From bench to bedside, to track and field
The context of enhancement and its ethical relevance

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King's College London

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Author: Silvia Camporesi

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FROM BENCH, TO BEDSIDE,
to Track & Field:
THE CONTEXT OF ENHANCEMENT
and its ETHICAL RELEVANCE.

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Abstract

This thesis addresses enhancement technologies and their ethical permissibility through a contextual, bottom up approach based on case studies. The first chapter presents various definitions of ‘enhancement’, arguments for and against, and discusses the therapy/enhancement distinction. The second chapter discusses applying genetic technologies from bench to bedside, analysing: the objections to reprogenetics grounded in ‘eugenics’; and, how pre-implantation genetic diagnosis (PGD) and other embryonic genetic screening techniques, as well as genetic tests sold online directly-to-the-consumer (DTC) to measure children’s athletic potential raise a conflict between parental reproductive freedom and children’s rights to an open future and capacity for self-determination. Chapter 3 turns to how genetic technologies are translated directly from the molecular medicine laboratory to “track & field,” analysing: the scientific and regulatory context of gene enhancement, and on which basis it is classified as doping; how the International Olympic Committee and the International Association for Athletics Federation incorrectly consider hyperandrogenism an unfair advantage; and, the World Anti-Doping Agency Code and its current revisions. Chapter 4 discusses enhancements in a democratic society, and addresses the neglected issue of justifying enhancement research (ER). I propose: a model in which cognitive enhancements, currently prescribed under a ‘disease’ model, could instead be prescribed under an ‘enhancement’ model; and, a possible justification for ER that translates the ethical criteria justifying clinical research to the enhancement context. I then consider possible changes society would need to implement to accommodate ER. The last chapter attempts to advance the discussion of enhancement by shifting the debate from ethics to policymaking, arguing for a deliberative democracy approach. Throughout, I adopt a casuistic approach to ethics, deploying tools from consequentialist, principled and virtue ethics. I try to break the stalemate between enhancement’s proponents and opponents, and discuss the ethical permissibility of technologies in ways that could inform policymaking.
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Introduction

This thesis addresses the issue of enhancement technologies and their ethical permissibility through a contextual, bottom up approach based on case studies. The first chapter is devoted to familiarizing the reader with the various definitions that have been put forward for ‘enhancement’, and the arguments for and against. After reviewing the different available definitions and their pros and cons, I argue in favour of a neutral definition of enhancement, where decisions regarding the ethical permissibility of a technology are reached through a contextual analysis aimed at spelling out the values intrinsic in the particular practice under scrutiny. In this chapter I also discuss the value of therapy versus enhancement distinction, and of the absolute versus positional good distinction, offering examples.

In the second chapter I discuss the application of genetic technologies from bench to bedside. The first part of the chapter is dedicated to the analysis of the objections to reprogenetics grounded in the resurgence of ‘eugenics’ and its negative moral connotation. The second part of the chapter is dedicated to the analysis of how pre-implantation genetic diagnosis (PGD) and other genetic screening techniques at the level of the embryo raise a conflict of interest between parental reproductive freedom and the children’s right to an open future and capacity for self-determination. As a case study, the publication (Camporesi CQHE 2010) is included here, where I analyse the case of parents choosing to have deaf children through PGD. The expressivist arguments that deafness (or other traits traditionally considered a disability) is ‘only a difference’ is taken into consideration and refuted. Genetic technologies impact all stages of life, and in the last part of the chapter I address how genetic tests sold online directly-to-the-consumer (DTC) and aimed at measuring children’s athletic potential represent another conflictual issue between parental reproductive freedom, and children’s autonomy and right to an open future. As a case study, the publication (Camporesi SEP 2013) is included, where I discuss also the meaning of sport in children as a ‘practice’.
In Chapter 3 I analyse how genetic technologies, and in particular gene transfer, are translated directly from the molecular genetics/biology laboratory to “track & field”, where they are applied with the goal of enhancing athletic performance. I analyse the scientific and regulatory context of gene enhancement, and on which basis these technologies are classified as doping. The publication (Camporesi & McNamee GSP 2012) is included at this stage, where I focus on a real case study of a gene transfer clinical trial aimed at raising the tolerance to pain, and discuss its ethical permissibility in a therapeutic and in a professional sport context. In the second part of the chapter I discuss how a natural occurring variation, i.e. hyper-androgenism, has been considered by the International Olympic Committee and the International Association for Athletics Federation an unfair advantage. In the last section of the chapter, I critically analyse the World Anti-Doping Agency Code and its current revisions, and argue in favour of establishing a framework for performance-enhancing agents.

Chapter 4 discusses the place of enhancements in a democratic society, and addresses the neglected issue of the justification of enhancement research (ER). Two case studies are analysed: cognitive enhancements and performance-enhancing agents in sports. I argue in favour of establishing a regulatory framework for ER, and propose a model in which cognitive enhancements such as Ritalin and Adderall, which are currently prescribed only after a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) and therefore only under a ‘disease’ model, could instead be prescribed under an ‘enhancement’ model. The pros and cons of such a shift are discussed. I also describe a possible approach to an ethical justification of ER based on translating the ethical criteria for justification of clinical research to the enhancement context. Finally, I consider what kind of changes would need to be implemented in society to accommodate ER, with a focus on the US system.

In the last chapter, I discuss how to make progress in the discussion of enhancement by shifting the debate from the ethical to the policy level. The publication (Camporesi & MaugerI CQHE 2011) is included, where I analyse the case of gene enhancement in sport as paradigmatic of the different ethical frameworks
used implicitly in the enhancement debate, and I argue in favour of a deliberative democracy approach to the discussion of enhancement debate.

All throughout this work I adopt a casuistic approach to ethics, meaning I deploy different tools from a deontologist, consequentialist, principled and virtue-ethics approach, trying to bring the debate on enhancement out of the stalemate caused by its actual polarization between proponents and opponents. I also try to discuss the ethical permissibility of a technology in a way that could be used to inform policymaking.

**Publications included**

**Appendix 1**

**Appendix 2**

**Appendix 3**

**Appendix 4**

**Appendix 5**
Chapter 1: What we talk about when we talk about ‘enhancement’

1.1 Definitions

The term ‘enhancement’ has its origin in genetic technology in the late 1980s, when it arose in opposition to the term ‘therapy’ from the discussion of cases that were considered legitimate for gene therapy, in contrast to applications of the same techniques that were considered illegitimate and ethically troublesome. The first gene therapy trials involved the treatment of severe adenosine deaminase (ADA) immunodeficiency in 1990 at National Health Institutes, US. (Aiuti et al. 2009) Also known as ‘children in a bubble’ disease, it is a devastating condition caused by a mutation in the adenosine deaminase gene (ADA), which reduces or eliminates completely the activity of the corresponding enzyme, resulting in toxic levels of the same that lead to the death of lymphocytes. As a pathological phenotypical consequence, individuals affected lack virtually all immune protection and are prone to subsequent and persistent opportunistic infections that can be life threatening. (“Adenosine Deaminase Deficiency” 2013)

In the past 25 years, a series of clinical trials, employing different and safer vectors have been conducted aimed at repairing the mutated gene. The most recent three studies have demonstrated that gene therapy can successfully correct the molecular disease and lead children to live a healthy life ‘out the bubble’ to which they had been confined. (Aiuti et al. 2009) (Gaspar 2012) At the time of the first clinical trials, the use of gene transfer to treat this severe disease was seen as a morally justifiable means, even though risks were very high, but people were worried about the prospect of other uses of gene transfer techniques, and with a different risk/benefit ratio. That is how the term gene enhancement came along, as it was thought that a terminological distinction could also serve as a moral distinction. (Elliott 2009) This would not prove to be so easy, though, as we will see in section 1.2 where I discuss the therapy/enhancement distinction, and its validity. But before doing that we need some definitions: borrowing from American
storyteller Raymond Carver\(^1\), let us understand what we talk about when we talk about ‘enhancement’. In what follows, I will adopt the framework by Menuz and co-authors who classify the current definitions of enhancements into four main categories: the implicit approach, the therapy-enhancement distinction, the improvement of general human capacities and the increase of well-being. (Menuz, Hurlimann, and Godard 2011)

The implicit approach:

This approach spells out no definition of enhancement. Authors who adopt this approach start *in medias res* without giving an explicit definition of what they refer to with enhancement. Some examples of this trend can be found in (Mansour and Azzazy 2009; McKanna and Toriello 2010; Sadler 2010). For example, Sadler, discussing the implications of enhancement technologies for transhumanist debate, while providing a critique of different accounts of the concepts of ‘dignity’ as used in the transhumanist debate offering examples, takes for granted that the technologies he discusses can be classified as enhancements. (Sadler 2010)

Two obvious shortcomings with such an approach are the following: 1) it does not acknowledge the complexity of the ‘enhancement’ concept, by taking for granted that we know what we are talking about when we talk about ‘enhancement’, which is usually not the case; 2) it does not acknowledge the constant evolution of social and political values, and therefore does not address the question of when we can stop considering a technology as an enhancement. For these reasons such an approach is not satisfactory. Of course, to be fair to Sadler and other authors who use an implicit approach, one cannot recapitulate the entire story of humankind – so to say – every time one writes, but one could – and should – make clear at the beginning of the text what definition of enhancement one is endorsing. Without doing so, it becomes impossible to discuss or bring forward the debate, as the different participants in the debate may be talking about different things.

\(^1\) Raymond Carver, *What we talk about when we talk about love*, 1981
The therapy-enhancement distinction approach

In this widely used approach (Daniels 2000; Resnik 2000; Wolpe 2002; President’s Council on Bioethics (U.S.) 2003) human enhancement is defined through its goal and the condition or state (disease versus ‘healthy’ state) it aims to modify. This approach suggests that the ‘therapy-enhancement’ distinction can function to draw a moral boundary between ethically permissible and impermissible technologies. To be valid such an approach needs a clear definition of ‘health’ and ‘disease’, which are both a source of considerable controversy. In addition, with such an approach interventions aimed at prevention and traditionally considered part of the scope of medicine (such as vaccination) should be viewed as enhancement. I find this approach only of limited usefulness, as I explain in section 1.3, where I take on a more extensive analysis of the value and role that this distinction can play in the enhancement debate.

Improvement of some human capacity/abilities

According to another widely used approach (Bostrom, Nick and Sandberg, Anders 2007; Alhoff, Lin, and Steinberg 2010; John Harris 2007; Chan and Harris 2008), human enhancement is defined as the application of a technology “to individuals so as to improve their body, mind or any ability beyond the species-typical level or statistically-normal range of functioning of a human being”. (Menuz, Hurlimann, and Godard 2011)

Let us take a closer look at some examples of this approach. According to John Harris, an enhancement is “by definition an improvement on what went before. If it wasn’t good for you, it wouldn’t be enhancement”. (John Harris 2007) Bostrom and Sandberg (2007) define enhancement as either a functional improvement over a ‘normal healthy state’, or as the addition of a capacity that was not present in the human species at a former time point. This latter meaning of the term enhancement is then considered by Bostrom and Sandberg as they see enhancements as means to transcend humanity as we know it today, and to produce ‘transhumans’. Here is their definition:
“We define an enhancement as an intervention that causes either an improvement in the functioning of some subsystem (e.g. long-term memory) beyond its normal healthy state in some individual or the addition of a new capacity” (e.g. magnetic sense). (Bostrom, Nick and Sandberg, Anders 2007)

Note that, in this definition, an enhancement is not necessarily a good thing, in contrast to John Harris’ account (Harris considers the benefits of an enhancement technology only in relation to the individual, and not to society). Their definition is neutral in values. Improving on a human trait, or providing a new trait does not necessarily have positive effects on a person’s life, as pointed out by De Melo-Martin in the welfaristic approach described below.

Increase in individual’s well-being (welfaristic approach)

This approach, which is adopted by a minority of scholars in the enhancement literature, defines enhancement as an increase on individual’s wellbeing, or welfare. One well-known proponent of this value-laden account is Julian Savulescu:

“The term human enhancement is itself ambiguous. It might mean enhancement of functioning as a member of the species homo sapiens. This would be a functionalist definition. But when we are considering human enhancement, we are considering improvement of the person’s life. The improvement is some change in state of the person - biological or psychological - which is good. Which changes are good depends on the value we are seeking to promote or maximize. In the context of human enhancement, the value in question is the goodness of a person’s life, that is, his/her wellbeing.” (Savulescu 2006)

Therefore, Savulescu proposes a ‘welfarist’ account of human enhancement, where the enhanced state is defined as a ‘capability’ and a capability is “Any state of a person’s biology or psychology which increases the chance of leading a good life [...]” (2006) (Note that the opposite of a capability is, in Savulescu’s account, a disability, which is seen as a condition that diminishes the chances of an individual to lead a good life).
While this approach has the advantage of undercutting the problem of determining what ‘health’ and ‘disease’ are, and of determining a species-typical level, it does not solve the problem but merely moves it elsewhere, as it is also based on other controversial concepts, namely: human flourishing, wellbeing, welfare, etc. Moreover, this approach runs the risk of underestimating the social and cultural pressures that influence individual choices in life (see 2.1 for a discussion). It seems to me that Savulescu’s definition of enhancement would be better referred to as ‘enhancement of wellbeing’, which is a narrower class of the class comprising all enhancements. Quite ironically, Savulescu himself seems to recognize that the term enhancement is probably not the right one in his account. Writes Savulescu: “Enhancement is a misnomer. It suggests luxury. But enhancement is no luxury. Insofar as it promoted wellbeing, it is the very essence of what is necessary for a good human life”. (Savulescu 2009) This absolutely positive connotation of the term is problematic, as the various applications of biomedical enhancement technologies need to be spelled out and discussed in detail, starting from an accurate scientific description of the technologies and their applications in society. Not necessarily enhancements will turn out to be necessary for a good human life, nor its very ‘essence’, nor will enhancement necessarily turn out to be good for society. Indeed, this approach does not take into consideration the social and collective consequences of the new trait need, but only the consequences of the new trait on the individual’s wellbeing.

