, take the bottom-up approach. For my purposes I

take these approaches as exemplary for all other top-down and bottom-up approaches in (bio)ethics.

One of the first methodological approaches in bioethics was principle-based ethics, or principlism. This top-down approach to ethics was developed by Thomas Beauchamps and James Childress (1979). They developed the idea of four universal principles that would be acceptable cross-culturally and that were to be applied to (bio)ethical practice. These principles, the ever-repeated principle of beneficence, non-maleficence, respect for autonomy and justice should be taken as central to regulating human behaviour. In the case of autonomy for example, one should treat a patient in such a way that he retains the right to decide for him , regardless of the doctor's opinion, as long as he is sufficiently well informed. These principles were taken to be universally applicable, therefore providing a method that could be applied to different cases and situations.

Top down approaches of ethics were criticised because the application of an ethical rule or principle to a specific practical case scenario is far from self evident. Other approaches were proposed such as casuistry or specified principlism. Bottom-up conceptions also came to be criticised since they do not provide for a clarification of how the social practice itself can automatically be regulative for one's actions. A conception of ethics without any reference to the concept of rules leads us in a reductionism of ethics to the mere factual: what people think is good in practice, is identical to what is good as such. As a consequence, there would be no justificatory criteria to discern right from wrong in bottom-up approaches either.

In ethics either one reverts to rules, without being able to show in what way they bear upon a specific practical case, or one reverts to the practice of social interaction, without being able to show in what way this practice leads to correct justifications. The content of the social practice on which these rules are not supposed to be applied to remains forever on the background. This issue is one of the reasons why in current day bioethics one cannot give either arguments for or against the implementation of a new eugenics; it lacks a proper account of human agency that is beyond these two approaches, whilst both are reductionist accounts of ethics.

In this chapter, I shall investigate the problematic relation between rules and the practices they are supposed to regulate, with specific regard to its philosophical background in the works of Wittgenstein, Kripke, Moore and Brandom. I shall show that taking a detour around this issue of methodology simultaneously provides us with an approach in bioethics that can also deal with issues of eugenics justification.

## 2. Principlism

Principlism, or principle based ethics, was one of the first approaches in bioethics. It was introduced in the late 1970s, and in subsequent years, became the dominant perspective in bioethics. It is an approach in ethics based upon four supposedly universal principles. As said earlier, the ‘founding fathers’ of principlism were Thomas Beauchamps and James Childress. The importance of their *Principles of Biomedical Ethics* (Beauchamps & Childress 2001 (1979)) for the development of bioethics as a discipline the discipline should not be underestimated. The four principles, as stated by Beauchamps and Childress (2001 (1979)), were:

1. *Respect for autonomy*: does my action impinge on an individual’s personal autonomy? Do all relevant parties consent to my action? Do I acknowledge and respect that others may choose differently?
2. *Beneficence*: Who should benefit from my action and in what way? What are my obligations to do well and in what situation, and for whom?
3. *Non-maleficence*: Which parties may be harmed by my action? What steps can I take to minimise this harm? Have I communicated risks involved in a truthful and open manner? In the event of a disaster, how can I avert the possible harm caused?
4. *Justice*: Have I identified all vulnerable groups that may be affected by my action? Is my proposed action equitable? How can I make it more equitable?

Rawls’ idea of a reflective equilibrium was used to balance these four principles towards each other and towards the social practice in which they were to be implemented. Through reflection rather than intuition, an equilibrium is supposed to be reached between the ethical demands of the four principles and the actual decisions to be made in the pluralist and particular nature of social practice.

An important problem in principlism is that the interpretation of these highly generalised principles to a certain social practice with all its particularities is not self-evident. Even with the idea of a reflective equilibrium, one still needs certain criteria that indicate how a principle is to be interpreted in social practice. Another issue of principle-based ethics, diagnosed at the beginning of the 1990s by several writers (including Richardson, DeGrazia and Strong (Richardson 2000; Strong 2000)) and by Beauchamps and Childress themselves (Beauchamp 2000), concerns the idea of balancing principles amongst each other. When two or more principles appear to conflict with each other in their application to a certain social practice, the approach does not offer a method of deciding how to prioritise the one principle over the other. The principle of autonomy (of a patient, for example) can in some cases conflict with the principle of beneficence. A balancing of these principles cannot always satisfy the demands of both. One might think that providing

such a method would resolve the issue, for example through reference to the method of reflective equilibrium. But balancing principles is still problematic if one does not provide criteria for why one principle is to be taken as more important than another. To base this merely on the intuitions of the person who is balancing does not in itself provide for a justificatory criterion. Therefore, neither balancing nor reflective equilibrium seems to solve the principlist problem of interpretation.

An example, derived from Carson Strong (Strong 2000), illustrates these points of criticism: The life expectancy of a child born with trisomy 18 syndrome is very short. A child with the condition rarely survives its first year and is severely handicapped, both physically and mentally. The oesophagus is not connected to the stomach. This means, even feeding the child will be impossible without surgery. Should one decide to operate and connect the stomach to the oesophagus? If the parents oppose such an operation, should one over-ride their wishes? If the parents agree with such an operation, should one proceed? Whose interests are best served and in which way? Should one feed the child intravenously (possible with dextrose dissolved in water)?

The two principles that seem to conflict here are the principle of autonomy and the principle of beneficence. One could say that the conflict between these two is resolved if one balances the principle of the (hypothetical future) child's autonomy with being beneficial when one considers what the child would want when adult. One can assume consent when generally any adult would agree with the line of action proposed. In that case, one would probably state that the child would be better served if one were not to feed the child intravenously. In which case, the principle of beneficence and the principle of autonomy would be harmonised. On the other hand, if one were to opt for another interpretation of the concept of autonomy, one might say that one cannot speak on behalf of an adult that does not yet exist, and will not exist either. In this case, one is to follow the autonomy of the parents. And if they want the child to be fed intravenously, and if one would adhere to the idea that medicine should prolong life wherever necessary in the name of beneficence, both principles are harmonised as well, but with an opposite conclusion. How can a grasping of the rule be shown by taking any course of action? One might be serving both rules or neither, by taking any course of action. Is the principle of beneficence served when one helps the child live longer, or when one relieves the child from its suffering by letting it die? And should one respect the autonomy of the parents or the autonomy of the child?

This dilemma is like a modern day version of Sophocles' *Antigone*: after Oedipus' death both of his sons (Eteocles and Polynices) fight to rule over the city. Polynices attacks the city whilst Eteocles is inside. They end up killing each other, upon which their uncle, Kreon, is required to take the throne. He declares that since Polynices attacked the city, he is not to receive a proper burial. Antigone, their sister, sees it as a holy obligation to bury her family members. The issue here is: is ethics served well when the ruler of the city is properly obeyed (him making a

statement about the importance of matters of the state and the city) or when family members are buried? Neither shifts ground in their adherence to two general, but in this case mutually exclusive, principles and they end up in a deadlock. Still, it is not merely the issue of stubbornness which plays into the moral problem: in this case, both principles are not reconcilable. As one can see in the problematic case of the child born with trisomy18 syndrome, issues of conflicting principles are not always resolved internally by merely adopting the method of balancing principles.

From the initial criticism on principlism an adjusted version of the theory was suggested at the beginning of the 1990s: 'specified principlism' (Richardson 1990). Beauchamps and Childress themselves also saw the initial issues with their theory, and made adjustments in later editions of *Principles of Biomedical Ethics*. Beauchamps stated:

“Childress and I (as well as DeGrazia and Richardson) have explicitly rejected the idea of a deductive ethics (implicit in the original version of principlism and given principled reasons for doing so). We have also rejected the language of applying principles and of ‘applied ethics’, in favour of specification and ‘practical ethics’. The image of working ‘down’ from principles to cases grips the imagination of many who work in bioethics, but it must be resisted. Often we have more reason to trust our responses to specific cases than a principle or rule to which we had previously not noted any exceptions (or which remained too vague or too unspecified to guide us in the case). Using a case judgment to motivate changing a rule or principle represents ‘upward’ movement in moral reasoning, but such reasoning presents no problem for principlism once the methods of coherence and specification are properly understood” (Beauchamps, 2001; pp. 345).

The idea was that specifying principles, maxims and intermediate rules towards the social practice on which they were brought to bear could solve the problem of conflicting principles in a certain social practice. Norms, principles and guidelines were to be rephrased in their application in order for them to be more directly applicable to a certain case. Not only the original basis from which one had arrived at these four principles was to count in this specification, but there should also be an influence of the specified issue at hand. Rather than run the risk of ending up with a merely deductive top-down-model, a *reciprocal* relation between principles and social practice was to be the format of this new version of principlism. Next to balancing this concept of specification was an additional component aimed at attaining a reflective equilibrium.

Perhaps another concept of what an ethical principle is can help clarify the situation. Michael Quante and Andreas Vieth tried to defend principlism through this route. They state:

“It becomes clear, at least on the second glance, that the Utility Principle of utilitarianism and Immanuel Kant’s Categorical Imperative are very distinct from the concept of a principle which Beauchamp and Childress employ in their approach. Their theory is (a) not ‘monistic’, but rather ‘pluralistic’, and the principles are (b) not brought into a fixed order or an intra-theoretical relation of derivation. Above all, though, (c) these principles are not first justified through a specific ethical theory in order that they can then be – in a second step – brought to bear on moral experience, but rather they are formed out of experience and in fact reveal a part of that experience” ((Quante 2002); pp. 3).

This concept was extended in later editions of *Principles of Biomedical Ethics*, to incorporate a reciprocal balancing from the one principle to the other(s). As Daniels now defines the concept, reflective equilibrium means:

“The method of reflective equilibrium consists in working back and forth among our considered judgments (some say our ‘intuitions’) about particular instances or cases, the principles or rules that we believe govern them, and the theoretical considerations that we believe bear on accepting these considered judgments, principles, or rules, revising any of these elements wherever necessary in order to achieve an acceptable coherence among them. The method succeeds and we achieve reflective equilibrium when we arrive at an acceptable coherence among these beliefs. An acceptable coherence requires that our beliefs not only be consistent with each other (a weak requirement), but that some of these beliefs provide support or provide a best explanation for others. Moreover, in the process we may not only modify a priori beliefs but add new beliefs too. In practical contexts, this deliberation may help us come to a conclusion about what we ought to do when we had not at all been sure earlier...We arrive at an optimal equilibrium when the component judgments, principles, and theories are ones we are un-inclined to revise any further because together they have the highest degree of acceptability or credibility for us” (Daniels 1996).

The method is applied successfully when we arrive at an acceptable coherence in these beliefs.

I shall now return to the case presented above. Can *specified* principlism help us to decide whether we should proceed to such an operation on the child or not? One could specify the principle of ‘nonmaleficence’ and state that in general it is wrong to withhold food from newborn children. One could also specify the principle of autonomy that in general the parents’ wishes concerning their newborn child should be respected as long as these wishes coincide with the (future) rights and best interests of the newborn child. Both are specifications of the principle of autonomy – i.e. that the principle of autonomy is made compatible with the principle of non-maleficence. In this sense specification offers a way of solving the

problem of conflicting principles. Moreover, in both scenarios the issue of the generality of principles is solved. However, the specification in the first scenario leads to the opposite of the specification of the second. In the first case, it seems evident that the child should receive surgery to enable it to be fed. In the second, that food should be withheld and the child be allowed to die.

Although specification offers something more of a criterion with which one can balance the principles reciprocally, with the principles on the one hand and the practice on the other, it remains under dispute whether it can serve as a complete method of applied ethics. Specification offers an add-in between principles and practical situations, but this add-in suffers from the same complication as the original. As I defended elsewhere (Landeweerd 2006), in principlism the application of the four principles is taken too much as self-evident, while in specified principlism the way in which these principles are to be specified is taken too much to be self-evident. By inserting specifications, one merely wedges in another version of the original problem. This problem did not go unnoticed.

Both the original version of principlism and in its later adjustments adhere to intuition as a means to solve the problem of interpretation as well as the problem of the original justification of the principle at hand. However, intuitionism is not sufficient to resolve the issue, as we will see with regard to casuistry and neo-pragmatism. I shall now turn to these two approaches in practical ethics that start from the practical ethical life world without reference to either theory or aprioristic principles to discern what course of action to take; casuistry and neo-pragmatism.

### 3. Casuistry and Neo-pragmatism

As a reaction to the issues in principlism, Albert Jonsen and Stephen Toulmin revived the method of casuistry. This approach, which already has a rich history in Catholicism, was criticised by Blaise Pascal, after which it fell out of favour. Jonsen and Toulmin's *The Abuse of Casuistry* was written in 1988, and came to be a new method specifically in bioethics (Jonsen 1988). According to Jonsen and Toulmin, the emphasis on general theoretical moral principles and the belief that an algorithmic application of those principles to moral actions is self evident, has distorted both our sense of ethics and our ability to deal convincingly with difficult moral choices. Casuistry does not make use of loose-standing principles but of paradigmatic cases, that are to be taken as exemplary. By not making use of background theories in dealing with ethical dilemmas, Jonsen and Toulmin tried to accommodate for the pluralistic nature of contemporary morality. Casuistry does not want to provide us with 'the' answer to a specific ethical dilemma, it merely presents itself as a practical instrument for choice. The key element of this method is that one should start out with what is certain. One is to construe two or more of these paradigmatic cases, in which the ethical issue is clear and solvable, and then com-

pare the relevant features of these cases to the practical case at hand. When one does not know what to do in a specific situation, one is to compare it with two or more certain positions. This way an ethical position is built up rather than taken as a foundation.

Within casuistry there are two elements and one proviso in making moral judgments in difficult cases:

1. *Collection of moral data:* Particular moral judgments that are intuitively appealing are taken as the foundation.
2. *Generalisation:* The moral theory is a generalisation based on the particular moral judgments that are intuitively appealing.

A proviso is that casuistry only knows a limited application. The moral theory of casuistry can be applied only in cases where people have no strong intuitive judgments. The generalisation is to take place in such a way that one gets a more concise version of the case at hand. In this phase, one is to construe two possibly hypothetical cases; one in which one ethically problematic element is rendered unimportant by rephrasing the case, the other is a mirror image of this case, with a similar unproblematic nature. The paradigmatic case of the two which strikes one as most similar to the case at hand is to be taken as a guide for decision making. I shall give an example of this version of casuistry, suggested by Carson Strong:

Carson Strong explains two forms of casuistry, but here I shall restrict myself to an account of the second one, since it is better known in bioethics. I start out with a problematic case scenario and give two paradigmatic cases that are to be compared to the original case:

*“Case 1* Twelve-year-old Pamela Hamilton was taken to an orthopedic surgeon for treatment of a fractured femur. The physician discovered a tumor in her thigh that was diagnosed as Ewing’s sarcoma, a type of bone cancer. The tumor had arisen in her femur and had contributed to the fracture. Pamela was taken to St. Jude Children’s Research Hospital in Memphis for tests and treatment. A work-up confirmed the diagnosis and included a bone scan that revealed a lesion on the spine, which was considered possibly a metastatic tumor. The long-term prognosis was very guarded. If indeed there was metastatic cancer, then the chances that treatment would result in five-year disease-free survival were less than 25%. On the other hand, if the spinal lesion was not tumor, then the best estimate of five-year disease free survival would be 25–50%. However, without treatment Pamela would die from the cancer within six to nine months. The proposed treatment would consist of high-dose radiation to the local area around the primary tumor and multiagent chemotherapy to try to eradicate and prevent development of metastatic tumors. Possible complications associated with the radiation therapy include failure

of bone growth, fibrosis, and development of secondary cancer, most commonly osteosarcoma. The chemotherapy drugs used against Ewing's sarcoma were vincristine, cyclophosphamide, dactinomycin, and adriamycin. The side-effect of these drugs include nausea, vomiting, fever, hair loss, and decreased blood cell counts with associated increased risks of infection and hemorrhage. Pamela's father stated that he did not want her to undergo the proposed treatment. He explained that their family belonged to a Protestant religious sect, The Church of God of the Union Assembly, Incorporated. He was himself a lay minister in this church. A tenet of the church is that all members are forbidden to use medicine, vaccinations, or shots of any kind, but are instructed to live by faith. Certain types of medical treatment, such as suturing wounds, extracting teeth, and setting broken bones, do not fall within this prohibition. The fact that there are such exceptions had provided the rationale for taking Pamela to the orthopedic surgeon. However, the proposed treatment of the Ewing's sarcoma was considered to be forbidden. Pamela concurred in this decision, and efforts to persuade the father and patient to agree to treatment were unsuccessful. The question raised by this situation was whether a court order authorizing the proposed treatment would be justifiable. In support of a court order, it could be argued that treatment might extend her life for several years. The treatment would also have the palliative effect of reducing tumor size, thereby lessening pain. After the treatment, the side-effects would likely diminish, and Pamela might very well have a quality of life that would be acceptable to her, at least until the disease became more advanced." (Strong 2000; pp. 399-400)

As Strong suggests, in casuistry, one is to identify the ethical values that are relevant in this case scenario. According to him, the values that can be identified are: the well-being of the patient, the autonomy of the parents with regard to their child, respect for the autonomy of the child, the well-being of the parents and the religious community to which the family belonged. Next, one should try to discern what options there are. One option is to aim at consensus between the family in question and the doctors, another is to respect the wishes of the parents, a third is to enforce medical treatment through a court order. Then, one is to discern what casuistic factors play into this scenario. These are the factors that, if changed, would alter the scenario into a scenario without a problematic nature. These are, for example, the disease in question (what if it were a less severe disease?), the severity of the side-effects of the treatment, the success rate of the treatment, the religion of the parents and their community, and the harms caused by a court order. From these factors, one is to construe hypothetical paradigmatic case scenarios that are similar to the case at hand, but in which a specific course of action is more self-evidently suggested by the altered casuistic factors. Strong therefore construes the following two case scenarios:

*“Case 2: An eight-day-old female infant was diagnosed as having erythroblastosis fetalis, or Rh disease [11]. The conditions that cause this disease arise when foetal blood containing a specific antigen enters the bloodstream of a mother whose blood lacks that antigen. Maternal antibodies are then produced, and in subsequent pregnancies the antibodies cross the placenta and attack foetal blood cells that have the antigen. In this case, the infant was rapidly losing her red blood cells due to hemolysis caused by the antibodies. The physician informed the parents that the child needed blood transfusions to survive. However, the parents were Jehovah’s Witnesses and refused to permit transfusions for the infant. Without transfusions, it was highly probable that the patient would die. In the unlikely event that she would survive without transfusions, she probably would have brain damage and mental retardation caused by hypoxia resulting from the low red blood cell count. Blood transfusions are effective in treating Rh disease and would likely result in the survival of a healthy child. For this type of case, the transfusion therapy itself has a risk of mortality estimated to be three deaths per 1000 cases [12]. However, a comparison of the medical benefits and risks greatly favors carrying out the transfusions” (Strong 2000; pp. 401).*

In this case, at least according to Strong, it is much more evident to overrule the parental authority through a court order for the sake of the child’s well-being. This also depends on whether one prioritises religious freedom and parental authority over a child’s well-being or not. Strong’s conclusions might hinge more on his convictions than on his adoption of casuistry. A third scenario is taken by Strong to indicate a different conclusion, in which applying for a court order apparently is not a justified course of action.

*“Case 3: An 18-month-old female child developed a large tumor in the abdomen and was diagnosed as having neuroblastoma, a relatively common type of childhood cancer [13]. A pediatric oncologist explained to the parents that there was no standard treatment for neuroblastoma but that an experimental treatment program was available. This would involve surgery to remove as much of the tumor as possible, followed by four months of chemotherapy. Then a second surgery would be performed to see if there was any visible tumor remaining. If no tumor could be seen, then there would be three additional months of chemotherapy. The drugs that would be used were cyclophosphamide, adriamycin, and cis-platinum. These drugs have side effects including nausea and vomiting, bloody and painful urination, and decreased blood cell counts resulting in increased risks of infection and hemorrhage. Cis-platinum can cause serious, permanent loss of hearing in some patients, and adriamycin can result in congestive heart failure. Given the fact that this patient had metastatic disease, the oncologist believed that the chance of five-year disease-free survival with the experimental treatment was only about 15%. Nevertheless, she recommended the treatment because without it the patient was*

unlikely to survive more than six months. The parents appeared somewhat dazed and asked few questions, but signed the consent form. However, several days later the mother called to say that they would not return for treatment. They belonged to a small fundamentalist religious sect, and they had been reassured by their minister that their child would be cured by God if they showed faith in his power. The mother said that their interpretation of the Bible required them to rely on the Lord rather than physicians” (Strong 2000; pp. 402-403).

Again, it is the casuistic factors that are decisive for our ethical judgment, since survival chances in the short term are small, and the side-effects of treatment are rather severe. Parental authority seems to weigh up to the medical interest for the well-being of the child.

Now, the last step in this version of casuistry is to seek to compare these two paradigmatic cases to the original case. It appears that the original case is more similar to case 3 than to case 2, therefore seeking a court order does not appear to be a justified course of action. Whose intuition is at play here? Apparently, the comparison to case 3 rather than case 2 would not be embraced by the parents that figure in the original case. Is it society’s tentative conclusion Strong brings forward, or is it Strong’s own intuition? Or might it be that the construction of the two paradigmatic examples themselves already steers us towards a certain conclusion, whilst with the discernment of other ethically and casuistically relevant factors one can easily steer the argument in the opposite direction? This issue unfortunately does not get to be resolved within the method of casuistry as such. It leans heavily on an implicit embracement of intuitionism.

Casuistry is, to a certain extent, an alternative to principlism that has the problem of being unable to explain how general principles bear upon practical cases or practical judgments. However, casuistry still offers a method to show what cases are to be taken as paradigmatic and which aspects in a practical case should count as ethically relevant, and this method is again to be applied without it being specified how. There is no method of justification or selection to discern what elements of a case are ethically relevant and what elements are not, aside from the traditional framework of the Hippocratic oath, with notions of quality of life, best interests, preferences of patients and justice and so on. Nevertheless, these notions are too vague to steer one’s actions in a self-evident fashion. One can find a paradigm case to justify any option available. Because of this, the method threatens to revert to either stark intuitionism, or descriptions of mere regularities of our behaviour, rather than providing us with a proper justificatory instrument. One will have to lean on a more explicit picture of what moral intuitions are, and if or how they can be used as (the beginning of) a justificatory criterion.

Next to casuistry, there are several other methods that pose a priority of the practical life world. The most notable ones are ethical pluralism, ethical relativism and neo-pragmatism. In recent years, the latter has received the most attention in

bioethics. More than in casuistry, these approaches do not adopt the idea of a metaphysical dividing line between fact and value. Objectivity, from a neo-pragmatic perspective, always appears to be merely a pretension of objectivity that hides other presuppositions. This means that consensus between the different relevant parties, rather than ethical truth, should be the aim of ethics.

Neo-pragmatism, should, according to John D. Arras give sufficient attention to the richness and the pluralistic nature of the factual life world; and it should adopt an eclectic attitude to theories that at first glance seem to be incompatible. When one adopts this attitude, one is not obliged to opt for one specific method or theoretical basis. Since our life world is governed by inconsistencies too, one is not obliged to take a consistent ethical position. However, according to Arras (Arras 2001) one of the issues of specifically neo-pragmatism is that in renouncing any form of ethical theory, the pragmatist himself is still adopting the theories of Peirce, James, Dewey and the likes.

The oeuvre of Richard Rorty is one of the most clear-cut examples of neo-pragmatism. Renouncing any adherence to theory or universality forms the backbone of this approach. Rorty proposes an approach to ethics that he terms 'edifying philosophy'. Rather than basing itself in the presupposition of rationality or truth, edifying philosophy seeks to establish dialogue with no definite ends or answers as a new paradigm. According to Rorty, it attempts to invent new, interesting and fruitful self-descriptions. It tries to keep the conversation going, rather than being a systematic philosophy. In his book *Contingency, Irony and Solidarity* (Rorty 1989), Rorty tries to prove that edifying philosophy is the best type of philosophical approach for a liberal democracy. He does not back this up theoretically, but then, this would render his concept logically contradictory. Wolfgang Welsch, analyst and critic of post-modern philosophy and neo-pragmatism, analyses this relativist approach to philosophy in general and ethics in specific as follows:

"Conversational partners provide one another, at best, with stimulation and a basic encouragement: 'have the courage to develop a new, deviant description, one which might even seem mad at first'. But all processes of refutation, falsification, of argumentative discussion and clarifying dispute are eliminated. Hence it is to be expected that this results not, as Rorty says, in 'keeping a conversation going' (M. 378), but rather in the opposite: in the silting up of these conversations, in which nothing is really at stake, in peaceable conversational murmurs, in discursive entropy. Rorty's theory of conversations seems better suited to high-brow parlour talk amongst the educated and their inspiriters than to the business of philosophy. [...] According to him in some circumstances the edifying philosopher 'might just be saying something' (M. 371). This is what philosophy is supposed to be from now on. As prime examples Rorty even adduces Heidegger and Wittgenstein." (Welsch 2002)

The issue is that Rorty's allusion to a dialogue without necessity to reach conclusions or a definite consensus as the prime model for philosophy might be an interesting sociological or even psychoanalytical analysis of the history of philosophy, but that one cannot adopt it as statement of principle for philosophy itself. It either renders philosophy into a useless occupation, or it reverts implicitly to an adoption of truth claims anyway. As Welsch states:

“De facto of course, Rorty cannot help but raise claims to truth. The whole business of his critical explanations shows that in the context of edifying philosophy as well, one does not just say or accept arbitrary things. Besides which, Rorty himself once said the edifying philosopher ‘agree[s] with Lessing’s choice of the infinite striving for truth over “all of truth”’ (M. 377). This is something quite different to the straightforward abstinence from truth. On the other hand, Rorty thinks he can spare himself a clarification of his understanding of truth through the sweeping equation of the idea of truth with the adequation theorem. Recently he has been fond of declaring straightforwardly that truth is not an interesting subject for the pragmatist - something which permits no philosophically fruitful work.” (Welsch 2002)

The issue of neo-pragmatist approaches is that they do not truly offer guidelines or justificatory arguments for considered courses of action. Practices thus become their own guideline. In this way, one might be able to account for the factual richness of our life world or the pluralistic nature of society, but when for each case another norm becomes valid, justice will be hard to find. Therefore, neo-pragmatist approaches cannot satisfy practical demands either.

Both casuistry and neo-pragmatism seem methodologically sound, and they both seem to circumvent the problem of top-down interpretations. However, they cannot provide with a conclusive method to resolve ethical issues either. They cannot define a criterion of justification that is not ultimately self-defeating. These practical problems of top-down and bottom-up approaches reflect a deeper issue, one that has also been discussed in linguistic philosophy, Wittgenstein's later works in specific: the problem of rules and practices in rule-following. I shall devote the following paragraphs to this subject.

#### **4. The Problem of Rule-following: Issues of Meaning and Justification**

##### *i. Introduction*

In his later work (most notably the *Philosophical Investigations*<sup>33</sup>), Wittgenstein claims that meaning is not dependent of whether it represents true affairs, but by its use.

33 Originally published as *Philosophische Untersuchungen*.

Wittgenstein did not see how meaning was to be found in the 'external' world. After all, we can point to a certain object and make an infinite series of claims about it without this object in itself transforming into anything different. According to Wittgenstein, meaning is therefore generated in how we use words and concepts within a specific context, not in their reference to independently existing objects. Here, Wittgenstein made an important contribution to what came to be known as the linguistic turn of philosophy. It is a step away from the, often merely implicitly embraced, representationalist theory of language. Wittgenstein: 'Meaning just *is* use' - that is, the meaning of words is not determined by their reference to things in external reality, but rather by the context in which they are used in daily communicative processes. In paragraph 77 of the *Philosophical Investigations*, Wittgenstein states that a concept of *good* cannot exist independently of particular 'good deeds' (Wittgenstein 2001 (1953)).<sup>34</sup> Meaning is created solely within language, and not by its reference to reality. Language *creates* our perception of the world, and the meaning we attach to it, rather than passively mirroring it.

If meaning is created in linguistic use, it is dependent on our common, inter-subjective use of language. This means that language must be governed by some common norms. But the status of these norms is up for debate. If meaning is created in the relation between use and the norms this use seems to obey, these norms are defined as something outside of language use: the application of such a norm or rule is, in this perspective, necessarily guided by certain rules of interpretation. But how can one apply these rules of interpretation to the practice of applying the original rules and norms of language? Defining linguistic norms and rules as something outside of and above language itself leads us into a regression ad infinitum.<sup>35</sup> One cannot explain meaning either when one would see linguistic rules or norms as being completely accounted for within the use of language itself. In that case, language-use is merely a performance of regularities of behaviour; there is no rule or norm that accounts for meaningful content. This means one cannot properly define the relationship between linguistic rules and linguistic practices without a reductionist fallacy; one cannot show in what way language is governed by rules, but one cannot escape the notion of a rule either. Therefore, the conception of meaning as produced within language unfortunately creates new problems whilst solving an old one.

The problem of meaning that is created by looking at language as inter-subjective rather than referential was also perceived of by Wittgenstein himself. He derived his analysis of the problem from Kurt Gödel's two incompleteness theorems (Gödel 1992 (1931))<sup>36</sup> These theorems were the centre of a discussion in the

34 See *Philosophical Investigations*, paragraph 77.

35 This problem is a reflection of Aristotle's criticism on Plato's idealism.

36 When formulating the problem of rule-following, Wittgenstein did not merely lean on Gödel. He also seems to have leaned on G. E. Moore's arguments against reductions to either nature or divine law.

Wiener Kreis at the beginning of the 1930s. The centre of debate was whether one could derive a valid proof for a universally valid and complete logic. On the basis of the works of Gottlob Frege, Bertrand Russell and Alfred Whitehead had been working on such a proof, but Gödel proved that one fundamentally could not derive a valid argument to support a logical system within the language of such a logical system, even though it would only be valid if one would. Wittgenstein's theories on rule-following relate to this issue, since the problem of rule-following also demonstrates that one cannot incorporate a rule within the praxis on which it is to be applied, but that one cannot see a rule as loose-standing either.

On a purely linguistic level, the problem of rule following can also be phrased in a different way: apparently we are able to understand each other when we are communicating. Since we understand each other, language apparently has rules, which are followed in its usage. But how can we have a grasp of meaning without a grasp of these rules? And alternately, which rules are actually applied in our usage of language? It seems that we can use whatever rule we want to account for our linguistic practices. And then still, how are we able to know these rules without already having learnt language? How do we know whether we are using language correctly or not? Or in ethics, how do we know whether what we do is justified or not? In other words: how can one understand each other and our common language without having read a book on grammar? But conversely, how would one be able to read a grammar book if one had not been able to grasp that language yet.

In trying to define the relationship between rules and practices, either one reverts to a failure to derive a rule from a practice, since one can define infinitely many rules to account for a specific practice, or in trying to see what practice a rule accounts for, one will always need another extra explanation to show what the rule actually means and how it should be applied. This issue was elaborated upon by many and also had its roots in the works of others. I shall discuss three philosophers, Kripke, Moore and Brandom, and show in what way their view on this issue is related to problems of methodology in bioethics. Although Kripke and Brandom's preoccupation with the problem of rule-following is quite obvious, Moore has not been associated with it. Nevertheless, his distinctions show a definitive parallel to the problem of rule-following.

## *ii. The Monster of Kripkenstein*

Wittgenstein's issue with rule-following was later elaborated upon by Saul Kripke. In his paper *Wittgenstein on Rules and Private Language* (1982), Kripke states: "the present paper should be thought of as expounding neither 'Wittgenstein's argument nor 'Kripke's: rather Wittgenstein's argument as it struck Kripke, as it presented a problem to him". This is the reason why the views expressed in this paper also got to be known as the 'Kripkenstein-problem of rule-following'. The Kripkenstein problem puts forwards several sceptical challenges to the idea that following a rule can be shown by demonstrating the correct practices. Although discussion on this

issue is of a highly theoretical nature, its implications might serve to clarify some notions of the methodological debate on 'top-down' and 'bottom-up' approaches in bioethics.

To illustrate Wittgenstein's problem of rule-following, Kripke took the example of the difference between + and what he calls, quus (Kripke 1982; pp, 7), or between addition and quaddition. Plus is the normal addition, quus is the same, for any outcome smaller than 125, if higher, than the quaddition always amounts to 5. If one has grasped the rule of addition, this is supposed to show itself in how an individual is able to add in any new situation with any new numbers. However, in demonstrating this skill, it is not clear at all whether they have been grasping the rule of addition or the rule of quaddition. This also applies to demonstrations above 125. It is specifically the idea of demonstrating as grasping, the so-called dispositionalist thesis, which Kripke attacks. Kripke:

"Suppose I do mean addition by '+'. What is the relation of this supposition to the question how I shall respond to the problem '68 + 57'? The dispositionalist gives a *descriptive* account of this relation: if '+' meant addition, then I shall answer '125'. But this is not the proper account of the relation, which is *normative*, not descriptive. The point is *not* that, if I meant addition by '+', I shall answer '125', but that, if I intend to accord with my past meaning of '+', I *should* answer '125'. Computational error, finiteness of my capacity, and other disturbing factors may lead me not to be *disposed* to respond as I *should*, but if so, I have not acted in accordance with my intentions. The relation of meaning and intention to future action is *normative*, not *descriptive*.

In the beginning of our discussion of the dispositional analysis, we suggested that it had a certain air of irrelevance with respect to a significant aspect of the sceptical problem -- that the fact that the sceptic can maintain the hypothesis that I meant quus shows that I had no *justification* for answering '125' rather than '5'. How does the dispositional analysis even appear to touch this problem? [...] Precisely the fact that our answer to the question of which function I meant is *justificatory* of my present response is ignored in the dispositional account and leads to all its difficulties." (Kripke, 1982; pp. 37).

The sceptical problem referred to by Kripke is that we have no means of knowing when we are using plus and when quus by showing we are in the disposition to do so. To put it differently, dispositionalism cannot discern between when a rule is followed correctly and when incorrectly, since in practice itself it is not clear what rule is being followed. Suppose we were to refer to something with the word table. If we apply it to something else than a table, dispositionally speaking, we might just be correctly using a new meaning of that word rather than using it incorrectly. Whether we are following a new rule or merely making a mistake under the old one is not clear in our usage alone. If I were to say that 68 and 57 add up to

125, I might have been adding, but I might also have been mistakenly quadding, or applying yet another rule that is similar to addition and quaddition in the situations I have been demonstrating. The sceptical challenge is that

- I mean to add when doing +, but the relation between + and that this means addition is unclear.
- There is no means to show that when I did +, I was performing something that was an addition, a quaddition or something entirely different.

The fact that one demonstrates the correct or the incorrect phenomenological behaviour in itself does not show an understanding of the rules involved. That depends on the rule involved.

Kripke lists several claims to solve this meaning-scepticism, and refutes them all by putting forwards sceptical challenges that are variations of the two mentioned above. They all amount to the issue that it is impossible to prove that we can grasp a rule that is applicable on infinitely many cases by demonstrating them in a finite fashion. I shall name the most important ones:

One might claim that in demonstrating to be in the disposition to give proper answers, I show to have grasped a rule. I shall refer to this claim as claim 1. To this claim, Kripke puts forwards three sceptical challenges:

- *The challenge of Error*: Of course, we will sometimes make mistakes in addition. But then, how do we know we have made a mistake, instead of having applied just another rule?
- *The challenge of Finitude*: The totality of my dispositions as such is limited. This means that we cannot grasp certain numbers. Still, addition applies to other numbers as well. So how can we be sure to grasp the rule of addition and not another rule, if we do not and cannot apply it to all possible numbers?
- *The challenge of Normativity*: If I do grasp what addition means, this does not indicate itself in that I respond with 125 when asked to add 68 and 57. Grasping a rule means that I *ought* to respond with 125, apart from whether I do.

The challenge of *Error* is that in supposedly performing erroneously, we might actually have been following an alternative rule. The challenge of *Finitude* refers to the idea that if one has a series of examples that supposedly follow a certain rule, one can make up infinitely many alternative rules to account for these examples as following them. Thus, the sequence 1, 3, 5 might be continued with 1, 3, 5, 7, 9 etc., but also with 1, 3, 5, 11, 13, 15, 21 etc. In any finite set, it is not clear what rule we are following on the basis of practical demonstrations alone. The challenge of *Normativity* on the other hand, is that if one takes a rule like ‘add 2’ one will need to

know what '2' is and what 'adding' is, but that I know this is not demonstrated in any finite list of practical behaviour.

To take a classical example from ethics: giving alms to a beggar can be accounted for as following the rule of charity, of equality (by trying to equate societal inequalities), of autonomy (to render a beggar more financially independent) etc. In what I do, it is not shown which of these rules I am following (*Finitude*). I might even be following a totally different rule incorrectly (*Error*). Alternately, if one were to take one of these rules, for example, that one has to equate society's inequalities, this can be done in different manners. It can be done by giving alms to beggars, but perhaps it should be done by refusing them alms, which might induce them to find a job and fend for themselves. In doing either of these, it is not shown I have grasped the norm of equality (*Normativity*).

Principlism seems to have stumbled upon the issues associated with claim 2c. After all, principles are derived from what seem to be universal intuitions. But how can an intuition as such be a basis of justification for embracing it. Casuistry suffers from this same problem in its embracing of specific paradigmatic cases, rather than other ones on the basis of intuition alone. And neo-pragmatism seems to suffer from every problem associated with dispositionalism. It reverts to the practice of acting and speaking alone, but from that practice itself, it is not clear whether one is acting or speaking just, since one might have been following any rule.

Another counterclaim one might put forward from a dispositionalist's view is that in demonstrating correct examples of addition I have shown to have been applying certain algorithms that single out 'addition' as what I was doing. I shall call this claim 'claim 2'. To this claim, Kripke puts forward the sceptical challenge that this is merely giving a rule of interpretation for the original rule, carrying along the same problem of demonstration not being proof of a correct grasping of that rule.

As we have seen in the previous paragraph, in principlism, the problem is also that further rules of application and interpretation (balancing to a reflective equilibrium and specificationism) would have the same problem as Kripke's dispositionalist defending his views by adding in more rules of interpretation. As said, by inserting specifications one merely wedges in another version of the original problem. The rule in itself cannot be its own justification, but one cannot formulate yet another rule behind the original rule that demonstrates why the original one is justified. And practical demonstrations do not show what rule we will have been following. This only duplicates the original problem. Dispositionalism surfaces in a number of ethical theories in a variety of ways. The issue here is not whether an ethical theory can state a certain moral content, but that in approaching ethics as a form of rule-following, it fails to show how one should follow a rule or which rules should be followed when.

*iii. Brandom, Ethics and Rule-following: the Puppet and the Puppet master*

The American pragmatic philosopher Robert B. Brandom analyses the problem of rule-following from a different perspective. On the basis of the problem of rule-following, he poses two extremes in thought on the place and function of rules, in the problem of meaning, both of which fail to accommodate for the normative. The one he calls regulism, or rule-reductionism, the other regularism, or reductionism to regularities of behaviour. These two extremes can be compared to principle-based approaches in ethics on the one hand, and practice-based approaches such as casuistry and neo-pragmatism on the other, although one should keep in mind that rules in the context of linguistics pertain on states that 'ought to be', whilst in ethics they pertain on 'ought to do'. Regulistic approaches prioritise the rule above the practice. The rule is supposed to steer the praxis. In regulism, rules are seen as aprioristically given, whilst the correctness of their application is taken to be given within those rules. How one should act, is to be derived deductively from these rules. For ethics, moral agency is thus reduced to merely a correct following of a rule. This means the rule functions like a puppet master who is controlling a puppet. The problem of this deductive perspective on the relation between ethical rules – or principles – and practices is that it cannot account for the existence of 'wrong' decisions, since they would all have to be reduced to logical errors. Furthermore, what is supposed to be a rational act is reduced to the mere automatic following of a rule.

In regulism, the rule is considered as a given a priori to social practice, and the correctness (or incorrectness) of a certain way of speaking or acting would follow from this aprioristic rule. In this respect, Brandom analyses the same problem as Kripke, although Kripke aims his arrows at dispositionalism, departing from the impossibility of departing from performances, whilst Brandom analyses it from the point of view of those norms that cannot be made explicit as guiding practices without the possibility of guiding any practice. Although the rule in itself might seem clear enough, one cannot derive from that rule itself how it is to be applied, how to go on in practice: as with Kripke's issue in 'claim 2', the problem gets duplicated on another level. In Kripke's case, demonstrations of a practice of interpretation, as from a practice of application, fail to show how a rule is followed; whilst in Brandom's case, departing from an explicit rule of interpretation, as from an explicit rule in general, fail to account for their correct or incorrect application. Next to the correctness or incorrectness of a rule, there would also be a correctness or incorrectness of its application. That would mean another rule should be formulated to guide the application from rule to social practice. And if there is a rule to guide the interpretation of principles (rules) to social practices, this rule could also be applied incorrectly, which again means an additional rule to guide this application should be formulated. This leads ultimately to a similar *regressio ad infinitum*, time and again drawing the normativity problem back in.

The normative cannot solely stem from a rule, as far as one sees rules as loose standing from practice. As Joseph Heath states in his paper *Brandom and the Sources of Normativity*<sup>37</sup>:

“The regress [ad infinitum] arises because of the assumption that norms originally reside in ‘principles’, and are applied to ‘practices’ only secondarily. The issue is then that one can never get from principles to practices – more principles always seem to be required.” (Heath 2001; pp. 4, translated version)

The issue of the correctness of applying a rule was also signalled by proponents of principlism. Hence, they sketched several methods to bring different rules and rules and practices to accord with each other. But such methods seem to be in need of a rule of application just as well as the original rule or principle. One has attempted to solve this question in two ways: one has opted for a method of balancing principles amongst each other in the interpretation to a certain practical dilemma (Beauchamp and Childress 2001), the other for a method of specification to a certain practical dilemma (Richardson 1990; DeGrazia 1992; Richardson 2000; Beauchamp and Childress 2001). The problem is that neither of these approaches shows in what way one should balance or specify. Although the rule in itself might seem comprehensible enough, how and when to apply it remains unclear on the basis of that rule alone: although it might be clear what the rule states, it is not clear how one should apply it. The four principles, as stated in their original generality, seem to cohere with most people’s belief-systems. Principlists base the derivation of their universal principles on intuition. Both the method of specified principlism and balancing principles also lean heavily on an implicit intuitionism. And there seems to be no third way in between either this type of intuitionism or a deductive conception of the relationship between principles and practices.

Beauchamps and Childress’ method seems to hop from the one to the other, posing an intuistic derivation of their moral principles, but a handicapped deductivism to their application. Why would the intuition people apparently have sufficient justification for their acceptance? Principlism here suffers from another side of the dispositionalist’s problem. One cannot justify the usage of a principle in a certain case through specification, but one cannot do it by looking at the intuitions people apparently have either. Because if one’s intuition would have been different, a completely different principle (of, let’s say, maleficence or non-beneficence) would have to be accepted as well. Intuition alone bears the same problems with it as regularism. One cannot reduce the meaning of linguistic content, or the justification of some act or another on the basis of regularities of behaviour, sentiment or intuition alone. Furthermore, nothing shows that in practice one is actually following either of any principle. The same goes for casuistry. It is not clear how to apply

37 Originally published as *Brandom et les Sources de la Normativité*.

the paradigmatic case to the problematic case one has at hand. It is to serve as a guideline, but something additional always seems necessary to demonstrate how.

Regularistic approaches try to circumvent this issue by taking the practice as a basis of meaning and normativity, but without extrapolating general rules from that normativity. The normative thus gets reduced to regularities of behaviour, and the moral agent turns into a mere puppet, without a puppet master pulling the strings, or, to carry this metaphor further, the puppet's strings are attached to its own hands. In the extreme, regularistic approaches to the problem of rule-following emphasise what factually happens rather than the reflection on this actuality. There are only puppets, and no more puppet masters, a perspective that is untenable for an ethicist, since factual ethics does not exist. Rules are not free-standing they do not exist in some type of metaphysical realm outside of the reality on which they bear. Norms are completely implicit in social practice. Regularism goes beyond Kripke's challenge of Finitude: as with the problem of Finitude, in regularism one cannot unambiguously derive the rule that accounts for a practice from that practice in itself. There are infinitely many rules one can define to account for a practice. But a further consequence of regularism is that it embraces the idea that every practice has its own rule, rendering the notion of a rule as such redundant. As Joseph Heath poses:

“The problem with regularism, according to Brandom, is that it loses sight of the distinction between what *is* done and what *ought* to be done. In other words, it loses sight of the properly normative dimension of social norms. One symptom of this difficulty – and a crucial objection to regularism – is the problem of gerrymandering. For any finite batch of behaviour, one can dream up an arbitrarily large number of rules of which that behaviour would be an instantiation. As a result, when presented with a form of behaviour that appears to deviate from a rule, it is always possible to generate some other rule, with which that behaviour would be consistent.” (Heath 2001; pp. 5)

Rules cannot be seen as standing apart from the practice they apply to. However, to reduce these rules completely to that practice would also cause problems, because that would lead to a reductionism to the mere regularities of social practices (Brandom 1994; pp. 7). Although solving some issues of principle-based approaches to ethics, both casuistry and neo-pragmatism suffer from a disadvantage that does not appear to be connected to the problem of application in principlism, but on closer inspection appears to be its mirror image: whilst issues of interpretation in principlism reflect the normativity problem, thereby being a regulistic fallacy, it is the sceptical problem of Finitude that is reflected in approaches neo-pragmatism and to a lesser extent casuistry, thereby being a regularistic fallacy. If one starts from a practical case scenario, one can either see such a scenario as ethically justified or not, on the basis of an infinite number of rules. The practical scenario itself does

not provide us with a proper means to go on. When one tries to avoid the problem of regulism by reverting to the practice itself, one cannot but go back to one form or another of regulism, except when one reduces everything to the factual practical case at hand. But in moving to such a reduction to practicalities, any form of agency gets to be reduced to mere regularities of behaviour. All good and well from a psychological, sociological or socio-biological perspective, but it does not serve to explain why we ought to act in one way or another. This move fails to explain justification as such.

Neo-pragmatism can also be considered to be the (bio)ethical version of Kripke's dispositionalism, and it is affected by the same problems. Neo-pragmatists take the view that grasping morality merely consists of demonstrating a disposition to behave in a certain fashion. However, any behaviour can be made to accord with a rule, so in the end, no behaviour can be said to be unjustified. Abolishing the notion of a rule makes us leave the realm of ethics entirely. It leads to a reduction of the normative to the factual, and in this respect, there is no normativity to be found, merely things behaving in a certain arbitrary fashion. This behaviourist consequence of neo-pragmatism cannot function as a guideline for our actions. To consider it to be an ethical theory would be fallacious. Principlism is fallacious because of a problem of interpretation and justification; neo-pragmatism and casuistry are fallacious because of a problem of justification. When not extrapolating anything like a rule, one gets no further than descriptions of regularities, there is no division between rule and action. This brings along the dispositionalist problem that Kripke centred on. The regularist sticks to what actually happens, but is not able to derive any normativity from that factual description.

#### *iv. Rule-following and Methodology in Bioethics*

Seen from the perspective of the problem of rule-following, some ethicists like to adhere to the notion of aprioristic intuitions as a base for rules, thus presupposing a top-down ethical theory based on the unsteady soil of a bottom-up intuitionism. Others prioritise the practice and leave the notion of a free standing rule behind, but in such a way that contingency gets the upper hand. These approaches run the risk of ethical nihilism. Most try to stay somewhere in the uneasy middle ground between the extremes, but without providing for a good explanatory device for the problematic dualisms of theory and practice, rule and implementation, normativity and facticity, and all seem to revert to an uneasy foundation of intuitionism. Bioethics therefore runs aground in defences of positions on the basis of epistemological arguments, whilst the ethical practice of communication and action is neglected. Discussions on the level of reality are left behind in favour of discussions on the level of the preconditions of dealing with it. These discussions of a more secondary nature do not serve to clarify much. Both top-down and bottom-up approaches suffer from the problem of rule-following. Rules or principles can be brought to bear upon any specific practice, whilst a specific practice could be

accounted for by infinitely many rules. The latter issue also counts for bottom-up approaches, as far as they come to pose rules or principles at all.