The work by Inmaculada de Melo-Martin provides another example of a scholar who adopts a welfaristic approach to enhancement. In her work, de Melo-Martin objects to a “value-neutral” definition of enhancement (the “improvement approach”). Such an analysis, argues de Melo-Martin, is biased, as it presupposes value-neutrality. Her critique is not based on an analysis of regulation or funding, but on the need to discuss what counts as a risk, and what counts as a benefit before entering the analysis of the risk/benefit ratio. (de Melo-Martin 2010) de Melo-Martin then proceeds to discuss the necessity to spell out the values underlying enhancements before entering the discussion. In order to offer some examples, de Melo-Martin writes that some enhanced capacities, e.g. the ability to read a book in a very short time, or enhanced numerical abilities, should not
necessarily be considered enhancements, as they are not necessarily related to a more fulfilled life. (de Melo-Martin 2010) In this sense then, an improvement on the human capacity for reading, or on human mnemonic skills for example, would not necessarily constitute an enhancement, unless we had decided a priori that these increases in capacities were good things per se, on the basis of an intrinsic value – for example – in being able to read very fast. It seems plausible to infer that according to the analysis by de Melo-Martin, what counts as enhancement in a society or culture would not count as enhancement in another.

1.2 On the therapy versus enhancement distinction

As said above, the term ‘enhancement’ itself was coined in opposition to the term ‘therapy’ in the context of gene transfer technologies. It follows that the analysis of this opposition is a necessary premise to understand the debate about enhancement technologies. The distinction was initially brought in as it was thought to possess an intrinsic moral significance, and to be able to demarcate ethically legitimate applications of gene transfer technologies from other not so legitimate applications. But it would not prove to be so easy. In this paragraph I discuss the meaning and moral significance of the therapy/enhancement (T/E) distinction.

Norman Daniels spells out a limited defence of the T/E distinction. A US-based scholar, Daniels acknowledges that often this distinction is invoked in his country to demarcate conditions for which an insurance reimbursement would be appropriate (would-be treatments) and for conditions for which it would not (would-be enhancements). Such an approach could be generalised to include countries with a public health system or a mixed public-private health system between medical services for which the patient has to pay (even if partially), and services for which the patient does not have to pay. Writes Daniels:

“The treatment-enhancement distinction draws a line between services or interventions meant to prevent or cure (or otherwise ameliorate) conditions that we view as diseases or disabilities and interventions that improve a condition that we view as a normal function or feature of members of our species. The line drawn here is widely appealed to in
medical practice and medical insurance contexts, as well as in our everyday thinking about the medical services we do and should assist people in obtaining.” (Daniels 2000)

In this sense, the distinction is therefore closely related to the concept of ‘medical necessity’ that is used in legislation in the USA and Canada. Daniels offers the examples of children with a short stature receiving reimbursement (or not) for growth hormone (GH) therapy on the basis on the different causes of their short statures. Daniels also raises two very pertinent questions: “Does the concept of disease underlying the treatment-enhancement distinction force us to treat relevantly similar cases in dissimilar ways?” (Daniels 2000) and a second that follows from the first: is dissimilar treatment unfair? The answer to both questions is a positive one for Daniels, as he argues that providing treatment and reimbursement to a child, “Johnny”, with short stature because of a genetic cause, and not providing treatment (or not reimbursing) it to another child, “Billy” who is short either because of idiopathic conditions, or only because he “feels short” in society, would be unfair. What then can be the significance of the T/E distinction, if it is unfair to use it to demarcate ‘medical necessity’ from ‘non-medical’ necessity? Before answering this question, Daniels addresses two commonly raised objections to the T/E distinction:

1) The ‘non moral significance’ criticism: “One objection is that the treatment-enhancement distinction, even assuming that 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”; (Daniels 2000)

2) The ‘social construction’ criticism: “It is not because there is something biologically distinctive about Johnny’s condition, as opposed to Billy’s [the two fictitious children with short stature], that has led us to describe Johnny as having a disease and Billy not. (Although Johnny does have a tumor and Billy does not.) Rather, our “social construction” of disease draws on a set of values that happens to have singled out Johnny rather than Billy in this way. [...] 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.” (Daniels 2000)

Daniels objects to the notion that the natural baseline of the T/E distinction, according to which disease and disability are departures from species-typical functioning, has an ontological importance. He argues that it does not, but that we must recognize as a matter of fact that it has become a “focal point for convergence in our public conception of what we owe each other by way of medical assistance or healthcare protection.” (Daniels 2000)

An excursion into the history of GH can be enlightening to understand better how the ethical dilemma of the scarcity of GH and the application of a scarce hormone were justified in our recent past, in an occurrence of a problem that is still present today in many other instantiations. In the US in the 1950s, “stunted growth” was the term used to refer to “short stature”, while “pituitary dwarfs” was the term used to refer to individuals deficient in the GH, and “primordial dwarves” to individuals affected by achondroplasia. (Rothman and Rothman 2003) In the ’50s the only way to obtain GH (at that time known as ‘somatotropin’) was to collect it from the pituitary glands of human cadavers. To overcome this scarcity, the US NIH set up the National Pituitary Agency (NPA) at John Hopkins University in Baltimore to appeal for organ donation. (Rothman and Rothman 2003) How did the talk about T/E distinction play out to decide how to allocate a short resource? Initially the GH was allocated only to “pituitary dwarves”, but vocal patient advocacy requests pressed the NIH to allocate the GH also for other individuals affected by stunted growth, independently of the genetic causes of the short stature. Note that it was never demonstrated that administration of GH in individuals who had no GH deficiency was successful in the long-term to obtain an increase in stature, though it was demonstrated that they were able to cause spurts in growth in the short term. (Rothman and Rothman 2003, 188-190)

In 1985, the problem of the scarcity of the resource was solved when the San Francisco Bay area biotech company Genentech started the synthetic production of GH (hence, the legal dispute with UCSF about the primacy of the invention, that was settled with $200M from Genentech to UCSF in 1999 (Barinaga
1999)), and the discussion of the ethical use of the hormone was quenched by its new availability. Quenched, but not extinguished, as a lingering discussion remained of how far patients’ requests should be satisfied: what was, if any, the threshold under which an individual was to be classified as ‘short’? In 1990, the NIH organized a clinical trial to, after many decades of use, once and for all test the efficacy of GH for short, non-hormone deficient children. (Tauer 1994) The results of the study, though, were not able to provide a clear-cut answer to the question because of the way they had been designed. The trial concluded that if a “condition” (e.g. short stature) causes “unhappiness, psychological pain, and social disadvantage”, then interventions to remedy it should be considered “cures”, irrespective of the biological cause. (Rothman and Rothman 2003) We have here a clear example of the social construction of a disease by the NIH in order to respond to the patients’ and society requests. Finally, in July 2003, the FDA accepted the NIH recommendation and approved GH for “otherwise medically normal but unusually short” children. (LATimes Associated Press 2003) As pioneer US plastic surgeon Max Thorek was reported saying in the 1930s, anything that could raise “the quotient of patient happiness” was to be considered a legitimate medical task. (Rothman and Rothman 2003, 143) I will return to Thorek’s pioneer view on the scope of medicine when discussing the legitimacy of adults’ requests for cognitive stimulants in the US in section 4.2.

As we can see, the use of the T/E distinction as a demarcation line between what is reimbursable and what is not, is problematic both from an historical and philosophical point of view. Therefore, moving away from the role of the distinction in demarcating reimbursable from non reimbursable treatment, or as Daniels calls it “the obligatory/nonobligatory boundary”, and from the [ethically] permissable from impermissible boundary, what is the role, if any, for the distinction? Daniels thinks there is one as a “primary rationale for including medical services in a healthcare benefit package” (Daniels 2000). Daniels also thinks that dropping the distinction in favour of an expansion of the scope of medicine “has distinct disadvantages from a public policy perspective and no compelling arguments for it from a moral perspective”. (Daniels 2000) His conclusion is therefore that in a kind of pragmatic
approach, the T/E distinction can play a *prima facie* role in demarcating the scope of medical necessity from other scopes. This *prima facie* role though needs to withhold scrutiny and may not constitute a sufficient reason to treat similar cases (e.g. short children) in dissimilar ways.

While the distinction traced by Daniels is an interesting one and illustrates one of the concrete applications of labelling a technology as an ‘enhancement’ or as ‘therapy’, it is not one of the central concerns of my thesis focused mostly on genetic technologies. I think that a more helpful perspective for the kind of contextual analysis and the choice of technologies that I carry out in this work is offered by David Resnik (2000), and to conclude this section by returning to how the distinction came first into being, I present below the position put forward by Resnik (2000) in relation to genetic interventions that could count as enhancements.

Genetic interventions are of particular interest for the scope of this work, which includes analysis of how they can be applied to enhance athletic performance in a professional sports context (*Appendix 3*), to decide what kind of children to bring into the world (*Appendix 1*) and to scout out children’s talents (*appendix 2*). Resnik (2000) argues that the T/E distinction does not mark a firm boundary between moral and immoral genetic interventions, for which it was originally conceived:

“Perhaps the most popular way of thinking about the moral significance of the therapy-enhancement distinction is to argue that the aim of genetic therapy is to treat human diseases while the aim of genetic enhancement is to perform other kinds of interventions, such as altering or “improving” the human body. Since genetic therapy serves morally legitimate goals, genetic therapy is morally acceptable; but since genetic enhancement serves morally questionable or illicit goals, genetic enhancement is not morally acceptable.” (Resnik 2000)

According to Resnik, this way of thinking of medical genetics is flawed as it based on at least two questionable assumptions, namely: a) that we have a clear and uncontroversial account of health and disease (and we do not); and b) that the goal of treating diseases is morally legitimate, while other goals are not. I concur
with his analysis. In this thesis I do not wish to dwell on the questions of the accounts of health and disease (this would require a whole separate dissertation!), and I will only briefly touch upon what the proper goals and scopes of medicine are in relation to the requests for cognitive stimulants, in section 4.3.

Setting aside for a moment as uncontrovertial (as they are not) the definitions of ‘health’ and ‘disease’ and the proper scope of medicine, what interests me most is the following question: would this [assumed non-controversy] imply that using biomedical technologies for enhancement purposes would not be ethically justifiable? Indeed, I do not think that such an inference would be valid, at least not in general and not without spelling out why the use of a particular biomedical technology would not be ethically justifiable in a particular case. I am sympathetic with Resnik when he writes that what is really ethically troubling with the use of, for example, steroids by athletes, is not the non-medical use of steroid (or another pharmacological enhancer), but the violation of a moral principle or value, for example of ‘fairness’ in the context of professional sport. (Resnik 2000)

To offer another example in the realm of sport, in the analysis co-authored with Mike McNamee (Camporesi and McNamee 2012) of the use of genetic transfer to raise the individual’s tolerance to pain, we include a discussion of the values relevant for the treatment of pain refractory to pharmacological intervention, and relevant for the treatment of pain in professional sport and competition in endurance races. For a full argument see Appendix 3. It is this discussion at the level of values that brings us to the conclusion that the same technology is ethically justifiable in one scenario and not in the other, not the fact that it counts as a non-medical use of medicine (assuming this is a valid position, which, as I discuss in 4.2, I doubt it is).

1.3 Absolute versus positional goods

Another feature of the definition of ‘enhancement’ that is a matter of controversy hinges on the distinction between absolute and positional goods. To the former category belong objects that everybody can enjoy without risking that they lose their status of ‘goods’ (e.g. radio, sunlight, etc.); while to the latter belong
goods that only some can enjoy for the objects not to lose their status of goods (e.g. height. Not everybody can be tall; there must be at least one short person around. The definition itself of being ‘tall’ has changed over time.).

Goods that belong to this latter category are referred to as ‘positional goods’, as they place the individual who enjoys them in a better position with respect to another person. In other words, they offer a competitive advantage to the individuals. Performance enhancing drugs in sport are one of the classical examples of instruments which provide a positional good, such as strenght, endurance, resistance to pain etc. Athletes seek the use of performance enhancing drugs as they seek to obtain that competitive advantage which, even if marginal, is necessary to them to secure them victory. As I discuss in section 3.4, it is problematic that the demonstration of the performance enhancing effects of substances included in the World Anti-Doping Agency (WADA) Prohibited List is not a necessary criterion for inclusion in the List, but that only the potential to do so is sufficient (with another of two criteria: potential risk to the athlete’s health and the violation of the spirit of sport) for inclusion. (WADA Code 2009)

John Harris favours enhancements as absolute rather than positional good. He writes: “I defend them because they are good for people not because they confer advantages” (Harris 2007, 29) This view, while attractive in its simplicity, risks being too simplistic: Harris is neglecting important and often fundamental factors that underlie the reasons why individuals may seek enhancements. These factors are, more often than not, rooted in the search for a positional advantage, or in the pressure of peers, of society, of the market, or a combination of these factors. Note that these are the very same factors that result in inequalities of access to enhancements. I find the problem of the differential access to enhancements one of the major ethical issues that need to be discussed when analysing the ethical permissibility of a new enhancement technology. By stating that an enhancement is ‘good for people’ in all cases, Harris is neglecting this fundamental issue. Indeed, not all things that are ‘good for people’ are good also for society, and not all things that can be considered on a subjective account ‘good for people’ are allowed in society (think of gambling, or of recreational drugs).
Elsewhere, writes Harris with Chan: “It follows [from the fact that something is good for people] that there can be nothing morally wrong with human enhancement per se” (Chan and Harris 2008). This view seems incorrect to me, as there are other values to take into account when judging the permissibility of enhancement technologies, apart from the personal freedom to pursue one’s goals in life, and also as stated above the fact that a technology is good for one individual does not mean that the technology is good for society (especially if there is differential access to the technology), therefore the inference drawn by Harris that ‘there can be nothing morally wrong with human enhancement per se’ is incorrect. Indeed, the relations and implications of one’s pursuit of one’s own goals in life, including enhancements, need to be put in perspective with the goals of others in a society. This is also the position shared by Michael Selgelid, who argues that the most important and unaddressed question in the contemporary debate about genetic enhancement is exactly the place that personal liberty should have/should be given against the weight/value of social equality and welfare in cases in which these two values conflict (as often they do). (Selgelid 2012) Selgelid’s approach is discussed at length in section 5.2.