On the one hand, in top-down approaches, rules seem to float in a transcendental space, in which following such a rule is taken for granted, on the other hand, bottom-up approaches merely seem to point at regularities of behaviour rather than ethical justifications. One might factually assert that such regularities are an expression of implicit moral values, but this is not taken into consideration as to the justification of the regularities described. The main question is, how can one steer in between this Scylla and Charybdis of regulism and regularism? For any attempt to combine top-down and bottom-up approaches has us ultimately revert again to either; thus dragging their associated epistemological issues back in.

## 5. Brandom and Inferentialism: a Game of Chess

The occurrence of regulistic and regularistic reductionism in practical ethics stems from the very idea of a method of ethics. Rules, norms or principles cannot be seen as loose-standing from social practice, but they cannot be seen as fully immanent, fully integrated in that practice either. The relation between principle and practice cannot be explained as a one-directional relationship, as if we were speaking about cause and event. But to do away with the notion of rules, principles or norms altogether could not solve the problem of regulism without invoking the problem of regularism. Normativity should be looked for within the social practice. In so far as there are rules or principles, they should be considered as part of these social practices.

According to Brandom (1994), there is neither a line from principle to practice nor is there a reciprocal relation between the two. Instead, Brandom posits that there is a line from social practice to principle. The genus of a rule is not *a priori* to social practice, but is implicit in that practice. What linguistic practices consist of is a set of negotiations, in which we keep track of each other's commitments and entitlements. One will still need to describe what it means for norms to be implicit in practices (Heath 2001; pp. 5).

Brandom bases his conception of linguistic content on inferences: a so-called inferential semantics (rather than referentiality). Brandom's notion of inferentialism, proposed in his *Making it Explicit* (1994), can be used to clarify some issues on rule-following in the field of ethics. The position he takes, holds that one has to take the pragmatics of speech acts as the basis for language, rather than what linguistic content is supposed to refer to. He tries to escape nihilist criticism, not by reverting back to theory but by specifying the source of meaning as something that takes place in practice:

“[...] an expression comes to *refer by* being employed in a certain way within a specific kind of human (normative) practice. Variants of this answer were tabled by Immanuel Kant, Ludwig Wittgenstein, and recently by Robert Brandom. Brandom, in particular, suggested that even in the case of empirical terms and their referential capacities, it is still the *inferential articulation* which is crucial.” (Peregrin 2004; pp. 8, translated version)

In spite of obvious parallels, Brandom only grudgingly refers to Wittgenstein, although he does follow Kripke in several respects:

“Brandom follows Kripke in claiming that a naturalistic account in terms of dispositions to behaviour is not able to solve the problem of rule following: according to Brandom, any dispositions can be specified in infinitely many ways (pp. 26–30). Furthermore, Brandom, like Kripke, argues that assuming meanings beyond the spatio-temporal realm does not solve the problem of rule-following either: according to Brandom, these meanings would be explicit rules; instead of these meanings being able to guide our actions, we would end up in an infinite regress of rules (pp. 18–26). The alternative to both a reductionist account of rule-following and an account that reifies rules is, in the light of Kripke as well as in the light of Brandom, a pragmatic account in terms of social practices. Social practices are necessary in order to (a) select for a person one of infinitely many meanings in a finite sequence of examples or of actions and (b) enable a person to have a distinction between correct and incorrect rule-following at her disposal.” (Esfeld 1999; pp. 335)

According to Brandom, the ethical or the normative, is not brought into practice from outside or above the social practice itself. But the world of social and linguistic practices is not ethically neutral either. It already contains normativity. One cannot abolish the notion of a rule. Rules, principles and guidelines play an important role. Normally they are regarded as being premises to certain praxis of (speech) acts, but according to Brandom they should not be regarded as aprioristic to and standing apart from social reality. As such, they cannot influence this social reality.

If one wants to safeguard a notion of normativity that reverts to neither of the two reductionisms mentioned, one will have to show how one does not necessarily have to distinguish strictly between rules and practices that answer to those rules. We have the ability to give reasons for our actions. All of these attempts to retain a conception of social practices that is consistent with the notion of human agency aim at a circumvention of reductionism to either behaviour or empty transcendentalism. How can one avoid both rule-reductionism and reductionism to practices? How can one maintain a conception of norms that does not ultimately revert again to either? This is only possible when one posits that norms are implicit in practice, without reducing them completely to that practice. In that sense, practices implic-

itly follow a norm that does not steer those practices *a priori*, or as a predicate to those practices.

This conception of social practices has a parallel in sociology. In Antony Giddens' conception, social practices are not merely the following of an *a priori* rule either. Giddens demonstrates this on a more sociological level in his *Modernity and Self-Identity*:

“All human beings continuously monitor the circumstances of their activities as a feature of doing what they do, and such monitoring always has discursive features. In other words, agents are normally able, if asked, to provide discursive interpretations of the nature of, and the reasons for, the behaviour in which they engage.” (Giddens 1991; pp. 35)

These reasons should not be seen as a predicate to one's behaviour in the form of an *a priori* norm, but rather as something that can be potentially given when asked for. But in general, these reasons are only implicitly present in social practice. The relation one has to oneself should not be seen as fixed. It rather is a process of giving reasons by making them explicit for one's acts and utterances, thereby creating meaning. In one's social practices and the motivation for such actions, the motivation does not have a bearing on one's actions in an aprioristic or predicative fashion. The rule one takes of one's actions should not be seen as a predicate to one's actions, but rather as something that is implicit in one's actions and can be given explicitly when asked for:

“Most forms of practical consciousness could not be ‘held in mind’ during the course of social activities, since their tacit, or taken-for-granted qualities form the essential condition which allows actors to concentrate on tasks at hand.” (Giddens 1991; pp. 36)

Giddens supposes that whilst entering into social practices, one is not consciously preoccupied with motivating one's actions, but this does not render our actions merely to automatic behaviour either. If one takes this position, one also pulls along in one's tracks the question of how a motivation for an action and an action are inter-related

Brandom, in his criticism of the linguistic philosopher Davidson, offers a solution. Brandom considers three forms of practical reasoning (Brandom 2000; pp. 84ff):

- Only opening my umbrella will keep me dry, so I shall open my umbrella.
- I am a bank employee going to work, so I shall wear a necktie.

- Repeating the gossip would harm someone, to no purpose, so I shall not repeat the gossip.

In all three, 'shall' signifies a practical commitment. According to Davidson, the way these practical commitments are inferred is that they follow a more general rule, such as:

- Let me stay dry.
- Bank employees are obliged to wear neckties.
- It is wrong to harm someone to no purpose.

According to Brandom, it would be more fruitful to treat the three general rules not as suppressed premises but as the explicit versions of what is implicit in practical reasoning. In that sense, as Aristotle already suggested (and it has been held as such by many, amongst others Immanuel Kant), ethics counts as *practical* rather than theoretical reason. Wittgenstein also refers to a similar position. And, in the words of the Canadian philosopher Burbules:

“In this epistemology, Wittgenstein made it clear that following a rule is not just a matter of mimicking a particular behaviour from one situation to another. Though we follow rules, they cannot be fully made explicit; it is always necessary to take into account all the elements of the new situation one finds oneself in, which implies, among other things, communication, dialogue, and above all commitment. One can only be ‘certain’ of the frame of reference itself; this is part of the life we have inherited, not the result of systematic (rational) teaching. When one has learned to follow a rule, Wittgenstein says, this is manifested only in the claim ‘Now I know how to go on’, which is a *performative ability*, not a rationally articulatable understanding (Wittgenstein 2002 (1953); pp. 151 and 179).

Wittgenstein’s ideas concerning particular epistemological positions and language have far-reaching implications for the domain of ethics. To say that the meanings of ‘good’ or ‘right’ are not once and for all determined, does not imply that it does not matter what we do. But convincing someone on the ethical level is, for Wittgenstein, not (simply) a matter of giving them reasons. It is more like a practice in which other people are interactively involved. Here again he draws our attention to the importance of context and to how one has *learned* to use concepts like ‘good’ and ‘right’. Because of the fact that every context is necessarily particular I am answerable for what I do. There are no ultimate foundations.” (Burbules 2002)

Wittgenstein’s strategy to the problem of rule-following can be illustrated by the distinction between constitutive and regulative rules. Regulative rules govern an

activity that can exist independently of the rule involved, whilst constitutive rules are constitutive of that activity. In the game of chess for example, one can open with a Sicilian defence or a French defence, and these opening moves imply certain specific countermoves. Although one can reply in a different way from the expected moves, one would still be playing chess. Such moves that either follow or do not follow the pattern of a Sicilian or French opening are a matter of regulative rules. Constitutive rules concern something different. In the British television series 'Bottom', Rick Mayall and Ade Edmondson as the main protagonists Richie and Eddie, two roommates doomed to live with each other in a decrepit apartment, decide to play a game of chess with Richie's antique chess set. There are only a few pieces left, so they replace the missing pieces with frozen prawns (rather than pawns), a cactus, a ketchup bottle, a spiderman action figure and a plastic skeleton. Just as they are about to start playing, Richie decides to use the different pieces to shoot at the enemy whilst making machinegun noises. It is obvious the constitutive rules of the game are ignored here. Whatever they are playing, it is not a game of chess.

Indeed, constitutive rules instigate a praxis in which some statements and acts would be valid, and others would not, whilst regulative rules regulate the different statements and acts within that practice. In that sense, one should not look upon the rules by which one can discern between ethically justified and ethically unjustified actions as constitutive, but rather as regulative. The constitutive rules say what counts as a moral action as such (going to the toilet or brushing one's teeth does not belong to that realm, nor does smoking a cigarette, although in the past few years a categorical mistake seems to be made in this respect), whilst regulative rules state what counts as more and what counts as less justified. To know the regulative rule stating what a Sicilian opening is, means that one also knows the constitutive rules of what playing a game of chess means. And this is something that arises from the practice of playing chess rather than the other way around. The rules might exist, but grasping them is not something that happens *a priori*, one can make them explicit *a posteriori*.

These explicit versions are not to be seen as necessary rules that guide practical reasoning, but rather as ways to open up the debate. In playing the game, one appears to have grasped the rule, but this is something which comes out of a mutual agreement. This is how one accords with both the different possibilities after a Spanish opening and on the rules of the game itself. One can create new rules: in football, the offside rule was invented after the game of football. And new games are invented too. But most of the time one will embrace the game as it is, and within that game one can follow different strategies. These are not followed as if the rules were there *a priori*, they are embraced and practiced during the game. I shall give an example, whilst referring to Dan-Cohen, who makes a similar point when talking about the distinction between willing and choosing.

As discussed in chapter IV, Dan-Cohen replaces the paradigm of choice with a paradigm of willing. The failures of the choice-paradigm run parallel to Brandom's regulism. When one embraces the paradigm of choice, one cannot demonstrate in what way different options are to be ranked. This is because in this paradigm one views the process of ranking as something that can be done with issues/things relative to each other on the basis of some sort of rule. Applying such a rule brings with it several questions. The valuation in willing something is not a ranking of options in relation to each other, but is specific to the object one wills. Furthermore, Dan-Cohen states that willing is not preference-based, but value-based. This means willing does not imply a comparative valuation (or a relative valuation), it takes the value of its object in itself. Willing (Dan-Cohen 2002) does not imply a choice set, it merges the object of attention and the act of valuation. Now, the choice-paradigm implies that one is continuously conscious of the motivation one has for an action, whilst the paradigm of willing does not. So, in willing, it is implied that one can make explicit what the motivation is for a certain action, but that it is not already a priori explicit.

Practices have an implicit normativity. One therefore needs to give priority to the social practice, but without leaving its normativity as merely implicit. This implicit normativity needs to be made explicit, through dialogue and critical assessment of the inferences in that dialogue. Such a strategy would resolve the Finitude problem and the normativity problem, since it neither reduces the content of justification to mere practices nor poses a set of finite rules, the application of which remain unclear. This way, through a mutual scorekeeping of the consistency of each other's utterances, what was already implicitly present in social practice can be made explicit. This means that the standard model of premise-conclusion can also be turned around. In which case, rules follow from practices, they do not precede them. The aim of universal solutions is thereby reduced to the process of debate itself, in which the different parties are challenged to put their own beliefs on the table and they are entitled to criticise the beliefs of the other parties.

Brandom bases this process of making explicit the implicit normativity in (social and linguistic) practices on the model of dialogical communication. In communicative processes, one ascribes certain meanings to what another person is stating, and one is ascribed certain meanings in the same game. To steer between the ascriptions that one makes oneself and the ascriptions the other person makes can be seen as a reciprocal 'deontic' score-keeping. Score-keepers do not construct theory, they merely keep track of the commitments and entitlements they themselves and the other person holds. On the basis of consistency, dialogue-partners have the right to state certain things, but they can also be held responsible for what they state. In essence, this is what 'understanding a language' means. In this sense, meaning is not dependent on a type of reference to an external world of facts or objects, paralleling it, but of inferences that are built up from such a mutual score-keeping.

I shall take an example that follows Dan-Cohen's conception of subject-responsibility: Suppose my son accidentally kicks a football through the kitchen window of my neighbour. In this case, I as a father am not to blame directly for the incident, since I am not causally implied in it. Whether I take responsibility or not depends on what stance I take towards my neighbour. On the one hand, I can apologise to my neighbour and pay for the broken window, since it is my son over whom I have responsibility. But suppose that my neighbour, in the last neighbourhood meeting, voted against a planned playground and because of this, my son and other children in the neighbourhood do not have any place to play, I could also tell him that the football that went through his window is, at least in part, his own fault. In both cases, I would not be following a general ethical rule in my practical reasoning. Taking the second scenario, when forced to in a discussion with my neighbour, I would need to make explicit my motives to not pay for his broken window. In this way, they would be up for debate, subject to challenge and justification. I do not need a rule that I appear to have been following in my actions, I merely need to be able to make explicit the motives and reasons that guided my actions; thus they are up for debate.

Brandom's inferentialism offers space for an account of agency that neither reverts to the pseudo-Kantian<sup>38</sup> concept of agency, nor to a naturalistic account of agency as regularities of behaviour. It does not need to, since it does not revert to the idea that there is a rational nucleus that holds contingent traits, nor to the idea that there are only such contingent traits which are determinative of our behaviour. The morality that is implicit in this inferentialist account of agency is a morality of giving the other person the communicative space to offer reasons for his actions. They do not belong to the natural world. As Brandom puts it:

"Norms (in the sense of normative statuses) are not objects in the causal order. Natural science, eschewing categories of social practice, will never run across commitments in its cataloguing of the furniture of the world; they are not by themselves causally efficacious-any more than strikes or outs are in baseball. Nonetheless, there are norms, and their existence is neither supernatural nor mysterious. Normative statuses are domesticated by being understood in terms of normative attitudes, which are in the causal order." (Brandom 1994; pp. 626)

One can derive a conception of agency from Brandom's inferentialism as something in which one becomes entitled to act and hold beliefs and commits oneself to these beliefs. This being entitled, and entitling others and committing oneself, and holding the other to his commitments offers the person the space to be an agent in a reciprocal fashion. This space is not given when one takes the position to dispose of those reasons oneself. Merely where one can reasonably assume that any future

38 Especially the interpretations of Kant that are specific to Anglo-American philosophy.

person will embrace these reasons, one is entitled to intervene in reproductive process to decide upon certain traits, or the absence of certain traits relevant to the existence of that future person. Otherwise one has to give voice to this future person to make such decisions himself, wherever possible.

In such a game of a reciprocal giving of reasons and committing oneself to them and being entitled to the reasons the other person has, one also constitutes a certain picture of the other person. One would need to take him to be more than merely an automaton, behaving according to the way his biology steers him. This does not mean that an agent follows rules as if he stands apart from his world either. One does not conduct one's life as a puppet master, nor is one a puppet of one's biology. Being an agent means that one is situated in a specific life world, that one has a certain background in one's life history, biology, culture, language, etc., and these form the conditions on the basis of which one can prefer something over something else, rather than forming restrictions on one's freedom. In dealing with other people it is this aspect of human existence that needs to be respected.

## 6. M(o)re problems with reductionism

When formulating the problem of rule-following (Chapter VI), Wittgenstein did not just lean on Kurt Gödel's theories. He also seems to have leaned on G. E. Moore's arguments against the aforementioned reductions to either nature or divine law, the 'naturalistic fallacy', and the less well known 'metaphysical fallacy'. The connection does not appear to have been made in philosophy, since Wittgenstein goes into the problem of rule-following from a background of logics and linguistic philosophy, whilst Moore went into the problem of reductionism as part of moral philosophy. The parallel does not become obvious except if one describes the problem of rule-following as a question of two types of reductionism, as Robert Brandom did. Still, it is not unlikely that Wittgenstein's thoughts on rule-following were influenced by Moore's ideas, since they both worked in Cambridge and commented on each other's work.

Wittgenstein seems to have applied the philosophical structure of both Moore's fallacies to the problem of meaning with regard to linguistic content. In his *Principia Ethica* (1903), Moore demonstrated that if one reduces ethics to the mere performance of natural behaviour, one cannot explain what type of behaviour is ethically justified. Similarly, reductions of ethics to metaphysics, to some type of externally given divine law, cannot be taken to steer moral judgments self-evidently either. In both cases, one can always ask the question, 'yes, but is it a good thing that we follow x as pattern of behaviour or is it a good thing to embrace x as a rule for our behaviour?'. This sceptical challenge was termed the 'open question argument'. It is phrased by Moore as follows:

“[...] it may easily be thought, at first sight, that to be good may mean to be that which we desire to desire. Thus if we apply this definition to a particular instance and say “When we think that A is good, we are thinking that A is one of the things which we desire to desire,” our proposition may seem quite plausible. But, if we carry the investigation further, and ask ourselves ‘Is it good to desire to desire A?’ it is apparent, on a little reflection, that this question is itself as intelligible, as the original question, ‘Is A good?’—that we are, in fact, now asking for exactly the same information about the desire to desire A, for which we formerly asked with regard to A itself. But it is also apparent that the meaning of this second question cannot be correctly analysed into ‘Is the desire to desire A one of the things which we desire to desire?’: we have not before our minds anything so complicated as the question ‘Do we desire to desire to desire to desire A?’ Moreover any one can easily convince himself by inspection that the predicate of this proposition - ‘good’ - is positively different from notion of ‘desiring to desire’ which enters into its subject: ‘That we should desire to desire A is good’ is not merely equivalent to ‘That A should be good is good’. It may indeed be true that what we desire to desire is always good; perhaps, even the converse may be true: but it is very doubtful whether this is the case, and the mere fact that we understand very well what is meant by doubting it, shows clearly that we have to different notions before our mind.” (Moore 2002 (1903); pp. 166)

The term naturalness holds a strong ethical connotation, and can be traced back as such to classical philosophy (Hume 2007 (1739-1740)). There are several definitions of the term ‘natural’ – those that are ethically relevant stem from a green bioethics or environmental ethics. One possible series of definitions is:

“(1) naturalness as that which is part of nature, (2) naturalness as a contrast to artefactuality, (3) naturalness as an historical independence from human actions, and (4) naturalness as possession of certain properties.” (Siipi 2004; pp. 457)

All these definitions of naturalness are interconnected. One could, for example, state that if something is part of nature (1), it is not an artefact (2), not manmade. Mankind has not intervened upon it (3). If mankind has, than one could say that one has robbed it of its basic properties (4). Its properties are given to it rather than being an original part of it. For example: if a tree is not planted by man but found in a forest, it would be part of nature. It is not an artefact, has not been made, shaped or pruned by man. But if one grows a tree in a garden, mankind will have intervened in its natural growth. Man might have chosen the spot where it stands, the way it grows or even the colour of the flowers it bears by breeding it to that end.

The intuitive difference between the grown or borne and the made seems to be based in the second and third definition of nature, which draws an ontological

distinction between artificiality and naturalness. In this case, the artificial is seen as something negative; and the natural as something positive. However, many theorists look upon this link between the nature we are and the morality we act upon as suspect (Takala 2004). For the usage of the term natural in an ethical context has several problematic sides. The sequence that can be built from the traditional notions of nature can just as easily be turned around: since it is in our nature to manipulate our surroundings (4), to try and manipulate these surroundings is our role in nature (1). We do not stand apart from nature, we are an integral part of it. Therefore, it would be highly artificial (2) to restrict ourselves by our own intervention (3) to manipulate our surroundings.

The problem of this possibility to turn the terms around to fit one's own argument was noted by Moore in 1903. On the basis of a distinction in language use noted by David Hume, in his *A Treatise on Human Nature*, Moore formulated the so called 'open question argument' (Moore 2002 (1903)). Hume recounts that it has come to his attention that there are two different ways of relating to the world, the one using 'is', the other using 'ought-to'. He states:

"In every system of morality, which I have hitherto met with, I have always remark'd, that the author proceeds for some time in the ordinary way of reasoning, and establishes the being of a God, or makes observations concerning human affairs: when of a sudden I am surpriz'd to find, that instead of the usual copulations of propositions, *is*, and *is not*, I meet with no propositions that is not connected with an *ought*, or an *ought not*. This change is imperceptible; but is, however, of the last consequence. For as this *ought*, or *ought not*, expresses some new relation or affirmation, 'tis necessary that it shou'd be observ'd and explain'd; and at the same time that a reason should be given, for what seems altogether inconceivable, how this new relation can be a deduction from others, which are entirely different from it." (Hume 2007 (1739-1740); pp. 469)

Hume notes a categorical difference between the moments people talk about how things are, and the moments people talk about how things ought to be. Moore's criticism on naturalism in ethics that was derived from this Humean perception is well known; it was built on the *is/ought* problem. He posited that one cannot deduce prescriptive linguistic uses from descriptive linguistic uses without winding up in a reductionist fallacy. One cannot derive an 'ought to' from an 'is'. For example, one cannot derive that we ought to adopt strategies in society that propagate survival from the fact that survival is the key notion in Darwin's evolution theory.

Moore elaborated on the problem in his *Principia Ethica* (Moore 2002 (1903)). According to Moore, any naturalistic reductionist ethics commits a naturalistic fallacy. This fallacy, then, consists of the attempt to define 'good' in terms of some other, natural property. To cite part of Moore's 'open question argument':

“The hypothesis that disagreement about the meaning of good is disagreement with regard to the correct analysis of a given whole, may be most plainly seen to be incorrect by consideration of the fact that, whatever definition be offered, it may be always asked, with significance, of the complex so defined, whether it is itself good. To take, for instance, one of the more plausible, because one of the more complicated, of such proposed definitions, it may easily be thought, at first sight, that to be good may mean to be that which we desire to desire. If we apply this definition to a particular instance and say ‘When we think that A is good, we are thinking that A is one of the things which we desire to desire,’ our proposition may sound quite plausible. But, if we carry the investigation further, and ask ourselves ‘Is it good to desire to desire A?’ it is apparent, on a little reflection, that this question is itself as intelligible, as the original question ‘Is A good?’” (Moore 2002 (1903); pp. 67)

In other words, one cannot reduce questions of good and bad to questions of pleasantness and unpleasantness that at the same time do not allow for a new qualification in terms of good and bad all over again. This goes for any type of ethical reductionism.

Naturalist ethics assumes that ethics is derivable from nature. In this sense our nature is causally linked to, and prescriptive for our ethical systems.<sup>39</sup> The example above of social Darwinism is a paradigmatic example of naturalism in ethics. So are several versions of utilitarianism. Moore’s fallacy is not directly targeted at naturalism in ethics, it only states one cannot reduce ‘good’ to natural properties. These ‘natural’ properties to which he refers, do refer to properties of the same category as biological properties.

One could summarise the problem of naturalism in ethics in one and sometimes two faulty presuppositions. A naturalist ethics assumes it is possible to infer contingent conclusions from necessary premises, but it also assumes that it is possible to insert contingent premises in a necessary argumentation. In the first case one could speak of a, more or less, causal derivation of ethics from nature. If nature shows that certain types of behaviour propagate survival, this in itself does not constitute a reason for us to adopt such types of behaviour. Killing one’s neighbour might in some circumstances enhance one’s chances of survival, but this is no reason to condone the killing of one’s neighbour. In the second case, one seems to infer an ethical argument within a causal (so not free to choice) natural order of things. It takes the theory of evolution to be teleological rather than merely factual. It states that not only survival of the fittest *is* the law of nature, but that it should be. This is logically inconsistent. In practice it boils down to two questions. 1. Can we make a deduction from the nature we are to what decisions we should make? 2. Are we introducing an unnecessary factor X in, for example, the principles of evolution with a naturalist ethics?

<sup>39</sup> The dualism between ‘defines’ and ‘should define’ already shows part of the problem.

1. *Can we make a deduction from the nature we are to what decisions we should make?*

If we have a certain nature that consists of tendencies we call ethical behaviour, there would be no necessity to make them explicit in a set of ethical *rules*. We are *already* following these rules by definition of that very nature. To derive a normative rule from a descriptive rule is in that sense as superfluous as adding to the law of gravity the normative imperative 'fall!' But if there is no such direct and causal connection between our nature and our ethical systems, why would we then have to choose for our nature as the base for our ethics instead of something else? As I defended elsewhere (Landeweerd 2006), an argument which goes beyond naturalism should be provided for. In spite of Heidegger's avoidance of both essentialism and existentialism, this is the mistake made by Sloterdijk as well. He takes the nature we are as a guiding line for what should be ameliorated.

2. *Do we introduce an unnecessary factor X in the principles of evolution with a naturalist ethics?*

Naturalism tends to introduce an unnecessary normative dimension to the factual mechanism of evolution, namely that survival is an *imperative* instead of something which *just happens*. For the naturalist the fact that what survives shapes future generations and thus the species, and the fact that what is most adapted is what survives, is not enough. Survival is something which has to be *strived* for. But according to the principle underlying survival in Darwinism the individual does not *strive* to survive, nor has he the *task* of survival. he just survives or does not survive. No reason for it, just causes. This reduction from 'striving to survive and succeeding or not' to 'surviving or not' is what makes Darwin worthwhile. The Darwinist theory does not need a factor X of teleology or the normative to be logically consistent. Adding such a factor effectively introduces a 'ghost in the machine'.<sup>40</sup>

To moralise nature apparently carries several disadvantages. This, however, does not mean that one cannot do anything with nature as a term in an ethical debate. However, one should always take care not to reduce matters of ethics to matters of naturalness. If one takes naturalness to be a positive thing, one will also need to incorporate the choice for naturalness as a positive thing. This is not given in the naturalness of nature itself. One cannot reduce issues of ethics to issues of pleasure, or to put it more broadly, one cannot reduce issues of ethics to mere issues of actual behaviour. One needs some transcendent notion. However, one cannot revert to a metaphysical notion of divine rules either. In that case, the fact that such and such a rule was given is in itself no proof for that it is a good rule to follow.

40 The problems of the naturalist fallacy, however, are non-existent in a total reduction of ethics to behaviour. In that case one does not make use of the word 'should' or 'ought to'. In such a view, ethical behaviour is a natural tendency of humans as well as other behaviours are for other species. As long as one does not derive ethics, 'ought-to'-accounts, from such descriptions, there is no naturalist fallacy. If one does make such derivations (either by putting an 'ought-to' on top of the 'is', or by deriving an 'ought-to' from the 'is') one ends up in the fallacy.

These two reductionisms in ethics, to natural behaviour on the one side and to metaphysical rules on the other, run quite parallel to both Wittgenstein's account of rule-following.

Moore's naturalistic fallacy is a regularistic side-version of the Finitude-problem: if one starts out with practical accounts of how people apparently act, one can derive infinitely many rules to account for that practice. Naturalists even leave out the notion of a rule, and replace it with 'natural law'. They cannot distinguish between agency and behaviour. Moore's metaphysical fallacy is a regularistic version of the normativity-problem. A rule in itself does not show how it is to be applied, and automatic application of a rule in a finite set of examples does not mean that one has grasped the rule. Metaphysicians commit a regularistic fallacy: they start out with an account of agency as rule guided, whilst these rules are self-chosen, but these rules cannot be linked to what they actually do. They cannot explain what the relationship is from a metaphysical rule to an ethical praxis since such a rule is regarded as standing outside and above that practice. Furthermore, the rule itself is not self-evidently justified.

Both the regulist and the regularist fallacy can be found in eugenics thought.<sup>41</sup> The eugenicist makes the mistake of regulism, when he embraces the idea that an agent can be made freer through enhancing his capacities, whilst he makes the mistake of regularism if he considers the product of eugenics to be the mere design of his efforts. The reductionist attitudes of the principlist and the pragmatist are also reflected in the two approaches that exist towards a new eugenics. There are two reductionist fallacies concerning human agency: one is a reductionist fallacy since it treats a human agent as merely performing regularities of behaviour, the other as a reductionist fallacy since it reduces the moral agent to a transcendental ego or point zero of action and perception and in doing so, it fails to show in what way such an agent is placed in the world. The separation between agent and traits is artificial. Any concept of self or personhood is therefore often left out of neo-liberalism.

## 7. Conclusion

The struggle between top-down and bottom-up approaches in bioethics still often stands in the way of discussing the existing ethical dilemmas in medicine or biology. Epistemological reductionism is the cause of a focus on methodology rather than subject. This is symptomatic for a discipline that threatens to descend into a solipsistic circle of mere self-referentiality. The current discussion on eugenics is therefore often approached not from these differing traditions in bioethics, but from other areas in moral or political philosophy. Still, next to what the issues are that

<sup>41</sup> As stated in chapter VII.

one approaches, some account of how one is to approach issues of practical ethics is necessary. But to entirely discard with these issues in favour of solving issues of methodology would result in a barren practical ethics.

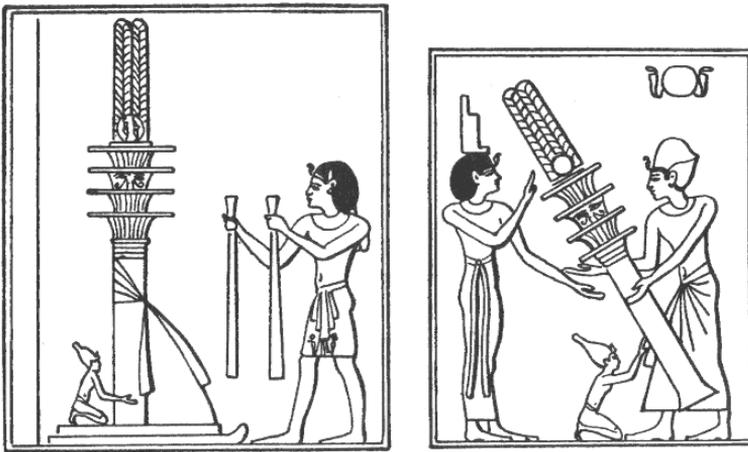
In approaching the issue of a new liberal eugenics, the discussion between top-down and bottom-up approaches in bioethics does have an indirect importance. Both top-down and bottom-up approaches ultimately look for a basis for justification in specific accounts of moral agency. The interesting character of the discussion on eugenics consists of the fact that it addresses ethics both on the level of content and presupposition: one should measure the justness of a new liberal eugenics both against the background of morality and the level of the conditions of moral agency.

The last chapter of this book will be devoted to an analysis of the issue of the self in connection with the discussion on eugenics. Rather than getting stuck in the debate on methodology, I shall investigate how issues of the self and of moral agency are interconnected with the ethical debate on a new liberal eugenics. To this aim, I shall first analyse the discussion in continental Europe, with a specific regard for the case Peter Sloterdijk. Then I shall venture into the discussion triggered by Jürgen Habermas on human identity and eugenics.



## Chapter VII

# Reconstructing the Self: Eugenics and the Ontology of Moral Agency



The 'Djed' is one of the older symbols of Osiris, the Egyptian God who was killed and chopped to pieces by his jealous brother Seth, but reconstructed by his sister and lover Isis. The reconstruction of Osiris' body supposedly took place at *Djedu*, where the 'Djed Pillar' was raised at an annual festival (Egyptian reads from right to left).

## 1. Introduction

The difference between continental and Anglo-American philosophy can be illustrated quite clearly with the clash between the German philosopher Peter Sloterdijk on the one hand, and the academic establishment (Habermas himself in particular) and the media on the other. This clash was triggered by Sloterdijk's infamous plea for a reintroduction of eugenics, in Bavaria in 1999 (Sloterdijk 1999). The case is illustrative of the sensitive nature of the subject, especially in Germany, where the Nazi-era still casts a rather menacing shadow over the subject of human genetics. However, it also requires our attention for another reason: continental European philosophy did not discard the notion of human identity in favour of a more political philosophical discussion, whilst in the Anglo-American discussion, issues that concern the interconnection between autonomy and identity are not seen as fundamental. This specifically concerns the discussion triggered by the publication of *From Chance to Choice*.

Norman Daniels and Allan Buchanan, writers of *From Chance to Choice* (Buchanan *et al.* 2000), were both scholars of Rawls. Their defence of eugenics is largely built on the idea that eugenics techniques can be used to compensate for natural inequalities. This need for a compensation they borrowed from Rawls' philosophy of justice (Rawls 1992 (1971)). Their defence of a liberal eugenics further elaborates on this issue by addressing questions of moral agency, freedom of choice or citizenship. In contrast, the European continental ethicists and philosophers, either in defence or in criticism of a revival of eugenics also address questions of being and existence. Here, the subject of human identity and the ontology of (human) being is regarded as the core issue in a new eugenics practice.

In the Rawlsian construction of morality, people are essentially driven by self-interest. To counter the social inequalities that are caused by this self-interest he suggests a deduction of principles of justice in which one is to look upon issues of morality from behind a so called 'veil of ignorance', that is to say, from a hypothetical position in which we do not have any knowledge of our position in society. The 'original position' thus taken – an old instrument in contractarian philosophy to derive what is to be the shape of state and society, is supposed to safeguard us from egoism being decisive on particular moral decisions. He used this construction to support the Kantian notion of a maxim – a further thought experiment in which one is to see whether a considered course of action can count as a general rule for society. Within this Rawlsian perspective, there is no room for issues of the self or of identity. Therefore, one can only embrace the aforementioned paradigm of free choice (see chapter IV), with all its flaws. Continental philosophy takes another turn.

If one does take into account issues of the self, of human identity and of the consequences thereof to the relation one has to oneself and others, other priorities surface, specifically with regard to the enhancement of human traits. In order to

explore these fundamental issues, I shall turn to the debate that followed Peter Sloterdijk's lecture in Bavaria to precisely because there the relationship between autonomy and identity was put in the centre of intellectual and philosophical discussion.

Jürgen Habermas elaborated the problem of the power relationship involved in eugenics choices in his *The Future of Human Nature* (Habermas 2003). But he argues against eugenics in a diffuse way, since he reverts to a distinction between nature and technology that seems suggestive of a similar notion in the defence of his adversaries. In this chapter, I shall investigate Habermas' arguments in more depth. I shall also show in what way, in spite of the apparent shortcoming of naturalistic reductionism, Habermas' core argument against a liberal eugenics still stands. Although it must be said that he did not pursue the difficult connection between his anthropological and metaphysical account of being as far as was necessary since he functionalised it in his own notion of a discourse ethics. His core argument can be found in his adherence to Kierkegaard's notion of the self, of one's subjective position in the world, as based on the existence of others, or an intersubjective space. In contrast with the liberal eugenicist's reverence for the outdated naïve capitalist notion of a liberalism that is purely built on 'free choice', Kierkegaard's notion of the self can be applied to show what issues are relevant when one speaks of inter-generational justice with regard to parental choices about the genetic quality of their children. To conclude, I shall show that the discussion on eugenics needs an ontological approach that also addresses the issue of the self, and an alternative conception of moral agency.

## 2. Der Fall Sloterdijk': Elmau

At the international Symposium 'Jenseits des Seins - Exodus from Being, Philosophie nach Heidegger' that was held in July 1999 in the castle of Elmau- Bavaria, Peter Sloterdijk's gave a lecture titled 'Rules for the Human Theme-Park: A Reply to the Letter on Humanism'<sup>42</sup> (Sloterdijk 1999)). In this lecture, Sloterdijk defends a new eugenics policy. This new policy was to be based on the new scientific potential of human genetics, and to be controlled by a team of 'wise men' who would decide upon which interventions were to be allowed for and which were not. The lecture gave rise to public outrage, as well as to a polemic battle between different strands within German philosophy. Next to the content of Sloterdijk's lecture, it was his adherence to the vocabulary now associated with the Nazi-period that caused public outcry, although this might well have been a choice for an ironic style. It would be fitting for his self-chosen role as 'enfant terrible' of German philosophy.

42 Regeln für den Menschenpark: Ein Antwortschreiben zum Brief über den Humanismus

Sloterdijk's lecture was a reply to Martin Heidegger's 1949 letter on humanism (Heidegger 1949 (2000)); which was itself a reply to several questions asked by a French scholar about the nature of ethics, bold questions seen Heidegger's own moral bankruptcy as a member of the Nazi party. In 1946, Heidegger lost his teaching permit for seven years, as part of the denazification-process in Germany. This of course led to a period of personal crisis. His letter on humanism is a criticism of the enlightenment tradition that, although written in a different philosophical tradition, draws the same conclusion as the Frankfurt School of Philosophy<sup>43</sup>. Adorno and Horkheimer perceived of the second world war, and its culmination in the holocaust as a proof of the moral bankruptcy of the ideals of the enlightenment (Adorno 1993 (1947)). Although written as a letter, it took the shape of a philosophical publication in its own right, in which he criticised Sartre's existentialist interpretation of his *Sein und Zeit* (1929). Sloterdijk's choice to focus on this letter by Heidegger in the light of the new reproductive technologies is not far-fetched, since it deals with the problematic aspects of the concept of human nature in the light of being and existence. As Heleen Pott states (Pott 2000), this criticism of enlightenment humanism is the central reason for Sloterdijk to adhere to Heidegger's letter.

In the classical conception of the relation between essence and existence, or being as such and (self-)directed being, essence (or substance) was taken to precede existence. One encounters essentialism in Platonic as well as Aristotelian philosophy, in describing man as having some type of core identity that is dependent of certain necessary attributes. The concept of essence as being defined by matter and form is an Aristotelian addition to the discussion. In this definition, it occurred under the banner of 'substance'. Sartre rejects this classical conception of the relation between essence and existence because of its deterministic consequences.

The problem of essentialism in philosophy is that it neglects the subjectivity of the subject, and therefore cannot accommodate for issues of autonomy, intentionality and responsibility. For if one's biological traits or one's cultural identity precede one's existence, one will be determined by them. In his *Existentialism is a Humanism*<sup>44</sup> (1996 (1946)), Sartre therefore opts for a precedence of existence over essence. This allows him to defend a view on humankind in which he has no given nature, only a nature we construe ourselves, a position that should be quite recognizable for those familiar with existentialist philosophy. From this starting position, existentialist humanism tries to define the human subject and human dignity as based on autonomy, responsibility and intentionality.

Heidegger rejects the Cartesian version of humanism as interpreted by Sartre who, in his lecture *L'Existentialisme est un Humanisme* (Sartre 1996 (1946)) assumed he was following Heidegger's *Sein und Zeit* (1929). Heidegger thinks this move in metaphysics does not go far enough. He discards metaphysics itself, by criticising

43 Frankfurter Schule

44 Originally published as *L'Existentialisme est un Humanisme*.

the distinction between essence and existence, whichever of the two gets precedence. Self-creation would involve an external position. Self-creation necessitates a dualism on the level of the human being as well, an artificial division between the identity we have and the person we are, that seemingly has the power to form this identity. Heidegger rejects the metaphysical split between essence and existence, and Sartre's approach as well, since he actually reaffirms it in his reversal of essence and existence. In his view, Sartre's account of humanism remains Cartesian in two ways: it is Cartesian in that it differentiates between essence or substance (the attribute(s) that make(s) one into what one is (in contrast with contingent attributes)) and existence (being from a centre of consciousness, being directed at an outwardly world, and being goal-oriented). It is also Cartesian in that it takes self-consciousness ('I think, therefore I am') as first base, therefore taking the Cartesian Cogito as a first reality, rather than some type of core identity or set of necessary attributes (such as, in my case, being Dutch, being male, being an academic, etc.). In other words, one exists, prior to existing as something. The only one to direct the contents of one's life is the person himself. He therefore needs to take his existential orientation (his societal place) as preceding his essential determinants (what he is)<sup>45</sup>. The problem of this approach is that it disconnects a person from his situation. Liberalism makes a similar mistake in its adherence to a conception of the person that is presupposed to be free and able to act autonomously, whereby all restrictions on that freedom and autonomy are either based in one's own choices or in external limitations. Such an account of human being will either lead to either an account of the moral subject that cannot demonstrate how it relates to the praxis it inhabits, and therefore it makes the same mistake as *rulistic* reductionism, or an account of the moral subject that reduces it to mere factualities, therefore reducing it to its object-ness, and therefore it makes the same mistake as *regulistic* reductionism. Heidegger therefore favours a different tradition which, according to him, runs deeper. It consists of an adherence to a Being in the World<sup>46</sup> instead of a mere creating of oneself (as Sartre defended), or mere being as such (as Platonic and Aristotelean metaphysics defended). According to Heidegger, we have to try to find our proper truth in Being<sup>47</sup>, instead of focusing merely on Human Being<sup>48</sup> on the one hand, or on ourselves as merely a being amongst 'beings in the world' on the other.

Heidegger's move beyond humanism is an attempt to resolve the bankruptcy of the ideals of the enlightenment, the cause of which he takes to have found in the

45 From this position, in *Being and Nothingness* Sartre, Sartre, J. (2003 (1958)) Sartre derives his concepts of 'être-en-soi' (being in itself; that part of being of which we do not have consciousness), 'être-pour-soi' (being for itself; consciousness, and therefore standing outside of being in itself) and 'être-pour-l'autrui' (being for others; being at other people's disposal, as an object).

46 *In-der-Welt-sein*

47 *Sein*

48 *Dasein*

adherence to an idealism of self-creation. The source of this idealism he ascribes to the, implicit, metaphysical position of humanism. Heidegger's message seems to be rather opaque. He holds that the problem for ethics lies at the heart of western metaphysics, but although the first step to a solution strategy, according to him, is to be found in sidestepping both essentialism and existentialism, he does not see to what type of ethics this is to lead. Sloterdijk's reply to Heidegger's letter focuses on the new genetic techniques as the new locus of man's Being. He also attempts to step away from humanism and provide for an alternative. Ernst Tugendhat summarised Sloterdijk's stance in an article in *die Zeit* as follows (my translation<sup>49</sup>): "seen the fact that the function of humanism was to tame 'wild' man, this task [...] is now to be carried out by a program of genetic disciplining" (Tugendhat 1999). This means that in his lecture, Sloterdijk posited that the project of humanism to 'tame' humankind had proved itself a failure – especially in the light of the disastrous effects of war in the last century. Humanism (at least, the humanism Heidegger referred to) tried to civilise humankind through societal projects of enlightenment, education, knowledge and self-liberalisation. But the very products of the enlightenment have led to an industrialisation with many victims and (seemingly) caused deterioration in the quality of life, whilst the inventions of the nineteenth and twentieth century fed a war machine that was unprecedented. This echoes the criticism of enlightenment of Theodor Adorno and Max Horkheimer's *Dialectic of Enlightenment* (Adorno 1993 (1947)). According to Heidegger and Sloterdijk, it is clear that we should no longer hold on to humanism as the background philosophy from which to shape the world, since it led to bestialities rather than enlightenment. One should rather focus on our being as such. But in contrast to Heidegger's rather defeatist conclusions with regard to the possibility of an ethics as such, Sloterdijk thinks it is possible to find different means with which to discipline humankind, to tame the darker side of humankind: the new genetic techniques!

Sloterdijk supports Heidegger's attempt to bring our understanding of ourselves beyond a mere humanistic focus, but he criticises Heidegger for not showing where we may locate that deeper form of Being; how being human is shaped by biological and social forces. Sloterdijk assumes we cannot hold back the development of techniques that will ultimately steer our procreation. Apart from whether one would agree with such a technological determinist view on the new genetic technologies, one can state that we indeed already make choices that influence the genetic make-up of our posterity. However, in Sloterdijk's view we should regain control over the choices that are made towards the shaping of our posterity. Sloterdijk therefore suggests the formation of a working group of ethicists and philosophers, who would decide which applications of prenatal genetic diagnosis and (in utero) stem cell intervention should be allowed for and which ones should not.

49 "Gesehen werden, dass die Funktion des Humanismus darin bestand, das 'Wilde' der Menschen zu 'zähmen'; diese Aufgabe [...] müsse jetzt von einem Programm genetischer Züchtung wahrgenommen werden (Tugendhat 1999)".

This would provide us with an alternative to the now failing humanist ways to raise us from barbarism, it would enable us to 'tame' the human animal by different means. Sloterdijk therefore suggests we should look at our biological state and the way we can intervene in that state as a form of relating to our being. Our 'first reality' in that sense, is our genetic-biological nature. In that sense Sloterdijk appears to close the circle from a (post)metaphysics of Being to a socio-biological reductionist conception of 'Dasein'; a circle Heidegger himself would probably have rather left unclosed following his indefinite ban from teaching that resulted from the trial on his membership of the Nazi party.

The vocabulary Sloterdijk used in his lecture caused a witch-hunt in the media. Sloterdijk himself suspected Jürgen Habermas to have leaked a written version of his lecture to the media, through his former students. Sloterdijk wrote an open letter to Habermas, published in *Die Zeit* (Sloterdijk 1999), in which he blamed Habermas for creating the uproar in the media. But the vocabulary he used was sure to bring back the memories of the atrocities committed by the Nazis in the name of racial hygiene. This can hardly be surprising when using phrases like 'breeding posterity' and 'the disciplining of the human race'. However, not only the form but also the content of his lecture led to public outrage. Since the end of the Second World War, any form of intervention aimed at changing the nature of the human race (by selection or sterilization) is still considered ethically suspect in Germany. The discussion spread out to *der Spiegel*, *die Zeit* (Tugendhat; see above), *die Frankfurter Zeitung*, and ultimately it went abroad. Criticism might have been organised behind closed doors, and it might have been overly judgemental. This has stood in the way of a well-informed debate on the implications of Sloterdijk's position.

Unlike Adorno and Horkheimer, Heidegger saw no clear way to take up the project of ethics. He was even very critical of those who did attempt to reconstruct these ideals after the war. This forms the core of Heidegger's criticism of Sartre's interpretation of Heidegger. The project of western thought should not turn back to the classical distinction between essence and existence at all, whether the one is taken to have the priority or the other. He calls for a deeper self-understanding of humanity, but fails to show how and asks whether humanity is ready at all for a true definition of ethics. Sloterdijk reads Heidegger's letter on humanism as a manifesto in which the dualistic tension between the societal and being as such is to be replaced by a biological notion of being. This interpretation fails to acknowledge Heidegger's deep-felt disillusion with both his own position and that of western society after the Second World War, but it is also flawed in a more philosophical sense. The issue of essence-existence, and something deeper, cannot be translated into an issue of the societal, or the cultural, versus the biological. Such a translation amounts to a categorical mistake. In this choice, Sloterdijk remains locked in between having to choose either for essence or for existence as well. He chooses the former, reducing mankind to his biological features, whilst embracing an

ideological approach to how these could be adjusted to fit the needs of a just society (as in trans- or post-humanism). Therefore, the answer Sloterdijk gave to Heidegger's letter does not provide with a clear way to take up the project of ethics either.

Sloterdijk published his lecture in book-form in autumn 1999. One of the more influential reactions to this lecture was the working paper 'Towards a liberal eugenics?' by Jürgen Habermas, later elaborated as the aforementioned publication *The Future of Human Nature* (Habermas 2003). This work, by the Eminence Grise of German philosophy, is quite different from his earlier works. Rather than replying Sloterdijk directly, he decided to take up swords with Buchanan *et al.*'s *From Chance to Choice*. This enables him to address the issue more broadly, and without the restriction of the polemic nature the debate on Sloterdijk had by then become. In this work, Habermas does not take up the sword in defence of the ideals of the enlightenment. He sets out with an account of the connection between Kierkegaard's existentialism and post-metaphysical linguistic philosophy. From this connection he tries to base a conception of ethics alternative to either foundationalism or pragmatism. On this basis Habermas is able to pinpoint the ethical problem of a liberal eugenics much more exactly: the problem of human identity.