It must also be noted that it is theoretically very difficult, and if not impossible in practice, for a single enhancement technology to possess only characteristics that would qualify it as an intrinsic good, or only characteristics that qualify it as a positional good. As a matter of fact, most enhancement technologies possess a combination of the two characteristics. On this point, DeGrazia offers an example in relation to an enhancement which would give a person a ‘sunnier disposition’ (it is not clear how the technology could achieve the result of giving a person a sunnier disposition; probably DeGrazia has in mind Paxil, the anti-depressant already mentioned earlier in his work):

“One might think that an enhancement that gave someone a sunnier disposition, making his life more enjoyable, would provide a major intrinsic benefit without conferring any positional goods. One might think again. For a sunnier disposition offers competitive advantages to politicians, salespersons, real estate agents, and others whose job performance is
improved by extroversion and the expression of optimism”. (DeGrazia 2012, 129)

The absolute value of a biomedical enhancement acquires therefore an instrumental, external value when put in the context of the workplace. Plausibly, this would be a very common occurrence for most if not all biomedical enhancements. In addition, DeGrazia notes how positional goods create concerns about coercion, fairness (of access), and possibly concerns about collective self-defeat: if everybody, or at least a substantial portion of the population, had access to positional enhancements, they would lose their character of conferring an advantage to others. These are all issues that need to be taken into account when assessing the ethical permissibility of an enhancement technology.

1.4 Arguments in favour and against enhancement

The mere mention of the possibility of ‘human enhancement’ is able to spark a vehement discussion between both fans and vocal opponents:

“Because human enhancement apparently involves altering human nature, it is meant to be the sort of thing that sends shivers down the spine. For ‘transhumanists’, these are frissons of excitement at the thought of a wonderful new world of genetically and pharmaceutically augmented, ultra-intelligent, long-lived super-persons. For conservatives such as Leon Kass, our shivers are the wise verdict of an instinctive moral repugnance.” (Lewens 2009)

Lewens is quite right in putting the finger on the instinctive opposite reactions triggered by some new possibility of biomedical enhancements. But exactly what is so unique about human enhancement that is able to elicit such visceral reactions? It seems to be the perception that human enhancement technologies are tinkering with human nature, and that humans engaging with biomedical enhancements are playing at projects of self-creation and self-evolution that are hubristic and may lead to dangerous slippery slopes.
Before addressing the arguments on both sides, one disclaimer needs to be pointed out: both reactions described above are two extreme examples triggered by misrepresentation of the real scientifically feasible prospects of biomedical enhancement. Often the scenarios portrayed by the media are science fictional, and as such will not be discussed in this thesis, where I am interested in an empirically grounded discussion of enhancement technologies.

One of the frequently raised objections to biomedical enhancements is that they alter human nature. This is what sends “shivers” down the spine of some most vehement opponents of biomedical enhancements, including Leon Kass (Kass 2002) (former Chair of the President’s Council on Bioethics under President Bush Jr), Francis Fukuyama (Fukuyama 2003), and Juergen Habermas (Habermas 2003). These authors embrace what Allen Buchanan refers to as “normative essentialism”: they believe it is possible to derive substantive moral rules from reflection on human nature. (Buchanan 2009) Juergen Habermas worries that interventions aimed at modifying human nature will affect “the necessary presupposition for being-able-to-be-oneself and [affect] the fundamentally egalitarian nature of our interpersonal relationships”. (Habermas 2003, 13) For Habermas, what is most unsettling in genetic interventions and other kinds of biomedical interventions aimed at shaping oneself or others is “the fact that the dividing line between the nature we are and the organic equipment we give ourselves is being blurred”. (Habermas 2003, 22) This blurring, he continues, shifts the “line between chance and choice”, and by doing so “affects the self-understanding of persons who act on moral grounds”. (Habermas 2003, 28) Moreover, this blurring of the categories of the ‘nature we are’ and the ‘organic equipment’ we give ourselves might “change our ethical self-understanding as a species” and give rise to a “novel, curiously asymmetrical type of relationship between persons”. (Habermas 2003, 42) This is especially problematic for Habermas as it will touch upon “a necessary condition for an autonomous conduct of life and a universalistic understanding of morality”. (Habermas 2003, 48) David DeGrazia objects to the arguments against enhancements rooted in concerns about threat to human nature. DeGrazia distinguishes two sorts of concerns: a) the threat of surpassing (or crossing the boundaries of) human nature; and b) the threat of altering human nature. DeGrazia
then specifically objects to Francis Fukuyama’s essentialist notion of human nature. (Fukuyama 2003) While recognizing that there are “powerful theoretical and intuitive grounds for maintaining that certain kinds of things have essential features” (DeGrazia 2012, 79) (‘humanity’ being one of those), DeGrazia objects to the argument that there is a single characteristic that could be regarded as the basis for the special moral status possessed by human beings. In other words, the mistake that some authors – including Fukuyama – make, is to assume that human nature must involve ‘essential’ features, where an essential feature for a kind of thing is defined as a ‘feature that X necessarily has in order to be a member of that kind’. (DeGrazia 2012, 80) Buchanan also debunks these arguments on two grounds: a) that on all plausible accounts, human nature “contains bad as well as good characteristics and there is no reason to believe that in every case eliminating some of the bad characteristics would so imperil the good ones as to make the elimination of the bad impermissible; and b) that modifications of human nature will not affect our ability to make judgment about the good. (A. Buchanan 2009) I concur with the analysis by DeGrazia and Buchanan (while not concurring with DeGrazia’s essentialist point), as I do not think that biomedical interventions would change the way a person perceives herself more than other kinds of parental intervention early in life already shape the kind of person one is, and perceives herself, nor that human nature should be considered as the basis of the moral self-understanding of a person. I also do not think that genetic interventions, only by virtue of being genetic, are substantially different from other kinds of interventions and that as such they should deserve a special scrutiny (See Appendix 5 for a full argument debunking the genetic exceptionalism perspective).

At the other end of the spectrum of the debate, we find scholars who are so excited about the prospect of biomedical enhancements that they get “frissons” down their spines, to borrow again from Lewens quoted above (Bostrom, Nick and Sandberg, Anders 2007; J Harris and Chan 2008; Chan and Harris 2008) John Harris is one of the strongest proponents of enhancements tout court. According to Harris, “enhancing human capacities is taken to be a self-evident good” and we have a moral duty to enhance ourselves, and our children. In Harris’ view, enhancing human capacities is seen as the pursuit of a linear progress without any apparent
end, along the lines of the Olympic motto of ‘citius, altius, fortius’ (swifter, higher, stronger). (John Harris 2012) Harris dismisses worries about enhancement as being a function of unnecessary anxiety, or a similarly unnecessary fear of hubris. Together with the pursuit of ‘a linear progress’, Harris stresses the continuity between kinds of enhancements that humans have resorted to in the past, and new kinds of biomedical enhancements that are being developed thanks to the most recent advances in biotechnology and biomedicine. But, as correctly pointed out by Erik Parens: “It would be a mistake to think that the new biotechnologies are just more of the same. We should give up the arguments that take the form, ‘we’ve always done it.’” While “It is true that we have always sought enhancement […], arguments from precedent glibly excuse us from thinking about how new means to achieve old ends make a moral difference” (Parens 1998, 13) and: “We must all become cognizant of the fact that ‘enhancements’ have the potential to widen the gap between the haves and have nots” (Parens 1998, 13), a problem that Harris does not take sufficiently into account, or that he dismisses because it is already present in other forms in our society. Instead the exacerbation of the problem of access to enhancement technologies should prompt us to reflect on already existing problems of access, not condone new and old problems at the same time. This is also the approach I adopt in (Camporesi 2013) included in this thesis as Appendix 2, where I discuss the application of genetic technologies to scout out a child’s talent, which are by some scholars justified on the basis of other older and already established childrearing practices.

The analysis by Carl Elliott also touches upon the new means that enhancement technologies offer us to achieve old ends. (Elliott, Carl 2009) Elliott proceeds to spell out five problems related to the use enhancement technologies that other authors have not touched upon, namely the problems of:

1. cultural complicity
2. relative ends
3. role of the market
4. authenticity
5. relativism
I will discuss these in turn, and point out how they relate to the analyses carried out in this thesis. The problem of cultural complicity was first identified by Margaret Olivia Little, who pointed out how the demand for certain technologies is construed by cultural forces which can be harmful. (Little 1998) Some examples include cosmetic surgery to delete markers of ethnicity (e.g. “Jewish nose”, “Asian eyes” etc.) and make people more conform to accepted European standards, and cosmetic surgery for breast or plastic surgery anti-ageing for women. What is problematic in these practices is that ‘by giving in’ to these cultural forces and agreeing to have a surgery, these underlying societal (and problematic) trends become reinforced, and the individual who engages in them becomes culturally complicit with them. (Little 1998) As pointed out by Little, the cultural complicity goes hand in hand with the rhetoric of self-fulfilment and the pursuit of happiness that pervades the contemporary Western world, starting in and spreading out to the rest of the world from the USA. Already more than fifteen years ago, Erik Parens wrote on this point:

“Given that many of us Americans feel it is our duty to pursue self-fulfillment and happiness on the Weberian model, it would not be surprising if many of us came to feel it our duty to use any means possible to fulfill it – including taking drugs like Prozac”. (Parens 1998, 12)

As pointed out by Scripko, the pursuit of wellbeing permeates the daily lives of Americans and enhancement technologies are seen as a way to liberate one’s considered “authentic self”, in a narrative where ‘being well becomes being one’s optimal self in the society in which a person lives’. (Scripko 2010, 294). For this reason, much of my work on this topic is focused on the US system. This happens also because I was thinking and writing about these issues during my period as a visiting PhD student at University of California, San Francisco in 2011/12. I also find that many of the ethical issues related to enhancement find their applications first in the US context, where the system is more liberal, and then find their ways through or outside regulation in the UK and Europe. Therefore in other parts of this thesis, for example in the analysis of direct-to-consumer genetic tests to scout out children’s talents included in Appendix 2, the discussion is also first grounded in the
US system and the liberal market. In addition, I discuss the problem of cultural complicity as applied to the increasing trend of requests of adults for cognitive enhancements (i.e. Ritalin and Adderall) in section 4.3.

The problem of relative ends relates to the positionality or intrinsic status of enhancement technology, already presented in section 1.3, under the heading of absolute versus positional goods. This problem can also be combined with the problem of ‘competitive advantage’, which Elliott spells out in relation to the use of performance-enhancing drugs in sports, but that can be applied also to Ritalin and Adderall. The point here would be that since everybody uses them, the athlete is pressured to use them too in search of the small competitive advantage which is necessary in competition. I analyse the problem of relative ends in my discussion of the use of gene transfer technologies applied to raise one’s own tolerance to pain in endurance races. (Camporesi and McNamee 2012) (Appendix 3)

The third problem identified by Elliott relates to the role of the market, in particular to the US widespread practice of advertising enhancement technologies online or on television through direct-to-consumer (DTC) advertising. This has been possible in the USA since 1997, when the FDA relaxed its restriction on DTC advertising for prescription drugs. In particular, this is especially prevalent for antidepressant drugs, and more recently for DTC-genetic tests to predict one’s talent. (See Appendix 2 and section 4.3) The problem of authenticity relates to the narratives of restoration to ‘authentic self’ through antidepressants that individuals make up. These kinds of ‘restitution narratives’, as put by Elliott, are very common for people who consume antidepressants. Restitution must be understood in the sense that the self to which they are aspiring never existed before, but was only desired. Note that the same language of authenticity can also be used for opposite ends (even though less frequently) by people who claim they do not feel like themselves anymore when on antidepressants. I address this problem in relation to the use of cognitive stimulants such as Ritalin and Adderall and the possibility that adults who consume these drugs are victims of self-deception. (See section 4.3)

Erik Parness (2005) argues that the idea of ‘authenticity’ is at the centre, even if not explicitly, of the debate about enhancement. He defines it as follows:
“While the idea of authenticity has a complex history, the core of it is that we are authentic when we exhibit or are in possession of what is most our own: our own way of flourishing or being fulfilled. To be separated from what is most our own is to be in a state of alienation.” (Parens 2005)

He also writes: “[...] To live authentically is to perceive the world and oneself as they really are, in the face of the ever-present temptation to look away.” (ibidem)

For Parens, the current polarization of the debate on enhancement harks back to the different understandings of authenticity that the opponents and supporters of enhancement take as implicit assumptions of their arguments. These different understandings grow out of what Parens refers to as two different ethical ‘frameworks’, where by framework he means a “constellation of commitments that support and shape our responses to questions about, among many other things, new enhancement technologies”. (Parens 2005) One framework revolves around the concept of ‘gratitude’, while the other revolves around the concept of ‘creativity’. Scholars often shift from one framework to the other, and it is important to recognize this and spell out the values underlying the arguments when discussing a particular technology, especially when moral judgments are hoped to inform policy (see Appendix 5 and section 5.2).