According to Habermas, the idea of merely being an extension of another person's ideology differs from more contingent conceptions of 'being caused' by fate in one's initial position. One cannot 'belong to oneself' in the same way. A liberal eugenics would, because of its implicit naturalist functionalism, be unable to address this problem. It is not the ontological nature of the eugenically created that is at the core of what might be wrong (or in Sloterdijk's case, right) with eugenics, nor the changed self-perception of the species, but the fact that in eugenics, what is chance for the one, is choice for the other, what is to become fate for the eugenically designed will have been optional for the designer. This optionality is distinct from the option to have a child in the first place, or the fact that one's choice for a specific partner also affects the genetic make-up of one's children. Genetic engineering, if applied to humans, would change our identity (as something we are, as well as something we perceive and construct) because it affects the view we have of ourselves as beings created by 'happy accident', to a much more problematic view of ourselves as beings, part of the plan of our parents. This instrumentalisation of people within other people's plans or ideals should be taken in account, if one wants to map the ethical dimensions and implications of genetic technology and genetic engineering. Habermas' arguments appear to focus predominantly on positive eugenics, but they are also relevant to the issue of a negative eugenics. Although in the case of a negative eugenics, there are no concrete affected individuals, communities and society at large are affected. Here, it is not individual personal identity that is at stake, but the identity of the community.

### 3. Habermas on the Issue of the Self

#### *i. Introduction*

Habermas' opens his *The Future of Human Nature* with an account of the break between metaphysics and post-metaphysics; a break which forms a radical moment in the history of western thought. We have lost confidence in our ability to prescribe universal 'rules' for 'the good life', because the ideals of the enlightenment in themselves have become morally suspect: philosophy has become a fragmented discipline. It can only reflect in bits and pieces on aspects of a damaged life. Philosophy, in Adorno's words, has become a melancholic science (Adorno 2003 (1951)) because it can no longer redefine a new universalistic ethical point of view. As Habermas puts it, philosophy has retired to the investigation of formal properties of processes of self understanding, without taking a position on the contents of these processes. An additional problem which, according to Habermas, haunts contemporary ethics and philosophy is that Kantian moral philosophy has never been able to satisfactorily answer the question of why we should act morally at all. Because of this, and in order to be able to have an influence on the world at all, Habermas says philosophy should meet society and politics half way.

One of the results of the break with metaphysics is, according to Habermas, a shift from a universal monistic ethics to an individualistic particular and democratic pluralism. This particularistic shift to individualism makes it necessary to put the concept of identity firmly back on the chart of ethical philosophy. Habermas takes Kierkegaard to be the first philosopher who made a connection between particularistic existentialism and ethics. In Kierkegaard's eyes one necessarily takes a moral position towards oneself in reflecting and objectifying one's identity, one's present and future. Self-reflection and self-relation are necessarily based in one's relation to others. And this relation, in his view, is based in a relation to God, as the absolute Other. For Kierkegaard religion was a necessary constituent of ethics, but this would not hold for contemporary secular society. Habermas therefore, by reference to the linguistic turn of philosophy and to phenomenology, transforms this Kierkegaardian absolute theological concept of the 'wholly Other' into a more secular concept (Habermas 2003; pp. 10)<sup>50</sup>. Habermas takes Kierkegaard's philosophy

50 This is actually the move Emmanuel Levinas made in his philosophy, by referring to the concept of intersubjectivity. Language is the locus and initiator of intersubjectivity as well as subjective identity. Although identity cannot be regarded as a given in the absolute sense, it is trans-subjective because of its being constituted in language. Because of this trans-, or intersubjectivity of identity, having a relation to oneself and reflecting one's identity, necessitates a relation to the other person. Although Levinas is often more directly associated with Heideggerian tradition, his philosophy can also be seen as a middle way between Kierkegaard's notion of the Other in a theological perspective, and Husserl's (Heidegger's teacher) notion of intersubjectivity. In Husserl's work, this notion was stressed with regard to giving objectivity a new metaphysical foundation, that renders the Kantian idea of a 'Ding an sich' (thing or world upon itself, outside of being perceived of) unnecessary. In his later works, however, Husserl also tried to apply the notion of intersubjectivity to giving the subject a new foundation, thereby turning to

because it can serve as a basis for an ethics in a pluralist world. It provides a certain picture of human existence without filling in its content and direction. Habermas also refers to Kierkegaard's conception of the self with respect to eugenics. Kierkegaard stated in *Either/Or*, that in order to be able to take on responsibility over one's actions, one should try and emancipate oneself from self-induced forms of objectification (Habermas 2003; pp. 6). This means that one has to articulate a self-understanding of one's personhood, that is, the kind of person one "would like others to know and acknowledge" (Habermas 2003; pp. 7). Habermas uses the Kierkegaardian notion of the self, but without the religious conclusion Kierkegaard draws from it. He refers to it with regard to the self as an act of the will rather than a given; a thesis that was elaborated in Kierkegaard's *Either/or*.

The self-transformation that is now made possible through new genetics technology is of a totally different nature than the transcendent Kierkegaardian self-transformation, which is a process of self-reflection. With the possibilities of gene technology, a problem arises in the development of a relation to one's identity. One's biological identity, which could formerly be considered as a given (it could, at the most, be bred), is now shifting 'to the realm of artefacts and their production'. Because of recent technological developments, as Habermas writes, "[...] the dividing line between the nature we are and the organic equipment we give ourselves is being blurred" (Habermas 2003; pp. 22). This blurring is not literally something new, but the fact that it has become so much within our grasp is. What is at stake is that because the limit between being and creating is changing, what we once were can now be at our disposal, in the sense of a creatable artefact. We can now transform our identity. To show in what way our law and morality would be affected by a liberal eugenics practice, Habermas demonstrates how the capacity to conduct oneself ethically is based in a specific concept of a species-ethics, which he builds on Kierkegaard's notion of self-referentiality.

## *ii. Choice and Fate*

In the proposals for a new liberal eugenics, Habermas perceives of a renewed alliance between Darwinism and the ideology of free trade (Habermas 2003; pp. 21). He claims there is a weakening of moral restrictions on the application of genetics in reproductive medicine on a medical and economical basis. It is not so much the old mistake of a societal interpretation of the evolution theory that feeds into this new alliance, but rather the demands of the post-industrial neo-liberal society that are called into action and translated in genetic preferences, by enhancing human capacities, and adjusting future people's traits to what counts as 'best' in

ethics. The other as it appears in an intersubjective perspective is to be understood as an Other to which the person in question does not owe everything, in the religious Kierkegaardian sense of the word. He rather is, as can be seen in the works of Levinas, a wholly Other, who is a necessary constituent of individual identity, because of the binding and intersubjective nature of language.

that society. Until now, one could only determine the age at which one wanted to have children; further determinations did not exist yet. Except, not having Down's syndrome, a significant case here, since it is a prime example of negative eugenics<sup>51</sup>. That we are on the verge of an era in which such choices are technical possibilities, might change the ontology of having/receiving children to an ontology of choosing children.

The problem is that the initial position with which we start our lives has lost its contingency. The shape of this position now lies in man's own hands, whilst, according to Habermas, the fact that this position is unforeseeable and uncontrollable is essential to man's normative self-understanding and his 'being-able-to-be-oneself'. The coincidental nature of our conception enables us to be free in what we are; if this coincidence were to be other people's choice, it would fundamentally alter that freedom. Genetic intervention in offspring disturbs the ability to relate to oneself spontaneously and in moral freedom. Genetically engineering offspring would take away the freedom of being 'a product of fate', thus complicating or even removing the ability of an individual to 'take possession of one-self, taking over the responsibility of the parent. As Habermas puts it, the genetically engineered offspring would remain dependent on the irreversible decisions of their parents, only having the choice between fatalism and resentment. Naturalist functionalism (instead of a normative conception of self-understanding) has become a very literal possibility, and discussion on this alternative can no longer be left to the speculations of science fiction. An instrumentalisation of human nature might be fundamentally undermining this ethical self-understanding, because it would make it unable to see ourselves as ethically free and morally equal. That is why only in the case of very obvious disadvantages in later life for the future child, one can assume a consensus (also implementing the opinion of the future child itself).

If someone has been determined genetically through other peoples' choices, this will be a necessary precondition for that person's existence. He will not be able to transcend it as a contingency, even if the choice as such only concerns one trait, even if this trait occurs quite commonly in the population (one's gender, being 1.95m tall), instead of being rare and very specific (being a dwarf, being deaf, being a homosexual). Its having been a precondition of his existence having that trait, or being that person, will play a very specific role for that individual. The not yet existing person that is to be determined will owe his existence to such a choice.

51 Even though the separation between positive and negative eugenics is blurry, the objections one could make from a Habermasian point of view against a positive eugenics are not necessarily valid for a negative eugenics: in the case of a positive eugenics, a specific person who will be born would be affected. In the case of a negative eugenics, the only possibly problematic influence would be a change on a societal level of what is accepted as 'normal'. And in the case of increasing a future person's immune system, the consequences may be marginal even in that respect (although the invasiveness of the techniques involved might lead to an undesirable increase of medicalisation of reproduction, and may have detrimental consequences for those who have a 'normal' immune system whilst diseases may adept to the increased level of immunity).

And the very fact that one's identity, contrary to the common conception of moral agency, always plays an important role in what choices one makes, and how one's autonomy is constituted, makes having a predetermined identity a determinative factor in how one considers one's autonomy to be constituted. Furthermore, the choices made by the one determining the genotype of the future person are not seen as contingent either, they are seen as necessary preconditions of having a child.

What does this say about the possibility of a liberal eugenics, in which man is also artificially created, but in which the artificiality might not be that different from inbreeding in aristocratic families throughout Europe? Or what does it say about an individual who chooses elective egg cell donation to have a child that fits the phenotype of the parent? Or even the subconscious processes by which we choose our partners to fit one's subconscious preference for a specific phenotype? The problem, in Habermas' view, lies in the fact that creating our children to fit our preferences through artificial means rather than natural reproduction disturbs the relationship between what we are and how we see ourselves:

“Against the background of the possibility of liberal eugenics, this internal relation between the image of man and our self-understanding as autonomous beings having equal rights and abiding by moral reasons stands out more clearly. The moral reasons that hypothetically speak against such a practice cast a shadow also on the practices which open the way to it. Today, we must ask ourselves whether later generations will eventually come to terms with the fact that they may no longer see themselves as the undivided authors of their life-style - nor will be called upon to account for themselves as such. Will they accept an inter-personal relationship that no longer is consistent with the egalitarian premises of modern morality and law? And would not, then, the grammatical form of our moral language game – the self-understanding of subjects capable of language and action speakers and actors as beings for whom normative reasons count – be changed as a whole? [...] There is, after all, the alarming prospect of a practice of genetic interventions aiming at the modification of traits which will go beyond the boundaries of the essentially communicative relationship between doctor and patient, parents and children, and undermine, through eugenic autoselection, our normatively structured forms of life.” (Habermas 2003; pp. 67)

Since the internal relationship between one's view on man and our understanding of oneself as autonomous is disturbed by a liberal eugenics, it takes away the possibility to be author of one's own lifestyle.

Some would question whether a person that has a genetic makeup that was chosen rather than a haphazard accident will not be able to 'be himself' in the same way. For one, since he owes his very existence to the choice made by his parents, he will not be able to stand outside of himself to see whether he would agree with

those choices. For another, the fact that he is who he is, is no more an infringement on his life than for another person who is also restricted or steered in his choices by whom he is by accident. One might say that it is irrelevant whether one's genetic makeup is the result of coincidence or of choices made by others that will have been fundamental to one's existence.

Education also forms who one is and traumatic childhood can indeed shape a person. But one can always choose to take a different direction in life than the direction chosen by one's parents: an education does not construct a person, it is more of a transference, or attempt thereto, of parental values and ways of life to a child. One does not raise one's children according to a preset formula that will determine in a direct way what the result will be after eighteen years. Educational choices that determine what someone will be and genetic choices that will similarly determine someone, are distinct. In the first case one can speak of a two-sided relationship between parent and child whilst in the first the relationship only has one direction: from the parent to their (future) child. The choices in question that specify a person's identity and are at the same time conditional for that person's existence, are inalienable and, at the same time, part of another person's project, ideals, wishes and preferences. This creates a perpetual dependency on factors outside of one's own grasp. One cannot wonder what it would be to be someone different than who one is, since being who one is, is inalienable as well. This goes for everyone, but being who one is, for the non-selected, is not a matter that was in other people's hands. Although the trait in question might not be as fundamental or as meaningful to others possessing the same trait, not having it through choice but through chance makes all the difference in how the individual will regard it. However, it is not merely what the person resulting from a prenatal genetics choice will think of the choice that matters ethically. That someone chooses to have such an impact on a person's existence in itself constitutes an injustice. Children are not a commodity. Commodities are apt to adjustments, functionalising, use, and answer only to their owner (although this does not always apply with electrical appliances). Chairs, microwave ovens and lamps are not entitled to rights, and only rarely to a value that brings an ethics with it (we do attribute a value that goes beyond ownership to, for instance, a black Madonna from the eleventh century; the Venus of Willendorf; van Gogh's sunflowers; Picasso's *Guernica*; or the original manuscript of Proust's *à la Recherche du Temps Perdu*). However, a person is entitled to rights and obliged to take on responsibilities. This is why Habermas does not embrace the idea of a liberal eugenics.

### *iii. Choice, Fate and identity*

Habermas' position is not that far removed from neo-liberalism. In his working paper 'On the Way to Liberal Eugenics?', a preparatory piece for *The Future of Human Nature*, that was published as *Die Zukunft der Menschlichen Natur. Auf dem Weg zu einer liberalen Eugenetik?* Habermas agrees with the deontological perspective of

the writers of *From Chance to Choice* (Buchanan *et al.* 2000). But there is one crucial distinction between the position taken by Habermas and the one taken by Buchanan *et al.* Whilst Buchanan *et al.* think ethics to be a question of public interest versus private freedom, Habermas takes into account the anthropological undercurrent that he perceives of as constitutive of morality. Or, as A. F. Timm puts it in a working paper:

“Habermas, I think, gets to the heart of the matter. He asks whether new technologies, particularly preimplantation diagnosis and the possibilities now being discussed for genetic engineering, require new laws to prevent a system of normalized ‘liberal eugenics’ that would remove the contingency and naturalness from procreation, thus changing our self-definition as a species. Our value system is currently based, he argues, on the line between chance and choice: between how we are born and how we deal with the bodies that we and others are born with. The ability to create ‘designer humans’, he argues, may well allow for the optimization of the species and may mean increased autonomy for the individual, but it may also ‘undermine our normative self-understanding as persons leading their own lives and showing one another equal respect’” (Timm 2002; pp. 13).

According to Habermas (Habermas 2003; pp. 23), our anthropological self-understanding will be changed by gene-manipulation. Such a change of one’s self-understanding will have repercussions on how one relates to oneself, and whether one can still consider oneself as free and equal to others, specifically in an inter-generational sense: one’s parents were able to make decisions on one’s place in the world and one’s goal in life, where one is no longer able to do so oneself. And it is more difficult to accept one’s boundaries if they were chosen by someone else than if one were to be able to ‘blame’ it on fate. According to Habermas, this is detrimental, specifically because our current self-understanding forms the very base of our law and morality (Habermas 2003; pp. 40), even if the latter will be implemented in society in a liberal, bottom-up fashion.

Habermas explains in what way our self-relatedness would change as follows:

“[...] the dividing line between the nature we *are* and the organic equipment we *give* ourselves is being blurred. My perspective in this examination of the current debate over the need to regulate genetic engineering is therefore guided by the question of the meaning, for our own life prospects and for our self-understanding as moral beings, of the proposition that the genetic foundations of our existence should not be disposed over.” (Habermas 2003; pp. 22-23)

Because we now have the ability to make reproductive decisions that steer the genetic quality of posterity according to our preferences, we can no longer distinguish between that which belongs to our identity and that which we use as an

artefact. The reflection of Marxist romanticism quite clearly demonstrates that Habermas is indeed a late extension of the Critical or Frankfurt School in German philosophy. As Habermas himself states: “what hitherto was ‘given’ as organic nature, and could at most be ‘bred’, now shifts to the realm of artefacts and their production” (Habermas 2003; pp. 12).

To illustrate his point on the distinction between the realm of the subjective and the realm of the objective, Habermas discusses Helmut Plessner’s notion of eccentric positionality (Plessner 1981). Plessner considers man as being typified as being positioned outside of his own existential centre. By doing this, he could distinguish between ‘having and being a body’. . Man is a centre of his experience of the world, but he can also relate to himself as such, therefore again standing outside of this centre. By referring to this eccentric positionality, Plessner was able to distinguish between ‘having and being a body’. In Habermas’ words:

“A person ‘has’ or ‘possesses’ her body only through ‘being’ this body in proceeding with her life. It is from this phenomenon of being a body and, at the same time, having a body [*Leibsein und Körperhaben*] that Helmut Plessner sets out to describe and analyse the ‘excentric position’ of man. [...]. To the extent that his body is revealed to the adolescent who was eugenically manipulated as something which is also made, the participant perspective of the actual experience of living one’s own life collides with the reifying perspective of a producer [...].” (Habermas 2003; pp. 50-51)

It is in the way in which having a body is constituted by being a body that we have a relation to ourselves and the world we live in. If our body was at our parents’ disposal in such a way that irreversible decisions by them influence what I am, then one might no longer be able to take on this ‘being a body’, from this ‘having a body’. What is at stake, according to Habermas, is the limit between being and creation. What we once were, can now be at our disposal; we are becoming our own creatable artefact, not just in our societal but also on our biological level. We can now transform our biological identity. This raises the question of whether or not we should regard this self-transformation as increase of our freedom that is not very different from the self-liberation our society reached in the cultural sense of the meaning. Is the auto-transformation we would create through the biological identity of our children different from the auto-transformation we already created by saying our farewell to the traditional niches we inhabited in the past? If we follow Habermas, the fact that one would become a blacksmith when one is the village’s blacksmith’s son, is different from being governed by one’s parents’ preferences if expressed through one’s genes. The locus of the moral subject, according to Habermas, is to be found somewhere in the duality of ‘having and being a body’ (Plessner 1981). Its identity lies in the tension between the contingency of the properties nature has endowed us with at birth and the way we relate

to this contingent given. Genetic intervention before birth or in childhood would alter the contingency-part of human identity.

Although one should avoid an exclusively genetic determinist picture of identity, there is a seemingly minor, yet fundamental difference between the genetic and the environmental, or the linguistic and the educational when it comes to prenatal selections or interventions beyond avoiding severe diseases and disabilities. Most would state that modifications through education and environment can, at least in part, be sidestepped or altered by a person; whilst genetic modifications are much more constituents of one's identity. Someone can decide to part with his Catholic background, but someone cannot part with the way their phenotype is determined by their genetic make-up. Even if this were possible (and in some cases in the future it might be; through adult germ line modifications), having a specific genetic make-up will have been a necessary precondition of existing as such. This is not the case with environmental or educational factors.

The nature of the contingency in how one is born is a fundamental constituent of one's autonomy. Although one's biology is laid down in an equally influential way by coincidence or by parental choice (either induced by indirect governmental coercion, indirect societal coercion or individual parents' conception of 'the good life'), the role it plays in one's autonomy is very different. If parental decisions implied a specification of one's traits, this would be conditional to one's existence and therefore it would create a perpetual dependence on that parental choice in what one is. One cannot step outside of what one is, so one cannot even contemplate the question how it would have been to be born differently (or, for that matter, not at all).

Liberal societies, according to Habermas, should only tolerate eugenics in so far as it would not limit one's freedom to lead an autonomous life, nor stand in the way of one's free and equal interaction. In that sense liberal eugenics misses the point. One needs to be able to refer to one's origin as beyond the scope of human disposal to be able to have any sense of freedom, in which one can consider one's actions as one's own. Referring to Hannah Ahrendt's concept of natality (Ahrendt 1958), Habermas describes natural contingency as something which still constitutes such an origin beyond the scope of another. Genetic engineering would alter this. It would not only create a problem in the way one relates to oneself (the problem that one cannot consider oneself as the autonomous author of one's life), but it would also create a relationship of dependency between the parent (who remains responsible) and the genetically-engineered child. Under the well-intended goal to give a child a better starting position in life, it creates a distorted relationship between him and his parents. The relationship between that future person and his abilities and restrictions will forever be the choice of the person that makes the decision on a certain genotype preferred by his parents. In Habermas' words, "[e]ugenetic programming [...] gives rise to moral misgivings as soon as it commits the person concerned to a specific life-project, or, in any case, puts specific restrictions on his

freedom to choose a life of his own” (Habermas, 2003, p. 61). And in spite of the downfall of religious and metaphysical worldviews, we still seem to want to hold on to a concept of ourselves as free, autonomous and equally interacting subjects.

#### *iv. Boundary Cases*

Many ethicists claim that ethics should not go beyond the avoidance of harm, a claim I will defend as well in a later paragraph of this chapter. Some think that promotion of the good is the central goal of ethics. In that case, one would be morally obliged to enhance. John Harris argues along these lines, stating that if it were possible to enhance the health of future people or engineer a disposition for high intelligence, we would be obliged to do so (Harris 2007 (II)). An obligation to enhance goes rather far, since it would tread reproductive rights. One cannot demand genetic selection and intervention from prospective parents. One cannot oblige people to undergo any medical procedure. But it seems less problematic to merely open up the option as a possibility, that parents may choose themselves whether they want to enhance their children or not. This is not an obligation to avoid harm, but indeed one that does more, promoting the good.

Most people would consider health, beauty or intelligence as good things. They can contribute to the quality of one’s life and enhance one’s capacities. Why would a person who is a result of a selection for a high IQ or an enhanced immune system be worse off? After all, they will have a better starting position in contemporary society, will be less susceptible to harm, and will have a greater potential in terms of career choice, survival rate, intellectual development etc. and apparently with no harms or disadvantages attached. Habermas argues that if parents determine the genetic identity of their child, they exert a power over his life and future that he will never be able to exert himself. But this argument seems more applicable to something like musical talent than to something like an enhanced immune system. The uniqueness of a specific trait and the role it is given in a specific socio-cultural setting seem to be more relevant than Habermas seems to suggest. Habermas’ arguments hold quite firmly when we look at cases in which parental couples choose a child on the basis of personal preferences for a specific identity, but not when we look at cases in which the trait in question hardly bears on the identity of the person to be created. It therefore appears that cases should be assessed on a case to/by? case basis, to see to what extent a certain pre-selection or intervention could become problematic to a future person’s sense of self.

To be able to apply Habermas’ criterion for prenatal selection therefore begs not a ‘strong’ (universally valid) interpretation of his arguments but a ‘weak’ one (only valid when argued in the context of a particular case scenario). We shall therefore investigate several ‘milder’ or ‘boundary’ cases of eugenics, in which the trait in question does not lay down a specific life plan, or does not seem to be morally wrong for other reasons.

There are cases that appear to be more controversial in the light of Habermas's arguments. Next to the enhancement/prenatal selection on a higher IQ, on general fitness, one could mention enhancement through prenatal selection of a stronger immune system and the rather separate case of sex-selection. The enhancement of the immune system through prenatal intervention is a controversial case. Here, the boundaries between enhancement and therapy are hardly applicable. As Chadwick states:

“To try to explain enhancement through making an opposition with therapy is far from a simple matter – and there is yet another complication, which is the issue of prevention. There is a view that preventive interventions can be enhancing: an example is a boost to the immune system to protect against infectious disease. Is it possible, also, for a preventive intervention to be therapeutic: what would count as an example of such?” (Chadwick 2008 (2009); pp. 28)

Is it preventive medicine or enhancement to boost the immune system? That such questions cannot be answered unequivocally was a subject of discussion at the beginning of this thesis. Here, something cannot be termed ‘therapy’. Chadwick could also have tried to put the idea of boosting one’s immune system under the heading of prevention. This would have resulted in a semantic struggle to keep what one wants to allow for under the heading of conventional medical practice. It is better to say it out loud, and indeed term boosting the immune system an enhancement, and pre-selection or prenatal genetic intervention as a form of eugenics. Is this a problematic form of eugenics?