Finally, another dilemma of the enhancement debate is exemplified by the following argument: enhancement technologies will in any case be pursued somewhere in the world, once the technologies enable them in practice, notwithstanding their moral justification or not. As put by Nicholas Agar (Agar 2005), discussion about the ethical permissibility of enhancement technologies – or of biomedical enhancements in general – runs the risk of falling prey to ‘technological determinism’ about morality, defined as the certainty that “moral pronouncements have little or no influence on which technologies will be developed and who will use them”. (Agar 2005, 170) Examples of technological determinism abound in the debate about gene therapy, or cloning; e.g., there will always be the possibility, that some researcher in another part of the world that is not subject to the regulation of the Food and Drug Administration (FDA), the European Medicines Agency (EMA), or the UK Medicines and Healthcare Products
Regulatory Agency (MHRA) could put in place and implement the biomedical enhancements. For example, in China the regulation for gene therapy were much more lax, and gene therapy products have been approved that have been not in the Europe or the USA, (Wilson 2005) leading to the ethically problematic from a global perspective instances of medical tourism described in (Meghani 2011; Cohen 2012) among others. It would therefore seem that we are left in this field of applied ethics with a ‘biotechnological catch-22’ (borrowing from Agar, and from Joseph Heller from whom he borrowed before²): if we deliberate that research on the latest development of biomedicine is ethically impermissible, it would be plausible to speculate that somebody else in another part of the world will still develop it irrespective of our deliberation (and then we will be left with the not easy question of what to do with the products of knowledge developed elsewhere with means that we have deemed ethically impermissible. For example the results of clinical trials developed without informed consent/on children/prisoners/on Nazi camps etc.). Alternatively, we recognize the fact that somebody else elsewhere will develop it and we renounce deliberating from this field of morality. But this is a very dangerous move because by reasoning in this way it would constitute a retreat on morality on many different fronts! To escape (at least, as best as we can), this technological catch-22, we must recognize that “technological determinism does not render morality redundant. There will almost certainly never be a human society in which there is no murder – but this is no reason not to pass moral judgements on murderers”. (Agar 2005, 172)

Having concluded that a philosophical analysis of enhancement technologies (and therefore, this thesis!) is not completely useless, let us proceed to the contextual analysis of case studies. In the next chapter I turn to the consideration of arguments against genetic technologies aimed at enhancing individuals and future generation, analysing first the arguments based on parallelisms with the old eugenics, and then proceeding to consider the application of genetic technologies to choose what kind of children to bring into the world, and to scout out children’s talents.

² Joseph Heller, *Catch 22*, 1961
Chapter 2: From bench to bedside: Pre-natal and post-natal genetic technologies to choose children’s traits

2.1 Genetic enhancements and the ghost of eugenics

Often, arguments against enhancement single out genetic technologies as being especially unacceptable. Lewens comments: “Some people might think that, even if enhancement can take many forms, there is something especially disturbing about genetic enhancement, for it represents a return to the wrongs of eugenics.” (Lewens 2009) As a matter of fact, both pre-implantation diagnosis (PGD) and other genetic techniques aimed at human enhancement, along with screening programs to detect genetic disorders, have prompted a fierce controversy about the resurgence of eugenics. The recent writing by Gina Maranto exemplifies this current trend:

“The unfortunate truth is that discredited ideas never do die, they just rise again in slightly altered forms—witness eugenics. Despite the horrors perpetuated in its name, including forced sterilization and the Holocaust, the eugenic impulse is with us still. One of the forms it takes is schemes for “improving” offspring through the selection and manipulation of embryos.”(Maranto 2013)

Are such parallelisms between the Holocaust and contemporary modes of improving ourselves and others justified? Before discussing whether contemporary modes of genetic interventions can be classified as eugenics, and what if anything is wrong with that, it is necessary to understand what we talk about when we talk about ‘eugenics’, borrowing again from Raymond Carver. In order to do that, I will provide a brief comparative historical overview of eugenics in the UK, the US and Scandinavia, dividing the analysis into the periods: a) “classical eugenics” (1883-1945), b) “modern eugenics,” from the end of WW II to the first ‘test tube baby’ (1946-1978), and c) “contemporary eugenics”, from the birth of Louise Brown until now (1978-2013). I will highlight similarities and differences between the three
periods and address whether the objections to classical and modern eugenics are still valid today.

**Classical eugenics: 1883-1945**

I refer to ‘classical eugenics’ as the first period spanning from the invention of the word in 1883 by Francis Galton to the end of the WWII. The word ‘eugenics’ comes from Greek, meaning “good in birth”. As the story goes, after reading Charles Darwin’s “The Origin of Species,” Galton concluded that much human misery was caused by physical problems that were passed down through generations. Galton thought that such misfortunes could be avoided through positive measures aimed at actively encouraging reproduction among the ‘fittest’, and actively discouraging reproduction among the less fit. On May 16, 1904 Galton delivered a lecture on the definition, scope and aims of eugenics before the Sociological Society at a Meeting in the School of Economics and Political Science in London (currently the London School of Economics). While he defined eugenics in positive terms: “The science which deals with all influences that improve the inborn qualities of a race; also with those that develop them to the utmost advantage,” (Galton 1906, 35) he did not exclude negative measures in the interest of the State and the British race. At that time, fear of ‘race degeneration’ and the decline of the British Empire from the international scene were very pervasive.

Indeed, Galton considered efforts aimed at improving race a duty both for the individual and the society. He wrote, “Indeed, an enthusiasm to improve the race is so noble in its aim that it might well give rise to the sense of a religious obligation”. (Galton 1906, 25) He also thought that the means justified the end, as he wrote: “We are justified in following every path in a resolute and hopeful spirit that seems to lead towards that end”. (Galton 1906, 33) For Galton, eugenics was to become a new, “orthodox religion”, as he was persuaded that “few things are more needed by us in England than a revision of our religion, to adapt it to the intelligence and needs of the present time”. (Galton 1906, 59) The creed of eugenics for Galton was founded upon an active idea of human evolution towards the “fittest race”. In this regard, his assumptions are not that different from those
contemporary scholars who view biomedical enhancements as a means to evolve the human species. (John Harris 2007; A. Buchanan 2011) Wrote Galton more than one hundred years ago: “Evolution [...] assumes an infinitely more interesting aspect under the knowledge that the intelligent action of the human will is, in some small measure, capable of guiding its course”. (Galton 1906, 69) Writes John Harris today: “This ‘progress of evolution’ is unlikely now to be achieved accidentally or by letting nature take its course. If illness and poverty are indeed to become rare misfortunes, this is unlikely to occur by chance. [...] It may be that a nudge or two is needed: nudges that will start the process [...] of replacing natural selection with deliberate selection, Darwinian evolution with ‘enhancement evolution’”. (John Harris 2007, 11)

Galton developed a biometric model of heredity that he thought could be “harnessed to a social programme for improving the human breed through selective mating”. (Porter 2011, 272) As said above, ‘selective mating’ included both positive and negative measures to prohibit the less fit from breeding, and as pointed out by Dorothy Porter (2011), the combination of degenerationist fears about the decline of the British race, and the fear of Britain’s imperial decline, were the two main ‘movers’ of the eugenics movement in the UK, which aimed at reversing the degenerative trends. (Porter 2011) The Victorian poor were considered a “race apart”, and described as “noticeably smaller, stunted, scrawny, potbellied, rickety, scarred by sores, scrofulous lumps, and other stigmata of sickness”. (Porter 2011, 220) An Interdepartmental Committee was set up in England to investigate the question of physical deterioration, and in 1904 produced a report reaching the main conclusion that physical deterioration was due to bad environment and unsuitable nutrition. Notwithstanding the lack of hard evidence about the biological causes of the degeneration of race, that fear continued to propel eugenics policies in England. In 1907, the British ‘Eugenics Education Society’ was founded, with declared both positive and negative aims: to “protect the unborn” through selective breeding, to perform “voluntary sterilization” on the lower classes and to “sequestrate the unfit”. In the UK, negative eugenics measures targeted mainly the feeble-minded with sterilisation or life-long detention (sequestration) upon certificates by two doctors. This was made possible after the
enactment of the Mental Deficiency Act in 1913. To note also that a bill introduced by Winston Churchill advocating compulsory sterilisation of the ‘feeble minded and insane classes” was only narrowly defeated in 1913. (Porter 2011) After this failed attempt, England was never to pass laws restricting marriage among the “feebleminded” nor compelled their sterilisation.

On the contrary, forced sterilisation laws were passed in over thirty states in the US before 1914, the first being Indiana in 1907. (Lombardo 2011) In the US, fear of “degeneration” focused on immigrants from Eastern and Southern Europe, as well as non-whites. The Model Eugenical Sterilization Law, published by the US Eugenics Record Office in 1914, provided for the sterilisation of quite a large category of individuals including the “feeble-minded, insane, criminalistic, epileptic, inebriate, diseased, blind, deaf, deformed, and dependent”. (Lombardo 2011) Then in the 1920s the ideas stemming from Mendel’s genetics came into fashion, and with them came a long list of ill-defined traits, collected under the category of ‘feeble-mindedness’. This in practice became a “catch-all category linked more closely to poverty and perceived anti-social behaviour than to organic mental deficiency” (Dorr 2011, 164). Again as pointed out by Dorothy Porter, in the US eugenics was “moulded by racialist concerns with immigration restriction” (Porter 2011, 273), and its principles were incorporated in the Immigration Restriction Act of 1924, which set quotas limiting the immigration of “biologically inferior” ethnic groups into the United States (South and East Europe) and favoured the entrance of Northern Europeans. (Porter 2011; Suter 2007, 907) In 1908 the American psychologist Henry H. Goddard introduced the I.Q. test, which then became the main barrier for immigration at Ellis Island3. Keeping “unfit” immigrants from entering the US though was not considered sufficient by eugenicists. Negative eugenics measures aimed at reducing or prohibiting the reproduction of the feeble-minded were also soon implemented. In the United States, Charles Davenport, who would become the leader of American eugenics, received funds to study evolution from the Rockefeller Society and develop therein a eugenics research facility, a testament to the close link between the two. The Rockefeller Society was to fund

3 For a powerful fictional representation, see also the 2006 movie “Golden Door” directed by Emanuele Crialese
eugenics studies worldwide, including in Italy in the aftermath of the 2nd World War, as described in the next section. In 1989, Davenport became the Director of the Cold Spring Harbor laboratory on Long Island, where in 1910 he founded the Eugenics Record Office. (McCabe and McCabe 2011). Between 1968 and 1972, the US witnessed a sterilisation explosion: approximately 2 million Americans underwent sterilisation in 1973 alone (!) (Dorr 2011, 175) Often the sterilisations were performed under the guise of other abdominal surgeries on unaware patients, in what became known as “Mississippi appendectomies”. (Roberts 2000)

In a similar fashion to what happened in the UK, the US definition of “fitness” and “unfitness”, and consequently the targets for sterilisation, corresponded to American’s white Protestant racial class prejudices (the contemporary ‘WASP’, or “White Anglo-Saxon Protestant” racial, political and religious ideal). Baby contests and “fitter families” contests were very popular up to the 1970s all over the US in state fairs, and some have persisted even up to today, as represented in the 2006 movie ‘Little Miss Sunshine’ directed by Dayton and Faris. (Dorr and Logan 2011, 70–71)

Note also that as recently as in 1996, the State of California passed a law implementing voluntary or surgical castration for the first offense of child molesters, and mandating castration as a condition of parole for repeat offenders. Georgia, Florida, Louisiana, and Montana have adopted similar laws that offer sterilisation as an alternative to continued incarceration. (Mehlmann 2011, 229–30) These laws are very similar in principle, and in practice, to the eugenics laws that included sterilisation as a condition to leave an institution both in the UK and Scandinavia, and in the US in the 1920s and ‘30s.