In this thesis, we have seen several examples of eugenics or dysgenics that are obviously very decisive for the identity a future person may have, examples of traits that are only useful for one specific talent, traits that specify a person’s identity, walk in life, or the community to which he will belong in a very definitive fashion. Traits such as general fitness or intelligence are different in that they do not lay down such definitive and specific identities and lives. The argument that what is choice for parents remains fate for the person that results from it may therefore not apply.

For most, one’s immune system does not play an important symbolic part in the way one defines oneself in life. We do not hold any deep cultural notions on immune systems. Nor do we hold such deep notions on whether the length of our index finger is exactly 8cm or slightly above or below. An enhanced immune system, built in by one’s parents, will probably be not detrimental to one’s sense of self. Still, secondary reasons may be if the context of such a choice would be that parents want a child that fits some standard of medical perfection. To take the unlikely (and up to now impossible) case of a parental couple that desires a child that will have an index finger measuring exactly 8cm, for the person in question, that finger may play a very awkward role in his definition of himself and his exis-

tence: I was named after the cigarette brand of my grandfather. This has a similarly awkward part to play for my sense of self. One's name is to a high degree considered to be arbitrary, although it plays a recurrent role in one's life. In most cases an enhanced immune system will not likely be taken as such an exclusive condition for the choice of a child. It will rather be chosen as an added benefit for that future person that plays no role in his sense of self. Similarly, an enhanced IQ or an enhancement of general fitness does not seem to be problematic in the light of one's sense of self. Still, underlying parental expectations in the case of IQ or fitness may very well be associated with specific life plans. Not that the traits in question inescapably lay down a specific life plan, but the fact that they were conditional to one's existence may well bring along a feeling of being locked in. Not the trait(s) in question but their symbolic role in society should be the focus of the ethical assessment of prenatal selection and intervention. It remains questionable in how far a parental couple desires an adjustment or preselection for a child with a higher immune system for the sake of that child, or for their own sake. How can one assess whether a parental couple desires a higher IQ, an enhanced immune system or a specific gender for their child as part of their own ideal picture of what their child should be or as part of a genuine concern for that future person's well-being. The two can hardly be distinguished in having children, but their moral relevance is quite different. In the one case, the trait in question will merely play an arbitrary role in someone's life, in another it would not.

The issue is different for prenatal selection to specify the gender of a future child. Gender will definitely play an important role in one's sense of self. It also lays down certain life-plans. But gender selection cannot be measured along the rod of either enhancement or dysenhancement. In our contemporary society both genders are treated as equal. Choosing a future child's gender, at least when the motive is balancing the make-up of a family rather than qualifying one or the other gender as less valuable, does not appear to be problematic.

Jonathan Glover thinks the criterion should not be whether a specific genetics choice still fits the medical paradigm or not. He takes the concept of flourishing to be central to what genetic choices can be allowed for, and what choices cannot. On that basis he states that "in thinking what we owe to our children, one idea is the right to an open future. Perhaps an open future is what we should leave to our descendants as well" (Glover 2006; pp. 104). This right to an open future should be the moral criterion to assess which forms of prenatal selection should be allowed for and which should not (Glover 2006; pp. 102-104), since one cannot flourish with a future that is already laid down by genetics choices of one's parents. On the basis of the right to an open future criterion he perceives of possibilities for a new liberal eugenics that are not morally problematic (including the case of the enhancement of intelligence).

Whether one's future is open or not is not merely dependent of the trait that is chosen, but also the significance we give to it and the motive for choosing it. Two

parents wanting a smart child on demand, desiring a child with superior intelligence performing as condition to having child, rather than for its own sake will probably not raise a child liberally. He will have to answer to the ideals set by his parents. Is it all right to medically assist parents to make such choices? According to Jonathan Glover, these types of enhancement would not be problematic seen the fact that they open up one's future and provide for more opportunity to flourish in life. Maybe a higher intelligence does create the possibility to flourish better than others. But does a higher intelligence that has been created for the purpose of satisfying the desires of one's parents also create such potential? To assess this better, one will have to look again at whether the relationship parent-child would be different in eugenics rather than apart from it.

Habermas sees the link between genetic trait and identity as a necessary link. This does not imply that he takes traits to determine identity. It means that one's relation to oneself is in part also constituted by ones genetic traits. Habermas's aim is to demonstrate that there is a distinction between traits that have been chosen, and those that are the result of haphazard accident. In other words, the nature of chosen genes or traits is no different than that of genes and traits that are the result of chance combinations, but the nature of how one relates to them is: what is 'choice' for parents will irreversibly remain 'chance' for children, even beyond childhood. For Habermas it is not genetic determinism but this type of parental determinism through genes that raises serious ethical concerns.

Prevention of harm is not restricted to cases of medical prevention and therapy. This means eugenics choices that aim at the prevention of harm could be justifiable. Contemporary society often already condones of such choices, but the moral justification for choices in prenatal selection is often restricted to therapy or prevention. Therefore, these concepts are stretched to the limit by terming the prevention of the birth of a person with a disease, prevention of that disease. With the broader justificatory criterion of prevention of harm, such semantic absurdities can be limited. There is a further specification of this criterion. The central problem with many eugenics choices is that an essential element for the identity of a future person has been chosen by parents, but can never be discarded with by the child. For traits that have a symbolic significance in our culture, the choice-identity-argument against eugenics appears more self-evident. The argument of intergenerational inequality with respect to chance and choice should therefore overrule any other interest by proxy that might be defined for the child in question. This means the following; any positive eugenics aiming at the birth of children with a specific trait or subset of traits, aiming at a specific identity or life plan, or a more general one, raises serious concerns with regard to the liberty of a person to build his own life, rather than the one envisaged by his parents. Buchanan *et al.* may have chosen a very appealing and fitting title for their book, the road does not run 'from chance to choice' for all involved.

#### 4. Habermas and the Problem of Naturalism

In *The Future of Human Nature*, Habermas makes use of the term nature in a moral sense. His argument therefore threatens to suffer from the very same problems as the arguments of liberal eugenicist. For the genetically selected, how one would be was a condition of the way one was conceived: not only the fact that he exists is dependent on parental decision-making (or lack thereof in some cases) but also the way one is, what one is. Now, one could raise the objection that one is formed as much by one's education as much as by one's genetic background. What I am influences what I choose and how I choose, and what I am in turn is influenced by how I was raised, what my environment was and is, and how I was born. How I was raised and what my environment was are things we usually perceive of as factors that may be influenced by others, the parents in particular, but also governments (in regard to my education), doctors (in regard to my health) and other civilians (with regard to an inexhaustible list of things) can be of influence on who I am, whom I have become to be and what I learned to desire or dislike. And we do not object to educational enhancement or specification, so why would we object to a genetic enhancement or, more neutrally, a genetic specification of posterity? The grown, the natural, is contrasted with the made as if these were two separate categories in reality, that should not be mixed.

In reference to his duality of the modes of the man-made and the naturally given, Habermas seems to embrace a pre-Kantian worldview. In this worldview, or metaphysical ground, one only distinguished between differences within the level of being. There was no account of the place of the perspective on being. In most readings of Descartes' difference between *res extensa* (matter in three dimensions) and *res cogitans* (thinking matter), both modes are also merely seen as two qualities of being, without taking into account the perspective quality implied in the relation of thought to experience<sup>52</sup>. The difference between what is grown and what is made as far as it is associated with human being is quite easily contested after both neo-pragmatism and structuralism; whether one is an essence, or whether one only consists of marginal properties has already been perceived of as matter of choice rather than being categorical distinctions for quite some time. Habermas does tone down his distinction between what is given by nature and what is culture, stating it is a distinction that was once made in (Aristotelian) metaphysics, which are now merely valid as contemporary daily references to ourselves and the world around us. Habermas uses the terms natural and artificial not in their original ontological

52 This reading of Descartes was corrected by Martin Heidegger's teacher, Edmund Husserl, who, at the end of his career, took on the task of reinterpreting Descartes seventh meditation in which this presupposition about Descartes dualistic differentiation between the two modes of 'res' is contested, which steered the interpretation of Descartes' work into the direction of Kant's ideas of the status of the world perceived in relation to the perceiver.

meaning, but as categories of pragmatic reference. Even though nature and artifice, biology and society are “no longer connected with ontological claims”, they are still “closely interlaced with certain modes of dealing with the world” (Habermas 2003; pp. 44). They are ways in which we refer to the world rather than different categories. Habermas therefore only uses them to state something on the nature of the way we relate to ourselves and the world, not on the nature (ontological status) of us or the world in itself. At the basis of the distinction between the grown and the made lies another issue that holds more ethical relevance than the differentiation between these two categories themselves.

“Gene manipulation is bound up with issues touching upon the identity of the species, while such an anthropological self-understanding provides the context in which our conceptions of law and of morality are embedded. My particular concern is with the question of how the biotechnological de-differentiation of the habitual distinction between the ‘grown’ and the ‘made’, the ‘subjective’ and the ‘objective’, may change our ethical self-understanding as members of the species and how it might affect the self-understanding of a genetically programmed person. We cannot rule out that knowledge of one’s own hereditary factors being programmed may put certain constraints on an individual’s right to an open future, while undermining the essentially symmetrical relations between free and equal human beings.” (Habermas 2003; pp. 22-23)

In effect, it is not the ontological status of the person that might be changed by biotechnological interventions in reproduction, but a person’s self-perception and self-understanding. This may not be a necessary consequence. It depends on what type of eugenics intervention is aimed at. In some cases it might rather be societal than individual consequences that matter. But in Habermas’ case, the fact that it may put constraints on a future individual’s right to an open future is reason enough to refrain from programming a person genetically.

## **5. Personal Identity and Community-ethics**

As Habermas states, we make an intuitive distinction between grown and made: grown being seen as belonging to the sphere of the subjective, whilst the made, the artefact, is seen as belonging to the objective sphere. For our part, to have grown means to have been conceived of and born naturally. Habermas thinks, we should aim at a renewal of interpretations of nature as moral (rather than morality as a natural). Moralising human nature leads him to the definition of an ethics of the species that can account for the importance of an understanding of ourselves as moral beings., whilst naturalising morality is the hidden presupposition of eugenics. This self-understanding would be endangered since, according to him:

“a previously unheard-of interpersonal relation arises when a person makes an irreversible decision about the natural traits of another person [...] when one person makes an irreversible decision that deeply intervenes in another’s organic disposition, the fundamental symmetry of responsibility that exists among free and equal persons is restricted.” (Habermas 2003; pp. 14)

The fundamental reason for this unbalance is to be found in the following: “the adult [that grows from a child that is genetically specified] would remain blindly dependent on the nonrevisable decision of another person, without an opportunity to establish the symmetrical responsibility required if one is to enter into a retroactive ethical self-reflection as a process among *peers*.” (Habermas 2003; pp. 14). The fact that one can influence the genetic quality of future people creates an unprecedented moral relationship between generations. It is not the artificiality or unnaturalness as such that is cause of ethical problems in steering our children’s genetic disposition, but rather in the way this creates different modes of dependence between generations than the ones we already know. However, for Habermas, in the eugenics debate, it is not so much the difference between the born and the made, but the difference in self-consciousness between having been born and having been made that is ethically relevant. It is relevant because of the irreversible dependence it creates between two generations. As Habermas states:

“Up to now, only persons born, not persons made have participated in social interaction. In the bio-political future prophesied by liberal eugenicists, this horizontal cohesion connection would be superseded by an intergenerational cohesion stream of action and communication reaching vertically across the deliberately modified genome of future generations.” (Habermas 2003; pp. 22-23)

The issue is whether it holds moral relevance that this horizontal social cohesion is added upon with a vertical one. Habermas believes that the moral problem that arises in vertical cohesions is that it fundamentally affects the equality between persons of different generations. This is not an issue that is visible in the practical ethical field, it is an issue that precedes this field, and affects its preconditions, namely to participate freely and equally in the social sphere. For Habermas, the intergenerational dependency in itself is not the central moral issue. The moral issue lies in its consequences, since this dependency would ultimately be detrimental to our standard conception of ourselves as free and autonomous moral beings. This would change the ‘ethical self-understanding of the species’ – as a basis for our self-understanding and our understanding of the others as moral creatures.

Habermas proposes to (re-)moralize human nature, in order to account for an understanding of ourselves as members of the species, and in this membership as authors of our own lives. To be able to see ourselves as of equal dignity, one has to see oneself anthropologically speaking as members of the species (Habermas 2003;

pp. 28-29). Also, to be able to understand oneself as a moral being, one has to understand oneself as a member of the species. Or, in Habermas' own terms:

"[...] the advances of genetic engineering tend to blur the deeply rooted categorical distinctions between the subjective and the objective, the grown and the made. What is at stake, therefore, with the instrumentalization of prepersonal life is the ethical self-understanding of the species, which is crucial for whether or not we may go on to see ourselves as beings committed to moral judgment and action." (Habermas 2003; pp. 71)

Habermas takes an anti-eugenics stance since according to him it would be detrimental to our capacity to be moral. Although in an earlier part of the book, he discards with the ontological and metaphysical basis of the distinction between grown and made (pp. 44), he does administer them a categorical status. This argument therefore lies tantalisingly close to the argument against eugenics that was provided by Francis Fukuyama in *Our Posthuman Future* (2002). Fukuyama also fears that to allow for a eugenics programme would ultimately change our morality. However, Fukuyama identifies this change of morality with changes in our genome, whilst Habermas defends the same position without resorting to a socio-biological determinism<sup>53</sup>.

Habermas' concept of an ethics of the species is somewhat misleading. For one, an ethics that is based on the ability to still consider oneself as belonging to the same species seems to prioritise the discursive environment above the inhabitants of that environment. Secondly, a new eugenics does not necessarily aim at the old goal of an optimisation of the species (Habermas 2003; pp. 29), it aims at giving people better starting positions in life. Thirdly, the moral problem of a new eugenics is not its potential detrimental effect on our current culture, society or discursive environment, but its direct consequences for those affected by it. The moral aberration of proponents of a liberal eugenics can already be found in the problem of inter-generational dependency itself, not the effects thereof on the discursive environment. What was choice for the parent will be fate for the eugenically created, creating a fundamental non-equality between both partners. The inequality implied is an ethical injustice in itself, whether or not one would want to hold it as a threat to the presuppositions of a moral discourse. Habermas therefore seems to revert to a societal idealism by posing that eugenics poses a threat to his ideal of a discursive society, when he already makes the most important ethical point in an earlier stage of his argumentation, namely, in posing that the idea of designing posterity leads to

<sup>53</sup> He however does not discuss the possibility of a eugenics intervention that can be turned back by the person resulting from it. In that sense, he takes genes to be determinative. One might be able to render a born deaf hearing later in life. But in the case of deafness, becoming a hearing person later in life would not fully annul the condition; one will always have a speaking disorder.

a problem of individual self-understanding in relation to others, apart from further consequences for society or the self-understanding of the species. Reference to a 'species ethics' in building an argument against a new liberal eugenics therefore might have been to be superfluous.

One does not need to define in what way a person is less author of his life when eugenically 'programmed' to show where it is at fault. It is not that one is less author of one's own life, but that another person took the position to be author of one's life where the moral problem can be found. It is not in a change of our anthropological status as being grown or made that the injustice of eugenics lies, nor in our understanding thereof, but a matter of our freedom: eugenics is unjust when it implies choices that are made in our stead that will act as purely biological causes to our identity. It is the exclusive authorship of the other in these choices that is fundamental to the moral assessment of eugenics. Apart from whether inequality would form a problem for the eugenically preselected person, or apart from whether it would even be perceived as such, this choosing in another person's stead should not be the attitude of the eugenically selector<sup>54</sup>. To be able to gain clarity on these issues, one will need to have a more consistent conception of human agency as self-referential in its reference to others. If one takes such a view on eugenics rather than either a conception of man as an automaton performing behaviour or man as a rational nucleus that has his biological traits at his disposal, this will result in a different moral analysis of eugenic as well. In the next paragraph, I shall give an account of human agency that does include the issue of self-referentiality.

## 6. Moral Agency and Eugenics: a Reconstruction of the Self

In *Enhancing Evolution* (2007) John Harris states that since all would agree that there is nothing wrong with the desire for a healthy child, we should consequently not condemn the desire for a child with improved traits either. Harris poses the rhetorical question: "If it is not wrong to wish for a bonny, bouncing, brown-eyed baby girl, why or how would it become wrong if we had the technology, the choice, to play fairy godmother to ourselves and grant our own wishes?" (Harris 2007 (I); pp. 145). Harris does not take arguments against a positive eugenics arising from the discussion on the self to be valid. Somewhat further in his book, he states: "[...] while the personal identity issues are fun philosophically, they don't seem, to me at least, to have any ethical impact at all" (Harris 2007 (I); pp. 180). Harris criticises Habermas' strategy to pick up the problem of the self in his approach to the ethics of prenatal selection. Harris considers the identity-argument to be a scholastic

<sup>54</sup> One cannot even assume a hypothetical consent or non-consent by retrospect (a retrospective consent by proxy) since that (future) person cannot but agree with the circumstances that lead to his existence.

argument. He terms the preoccupation with the issue of personal identity a gross form of philosophical indulgence at the expense of moral decency. He seems to be under the impression that Habermas wants to put people with a handicap in the world on purpose even going as far as to call it cruel to ban prenatal selection to avoid the birth of disabled people (Harris 2007 (I); pp 181).

I treat the question why should we not enhance posterity' as if it were not rhetorical, and would give the answer that it is wrong, because we are not granting our own wishes by adjusting ourselves, but our desires for how another, future person is to be. What is beneficial for posterity of course is presented as objectively derivable, but in essence it is what Harris personally thinks is beneficial, in his conception of the ideal society. Harris considers the debate on personal identity overly intellectualized. English philosophy is no stranger to anti-intellectualism, but apart from being right or wrong in that respect, the issue of identity cannot be dismissed with that easily. Harris aims to deflate the identity-argument, but the conception of identity Harris criticises is not the conception Habermas holds. Habermas takes the Kierkegaardian conception of the self as relational, not the conception of self or identity as the authentic core or essence of a person. Although this conception of the self is indeed a complex matter, this is no reason to dismiss with it. Rather than presenting the so-manieth picture perfect of society and demanding all to adjust to it, one should take into account the issue of identity and self-relatedness.

The issue of eugenics demonstrates that one needs a concept of the self that does not restrict itself to an essentialist notion of an authentic self, nor to an existentialistic notion that places the subject in a self-creational void. This is only possible if one circumvents the problem of free choice, and the problem of deterministic accounts of the self. Most moral justifications of eugenics revert to either of two faulty presuppositions concerning moral agency. They either suppose that a person's motivations can be reduced to his actual behaviour, or that these motivations can be captured purely by posing some kind of (metaphysical) rule. The historical eugenics movements tended to the first type of reductionism; whilst new style eugenics, liberal eugenics, tends to the latter one. Liberal eugenics takes the implicit anthropology of neo-liberalism in its position that all individuals are equal and (potentially) free moral agents, and it considers issues of biology, culture, language and religion as contingent. Such issues are merely relevant where they function as a handicap or restriction upon this free rational agency.

Eugenics either commits the sin of strong and coercive paternalism, or the sin of reductionism, not so much towards the eugenicist himself in his own self-perception, but in his relationship to the object of eugenics. It may not be surprising that proponents of eugenics often start from either a principled background or from a pragmatist background. One reason why contemporary bioethics cannot formulate a proper argument either in support of or against eugenics is that it also reverts into either the one or the other of these two reductionist fallacies. In an ethics that tries to reduce matters to mere performances of behaviour, one cannot

account for the normative nature of human existence, meaning that one can only perceive of human existence as a bundle of regularities of behaviour. In an ethics that reduces everything to rules, one perceives of the moral agent as standing apart from his life world, or as merely automatically steered by these rules. In that case, one fails to explain how a moral agent can make decisions in the first place. This agent stands apart from the world in which he acts, without any background, be it cultural, social, linguistic or biological, to shape his preferences.

Why would these wrongful conceptions of agency pose a moral issue in the current eugenics debate? If one takes the neo-liberalist's conception of agency, there does not seem to be much of an issue with eugenics choices. After all, the rational agent that has eugenically enhanced (or selected) traits, has assets that enable him or her to lead a life with more options, giving him or her the opportunity to pursue his life goals in a better fashion. However, this would only be possible if we had split personalities: the one part being a general rational moral agent, the other being a set of more or less convenient traits. This is also what is the case according to Buchanan *et al.* . As said, they state with regard to disabilities that it should be noted that it is not the disabled person, but the disability that is devalued (Buchanan *et al.*; pp. 278). But, since this is not the case, this picture needs to be adjusted. And in that adjustment, an injustice emerges that is not visible within a neo-liberalist conception of agency. In order to clarify what type of injustice, we will need to sketch out a more consistent picture of what it is to be human.

The eugenicist fails to acknowledge the actual relationship a person has to himself, to others, and to the world. An agent does not stand apart from his cultural, social, linguistic or biological background. This does not determine him, it places him in a world that holds meaning for him, motivates his actions. Thereby he can give reasons for his actions, but he does not necessarily consciously motivate all his actions a priori. His rational justification is there in potentia. And the major issue of any eugenics that specifies a person takes away the option of giving reasons for certain actions, since it all reverts to a choice that was made before the agent came into existence, but simultaneously as a *condition* of that agent's existence. This may not de facto be a problem for the eugenically created (the person in question is more than merely a designed person), but since there is a chance that it will be, there is reason to abandon such initiatives. The eugenicist therefore treads on morally dangerous ground if he takes the responsibility to shape a future person's biology, since in that shaping, he also takes away the condition on the basis of which a future person can take responsibility over himself. This is the essential moral issue in any eugenics.

The eugenicist relates to the eugenically-bred, either as a puppet master to his puppets or as a puppet master to another puppet master. In the first case, the eugenically created is treated as merely a reflection of his hereditary traits; in the second, hereditary traits are merely seen as advantages or disadvantages to a person that stands apart from them in every other respect. A person is neither puppet

master nor puppet. One is not governed by the laws of biology nor does one govern one's traits. Nor, indeed, should anyone take that position towards another person. The idea of a 'designer baby' in the strong sense of the word is therefore morally problematic.

The two reductive approaches to agency, a reduction to behavioural aspects or a reduction to some transcendental subject stripped of any aspects of the self, ignore one important aspect of human existence. To quote from Kierkegaard:

"[...] If this relation which relates itself to its own self is constituted by another, the relation doubtless is the third term, but this relation (the third term) is in turn a relation relating itself to that which constituted the whole relation. Such a derived, constituted, relation is the human self, a relation which relates itself to its own self, and in relating itself to its own self relates itself to another." (Kierkegaard 1989 (1849); pp. 43-44)

What typifies humans, or more generally speaking human existence, is the fact that it is a mode of existence that can refer to its existence from within that existence. This referentiality is not like a reference to another thing. It is unlike referring to an object in the world. In our relationship to others we are able to relate to ourselves; and without others, there is no self-relation either. Many philosophers defend the notion that such a discursive relation is not possible without a linguistic communicative structure. There is no sense of self without a sense of others, and no sense of others without communication with others.<sup>55</sup> This inter-subjective basis of self-consciousness and self-relatedness carries consequences for issues of rights, duties and responsibilities. We take responsibility over ourselves (subject-responsibility) only in so far as we are able to claim authorship over our actions. This authorship stems from a form of self-consciousness by which we can post-factually motivate our actions, by means of giving reasons. For any adult, no other person can claim such subject-responsibility over his actions.

Reproductive choices aimed at the creation of a person with a specific genotype (leaving apart those instances where such a genotype circumvents the creation of a person that will suffer from a severe disease), are both irreversible and mono-directional. They are different from educational choices. For example over the past few decades in countries with a linguistic diversity parents often decide to raise their children to speak the national language rather than the local dialect they themselves were raised with, in order for their children to have an advantage in getting a job elsewhere in the country or in another social class. A child is thus, in part, excluded from its peer group – i.e. those children around the child that are raised in the local dialect. One might consider such upbringing irreversible: the

<sup>55</sup> The likelihood of this necessity can be illustrated quite easily with the example of wolf children such as Kaspar Hauser, who never developed a sense of self, since he was raised by wolves and could therefore not speak.

child might be able to learn to speak the dialect at a later age, but it will never speak it as a first language. On the other hand, if one is raised with a specific language, one is also made into the co-author of being raised as such. Raising a child is not mono-directional, one has to adapt to the child's needs and preferences as much as the child needs to become moulded to the shape its parent seek to establish. Even as a small infant, one is made into the co-author of one's life, even if it were merely because one learns one's place in the world, adapting to the attitudes of others, taking over, or refusing to take over the opinions, ideals and goals of one's parents.

Choices that aim at the creation of a person with specific genetic traits are different to modes of education in raising a child. Education is not a question of choosing a method and then applying it to the child; child and method of upbringing co-evolve. Although children are sometimes raised in a restrictive environment where the desires of the parents count harder than the individuality of the child, it is always possible to distance oneself from such an upbringing. In the case of genetic choices, there is no such co-evolution of genes and person. Normally speaking, a person learns to live with himself as he is, but one of the reasons he is able to do so, is that nobody has been intentionally responsible for his genetic make-up. This is not the case with genetic choices beyond avoiding the obvious, be they dysgenic or eugenic choices. The boundary between the avoiding the obvious and avoiding the non-obvious is to be placed somewhere between avoiding deafness and avoiding Huntington's. The avoidance of deafness is different from the avoidance of Huntington's. Whilst deafness is not lethal, Huntington's in the end is; whilst for some deaf, their deafness is not as impairment, this is not the case for anybody who has a predisposition to develop Huntington's. Although for some, to find out they have the disposition rids them from a feeling of guilt with regard to other siblings who carry the disease, they would probably all prefer neither them nor their siblings to have the disposition. Therefore, selection to avoid the birth of a child with deafness should not be allowed for, whilst selection to avoid the birth of a child with Huntington's should. Selection on deafness or Huntington's both should not be allowed for, although for different reasons. Although it is debatable whether deafness is an impairment, it is not debatable that it is a trait that defines a person rather specifically. Specifying a future person to have the disposition to develop Huntington is nothing short of cruelty, since it would enable that person to lead a perfectly normal life, but purposely with the disadvantage to develop a severe condition later in life. There can be no justification for such a choice. Not selecting should be allowed for in both cases, since it is a basic right to abstain from genetic diagnosis or from abortion. In the case of prenatal selection for deafness the reason not to allow it is different. Since not all accept that it is a disease or a disability, selection to avoid it is dubitable, but selection to specify it is as well, since it narrows down a future person's life plan.

The irreversibility of one's genotype in the case of a genetic selection beyond the avoidance of the obvious is different from the irreversibility of a genotype that

is the product of fate, contingency or accident. When one's (irreversible) genotype is caused by fate, it has not been at another person's disposal. Nobody is responsible for what naturally occurs (or, to use a less burdened terminology, what occurs without intent). However, when one's genotype has been at another person's disposal, it is that other person who will hold responsibility over the fact that one is so and so. What this person necessarily experiences as fate, was at the disposal of another person in the form of a choice. This creates a dissymmetry of responsibility. Someone who is the result of such a choice will have a lessened responsibility over himself, at least with regard to the actions and choices he will make on the basis of those features that were specified in his genotype. Both eugenics and dysgenics choices lessen a future person's agency.

As Habermas posited, can one still take responsibility over oneself if who one is, is not a matter of rowing with the paddles one has, but with someone else's paddles? It all boils down to the age-old question that can be dated back at least to Descartes, and probably to Plato or even the dawn of western philosophy: who steers the chariot, is it the horses or is it the charioteer? Esoteric gurus like Gurdieff, Blavatsky, Steiner and their more recent brothers in arms maintain the separation between horses and charioteer, providing with methods to gain control of the reins, without asking whether this separation in itself is correct or not. One should be careful with such metaphors. Man is not a division between a span of horses and a charioteer. We are not a hybrid combination of a nucleus of rational agency with a collection of traits. If there is one thing postmodern philosophy did get right, it is the notion of man as a pluralist being rather than a collection of traits charioted by free nucleus, the rational agent. In this wrongful conception of the person, as a conglomerate of an idealised rational agent and his traits that are at his disposal, this is not evident. It only becomes visible when one does understand the person as a more complex and non-dualistic entity. When, on the basis of a wrongful conception of human existence as a separation between traits and a rational agent, one would decide upon those traits for a future person, one takes responsibility over that other person, potentially damaging his ability to take responsibility over himself.

We do not consist of a rational nucleus with properties attached to it, we consist of our biology, language, culture and religion (or lack thereof); and in spite of sociology, psychology or social biology, we cannot be reduced to these (and more) converging lines, rather they enable us to be an agent. By way of mutual scorekeeping in a dialogue of committing ourselves to our social and communicative practices and being entitled to asking the other(s) for their reasons, we keep track of each other's motivations. This also means that we take responsibility over our social practices and claims. This becomes much more difficult if our biology, culture, language or religion have not emerged from the mere fact that we were brought up in a specific place and accidentally have that specific set of parents, but were decided upon previous to our existence as conditions to our very existence. In

short, those things that enable us to be an agent are the very things that are considered as contingent side-issues in neo-liberalism. But these are things that should not be at the disposal of another. Although our biology, language, culture and religion are being decided upon by the fact that we have that specific set of parents and no other, this does not mean that they are at our parents' disposal.

## 7. Discerning the promotion of justice from avoiding injustice

As Adorno and Horkheimer already stated, ideological thought has lost its innocence after the Second World War, and any form of ideological thought is therefore morally suspect. Heidegger's opaque ideas on the future of humanism are based on a similar conclusion. And the very reason for Rawls to abstain from giving a substantial account of ethics is also to be found here: ethics can no longer provide with accounts that define how one should live, it can only retreat into discussions on the preconditions to allow for people to apply their own concept of the good life. However, even in circumscribing such preconditions, one indirectly says something about how one is to lead one's life. The solution offered by Rawls to save ethics from the downfall of the ideals of Enlightenment (and the downfall of traditional metaphysics), and Heidegger's dismissal with a continuation of the ideals of humanism can therefore be easily converted into a system that still implicitly prescribes how one should live. This is indeed demonstrated by proposals for a new liberal eugenics such as that of Buchanan cum suis or Sloterdijk. To define what is wellbeing, to define what is enhancement, to define what is justice in positive ways always seems to lead to forms of ideological thought that preclude their reversal into unjust applications. It therefore seems to be a more cautious strategy to define ethics on the basis of a liberalism that merely aims at the prevention of harm, rather than the propagation of the good. In *The Faces of Injustice* (1964) Judith Shklar defends a similar position. Shklar stated:

“No form of liberalism has any business telling the citizenry to pursue happiness or even to define that wholly elusive condition. It is for each one of us to seek it or reject it in favor of duty or salvation or passivity, for example. Liberalism must restrict itself to politics and to proposals to restrain potential abusers of power in order to lift the burden of fear and favor from the shoulders of adult women and men, who can then conduct their lives in accordance with their own beliefs and preferences, as long as they do not prevent others from doing so as well.” (Shklar 1989; pp. 31).

As Benhabib (1994) states, Shklar's position is one of an anti-metaphysical liberalism. She rejects Lockean natural liberalism, because of the reductionist fallacies implied. Our nature has become part of social as well as technological manipula-

tion, and apart from which forms of manipulation we discard with as unjust, we cannot and should not want to return to a metaphysical notion of nature. However, Shklar does not search for the methodological conditions for consensus in justification either, seen the improbability of such consensus as well as the philosophical dangers implied in circumscribing such conditions. She was: “[...] more concerned with delineating the physiology of injustice than with erecting rationalist theorems about justice (Shklar, 1990, pp. 20ff); she was more interested in bringing into focus the indignities of exclusion from citizenship than in painting a picture of a perfect republican citizenry (Shklar, 1991).” (Benhabib 1994).

Shklar claims that the line that separates misfortune from injustice is a political choice and not a natural given (Shklar 1964; pp. 5). To treat this boundary as naturally given would therefore lead to its unintended use as a political instrument:

“[...] it is evident that when we can alleviate suffering, whatever its cause, it is passively unjust to stand by and do nothing. It is not the origin of injury, but the possibility of preventing and reducing its costs, that allows us to judge whether there was or was not unjustifiable passivity in the face of such disaster. Nor is the sense of injustice irrelevant. [...] If the victim’s suffering is due to accident or misfortune but could be remedied by public agents, then it is unjust if nothing is done to help. A valid expectation has been ignored and her sense of injustice should assert itself and we should all protest. It is at the very least what one should expect of the citizens of a democracy.” (Shklar 1990; pp. 82)

The decision to perceive of one’s genetic potential as not naturally given but as socially constructed to close ones eyes to people’s suffering would indeed form a grave injustice. There is no reason to oppose a eugenics per se, but there is ample reason to oppose applications of genetics to cohere with some ideal, be it individually or generally held, of the perfect person or society. The only applications of eugenics that seem to be condonable are those that aim at alleviating severe harm, and this would not be a practice that different from what we already allow for in prenatal diagnosis as it is. This defence-option of a negative eugenics is not discussed by Habermas.

The discerning moral criterion for prenatal genetic selection should be whether the selection in question creates an asymmetry between creator and created, in such a way that choices based on the preferences of prospective parents are fate to the intended child. A future person does not have an identity yet. Selection to avoid a severe impairment or disease will not restrict the future person. Although it will have been choice for the parents to have opted for a selection to avoid a child with a predisposition to develop a severe disease, it is not fate to the child in question not to have that impairment or disease, but rather fortune. When one cannot unequivocally state that is a positive thing not to have X, the role of such choices becomes different. Not to be deaf might indeed be perceived of as an advantage to

most, but so is not being ugly. The fact that there is no universal agreement on the negativity of being deaf, or on being ugly, this does not constitute enough reason to allow for pre-selection to purposely put a deaf child or an ugly child on the world. However, it does constitute a reason not to allow selection to avoid either trait, since deafness and ugliness do not constitute an intrinsic problem to one's sense of well-being. Having a disposition to die early, or to have a severe impairment does. Avoiding suffering by avoiding the birth of a child with traits that will intrinsically have a harmful effect on that child is the central issue here.

## 8. Conclusion

Ontology is usually not taken as relevant to practical ethical questions. Within the ethical discourse, one's traits and one's identity are considered as a contingency with regard to that discourse. All moral subjects are considered to be rational and free agents. But such a paradigm of moral agency as merely a matter of free choice oversimplifies matters. The practice of designing people genetically is a practice that, for the designed, changes the relation between Being and being a moral subject. One has to address the issue from an ontological perspective as well.

The question of the justness or unjustness of determining future people's genetic make-up (apart from avoiding severe diseases and disabilities), cannot be answered from within a discursive ethical framework (with acts, reasons, responsibilities and consequences in the communication and interdependence of people). It can only be addressed on the level of the preconditions of that ethics. After all, the ethical discourse is dependent on an inter-subjective structure, and the person that does not exist yet, is not a part of this inter-subjective sphere. The act of determining posterity or future people genetically is something that precedes the ethical discourse. One's identity is decisive of one's preferences and therefore of what one wills. As long as this decisiveness is not another person's responsibility, there is no reason to expect that this would be a constraint. But if one's identity has been another's choice, this causes an intergenerational asymmetry.

If one does not take the step to the level of the preconditions of ethics, or if one does not perceive of the possibility of such a step, it might seem that there are justifications of designing people to be found from within a certain ethical discourse. These would, for example, be those modifications that help a person to partake within that inter-subjective ethical discourse. The problem is that the not yet existing person who is to be determined will owe his existence to such a choice, and this excludes any ethical question to such choices because it precedes the discursive inter-subjective atmosphere: to determine traits in posterity on the basis of their desirability is always a determination on the basis of a desirability within a certain subjective historical structure. And the preconditions of any ethical relation are to be found outside of such historical subjective contingencies. In addition,

justification of something that takes place outside of the ethical discourse cannot be found inside of that discourse.

As far as one considers the question of being, the relation between ethics (moral agency in particular) and ontology is a relation that precedes the ethical discourse as we conceive of it. Changing this relation precedes the ethical too. But this relation is also preconditional for moral agency. Human being is not only a being that is given but also an intentional being, a being that can relate to itself. Within this self-relation, the question of identity plays a role of paramount importance. If one takes the question of identity and self-relation into our common conception of autonomy and choice in the moral discourse, then, having been chosen as having this or that genotype (and phenotype) will change one's conception of one's moral agency, and one's autonomy profoundly. What is conditional of having an ethical relation to others, or to one's acts concerning others, is the ability to do that. And this ability is to be found within the juxtaposition of an intersubjectivity that can only be found within a reciprocal ascription of intentionality, self-relatedness. This does not occur when one designs people, since in designing them, one takes the stance towards them as being instead of being and relating.

The self is not to be regarded essentialistically, as a nucleus, not as the true and authentic core of what one is, but as something that emerges from inter-personal relatedness. Identity, in Habermas' translation of Kierkegaard's position, lies in the tension between the contingency of birth and the properties nature has endowed us with, and the way this can be picked up by our own willing in a self-reflective taking on of responsibility over these properties. Genetic technologies could alter the contingency-part of human identity, which could bring forth severe disturbances in the balance between seeing oneself as being caused, a being caused by another person's ideology.

# Conclusion

The moral problem of eugenics is not unique, although opponents of a new eugenics often try to frame it as such (and most proponents do the opposite). Take for example the following case, that, although possibly somewhat charged, does demonstrate that there are parallels to be drawn. If someone would be born as the result from rape, he would probably wind up in an existential problem with regard to the fact that the very precondition to his existence consists of the atrocity performed to his mother, even apart from inheriting the genes of the perpetrator. Eugenics choices are not the result of such an atrocity but in their forming the situation of conception they are similar in their irreversibility. The eugenically chosen cannot oppose these choices without opposing himself. Some might not oppose their being eugenically created, not even experience it as a problem. But can he do otherwise? In any case, it is not just to put someone in such a problematic situation with regard to his relation to his being.

A more lucid illustration can perhaps be found in the following example: we pride in our achievements when they are the result of our own effort but also when they are the result of a happy coincidence of nature. Currently we tend to value the former higher than the latter, but in reality they are more likely to be a combination between both. A person priding himself in his handsomeness or her beauty does not seem to be concerned with the fact that his handsomeness or her beauty is hardly a result of his own effort. As long as they were not the sole result of another person's choice and design, the lack of one's own contribution to one's beauty does not render it impossible to pride in one's beauty. In contrast, even choices that are embraced by the eugenically created as positive, necessitate thankfulness to those that have chosen his genes. He will therefore not be able to be proud of his own nature or the achievements of which they form a precondition. Neither will he be able to discard with the motif behind these choices.

Another example can be found in recent history, and is indirectly bound up with the same context as the old eugenics movements. Until the 1980s, many Australian aboriginals were forced to give up their children for adoption to white families. The resulting generation of aborigines are from a lost generation. They are neither at home in the world of the aborigines nor in the world of the white Australians. Australian society now no longer supports these past choices. If a similar practice were to take place between peoples of similar phenotypes, making it possible to keep the child ignorant of his origin, this would not merely be an injustice to the parents, but also to the child. He would not be given the chance to get to know his heritage. If someone resulting from a eugenics choice would not know this fact, it would still be reprehensible to make such choices on that person's behalf. We do not condone of manipulating people, even when these people are ignorant of that fact.

The trouble with moral assessments of a liberal eugenics is that one cannot merely remain in the framework of ethics itself. If one selects prenatally, one does not only select on traits, one selects a certain person. One has to delve deeper, and

also look at what this means for the relation between the selector and the selected. This necessitates the definition of a concept of a self that is neither essentialist nor existentialist. One cannot regard a person as a rational moral agent that stands outside of his life world and makes decisions on the basis of his rationality. For eugenics this type of liberalism, in the worst case, means that he regards only himself and his co-eugenicists as true moral agents, planning the outlook of future generations as if they were breeding stock according to the preferences and demands of their day and age. In the best case, the eugenicists considers himself as standing free from the traits he has whilst taking it for granted that the future person will consider himself accordingly, being glad that he has been furnished with traits that further his life's success in the idealised liberal society. In such a scenario, the demands of the liberal society on the one hand and the fact that someone acts according to it on behalf of a future person's life on the other, puts a strain on the whole basis of liberalism.

Prenatal selection is not a wrong per se. It is only wrong when the reason behind these choices is given through personal or collective ideals and ideologies. Prevention of harm is not restricted to cases of medical prevention and therapy. Therefore, eugenics choices that aim at the prevention of harm could be justifiable. Contemporary society often already condones such choices, but the moral justification for choices in prenatal selection is often restricted to therapy or prevention. Therefore, these concepts are stretched to the limit by terming the prevention of the birth of a person with a disease, prevention of that disease. With the broader justificatory criterion of prevention of harm, such semantic absurdities can be limited.

The mistakes made in the discussion on eugenics are very much the result of the problem of, amongst others liberalism in retreating into debates on the epistemological conditions for a just society rather than on the people participating in it. It seems bioethics has focused too much on the question what would be the best methodology to approach ethical questions and too little on solving them directly. Bioethics aims at providing for the proper machinery to solve ethical issues, rather than providing for arguments and solutions for these issues themselves. The epistemological nature of many approaches and discussions in bioethics stems from the fact that bioethics is a discipline that evolved predominantly from Rawlsian philosophy, and from Anglo-American analytic philosophy. Hence the phenomenon that many discussions in bioethics run parallel to discussions that traditionally belong to linguistic philosophy may strike outsiders new to the area as strange.

The choice of an emphasis on methodology rather than content comes at a price. As much as because such an approach may have its merits, the level of abstraction of many discussions in bioethics is very high. Often, one gets the impression that the actual practical cases serve merely to prove the success of the method at hand, whilst they should be what the main focus is on. Whilst (bio)medical practice continues as it has always done, ethicists seem to hide more

and more in this theoretical debate. Bioethics has to deal with the reductionist consequences with regard to normativity that flow from an emphasis on epistemology. The issue with the methodological debates in bioethics is that they reduce matters of ethics to matters of epistemology. In that sense, they attempt to search for a descriptive basis, which is fundamentally impossible (at the price of inconsistency at least). This issue was dealt with by Wittgenstein, Kripke, Brandom and Moore - all returning to the same position: that one cannot reduce normativity to descriptivity. There is no fundamental theoretical basis for ethics. A move from epistemology to ontology, from method to content, therefore seems to be called for.

A way out of this dilemma cannot be found by diving into this same epistemological discussion again. One will need to make a more categorical move. As Wittgenstein states, doing well cannot be seen as separate from the specific context in which it is done. One cannot define universal rules or methodologies for ethics. Even anti-theoretical approaches such as neo-pragmatism remain, in the end, still just that, an ethical theory. One might think that an ethics of dialogue could solve these problems, but this is only true in so far as one does not restrict the perlocutors by summing up criteria for that dialogue.

The only thing one can do is to leave it up to the debate in practice itself. This means that the ethical epistemologist either remains isolated in his ivory tower, or takes the bold move to step down into the real world since most people in the real world are too preoccupied with dealing with actual problems to make time to free these academic Rapunzels from their towers. There are no princes lining up to climb up the hair that grew out of this secondary debate on methodology. And although no witch has robbed them from their long braid yet, the theoretical ethicists will still need to cut their disciplinary hair and use it as a rope to climb down themselves. They will then need to cut through each Gordian knot they put into it when trying to braid their hair one-by-one whilst lowering their feet closer to the ground.

In the end, beautiful as they may seem, these golden locks have to be discarded, since they keep the princesses wearing them as much imprisoned as the lack of a proper stairway. And, following Wittgenstein's example, this author has to say that that also applies to parts of this thesis itself. For those who choose to remain inside are like Schopenhauer's solipsists, residing in a vestige that cannot be overtaken, but which can be left behind safely, since nobody in there will ever be likely to venture outside without shedding their hair. Like Schopenhauer's solipsists, they risk finding their ivory tower to be more like a madhouse. They are not in need of logical refutations, but rather of a cure.

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# Summary

In the past decades issues of methodology rather than content became emphasised in bioethics. This focus on procedural aspects of ethics has pushed an important issue of ethics aside: the role of personal identity in moral agency. I discuss this issue in relation to the issue of a new liberal eugenics. To this aim, I discuss applied ethics in prenatal diagnosis, the moral autopsy of eugenics, the problematic notion of a neutral scale to rank good and bad traits, the philosophical background of liberalism, and the concept of free choice. These first five chapters have a deconstructive character. In four steps, these chapters demonstrate that current frameworks of ethics, be they connected to medical ethics, to the old eugenics movements, to liberalism, to the notion of choice and future people, are not fit to discuss the moral justification or refutation of a new liberal eugenics. The latter two chapters are more constructive. In the seventh chapter, it is demonstrated why a focus on methodology cannot be used to discuss the issue of eugenics, but that an approach that also discusses the content of the issue at hand can. This necessitates a reconstruction of the concept of the self in such a way that it does not restrict itself to some essentialist notion of an authentic self, nor to an existentialistic notion that places the subject in a self-creational void, something which I have tried to develop with a proposal for a different account of moral agency in chapter seven.

As I showed in chapter one, the current guidelines of medical ethics seem to hold back the reintroduction of a new eugenics, seen the distinction between medical and non-medical interventions and the central place of the principle of protecting patient autonomy through the principle of non-directiveness and informed consent and non-consent. The existing medical ethical framework is used to counter initiatives for a new eugenics. This framework focuses on patient autonomy, more specifically consent the right to be informed and then decide to know or remain ignorant of possible genetic risks, aiming at non-directive provision of information and the goals and limits of medicine. The current criterion in this framework for discerning between allowable and non-allowable forms of prenatal selection builds onto a division between normal and impaired as based in biology and medicine. This division is not tenable as an ethical criterion. Furthermore, there is no reason to assume that going beyond avoiding severe diseases in prenatal diagnosis and selection on that basis would restrict parent autonomy. And finally, with the concept of a presumed consent or consent by proxy one cannot assess the ethics of prenatal selection with regard to future people. Therefore, the current justificatory framework in medical ethics cannot answer the question whether

eugenics choices should be allowed for. So the distinction between medical and non-medical interventions is contestable, and a eugenics is not necessarily enforced. This means that the existing ethical framework on prenatal care does not offer a consistent argument against a new eugenics.

Chapter two was devoted to the way in which the existing tendency to hold back the development of a new eugenics has its origin in the verdict pronounced on the old eugenics movements. The injustice of their project consisted of the prejudices embedded in the perception they held of what counted as fit and what counted as unfit and their disregard of individual autonomy. Proponents of a new liberal eugenics state that these two features of the old eugenics movements are not intrinsically connected to the idea of prenatal selection to enhance the quality of future generations' genes. They hold that the principle of autonomy would not be harmed if a new eugenics would be introduced on the basis of the principles of liberalism and that the prejudice implicit in these movements can be avoided since one now has access to scientifically more founded knowledge on the human genome. Therefore, the current debate on going beyond the traditional scope of medicine focuses on parental rights to access to medical care and the rights of future generations to the best possible starting position in society. Within the framework of a liberal eugenics as elaborated by for example Buchanan *et al.*, the ethics of a new eugenics is placed in a context of fair distribution of opportunity and wellbeing. However, one should ask if this fair distribution of wellbeing and of opportunity remains instrumental to individual human life or if individual human life becomes instrumental to a fair distribution of opportunities. And one should ask who is to state which traits enhance these opportunities without instrumentalising individual human life.

As I demonstrated in chapter three, it is questionable whether we can derive a criterion to distinguish between genetic selection on the basis of sex-preferences, ethnicity, deafness or height that is both neutral and morally relevant. The current defenses of a new eugenics are often based on a presumably neutral scale ranking traits from disadvantageous to advantageous. This scale is connected to a biomedical paradigm of health or normality and disease or impairment. Choices made by future parents seem to be induced by personal preferences and cultural backgrounds rather than by medical factors, and not by a standard ideal. It seems there are many traits that are advantageous in the one context and disadvantageous in the other, or preferred by one group, whilst being valued negatively by another. One cannot use such scales as a criterion of distinction for traits on which it is allowed to select, and traits for which this is not allowed. This would not count as a liberal eugenics. It is either a genetic selection under one conception of good genes that is directly coercively or by the provision of a specific list of options introduced to society, or a complete liberalization of genetic selection of posterity, without any restriction whatsoever.