The debate about castration for child molesters and sex offenders is still very active today in the US and is spreading rapidly in Europe. As recently as in 2011, Francis Phillip Tullier, a child molester convicted in Louisiana to 27 years in prison, accepted to undergo surgical castration at his own expense in order to be released from prison on parole. (Associated Press 2013) In 2009, in Poland, the President at that time Lech Kaczynski signed a law to implement compulsory chemical castration for some sex offenders (Grubin and Beech 2010) In France, experimentation with sex offenders who ‘volunteered’ to undergo chemical
castration before discharge has been on-going since 2005. (Laurenson 2005) More recently, French Prime Minister Francois Fillon proposed to make it a compulsory treatment. (Associated Press 2009) In the UK, while on the one hand more than one hundred sex offenders have so far volunteered to undergo similar procedures according to a recent Guardian article, (Aitkenhead 2013) on the other hand, Alan Turing is officially to be given a posthumous pardon for having to undergo surgical castration — he later committed suicide — after an ‘indecency case’ (having homosexual intercourse). (Watt 2013) A similar debate is on-going in Italy, with several bills being proposed coming from different parties in the last few years, but the Senate rejecting the most recent proposed by the North League in 2012. (Oggi 24 2012) Similarly but for women, and again in the US, in the State of California, a recent report published by the Center for Investigative Reporting (CIR) uncovering the sterilisation of more than 50 female inmates from 2006 to 2010 without required state approvals, (Johnson 2013) made the headlines and stirred a fierce controversy about the resurgence of eugenics, which is still on-going. (Easley 2013; Ohlheiser 2013; N. Sullivan 2013)

Sweden and all of Scandinavia witnessed extensive sterilisation efforts just before WWI. These were prompted by eugenic policies that emerged together with the emergence of the social welfare state, which exploded in the 1930s and ‘40s. (Broberg and Roll-Hansen 2005) For this reason, the authors have coined the term ‘welfare state eugenics’ for Sweden, Norway, Finland and Denmark, where eugenics policies were seen as a subclass of a broader “Hygiene Movement”, precursor of the much praised North European model of the welfare state. (Broberg and Roll-Hansen 2005) The interests of the individual were to be subordinated to the interests of the state. At that time, as already pointed out for the US and the UK, there was a pervasive worry about “race degeneration”, and the declining birth rate, which pushed forward the eugenic policies. Notably, there was very little public opposition, and in general very little if not zero debate about the passing of eugenic and sterilisation laws. Also to note that in the Scandinavian countries there was no revision of the eugenics laws after WWII, and that the social democratic belief in eugenics continued up to the 1950s. Something similar happened in Italy,
though the eugenic policies were aimed – quite obviously – at a different ideal individual, and incorporated Fascist and Catholic values in fertility and privileged quantity versus quality of offspring. (Cassata 2011) In Sweden (the most efficient of Scandinavian countries for the implementation of eugenic laws, with up to 60,000 people sterilised between 1935 and 1975) the Sterilization law were not abrogated until as recently as 1975. (Broberg and Roll-Hansen 2005)

In all of Scandinavia sterilisation was used mainly for the mentally retarded (elsewhere referred to as the ‘feeble-minded’), and to a lesser extent as a measure of social control towards alcoholics, criminals, and in general – along similar lines to what happened in the US – towards all those who were considered incapable of caring and raising children. This category was stretched to include the category of “exhausted mothers”, or mothers who had too many children and were considered incapable of raising them/taking proper care of them. (Broberg and Roll-Hansen 2005) Contrary to what happened in Sweden, in Denmark, Norway and Finland, sterilisation remained on a “voluntary” basis, but even if direct coercion was not used, there were many other indirect means of coercing people to consent to sterilisation, including having sterilisation as a condition for leaving an institution, getting an abortion, or getting permission to marry. As already pointed out, these measures were not so distant from the sterilisation laws implemented in the US up to the 1970s.

As already pointed out above, it is also of interest to note that US eugenic laws, and not Germany laws as it might be thought, served as a model for the eugenic laws of Sweden and Norway. (Dorr 2011, 172) Sweden had compulsory sterilisation and both in relative and absolute number it was the most efficient Scandinavian country at implementing sterilisation. The uniqueness of Scandinavian countries in this regard is that they were the only countries in Europe (with the addition of Estonia) that introduced sterilisation laws in the 1930s under democracies. In Scandinavia, sterilisation was considered a rational and humane solution to the problem of economic and social burden of mentally retarded individuals. (Broberg and Roll-Hansen 2005) The welfare state helped many, but also demanded much from few.
Therefore, eugenics policies were the results of different ideological motivations and backgrounds in Scandinavia/Germany/UK/US. In England, eugenics policies focused more on ‘class’ than on ‘race’, and as pointed out by Dorothy Porter, eugenics was “less a scientific pursuit than a lay, voluntary movement of social reform in the Edwardian period”. (Porter 2011, 250). Always in England, the “unfit” were defined within the conventional terms of Victorian-British reform movements, where the social status combined with the considered anti-social behaviour produced the “unfitness” that included many different categories of deviant behaviour (alcoholism, promiscuity, criminality...) which were understood as hereditary traits and put together with others, such as mental retardation, considered to be “inborn errors of metabolism”. (Porter 2011, 250–1) Note that this is not so different from the definition of the ‘unfit’ in the US on the basis of the ‘WASP’ model (“White Anglo-Saxon Protestant”).

In Sweden, however, race biology became a subject of institutionalised scientific research before the 1st World War, and eugenics was considered a “philosophy” of social efficiency that fitted easily within a welfare ideology. Of the more than 60,000 sterilisations that were performed in Sweden between 1935 and 1975, over 90 % were women (it must be noted that these numbers do not distinguish those sterilisations that were at that time performed as a measure of contraception for women who had no other means). Swedish proponents of eugenics were very vocal in stressing the difference of Swedish eugenic laws with German eugenic laws, claiming that in Sweden sterilisations were not compulsory except for the “legally incompetent”. But, as noted above, other less coercive means were abundant, and sterilisation was a precondition for release from an institution, and for getting married.

As a matter of fact – and as exemplified in the quote by Maranto reported at the beginning of this chapter – it is the atrocities committed in Germany in the name of racial purity which gave the contemporary bad connotation to the word ‘eugenics’. Such a view though is over-simplistic, as highlighted below. Indeed, in the US before the war the term ‘eugenics’ started being used in the broader acceptation of ‘good’, not only ‘good in birth’. As pointed out by Lombardo, the term “encompassed everything from proud pedigrees to healthy births” and over
time the invocation of “eugenics” became so widespread that in 1915 a Chicago politician run for alderman as “the eugenics candidate”. (Lombardo 2011, 45)

After WWII the use of the word fell out of practice. But note though that even now in the US, only a handful of states have repealed their eugenics sterilisation laws, although the programs have been inactive for years in those states that still retain such legislation. (Suter 2007) On the contrary and as said before, castration laws for release on parole of child molesters and sex offenders are still active in many states and are being considered or enacted on a more or less voluntary basis also in many European countries.

Modern eugenics: 1945-1978

I refer to ‘modern eugenics’ as the period that goes from the end of WWII to the first ‘test tube-baby,’ Louise Brown, who was born in Oldham, England, on July 25, 1978. In those thirty years the practice of genetic counselling was established. Initially, it was limited only to prenatal screening for a very limited number of genetic diseases that present an abnormal karyotype (i.e. number and form of chromosomes), such as Down syndrome and other trisomies. During this period, choices concerning the future genetic pool shifted from the State to the parents, whose aim in using genetic screening was to have children free from disabilities. The nascent practice of genetic counselling was seen as a way for prospective parents to exercise autonomy and reproductive freedom. There was no mention of race or the community’s gene pool in the prospective parents’ decisions, but in the great majority of cases there were parents who wanted to give their children the best chance in life possible. The parents’ decision was exercised without coercion from the State, even if some kind of social pressure aimed at avoiding severe disabilities was present. (Suter 2007)

Italy played a prominent role in the international scene of medical genetics in the second post-war period. Indeed, Italy was chosen as the seat of the International Congress of Genetics in 1948. This decision placed the Italian Society of Genetics and Eugenics (SIGE) in a prominent position in relation to the international scientific community. In Italy, as pointed out by Francesco Cassata,
applied medical genetics to the new practice of genetic counselling was generally presented – and received – as a worthy and modern form of eugenics. (Cassata 2011) At least in Italy and elsewhere in Southern Europe, where eugenics had always differentiated itself from how eugenics was conducted in the Northern countries, the spectre of Nazism did not limit the possibility of a good eugenics based on “irrefutable scientific knowledge, and above all, conducted with liberal, non coercive methods”. (Cassata 2011, 304) Italian eugenics during the second World War indeed differentiated itself from the Nordic measures of eugenics by encompassing a natalist approach to population policies supported by the Fascist regime (in favour of “quantity” versus “quality” of the Italian race, and in support of the power of a “regenerative eugenics” through the values of fertility and prolificacy in contrast to the “conservative eugenics” of Anglo-Saxons or Germans which aimed at the sterilisation or elimination of ‘defective’ individuals), together with a neo-Lamarckian hereditary theory and a wide emphasis on positive eugenic measures. (Cassata 2011) Milan became the new capital of eugenics after the second World War: the first Italian genetic counselling centre was established at the Milan State University in 1946, and two years later the first public, “municipal eugenic counselling centre” was also established at the Milan Policlinic. (Cassata 2011, 309) The two centres were working primarily with premarital counselling for thalassemia and other kinds of microcytic anaemia which are endemic in Italy, especially in Sardinia and in other isolated regions of the country, as the healthy carrier (heterozygous for the mutation) had from an evolutionary standpoint an advantage by being more resistant to malaria than the homozygous individual. (Luzzatto 1981) In 1954, the Rockefeller Foundation mentioned above financed research conducted by a group based in Rome and based on the necessity of tackling “the eugenic aspect of the microcythemic problem, the establishment of official registers of persons carrying this gene, marriage counselling in some form”. (Cassata 2011, 324) Even Pope Pius XII intervened, publicly advising in favour of the necessity of premarital counselling, but advising against marriage prohibition based on genetic incompatibilities, as genetics “could not regard the human being in the

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4 SIE officially withdrew its membership from the International Federation of Eugenic Organisations in 1932.
same way as any other animal and vegetable species”, meaning that human beings had inviolable rights (including the right to marry, and to have children) that –and this was presumably the implicit comparison underlying the Pope’s statement – Mendel’s peas did not have. (Cassata 2011, 328, 342)

As noted by Suter though, even though the parental decisions in this second phase were ‘voluntary’, they were still taking place within a normative context biased towards prophylaxis (Suter 2007, 923), and prospective parents could very well feel societal pressure regarding the use of genetic technologies:

“All of these factors—advancing technologies and cultural norms—may exert a coercive effect on individuals’ reproductive choices. As the American Medical Association Council on Ethical and Judicial Affairs has stated, the most likely risk today is not “overt eugenics” or “government imposed constraints on marriage and reproduction” but instead “that the aggregate result of individual choices creates societal and cultural norms which substantially influence or limit the scope of autonomous decision making in regard to the use of genetic technology.” (Suter 2007, 936)

In general, though, it can be said with a reasonable degree of confidence that during this second phase genetic counselling strived toward an ideal of ‘non-directiveness’, advising but not directing – provided that this is possible in practice – prospective parents. Moreover, the actions of the parents were always aimed at bringing into the world children free from disabilities. As we will see, this was going to change in the current era of eugenics, as the choice of which traits parents were able to screen for was also expanding.

Contemporary eugenics: 1978 to now

This period in eugenics, beginning with the birth of first test tube baby Louise Brown in 1978 and continuing to today can be considered as “contemporary eugenics”, though in section 2.2 I will argue that a more appropriate term for this period would actually be ‘eligogenics’. This period comprises the use of various assisted reproduction techniques or AR techniques (such as in vitro fertilization or IVF, and intraspermic sperm injection or ICSI) for couples having problems conceiving, and, from 1989 on, the possibility of pre-implantation genetic diagnosis (PGD) in certain countries, depending on regulations. The motivations behind the
couples’ decisions are initially similar to those present in the second period, but people now have many more tools to exercise their reproductive freedom and to choose what kind of children they want to bring into the world. The year 1989 represented a landmark year not only for the fall of Berlin wall and the lifting of the Iron Curtain, but also because it was the year when the first babies were born that had been selected as free from a genetic condition using PGD. UK scientists Alan Handyside and Robert Winston used this technique to select embryos free from cystic fibrosis, adrenoleukodystrophy (a severe neurodegenerative disorder due to the accumulation of fatty acids in the neurons) or X-linked mental retardation. (Handyside et al. 1992)

PGD encompasses a series of different methods aimed at testing the embryo for genetic conditions, and it involves the removal of a single cell at the stage of blastomere from the 6 to 8-cell embryo using a fine glass needle to puncture the zona pellucida and aspirate the cell. (SenGupta and Delhanty 2012) As PGD is more technically challenging than IVF, it is estimated that only a couple of thousand babies around the world have been born following PGD, against an estimated more than 5 million children following IVF (up to 2012). (Harper et al. 2012) PGD is currently offered at only eight centres in the UK, all of which are fertility clinics licensed by the British Human Fertilization and Embryology Authority (HFEA). The list of the conditions available for screening for PGD is also constantly updated, and in 2012 it was altered to include only conditions deemed particularly severe. The entire list of licensed conditions for PGD can be found on the website of the HFEA and is periodically updated. (HFEA 2013)

PGD is prohibited in several countries, including Austria and Switzerland, and permitted with very strict limitations in Germany and Italy. (Soini 2007) In Germany, PGD was completed prohibited until recently, when on July 11, 2011, the Parliament passed a law allowing couples to resort to PGD to screen embryos only if the parents have a predisposition to a ‘serious genetic disease’. All applications for PGD must pass an ethics panel and couples are required to undergo genetic counselling. The bill outlines an exception to the Embryo Protection Act 1990 that bans PGD and any embryo experimentation. The Act remains intact and recommends a three year jail term for anyone using an embryo in a way that fails to
promote its survival. (Beier and Beckham 1991; Gottweis 2002) Previously, PGD was banned in Germany on ‘eugenic’ grounds and many people went abroad (to Switzerland, the UK, and France, for example) in instances of the medical tourism phenomenon, which is increasing especially for reproductive purposes within Europe. (Tuffs 2011; Zanini 2011) The stronger limitations to any kind of embryo manipulation or discard in Germany can and should be understood in their historical context as a moral and political response to the heinous crimes of the Holocaust.