As I defended in chapter four, the notion of choice in a liberal eugenics is distorted, since the division between trait and person is flawed, and the notion of free will cannot be reduced to choice without leaving out the person who chooses. The relation between the traits one has and the person one is, is more complicated. Not looking at this relatedness obscures the problem of the self in relation to himself with regard to the issue of having been designed. There is something wrong with the presuppositions of liberalism. This surfaces specifically when liberalism is applied to the issue of eugenics. Liberalism focuses on avoiding injustices between a coercive state and the individual. Autonomy is predominantly defined as freedom of choice free choice is seen as having an as broad range of options as possible. The person is merely seen as a free and rational agent, stripped of any contingent trait that would define his identity. The autonomy and freedom of choice for the future person cannot be perceived of from such a perspective since it does not include any conception of identity in relation to autonomy. The self that holds these options is disregarded. Liberalism makes an artificial division between the rational moral subject on the one hand, and the traits he possesses on the other. Choice is therefore framed as having an as wide a range of options as possible.

As I showed in chapter five we do not seem to be able to owe something to future people if a choice for one course of action will create another future generation than a choice for another. Is future people's autonomy definable? If they do not exist yet, how could they have rights where they cannot have duties? It is the question whether a child, or the person he will become, will be burdened by the knowledge having been designed, and this question in itself poses the problem whether a designed person that he cannot think himself away and give his right to existence speculatively to his unborn brother or sister who would have been born if he had not been chosen. It is not a question of finding the right conceptual tool to differentiate between what should count as a disadvantage and what as a disability, and what as an advantage or an enhancement. Instead, one should be asking the question of whether it is ethically justifiable to make decisions for future people that will determine their identity in a specific way. This is something that sets choices that affect future people apart from choices that affect existing people. The notion of responsibilities to future generation is difficult. What current generations choose will be conditional to what future people will come into existence, so how could they oppose our choices without opposing the conditions of who they are. However, this does not mean that there is no ethics that is relevant for future persons at all. Since eugenics choices are fundamental to one's very coming into existence, they cannot be denied by a person. Another person's choices form the very fabric of one's identity. In choosing the specific genetic make-up for one's child, one is assuming responsibility over the identity of that person whilst one should only remain responsible for one's own self. If one preselects one's children to fit one's ideals or preferences, one is *de facto* embracing a relationship with that other person as if he were not another person in his own right, apart from whether

one intends to do this or not. Eugenics can therefore not be discussed from the perspective of future people's autonomy, only on the level of the preconditions of that autonomy.

These first five chapters were meant to demonstrate in what fashion current frameworks of moral assessment are not sufficient to discuss the issue of a new liberal eugenics. It is not enough merely to show the handicaps of these frameworks. One will also need to show what alternative approach would be better. In the sixth chapter, I meant to show in what way the handicaps of current ethical frameworks is also caused by an overemphasis on epistemology, the rules and methods for ethics, not merely in how these rules and methods are applied. In the seventh chapter, I demonstrated that this issue is also connected to different conceptions of man's being as either merely an essence, a biological given, an object in the world, or an existence, a rational being capable of free choice but depleted of any context or 'situatedness'. As said, these two problems, the problem of epistemological reductionism and the problem of defining man's being are related.

As I demonstrated in chapter six, a focus on methodology has obscured discussion on content, since practical ethics retreated into defining criteria for the ethical debate, rather than judging right from wrong itself. This retreat followed the criticism of enlightenment idealism after two world wars. Because of it, issues of a more anthropological nature were dismissed with, whilst the debate on these criteria for debate itself got stranded in a fundamental epistemological problem. The question is whether communicative and behavioural practice should be taken as a starting point (a bottom up approach) or reflective theory (a top-down approach)? Top down approaches of ethics were criticised because the application of an ethical rule or principle to a specific practical case scenario is far from self evident. Other approaches were proposed such as casuistry or specified principlism. Bottom-up conceptions were criticised too, since they an ethics without any reference to the concept of rules reduces what people apparently think of as good in practice to what is good as such: one reverts to in rules, without being able to show in what way they bear upon a specific practical case, or one reverts to the practice of social interaction, without being able to show in what way this practice leads to correct justifications. This problematic relation between rules and the practices they are supposed to regulate, was analysed with specific regard to its philosophical background in the works of Wittgenstein, Kripke, Gödel, Moore and Brandom. Both top-down and bottom-up approaches ultimately look for a basis for justification in specific accounts of moral agency. The interesting character of the discussion on eugenics consists of the fact that it addresses ethics both on the level of content and presupposition: one should measure the justness of a new liberal eugenics both against the background of morality and the level of the conditions of moral agency. This did not go unnoticed in the field.

The problem of human identity, of the self, is the field I addressed in chapter seven. I discuss why continental European philosophy did not discard the notion of human identity in favour of a more political philosophical discussion, whilst in the Anglo-American discussion, specifically the one triggered by the publication of *From Chance to Choice*, issues that concern the interconnection between autonomy and identity are not seen as fundamental. The clash between German philosopher Peter Sloterdijk on the one hand, and the academic establishment (Habermas himself in particular) and the media on the other serves as a good introduction to this interconnection. Jürgen Habermas elaborated the problem of the power relationship involved in eugenics choices in his *The Future of Human Nature* (Habermas 2003). The question of the justness or unjustness of determining future people's genetic make-up (apart from avoiding severe diseases and disabilities), cannot be answered from within a discursive ethical framework (with acts, reasons, responsibilities and consequences in the communication and interdependence of people). It can only be addressed on the level of the preconditions of that ethics. He bases his argument against eugenics on Kierkegaard's notion of the self as based on the existence of others. In contrast with both the liberal eugenicist's reverence for the outdated naïve capitalist notion of a liberalism that is purely built on 'free choice' Kierkegaard's notion of the self demonstrates issues of inter-generational justice with regard to parental choices about the genetic quality of their children. This also results in alternative conception of moral agency. The ethical discourse is dependent on an inter-subjective structure, and the person that does not exist yet, is not a part of this inter-subjective sphere. The act of determining posterity or future people genetically is something that precedes the ethical discourse. One's identity is decisive of one's preferences and therefore of what one wills. As long as this decisiveness is not another person's responsibility, there is no reason to expect that this would be a constraint. But if one's identity has been another's choice, this causes an intergenerational asymmetry. In this respect, the self is not to be regarded essentialistically, as a nucleus, not as the true and authentic core of what one is, but as something that emerges from inter-personal relatedness. The discerning moral criterion for prenatal genetic selection should be whether the selection in question creates an asymmetry between those that select and those that are selected. This asymmetry in question is that what are choices based on preferences for prospective parents are fate to the intended child. Selection to avoid a severe impairment or disease will not restrict the future person. Although it will have been choice for the parents to have opted for a selection to avoid a child with a predisposition to develop a severe disease, it is not fateful, but fortunate. But when there is no universal agreement on the negativity of trait X, one should not allow for pre-selection. However, this *is* a reason not to allow selection to avoid such a trait, since it does not constitute an intrinsic problem to one's sense of well-being. Having a disposition to die early, or to have a severe impairment does.



# Samenvatting

In de toegepaste ethiek is de nadruk de laatste jaren steeds meer komen te liggen op de vraag naar de beste ethische methodiek en daardoor steeds minder op de inhoudelijke bespreking van ethische problemen in de maatschappelijke realiteit. Omdat de aandacht vooral uitgaat naar procedurele toepassingen van ethiek, is een belangrijk aspect van de ethiek uit het zicht verdwenen: de rol van persoonlijke identiteit in het morele handelen. Ik bespreek dit probleem tegen de achtergrond van het toepassen van biotechnologie in de prenatale sfeer om de genetische kwaliteit van het nageslacht te verbeteren, de zogenoemde eugenetica. De eerste vijf hoofdstukken van dit proefschrift hebben daarom een afbrekend karakter. Ik probeer in vijf stappen aan te tonen dat de interpretatieve kaders in de standaardbenaderingen van de liberalistische ethiek niet toereikend zijn om de toelaatbaarheid van een nieuwe liberale eugenetica te beoordelen. In het eerste hoofdstuk bespreek ik hoe toegepaste ethiek heden ten dage vraagstukken rondom prenatale diagnostiek behandelt. Dan bespreek ik de morele autopsie van de oude eugeneticabewegingen, dan het idee van een objectieve schaal voor goede en slechte eigenschappen, dan de filosofische achtergrond van het liberalisme, en dan conceptuele problemen rond het begrip van vrije keuze in het morele handelen. De laatste twee hoofdstukken zijn meer constructief. In het zesde hoofdstuk laat ik zien waarom een nadruk op methodologie, op een zogenaamd methodologisch of epistemologisch reductionisme, niet gebruikt kan worden om het probleem van een eugenetica te beoordelen. Een benadering die ook gericht is op de inhoudelijke ethische problematiek kan dit wel. Om dit specifieke probleem op te lossen is het nodig het concept van het *zelf* te *reconstrueren* zonder te vervallen in de notie van een authentieke kern van de persoon, of een existentialistische notie van het subject als geworpen in een leegte waarin hij de verantwoordelijkheid heeft zichzelf te construeren. Deze notie ontwikkel ik in hoofdstuk zeven op basis van onder andere de ideeën van de Duitse filosoof Jürgen Habermas. Op die manier probeer ik een nieuwe beschrijving te geven van moreel handelen waardoor beginselverklaringen voor een nieuwe eugenetica beter ethisch kunnen worden geanalyseerd.

In het eerste hoofdstuk zet ik uiteen dat de huidige medisch-ethische richtlijnen een herintroductie van de eugenetica lijken tegen te houden. Er wordt een onderscheid gemaakt tussen medische en niet medische interventies. Daarnaast staat het principe van respect voor de autonomie van de patiënt voorop. Dit bestaande kader wordt gebruikt om medisch handelen af te grenzen, en een nieuwe eugenetica valt erbuiten. Het bestaande kader richt zich vooral op die autonomie van de patiënt, met name in zijn recht om te worden geïnformeerd, en zijn recht

om al dan niet zijn genetische risico's te weten. Daarbij richt men zich op een niet-directief aanbieden van informatie.

Eugenetica zou nu het meest praktisch kunnen worden ingevoerd door prenatale selectie. Het huidige criterium om een onderscheid te maken tussen toelaatbare en niet-toelaatbare vormen van eugenetica is gebaseerd op het onderscheid tussen normaal functioneren en abnormaal functioneren, hetgeen vaak bio-statistisch wordt gedefinieerd. Zoals ik aantoon is dit onderscheid niet houdbaar als ethisch criterium. Bovendien is er geen reden om aan te nemen dat het voorbij gaan aan het vermijden van alleen ernstige ziekten in prenatale diagnostiek en selectie een restrictie zou vormen op de autonomie van de patiënt. En dan is het nog zo dat met het concept van hypothetische toestemming, de rechten van de toekomstige persoon niet kunnen worden veiliggesteld, omdat het concept niet werkt. Daarom kan de vraag of een nieuwe eugenetica toelaatbaar is niet worden beantwoord binnen het huidige kader van rechtvaardiging in de medische ethiek. Het onderscheid tussen medische en niet-medische interventies kan aangevochten worden en al wordt eugenetica vaak geassocieerd met dwang, dit is niet noodzakelijk het geval.

Hoofdstuk twee is gewijd de manier waarop de bestaande neiging om de ontwikkeling van een nieuwe eugenetica tegen te gaan haar oorsprong heeft in het oordeel dat over de oude eugeneticabewegingen is ugesproken. De onrechtvaardigheid van het deze oude eugenetica lag in de perceptie die zij had van wat telde als geschikt voor voortplanting en niet geschikt voor voortplanting, waarbij er geen aandacht was voor de autonomie van de mensen die het betrof. Voorstanders van een nieuwe liberale eugenetica verdedigen dat deze twee argumenten tegen de oude eugenetica niet gelden voor een nieuwe liberale eugenetica. Het verbeteren van de kwaliteit van de genen van ons nageslacht zou niet intrinsiek verbonden zijn aan deze twee argumenten. Zij stellen dat het principe van autonomie niet zou worden geschaad als een nieuwe eugenetica zou worden geïntroduceerd op basis van de principes van het liberalisme, en dat de vooroordelen van de oude eugenetica kunnen worden vermeden aangezien we nu veel meer weten over het menselijke genoom. Daarom motiveren voorstanders van een nieuwe eugenetica deze met een beroep op de vrije toegang tot medische zorg en het recht van toekomstige generaties op een zo goed mogelijke uitgangspositie in genetisch opzicht. In het liberalistische denkkader zoals uitgewerkt door bijvoorbeeld Buchanan et al. wordt de ethiek van een nieuwe eugenetica uitgewerkt op basis van een eerlijke verdeling van kansen en geluk. Het probleem is echter of men deze eerlijke verdeling van geluk en kansen bij een herinvoering van eugenetica instrumenteel laat zijn voor de individuele mens, of dat men deze instrumenteel maakt voor die eerlijke verdeling. Bovendien is het de vraag of men kan bepalen welke verbetering van eigenschappen individuele kansen vergroten en welke instrumentaliserend werkt.

In hoofdstuk drie betoog ik dat men geen neutraal criterium kan opstellen om een ethisch onderscheid te maken tussen selectie op basis van geslacht, etniciteit, doofheid, lengte, etc. De bestaande verdedigingen van een nieuwe eugenetica

worden vaak gebaseerd op een schaal van voordelige tot nadelige eigenschappen, waarvan wordt verondersteld dat ze neutraal is. Deze schaal wordt verbonden aan een biomedisch paradigma van gezondheid of normaal functioneren en ziekte of abnormaal functioneren. Keuzes die door wensouders gemaakt worden lijken eerder ingegeven te worden door persoonlijke voorkeuren en culturele achtergronden dan door biomedische factoren of door een universele ideaalstandaard. Het is erg contextafhankelijk of een bepaalde eigenschap voordelig of nadelig is. Daarom kunnen dit soort schalen niet worden gebruikt om te bepalen op welke eigenschap men mag selecteren en op welke niet. Als dergelijke schalen wel gebruikt zouden worden, dan gaat dit in tegen het beoogde liberalistische karakter van een nieuwe eugenetica. Ofwel men voert een prenatale selectie in op basis van een universeelstandaard van wat goed is en wat niet, daarmee direct of indirect dwang uitoefenend op de wensouders om voor die specifieke opties te kiezen, ofwel men laat alles toe, zonder beperking.

Zoals ik in hoofdstuk vier betoog, is de bestaande notie van vrije keuze in het liberalisme niet toepasbaar op het onderwerp van een nieuwe eugenetica, omdat de scheiding tussen persoon en eigenschap kunstmatig is en de notie van vrije wil niet kan worden gereduceerd tot louter keuzevrijheid zonder dat de persoon die kiest er ook uit wordt geschreven. De relatie tussen de eigenschappen die men heeft en de persoon die men is is gecompliceerder. En als niet naar deze verhouding wordt gekeken dan wordt het probleem van het 'ontworpen zijn' ook niet gezien. Er is iets mis met de vooronderstellingen van het liberalisme, en dit toont zich het beste in het probleem van een nieuwe eugenetica. Het liberalisme richt zich op het voorkomen van onrecht tussen een mogelijk dwingende staat en de individuele burger. Autonomie wordt hierbij voornamelijk gedefinieerd als de mogelijkheid tot vrije keuze, en vrije keuze wordt gezien als het hebben van een zo breed mogelijke lijst van opties. De persoon die kiest wordt gezien als een vrije handelende persoon zonder verdere eigenschappen die zijn identiteit zouden bepalen. De autonomie en vrijheid van een toekomstige persoon kan vanuit zo een perspectief niet worden behandeld omdat er geen relatie wordt gelegd tussen de voorwaarden van het bestaan van die persoon en zijn autonomie. Het zelf dat opties heeft en dat preferenties heeft op basis van wie hij is wordt niet in rekenschap genomen. Het liberalisme maakt daarom een kunstmatige scheiding tussen de rationele handelende persoon enerzijds en de eigenschappen die deze heeft anderzijds.

Zoals ik in hoofdstuk vijf betoog, we kunnen toekomstige mensen eigenlijk niets schuldig zijn, omdat de keuze voor handelingsweg A een andere generatie geboren zal doen worden dan de keuze voor handelingsweg B. Kan men de autonomie van toekomstige mensen überhaupt definiëren? Als zij nog niet bestaan, hoe kunnen ze dan rechten hebben? De notie van verantwoordelijkheid met betrekking tot toekomstige mensen is lastig, want wat wij in het nu kiezen zal voorwaardelijk zijn voor wie er geboren wordt. Hoe zouden ze dan onze keuzes kunnen afkeuren? Dit betekent echter niet dat er geen ethiek kan zijn die betrekking heeft op toekomstige mensen.

stige mensen. Omdat eugenetische keuzes fundamenteel zijn voor de mensen die eruit voortvloeien, kunnen ze niet door die mensen worden bekritiseerd. De keuzes van de een zullen de identiteit van de ander volledig bepalen. Het probleem is dat wanneer men dergelijke keuzes voor een toekomstige persoon maakt, men de positie inneemt verantwoordelijk te zijn en te blijven voor wie die persoon is, en dit is een positie die alleen door iemand zelf ingenomen kan worden. Daarom kan eugenetica ook niet besproken worden op basis van het criterium van de autonomie van toekomstige mensen, alleen op basis van de voorwaarden voor die autonomie.

Een kind of de persoon die dat kind gaat worden zou heel wel belast kunnen zijn door de wetenschap ontworpen te zijn. Het probleem hier is dat een persoon zichzelf niet weg kan denken ten voordele van de hypothetische broer of zus die anders zou zijn geboren. Het ethische kader ter beoordeling van een nieuwe eugenetica kan niet worden opgesteld op basis van het verschil tussen voordeel of positieve eigenschap en nadeel of negatieve eigenschap. De vraag is of het rechtvaardig is om beslissingen te nemen die een toekomstige persoon tot een bepaalde specifieke persoon zullen maken. Dit is het fundamentele verschil tussen bestaande en toekomstige mensen. Immers, Deze eerste vijf hoofdstukken tonen aan dat de huidige conceptuele kaders niet afdoende zijn om een nieuwe liberale eugenetica te verdedigen. Echter, het is niet afdoende om louter de nadelen van deze kaders te laten zien. Er zal ook een alternatief moeten worden geformuleerd. In het zesde hoofdstuk laat ik zien op welke wijze de huidige nadruk op methodologie in de bioethiek ook nadelig werkt in de behandeling van de vraag of een nieuwe eugenetica te rechtvaardigen is. In het zevende hoofdstuk toon ik dat het probleem van deze rechtvaardiging ook is verbonden aan de discussie tussen existentialisme en essentialisme.

Zoals ik in hoofdstuk zes bespreek, heeft de nadruk op methodologische kwesties in de bioethiek het juiste beoordelen van het onderwerp in de weg gestaan. Na de tweede wereldoorlog heeft de ethiek zich steeds verder teruggetrokken in discussies over de formele voorwaarden van het ethische discours, eerder dan de inhoud daarvan. Hierdoor werden kwesties van een meer antropologisch-filosofische aard buiten beschouwing gelaten. Het punt in deze methodologische discussie is of de normatieve praktijk of de formele principes in de ethiek voorrang moeten krijgen. In het eerste geval is het niet duidelijk waarom de praktijk zelf afdoende argumentatie zou leveren voor rechtvaardiging, in het tweede is het probleem dat niet duidelijk is hoe deze ethische principes naar een praktijk te vertalen zijn. Ik heb dit probleem in de ethiek besproken tegen de achtergrond van de werken van Wittgenstein, Kripke, Gödel, Moore en Brandom.

Het probleem van de identiteit of het zelf, is het centrale thema van hoofdstuk zeven. Het thema van persoonlijke identiteit is in de continentale filosofie niet overboord gezet. In de Engels-Amerikaanse filosofie is dit wel het geval en hierdoor worden de discussies over eugenetica daar op een andere manier gevoerd. De

relatie tussen autonomie en identiteit wordt in deze discussie grotendeels buiten beschouwing gelaten. Ik bespreek het aan de hand van Peter Sloterdijks voorstellen voor een nieuwe eugenetica, en het conflict dat hierdoor werd gegenereerd met het Duitse academische establishment. Jürgen Habermas speelde er een centrale rol in, en zijn *The Future of Human Nature* vormt de verdere basis van dit hoofdstuk. Hij bespreekt het vraagstuk of een nieuwe eugenetica te rechtvaardigen is op het niveau van de voorwaarden van autonomie en ethiek. Hij baseert zich op Kierkegaards inter-relatie tussen bestaan, zelf-relatie en relatie tot de ander als basis voor ethiek. Wat iemands identiteit is stuurt ook wat zijn preferenties zijn, en dus deels wat zij keuzes zijn. Dit zien we niet als een restrictie op iemands autonomie, het is daarvan juist de voorwaarde. Het wordt echter problematisch wanneer die identiteit onder andermans keuze valt. In het geval van eugenetische keuzes is datgene wat voor de één keuze is, voor de ander lot. Dit veroorzaakt een asymmetrie tussen verschillende generaties. Deze asymmetrie kan nooit worden opgeheven en is daarom een dwingende reden om bijna geen eugenetische interventies toe te laten.

Een ethiek zonder connectie naar een metafysische notie van wat wij zijn zal er niet toe in staat zijn het probleem van de rechtvaardiging op te lossen. Je moet een notie hebben van wat wij zijn om duidelijk te maken waarom wij op een bepaalde manier zouden moeten handelen. De reductie van dit probleem tot louter procedurele kwesties mag dan wel pragmatisch toepasbaarder lijken, ze is uiteindelijk op los zand gefundeerd.



# A word of thanks

These past years, I had to hop from the issue of patient consent to ethnographic research on the community of people with dwarfism, from the latest discoveries in human genetics to the history of circus side shows and from Wittgenstein's problem of rule following and Gödel's incompleteness theorems to the discussion on humanism between Sartre and Heidegger. This has not been easy, but the richness of the material I harvested through this approach has provided me with material for years to come. In reading this thesis, some will unavoidably put the emphasis on their own field rather than focusing on the red line that runs through these seven chapters. I do hope they will not find their own field underexposed; it has been necessary to take several shortcuts through different disciplines to arrive at (post)metaphysics: home.

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# Curriculum Vitae

After receiving his Gymnasium-B diploma (1994), Laurens Landeweerd (Eindhoven, 1976) started his studies at the Faculty of Culture and Science (now Arts and Social Sciences) at the University of Maastricht. After his propedeuse he decided for additionally studying philosophy at the University of Amsterdam. Philosophy would become his primary study, Culture and Science his secondary. His main focus was the history of post-cartesian metaphysics, the problem of identity in specific. Landeweerd graduated as drs. in both faculties in 2000. In the two years to follow, he worked on the revised publication of 25 Eeuwen (Westerse) Filosofie (2004 (1983)), a Dutch classic in the history of philosophy. In 2002 Landeweerd started as a junior researcher at the University of Maastricht's department of Health Sciences, disciplinary group of Health Ethics and Philosophy (now Health, Ethics and Society). Here he elaborated the problem of identity with regard to bioethics methodology (in 'red' but also in 'green' bioethics) and to human enhancement technologies, eugenics is specific. He cooperated in three European projects on ethics, philosophy and biotechnology, developing courses and studying issues of ethics and biotechnology: *BioTethics* and its follow-up *Biotethed*, both designed to study and develop courses in the ethics of 'red' and 'green' biotechnology, and *Enhance*, a research project focusing on issues of human enhancement technologies. Within his capacity as junior researcher, Landeweerd was honorary member of the Sheffield Institute of Biotechnology, Law and Ethics and honorary member of the Bristol Centre for Ethics in Medicine. From June 2007, he is a postdoc at the department of Biotechnology (section Biotechnology and Society) at the Technical University Delft. Here he works on issues of cultural identity, global land use, poverty and neo-colonialism in the development and implementation of white, or industrial biotechnologies applied to biomass-crops for biofuels. From December 2008, Landeweerd is again affiliated part-time to the University of Maastricht to further develop the theoretical side of his research profile.