In Italy, PGD has been prohibited since 2004, with the promulgation of law 40/2004, on different grounds from the German prohibition, but also to be understood historically due to the strong and persistent Vatican influence. (Fineschi, Neri, and Turillazzi 2005) In 2012, the European Court of Human Rights (ECHR) has ruled the Italian law 40/2004 unconstitutional as it “violates the right to respect for private and family life” guaranteed by Article 8 of the European Convention on Human Rights. (White 2012) In addition, the judges noted the inconsistency of the Italian law, which “on one side deprives the applicants access to PGD and on the other authorizes them to perform therapeutic termination of pregnancy when the fetus is affected from this same disease”. (White 2012) (Turone 2012) The case was brought to the ECHR through the case of Rosetta Costa and Walter Pavan v. Italy (no. 54270/10). Costa and Pavan are asymptomatic carriers of cystic fibrosis who were seeking PGD to conceive in vitro and artificially select an embryo free of the cystic fibrosis mutation. The couple complained they were “forced to abort” their potentially disabled child in 2010, while had they been able to resort to PGD earlier on, abortion would not have been necessary. The ECHR awarded the couple €15,000 as compensation, but denied further complaints of discrimination. (White 2012) To note that, unlike a national court, the ECHR does not directly have the power to overturn Italian law, and the government has the right to appeal the decision, which the Italian government did under Prime Minister Biondi in November 2012.5 (Biondi 2013) (Maggiorelli 2012) As noted above, the Italian ban on PGD was part of a law on assisted reproduction, introduced in 2004,

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5 A decision on the appeal has not been reached at the time of finalizing this thesis (August 2013)
which ruled that assisted reproduction was only available to infertile heterosexual couples. (Fineschi, Neri, and Turillazzi 2005) The same law ruled that it was illegal to freeze or destroy human embryos or use donated sperm and eggs. This has led to a dramatic decrease in the rates of successful delivery following IVF (in vitro oocytes do not freeze as well as embryos and are not viable upon thawing) (Levi Setti et al. 2013) and to a dramatic increase in the flux of medical tourism for reproductive purposes from Italy to Spain, Switzerland and other more permissive countries in the EU. (Manna and Nardo 2005)(Zanini 2011)

The US has a more permissive approach, though McCabe and McCabe point out that, while at first sight US medical practice appears to be more independent than medical practices in the UK, in the US there are state-based regulatory authorities that establish the rules of medical practice conduct and misconduct. In addition to state-based regulation, there is also the increasing influence of corporate incentives and pharmaceutical lobbies. While in theory, clinics are allowed to provide PGD for any possible technical reason for which it is requested, in practice, clinicians in the US adhere to professional guidelines issued by the American Society for Reproductive Medicine. (Practice Committee of the ASRM 2006) In the last ten years, PGD has been used not only to avoid traits traditionally considered as ‘disabilities,’ but also to choose the sex of the child. The use of PGD to select babies of a particular sex for ‘family balancing reasons’ (an expression very broadly applied also in cases where the couple seeking PGD has only one child, or has no child but has a preference to conceive a child of a determined sex) is permitted in the US, whereas it is currently banned in the UK by the HFEA. The HFEA allows sex selection only to avoid passing of conditions that are X-linked, i.e. for which a girl, having two X chromosomes, would not manifest the disease but only be a carrier, whereas a boy would manifest the disease.

In the US, PGD has also been used to choose for traits traditionally considered a disability, such as deafness or achondroplasia (genetic dwarfism). A recent survey of 190 American PGD clinics found that 3 % reported having intentionally administered PGD “to select an embryo for the presence of a disability”. I analyse this specific case in (Camporesi 2010), where I argue that, even
under the assumption that deafness were only a socially constructed disability, it
would still be wrong for parents to choose deafness based on an infringement of
the child’s right to an open future (see Appendix 1 and section 2.3).

2.2 Eugenics and eligogenics: past and present objections

As we have seen, the aim of eugenics was the improvement of the overall
quality of the gene pool, to be achieved both through positive and negative means.
Reproduction was understood as an act with social consequences, not a private
matter. The interests of the state always took precedence over the interests of the
individuals, and there was little or no discussion about it. Direct and less direct
means of coercion were used to restrain the mentally retarded, those considered
feeble-minded and in general all those considered a burden to society from
reproducing.

Are the ethical objections against classical eugenics still valid toward
modern practices of reproductive genetic choices? The key question to address is
whether eugenics was wrong in its very inception. Gina Maranto, quoted at the
beginning of this chapter, thinks that wrong ideas never die, but represent
themselves under a new guise. (Maranto 2013) But her statement needs qualifying.
First of all: can the contemporary use of genetic technologies to choose to have
deaf or dwarf children still be called ‘eugenic’? There is no word, yet, to define such
practices. The only attempt to date is by Isabel Karpin, who in 2008 defined it as
‘negative enhancement’. I am not satisfied with such a definition, since the
motivations these parents put forward to choose for deafness or dwarfism are that
such traits are not disabilities, but “only ‘differences’ that will enable their children
to ‘enter into a rich, and shared culture’”. (Sanghavi 2006) Sonia Suter (2007)
suggest the word ‘neo-eugenics’ for all contemporary uses of genetic technologies
to choose what kind of children to bring into the world. She writes:

“I refer to these modern practices as “neo-eugenics” to suggest that they
share some key features with classic eugenics—e.g., the goal of increasing
“good birth”—and that they differ because they occur primarily at the
individual, rather than state, level. (Suter 2007, 898)
Therefore, in contemporary practices the locus of what is ‘good’ has changed from the state to the individual. For this reason, it seems to me that another word which could capture better the full spectrum of parental choices to also include choosing deafness and dwarfism may be ‘eligogenics’, where ‘eligo’ in Latin means to ‘choose’, as this encompasses the narratives used by the prospective parents when asked why they are resorting to PGD. In the rest of this chapter I will refer to contemporary uses of genetic technologies to choose traits for the offspring, including choosing traits traditionally considered disabilities, as eligogenics.

Buchanan and co-authors argue that, reprehensible as much of the eugenic program was, there is something unobjectionable and perhaps even morally required in the part of its motivation that sought to endow future generations with genes that might enable them to live better lives. The authors also argue that these motivations need not to be abandoned, if they can be pursued justly. (A. E. Buchanan et al. 2000, 27–60) Suter writes along similar lines, (referring to contemporary eugenics practices as ‘neo-eugenics’):

“Neo-eugenics (and even eugenics), I shall argue, is not per se problematic. That is, many of the underlying goals are legitimate. This is not to say that neo-eugenics is not problematic in practice; [...] The analysis, however, is highly contextual, depending both on social factors and individual circumstances.” (Suter 2007, 899)

I will now consider the objections to classical eugenics and discuss whether they can be applied also to eligogenics practices, following the analysis by Buchanan et al. (2000), who identify five possible answers to why eugenics was morally wrong:

1) Replacement, not therapy: eugenics sought to bring into the world better people, rather than aiming at improving the conditions of any existing people.

2) Value pluralism: eugenicists assumed that the concept of ‘good’ was univocal.

3) Coercion: coercion was used in many, even if not all, eugenics programs.

4) Statism: the role of the State in shaping individuals’ wishes and desires, instead of preserving individual freedom
5) Justice: the problem of distribution of burdens and benefits in the eugenics programs (the most disadvantaged being always the target of the eugenic policies which made them even worse off), and the problem of equality of access to the technologies.
(Buchanan et al. 2000, 27–60)

Are the objections identified by Buchanan and co-authors still valid today for the eugenics practices described above?

The first objection identified (replacement, not therapy) is one of the arguments often brought forward today by the disability rights movement scholars (see for one, (Shakespeare 2006) and (Shakespeare 2013)). These scholars argue that the use of genetic technologies aimed at choosing ‘better people’ is *de facto* devaluing disabled existing people, and also damaging as it takes away from them important resources to improve their conditions in society. While I may agree with the possibility of the second part of the argument, the first part seems to me to be logically flawed, as choosing not to bring disabled people into the world does not imply devaluing existing people. (John Harris 2005)(Holm 2008) This objection is often referred to as the ‘expressivist objection’, which at its core claims that the use of PGD or termination of pregnancy expresses discriminatory attitudes towards disabled people. Holm, though, correctly points out that the point about the logical necessity raised by Harris among others is largely irrelevant outside academia. (Holm 2008) He also points out that, while it is possible to conceive in theory of a “socially embedded practice of prenatal diagnosis and termination of pregnancy that did not, as an empirical fact about that practice, express any negative attitudes towards the disabled and could not justifiably be construed to express such negative attitudes” (as for example in a particular context, where the problem of allocation of scarce resources would not exist), this scenario is not the one, or not even close, to the one we have at the moment in our society. Instead, at least to some degree, our current practices of prenatal diagnosis and termination of pregnancy do express those attitudes that proponents of the expressivist objection claim they do. The burden of proof, therefore, – Holm seems to imply – is on those that claim that current practices are not devaluing individuals with disabilities, not on individuals with disabilities to demonstrate that the practices are not devaluing.
Indeed, Holm notes that it is justified for individuals with disabilities to draw certain inferences (about the devaluing of themselves) from practices aimed at not conceiving individuals with such disabilities, as such inferences seem to be epistemically warranted (Holm 2008, 25). As an example, Holm offers the image of burning a flag: people seeing a flag being burnt are justified in drawing the inference about the symbolic meaning attached to the action, unless explicitly said otherwise. I agree with Holm on this point and would also add that probably it is not sufficient only to state otherwise, but to persuade/make a convincing case of why the practice is not actually devaluing them (therefore, words about logical necessity would probably not be sufficient, as Harris offers, but practical changes would be asked for).

I will take a closer look at the expressivist arguments when I discuss DeGrazia (2012) in section 2.3.

The second objection (‘value pluralism’) is a very powerful objection to classical eugenics practices, which subordinated the ‘good’ of the individual to the ‘good’ of the state that was considered objective and univocal. In this sense, contemporary eligogenic practices differ substantially from classical ones, as parents are able to choose subjective conceptions of the good (e.g. deafness, achondroplasia), at least in countries where the approach to PGD is more permissive than in the USA. Of course, the possibility of societal pressures or of cultural complicity, as identified by Little, is not to be dismissed. (Little 1998) See also the discussion of the following objection.

As to the problem of coercion, it would seem easy to dismiss this concern at first sight as not valid in contemporary practices of reproductive genetic choices. The parents claim that they exercise their autonomy and liberty in deciding whether to undergo IVF or PGD. It is true that there is no social enforcement, as there was with large-scale sterilisation practices. As defined by Beauchamp and Childress, “coercion occurs if and only if one person intentionally used a credible and severe threat of harm or force to control another”. (Beauchamp and Childress 2001, 94-96) Along these lines, a subjective response in which persons comply because they feel threatened does not qualify as coercion. I agree which
Beauchamp and Childress, who criticize the tendency in contemporary biomedical ethics debate to render “coercion” an all-purpose term of ethical criticism. Other terms that should be used are persuasion, where a person is led to believe in something through the merit of reasons, and manipulation, where persons are swayed into doing what the manipulator wants by means other than coercion or persuasion, e.g. informational manipulation. (Beauchamp and Childress 2001, 94-96) It needs to be noted that some kinds of social ‘pressure’ toward the best possible children could be described as forms of persuasion or manipulation. To what extent does the society in which these practices occur manipulate parents into taking such measure—to screen for children who have traits that mirror the values of that particular society? Robert Sparrow (2011) points out this problem in the practices of contemporary eugenics (see discussion below), and Little was the first scholar to identify the perils of cultural complicity inherent in enhancement technologies.(Little 1998)

Some distinctions need to be drawn concerning the validity of the fourth objection (Statism) on contemporary eligogenic practices. As Suter has pointed out, while a common distinction often made between eugenic and what she refers to as ‘neougenic’ is that the former had the interests of the State as its goal, while the latter has the interests of the individuals (Suter 2007, 946), such an analysis is oversimplifying, as in both periods, the motives were mixed. Writes Suter:

“The classic rationale for eugenic sterilization included benefits to the sterilized individual [...] Just as classic eugenics was not motivated solely by social well-being, current and future reproductive technologies are advocated not solely to allow individuals to make decisions compatible with their values and goals. The technologies are also promoted and encouraged as socially responsible.“(Suter 2007, 946-7)

This issue can be found as a new instance in eligogenics in the consequentialist arguments that some genetic enhancements will increase the total welfare of society, by increasing the percent of fit people in society. To be realistic, though, these objections are very weak because the percentage of people who will choose genetic traits for future people is not going to even minimally influence the human population on a worldwide scale.
The fifth and last issue identified by Buchanan and co-authors, ‘justice’, hinges on the problem of availability of the genetic technologies in society, and equality of access. As pointed out by Sparrow: “The real danger posed by the development of effective technologies of human enhancement is not that religious conservatives will prevent couples from making use of these technologies, but that parents will eventually have no choice but to make use of them. Without them, their children will stand no chance of competing effectively in the world”. (Sparrow 2011) The analysis by Sparrow is important as it points to a very concrete consequence of the use of genetic technologies to choose what kind of children to bring into the world. Even if there is no coercion from the State and parents are free to exercise their choices (to the point that they are free to choose traits traditionally considered ‘disabilities’), the pressures exercised by society and the problem of cultural complicity need to be taken into account when evaluating the ethical permissibility of the use of genetic technology to choose children. Sparrow points out also the “very unattractive consequences” that we would have to accept if we endorsed some of the libertarian claims made by Harris and Savulescu, who argue in favour of a moral obligation, or duty, to bring into the world the best possible people. (Savulescu 2005; Savulescu 2007; Harris 2007; Harris 2012). One of these ‘very unattractive consequences’ is the increase in the cultural complicity already pointed out in chapter 1 by Elliott and Little with societal problematic practices of discrimination towards minorities and conformism towards a ‘dominant’ conception of the good. Writes Sparrow:

“In many parts of the world today, prevailing social circumstances are likely to have a much greater impact on the welfare of individuals than are other environmental factors. When thinking about which genes are best for our children, then, Harris and Savulescu’s argument implies that we should take these factors into account. Thus, for instance, in a racist society, where children born with particular racial markers -skin color, hair type, shape of nose and lips, presence or absence of an epicanthic fold, and so on- will have reduced life prospects, a proper concern for their children’s well-being requires that parents work to mitigate the impact of racism by altering the child’s environment, or by manipulating the genes associated with these markers, or both. [...] Unfortunately, it will often be much easier to alter a
child’s genetics than the social conditions that will shape the ultimate impact of their genetics.” (Sparrow 2011)

Are we ready to accept this ‘repugnant conclusion’ (borrowing from Parfit (1984)) as a consequence of our obligation to enhance? As pointed out by Sparrow:

“In most of Europe, North America, and Australia, Harris and Savulescu’s argument would have parents choosing white male children who would grow up to be tall and (probably) blonde haired and blue eyed. When it comes to the sorts of people the consequentialist argument would have us choose to bring into the world, then, the ultimate conclusions of the new eugenics are remarkably similar to those of the old”. (Sparrow 2011)

In his book “Liberal Eugenics. In defense of human enhancement”, Nicholas Agar defends contemporary eugenics practices and replies (although, indirectly) to Sparrow’s concern (Agar 2005). For Agar, the main difference between liberal eugenics and what he refers to as ‘authoritarian eugenics’ is that the former is grounded in the principle of liberal societies for which there are many and often incompatible ideas of the good life and of human flourishing, and individuals should be left free to pursue their own idea with the tool of enhancement technologies. Agar’s conception of liberal eugenics is not, though, to be unbounded or unregulated. On the contrary: while individuals should be left free to pursue and choose with whom to mate/to reproduce, they should not be left completely free to choose what kind of children to have. This is because in the latter endeavour individuals will need to resort to the assistance of the state (or a private organization) which can and should impose conditions in this cooperation, “refusing to assist reproductive choices that are morally defective in some significant ways” (Agar 2005, 16). As examples of these morally defective choices, Agar includes the ‘very unattractive consequences’ pointed out by Sparrow, as choosing to have a straight child instead of a possibly gay one, or choosing to have a white child instead of a black one. Doing so would contribute to reinforcing ethically problematic societal practices, such as racism. Therefore, from a liberal viewpoint such as Agar’s, the new freedom of choice opened up by new genetic technologies can be seen as an extension of parental reproductive freedom, which could be
bounded in ‘morally defective cases’. The judgment on the ‘moral defectiveness’ needs to be made on a case-by-case analysis, though not further explored by Agar in his book. Suter also writes on the need of a contextual analysis of contemporary eligogenic practices:

“Some of the attitudes and concerns of eugenics remain today - a focus on the heritability of traits, a tendency toward genetic determinism, a privileging of science, a focus on societal benefits of genetic technologies, and most important, societal pressure to increase the chances of having “well-born” children or to decrease the incidence of “less fit” children. [...] I argue that the propriety of neoeugenics, or eugenics for that matter, depends on motivation, context, and results; it cannot easily be categorized as always or never problematic.” (Suter 2007, 948-9)

I agree with Suter’s point on the necessity of a contextual analysis of contemporary eligogenic practices to spell out all the dimensions of the use of a particular genetic technology by parents to select specific traits. Indeed, this is what I try to do in analysing genetic technologies used to choose to have deaf children (Appendix 1), and in my analysis of the use of genetic technologies to measure children’s talent (Appendix 3). Finally, other objections to decisions aimed at “choosing children” are raised in terms of consequences on the future of humankind but as pointed out already do not seem to be particularly powerful. Instead, objections raised not in terms of number of people, but of what values we are leaving to future generations seem to me to be a more significant but often overlooked argument. The possibility of exacerbating inequalities, and of differential access between people who can avail themselves of genetic technologies and others who cannot, are pressing questions. Moreover, as noted above in the case of PGD, the discrepancies in regulation of genetic technologies among countries make possible and have already led to the phenomenon of medical and reproductive tourism within and outside Europe, further exacerbating the above mentioned question of equality of access. (Meghani 2011; Zanini 2011)

To conclude this section, it seems to me that, if eligogenic practices are indeed morally problematic, they are so on different grounds than the possible consequences on the future of our species. A promising direction seems to be the
one of children’s autonomy and possibility of flourishing, and the right to have an open future, in addition to the problem of cultural complicity raised by Sparrow (2011). In the next section I am going to take a closer look at the conflict that may arise in the context of genetic technologies between parental procreative liberty and children’s interest.

2.3 Procreative liberty and children’s right to an open future

Individuals resort to genetic technologies to engage in new ways to reproduce. They also avail themselves of genetic technologies to shape the creation of what kind of people to bring into existence. Both these actions can be considered within the scope of ‘reprogenetics’, borrowing from Silver who coined the term in his 1997 book “Remaking Eden”. (L. M. Silver 1997) These kinds of choices take place both at the pre-natal and at the post-natal level. In this section and the following I will focus on the former, while in section 2.5 I will consider the latter.

‘Procreative liberty’ (PL) has been defined by Robertson as a “liberty or claim-right to decide whether or not to reproduce”.⁶ (Robertson 2003, 447) Robertson distinguishes between two components of PL: a negative component, and a positive component. The negative component amounts to the liberty to avoid reproducing, which includes the liberty to “avoiding intercourse, using contraceptives, refusing the transfer of embryos to the uterus, discarding embryos, terminating pregnancies, and being sterilized” (Roberston 2003, 447). The positive component amounts to the liberty to reproduce which involves “the freedom to take steps or make choices that result in the birth of biologic offspring, such as having intercourse, providing gametes for artificial or in vitro conception, placing embryos in the uterus, preserving gametes or embryos for later use, and avoiding the use of contraception, abortion, or sterilization.” (Roberston 2003, 447). Each component has an independent justification and can be conceived as a different claim-right. Like most rights in a liberal society, the PL claim-right is to be understood primarily as a negative right, i.e., a right against interference by the

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⁶ In this work I use the terms ‘reproductive freedom’ and ‘procreative liberty’ as synonyms.
state or others with reproductive decisions. A positive right of PL would entail a heavier burden on the state, i.e., to provide resources for assisted reproduction, facilities, infertility treatment, abortion, etc. While PL has both negative and positive components, in what follows I will concentrate on when we should refrain from interfering with PL, therefore with the negative component.

Why is PL so important? Buchanan and co-authors identify the interests and values that determine the moral importance of PL: (A. E. Buchanan et al. 2000, 204–256)

a) Self-determination: the interest of an individual in making significant decisions about one’s own life, according to own values or conceptions of a good life;

b) Individual good or wellbeing (the precise form of this argument depending on the account of wellbeing chosen);

c) Equality of expectation and opportunity: PL serves this value by helping mitigate the unjust gender disadvantages, and helping mitigate the effects of other forms of gender discrimination.

As pointed out by Robertson (448), recognizing PL “as a moral or legal right or important freedom does not mean that it is absolute, but rather that there is a strong presumption [emphasis, added] in its favor, with the burden on opponents to show that there is a good case for limiting it”. (Robertson 2003, 448) If this is the case, when is it justified to drop the presumption, and interfere with PL? Before answering this question I first distinguish between six aspects of the scope of PL, following the analysis by Buchanan et al., (2000), who spell out in more detail than Robertson the components of PL:

1. The choice of whether to procreate, with whom, and by what means;
2. The choice of when to procreate;
3. The choice of how many children to have;
4. The choice of what kind of children to have;
5. The choice of whether to have biologically related children;
6. The social conditions that support reproductive choices.

(Buchanan et al. 2000, 204–256)
Buchanan and co-authors note how a justified interference may be specific only to one component or another of PL. Genetic technologies used for current eligogenic practices focus on the 4\textsuperscript{th} component of PL. This, though, seems to be a component that is more distant from the individual’s self-determining oneself, and more related on the determinations of others. The overall moral case for determining what another is like is substantially weaker than the moral case for determining how one’s life should be. Does this argument represent sufficient ground to interfere with the use of genetic technologies that parents use to choose what kind of children to have? I argue that it is, in a paper where I analyse the case of parents that use PGD to choose a trait traditionally considered a disability: deafness, or achondroplasia (genetic dwarfism). (Camporesi 2010) In that paper, I frame the argument that a legitimate interference on parental PL is based on the right of the children to an open future (Feinberg 1994). Deafness, even under the assumption that it is a socially constructed disability, is still to be considered an impairment that substantially limits children’s right to an open future and their possibility of self-determination. Therefore an interference with parental reproductive freedom, and in particular with the fourth component identified by Buchanan and co-authors (2000), is justified. See Appendix 1 for the full argument.

In the next section I consider an alternative way of framing the deafness case which reaches a similar conclusion (i.e. justifying state interference on parental PL) on the basis of an objection to the expressivist argument that deafness is only a ‘difference’, and not a disability.

\subsection*{2.4 Choosing ‘disabilities’, or just ‘differences’?}

According to the expressivist objection, traits such as dyslexia, deafness, achondroplasia and others are not to be considered disabilities, but mere differences. Such traits, the objection continues, are not more disadvantageous per se than being born black in the US South in the 19th century, or being gay in contemporary Iran (which does not mean that they are not inherently
disadvantageous!). (Sanghavi 2006) From this perspective, all disadvantages are contingent on the socio- and cultural context the individual finds herself in. Those who resort to this argument reject the medical model of disability (according to which disability is a relatively long-lasting, biologically grounded condition that impairs the individual in one or more significant ways) and adopt the social model of disability, which maintains that disability involves a loss or limitation of opportunities due to institutional or social barriers. Mackenzie and Scully have elegantly argued that a particular embodiment is necessary to make claims about one’s own quality of life, and therefore that the incorporation of narratives of the disabled individuals becomes a necessary step when deliberating about PGD. They write:

“We do not dispute that the capacity for imaginative projection, or simulation, is central to our ability to understand other people’s mental states. However, there is a significant gap between the kinds of simple cases of belief and desire attribution about which philosophers of mind are concerned, and imaginatively entering into another’s point of view sufficient to understand, for example, how that person experiences disability or evaluates her quality of life.” (Mackenzie and Scully 2007, 339–40)

Scully has also pointed out the potential exacerbations of equality of access to the genetic technologies, and differential treatment in society that could be raised by technologies aimed at preventing individuals with disability to come into the world. (Scully 2008)

In my 2010 paper I objected to the argument that deafness is not only a difference by constructing it as an impairment, and not necessarily as a disability. I adopted therefore an interactive model of disability, where the disability is the product of the interaction between a biological dysfunction (the impairment), and the social and physical environment in which the individual finds herself, and argued that deafness as an impairment still constituted a limitation of children’s right to an open future. DeGrazia objects to the argument that disabilities are not only ‘differences’ with an excursion in value theory that I present below. (DeGrazia 2012, 108) His argument can be seen as a valid alternative to my argumentative strategy to reach similar conclusions that justify an interference with PL.
DeGrazia’s excursion into value theory takes into account the fact that many people with major disabilities claim to be happy with their lives. This is a matter of fact. They often claim that the disability added value to their lives, that it made them ‘better persons’, that if they could choose to be born again without the disabilities, they would not do so, etc. What weight should this kind of claim be given in relation to the discussion of cases such as that of individuals resorting to PGD to choose deafness? 

Some authors object to these narratives by arguing that individuals are subject to self-deception, but this does not seem to be a successful strategy for at least two reasons: a) the limited number of cases; and b) the presumption that the best judge of what is best for one’s own life is the individual living that life. In addition, it needs to be acknowledged the increasingly prominent role and significance of patients’ narratives in bioethics, which has been witnessing a shift in the last fifteen years from a ‘principled’ default to a reflective mode, in particular in the analysis of the doctor/patient dilemma that arise at the bedside. (Lindemann 1997; Charon and Montello 2002) Though I will not enter here into this discussion, I would like to recognize the importance of incorporating, and giving proper weight, to the narratives of patients or individuals with disability when discussing the ethical permissibility of a particular technology such as for example PGD as used to choose to have deaf children ‘like themselves’, quoting from Sanghavi (2006). I am aware that this is something that I may have not given full weight in my 2010 paper, and that - were I to re-analyse the issue now- I would consider more in detail. This though does not mean that I would be prepared to accept the use of PGD to choose deafness (see also the discussion of DeGrazia’s arguments below). 

DeGrazia too is cautious in attributing self-deception to individuals. He writes: “Generally speaking, it is the person herself who best knows how her life is going for her” (DeGrazia 2012, 112). Even if he acknowledges that some individuals may think they are satisfied with their lives as a consequence of the dampening of their desires due to the loss of functioning they experience, this judgment of ‘comparative achievement might not be relevant to the issue of how well the subject’s life is going for her’. (ibidem) On the one hand, DeGrazia adopts
subjectivist theories of values in contrast to objectivist theories of values, which he argues are ‘theoretically presumptuous’ and require a heavy burden of justification. On the other hand, though, DeGrazia does not accept subjectivist accounts of value tout court. In order to avoid the seemingly absurd implication of subjectivism that a person is happy when all her beliefs are systematically and profoundly distorted (deluded individuals), we need to define happiness in a way that is more plausible than the mere reduction to either pleasurable feelings or desire-satisfaction. This more plausible definition is to define happiness in terms of ‘life-satisfaction’, i.e., satisfaction with how one’s life on the whole is going. Also, this would require a reality-based check, understood as: ‘a person’s happiness makes her well-off only if it is based on a more or less accurate understanding of her circumstances’. This reality check for DeGrazia avoids defining happy an individual who is subject to delusions. To note though that this reality check introduces an objective element into an otherwise subjective account, making it a mixed subjective-objective model. I am not going to enter here into the discussion of delusions and happiness, to which I could not really contribute (see (Bortolotti 2010)).

To conclude, DeGrazia emphasizes the subjective element of his account, and argues that we should take into account the subjectivist report and avoid the argument of self-deception. As means of clarification, DeGrazia offers the example of the ‘happy slave’, and refers to it as the victory of stoicism: “If a slave is happy despite having no illusions about his situation then he has overcome the odds and is actually doing well. He is not less well-off just because his desires and expectations have been partly shaped by oppression”. (DeGrazia 2012, 114) Hannah Arendt’s analysis seems to be more sophisticated. Arendt distinguishes between two aspects of happiness of the slave: eudaimonia, “an objective status depending first of all upon wealth and health” (something the slave could not enjoy by definition because they were subjected both to physical necessity and to man-made violence), and the actual subjective wellbeing as declared by the slave. (Arendt 1958, 31) The analysis by Arendt makes sense of the possibility that a slave—or another person in a severely disadvantage condition – could still claim to be ‘happy’ without being deluded or subjected to self-deception, but could not
possibility enjoy the possibility of human flourishing captured by the Greek concept of eudaimonia.

Therefore, returning to the discussion of whether disability are just differences or not, DeGrazia argues that indeed disabilities need not be disadvantageous, as a person can fare just as well overall as a person without the disability, but from this it does not follow that disabilities are mere differences. ‘Disabilities involve the absence of a kind of functioning that plays a significant role in human life’ (ibidem, 115) and are ‘presumptively disadvantageous’ [emphasis added] since they present an obstacle to wellbeing (even in the best possible societal scenario) but are not necessarily disadvantageous, for despite their obstacles, people can – and indeed, do – fare well. But if they do so, they have overcome their odds. To conclude, “because disabilities are presumptively disadvantageous, it must be considered harmful to inflict a disability on an individual” (115). In this sense, the arguments by DeGrazia are not too far from mine, as I also argue that impairments such as deafness are disadvantageous for children. The right to an open future seems to be one of those arguments predominantly used in the context of children, while DeGrazia’s analysis focuses more on arguments of individuals who reached adulthood with a disability.

2.5 Post-natal genetic technologies to measure children’s talents

At first sight, the use of genetic technologies post-natally would seem to be less controversial than the use of genetic technology at the embryo or foetus stage: after all, how much can genetic technologies really shape an already existing person? And also, do we not already grant a great degree of leeway to parents in deciding how to rear and educate their children? Parents can impose their religion, hobbies, choice of school and friends on their children, and go to great lengths to ‘nurture’ their children’s talents: from submitting them to heavy training schedules, to hiring private teachers or tutors, to sending their children to intensive summer camps, and so on. While these practices are occasionally subjected to criticisms for their strictness, it is generally accepted that it is permissible within the parental role to steer children even aggressively in a particular direction. Not only, but in our
Western society, it seems that parents whose children exhibit talents have a *prima facie* duty to nurture that talent, and we often criticize parents if they did not fulfil their parental duty. Michael Sandel writes on this point:

“We usually admire parents who seek the best for their children, who spare no effort to help them achieve happiness and success. Some parents confer advantages on their children by enrolling them in expensive schools, hiring private tutors, sending them to tennis camp, providing them with piano lessons, ballet lessons, swimming lessons, SAT-prep courses, and so on. If it is permissible and even admirable for parents to help their children in these ways, why isn't it equally admirable for parents to use whatever genetic technologies may emerge (provided they are safe) to enhance their children's intelligence, musical ability, or athletic prowess?” (Sandel 2004)

But this parental quality is a degree-quality, i.e., it remains a quality only if exercised to a certain extent. To what extent is nurturing a talent an admirable attitude in parents? Is there a certain threshold above which parental attitudes cease to be admirable, and become actually criticisable? The premise I want to challenge is exactly whether it is always permissible or admirable for parents to “help” their children in these ways. Talented children are particularly difficult cases, as the nurturing of a precocious musical or sport talent is often essential to the realization a successful adult, but that will often have been achieved at the expenses of other skills (possibly, all other skills except that particular one which was nurtured) and of the person’s self-determination.

Instead of condoning new practices of talent-scouting and talent-nurturing on the basis of established old ones, I think we should question the latter ones through the light shed by the former, as I find that there is something particularly problematic about excessively competitive parental attitudes aimed at nurturing and developing their children’s talents. Writes Sandel again: “Parents have a duty to promote their children’s excellence. These days, however, overly ambitious parents are prone to get carried away with transforming love—promoting and demanding all manner of accomplishments from their children, seeking perfection”. (Sandel, Michael 2004) The examples of successful adults (musicians, athletes, mathematicians, artists) who have had a miserable childhood as talented kids/prodigies because of the very strict parental education they were subjected to
are abundant. (Solomon 2012, 405–476) Sonia Suter comments on these problematic parental practices:

“The harm in these anecdotes [of children being raised by overbearing parents] is not attempting to control reproduction, but attempting to control the existing child. The harm is not valuing athletic skills, intelligence, artistic ability, or any other talents, but doing so to the exclusion of other aspects of the child and failing to value the child’s fullness as a human being. Concerns about overbearing parental expectations in the context of neoeugenics seem to presume that the hopes underlying the reproductive choices will increase the possibility of being overbearing. Perhaps that is true if the parents engaging in neoeugenics take a genetics essentialist perspective. [...], Nevertheless [the fact that these concerns are not new] we should be concerned about the growing and cumulative ways in which parents may be tempted in this direction [by the availability of the new genetic technologies].” (Suter 2007, 964–5)

Along similar lines, Claudia Mills points out that the problem with aggressive parental practices for talent-scouting and development is not so much the infringement of the child’s open future, but the infringement of respect for the person, i.e., the child, that is in front of us now, and of whose preference, autonomy, and possibly childhood itself is being robbed. (Mills 2003) While I do not agree with Mills on her critique of Feinberg (for a full analysis see Appendix 3), I am very sympathetic to both her and Suter’s accounts putting the emphasis on thehic et nunc child, borrowing a felicitous expression from Mills. Parental attitudes like those described above by Sandel are not unique to genetic enhancements. They are, instead, new instances of the old practice of bad parenting and child-rearing, which was alive and well before there was any talk or discussion or enhancement. (DeGrazia 2012, 128–9) While I agree with DeGrazia on this point, I do not think such concerns can be dismissed so easily. Quite on the contrary, I think that a reflection on the problematic uses of genetic technologies for purposes of enhancement in children should function as a ‘wake up call’-borrowing from Dena Davis (Davis 1997) – to prompt an ethical reflection on other problematic parental attitudes. In fact, a consistent ethical approach would justify interference with the scope of “parental child-rearing” in both realms. Let us analyse a specific case: genetic tests to measure children’s potential.
John Robertson discusses the thought experiment of parents using genetic tests and PGD to select children with ‘perfect pitch’. The gene for perfect pitch runs in an autosomal dominant pattern, even though it has not been identified yet. (Robertson 2003, 464–466) Robertson therefore imagines a future in which the gene has been identified, and imagines that some parents who have a strong interest in the musical abilities of their children may be willing to undergo IVF and PGD “to ensure this foundation for musical ability in their child”. (Robertson 2003, 465) The question is whether this request should be accepted or denied. Robertson argues that it should be accepted on the basis of the following argument: since parents “clearly have a right to instil or develop their child’s musical ability after birth” (465) therefore, “they might plausibly argue that they should have that right before birth as well”. But is this really the case? To what extent do parents have a right to instil and develop their children’s musical ability? Do they have a right to do so from the age of 3, 4, or 5 years old? It is a matter of fact that putting talented children in music or sports programs at the earliest possible age is necessary to maximize the particular option to excel in music or competitive sport. But, if that is the case, how many hours a day, or a week, do they have a right to impose musical exercises on their children? Do parents have a right to do so at the expenses of children being “children”, (i.e., having a normal childhood) because the goal of creating successful musicians justifies any means?

I do not think that the broad leeway parents currently have on instilling in their children (or should we say ‘inculcate’?) with their religious views (e.g. Catholicism in Italy), should be justified, and therefore I do not agree with Robertson. Indeed, the religious example is another of the currently permissible practices (or, a “right” as put by Robertson) that parents have. Writes Robertson: “Parents [...] are free to instil and develop musical ability once the child is born, just as they are entitled to instil particular religious views”. (465) I resist such right-claims and I resist Robertson’s comparative strategy of justifying the new use of genetic technologies to select talent on the basis of older, established but only apparently “justified” practices of parents to nurture even aggressively their children’s talents or to instil in them parental attitudes and views.
Note that Robertson’s example should not be considered only a thought experiment. To some extent, it still is, as we are still unable to select for the perfect pitch, but to some other extent it is not anymore, as parents are now able to resort to genetic tests to scout out their children’s talents. This is the case of the recent boom in the US of DTC genetic tests to supposedly measure children’s athletic potential. (Macur 2008; Stein 2011) In the US, there are at least seven companies that sell DTC-genetic tests for sports performance or related traits, probably more. (Roth 2012) The companies’ data is proprietary, and therefore it is not clear exactly how many parents and coaches are using these tests, but we can speculate that hundreds, or possibly thousands, of parents and coaches are using them. (Brooks and Tarini 2011) In addition, since these tests are available on the Internet, the market is not limited only to the US, but is open to potential customers in the UK, Europe or the rest of the world, who can order the test online and only have to pay higher shipping expenses for the test kit. European regulations recommend, but do not require, genetic tests to be performed with a genetic counselling service. (Michael John McNamee et al. 2009; Camporesi and McNamee 2013b)

With DTC tests, parents aim to gain an early advantage (a “head start”) which would allow their children to turn already at an early age into professional athletes, and continue on a hoped-for chain of events from college scholarship to success, fame and money. In other words, they aim for an enhancement of which the main value is a positional advantage. In my paper (Camporesi 2013), included in this thesis as Appendix 2, I first discuss the flimsy scientific evidence behind these tests, and then criticise the parental decision in terms of education, and of investing in the children’s future, taken on the basis of the results of the tests. I then discuss how these parental practices impact on the children’s right to an open future, and on their ‘discretionary domains of autonomy’, borrowing from Tamar Schapiro. (Schapiro 1999) I also consider the meaning and role of sports in childhood, and conclude that the use of DTC genetic tests to measure children’s athletic potential should be seen as a cautionary tale for other problematic parental attitudes aimed at scouting and developing children’s talent.
In the next chapter I turn to the consideration of another type of genetic technology, namely gene transfer, and discuss how it can be applied both in a clinical research context for therapeutic purposes, and in a professional sport context for enhancement purposes. We will therefore analyse the other half of the ‘vector’ of the genetic enhancement technologies in society: from the bench to track & field.
Chapter 3: From bench to track & field: Genetic enhancement technologies in sport

Sport can be considered the first area in which enhancement has been heavily regulated, and has thus served as one of the first testing grounds for enhancement technologies, for anti-enhancement regulation, and for public reaction to enhancement. Contrary to what may be thought, the administration of substances with the aim to enhance athletic performance has not always been viewed with a negative connotation, but is instead a relatively recent acquisition. For a long time, what we now consider ‘doping’ was viewed as a legitimate way to extend the athlete’s capabilities, and sport was seen as the experimental terrain *par excellence* where it was possible to do so. Trying to enhance one’s own athletic performance with any available means was understood as the natural human reaction to coping with fatigue, and competition in sports was understood first as a challenge between athletes and fatigue, and only secondly between athletes/competitors. In this sense, the professional athlete was using his own body as the subject of experimentation, and the athlete himself was an experimental subject. This identification of the athlete’s body with an experimental terrain can be dated back to 1894, when the pioneering French sports physician Philippe Tissié started administering several types of beverages to cyclists to test their value as performance enhancer. (Hoerberman 2009) In this sense, Tissié was regarding the elite athlete as an experimental subject whose exertions and traumas could shed light onto the unexplained human physiology in a kind of reverse extrapolation from the track & field to the bedside. (Hoerberman 2009)

This ‘functional view’ of doping was promoted throughout the 1950s by a sharp distinction between amateur and professional athletes that does not exist anymore in our conception of sport. The professional athlete was seen as inhabiting a different moral universe in which the use of doping drugs was tolerated, and

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7 I refer here to the athlete as ‘he’, as throughout most of the XX century, it was most often a ‘he’.
promoted, because it was regarded as the means to an end, and it was the only way for the individual professional athlete to make a living. This was not the case for the amateur athlete, who was the privileged, and did not have to take on the risks associated with the consumption of substances often dangerous for his health in order to gain the competitive advantage, which was necessary to win competitions and remain a professional athlete. This is why the permission to dope was not accorded to the sports amateur, whose image became encapsulated as the British gentleman practising sports as a hobby, as a pastime. Going even further back in time, in the ancient Olympics, the amount of time to be devoted to training before competition was severely constrained, on the basis of the same reasoning that the real athlete was not to be a professional, even ‘menial’ so to say labourer (in the guise of a slave), but a healthy person merely expressing his natural talents. (Mathias 2004)

It is not easy to determine when and where the idea that doping violates the spirit of sport (the current stance of the World Anti-Doping Agency, hence WADA, discussed below) came into existence. Plausibly, it was not something which came into being quickly, but that rather came into existence gradually in the first two decades of the 20th century. As noted by Hoberman, nationalism was one medium for the emergence of this idea, as in the first decade of the 20th century scientists were accusing each other across the Atlantic to hide the possession of a supposedly secret formula to combat fatigue. (Hoberman 2009) At the beginning, objections of ‘reprehensible doping’ focused more on the medical dangers for the athlete’s health than on the idea that doping was a form of cheating and which would violate the spirit of sport as it is now. Then, in the 1920s and ‘30s, the idea that doping behaviours violated the ideals of sportsmanship as fair play emerged in parallel to the commercialization of sports and its increasing importance as mass culture. Though still in the 1950s, Sir Adolphe Abrahams, an Honorary Medical Officer to the International Athletics Board and the British Olympic Team, was expressing difficulties regarding how to distinguish between legitimate and less legitimate means to enhance athletic performance. He wrote:
“It is not easy [...] to draw the line where legitimate stimulation ends and reprehensible ‘doping’ beings; the distinction is largely a matter of opinion and of conscience”. (Abrahams 1958)

Therefore, as it is evident from this brief excursion, elite sport has long been a laboratory for biomedical and biotechnological innovations regarding injury, treatment of injury and performance optimization through training regimes, diets, etc. In this section, I consider one of the latest applications of biomedical innovation applied directly from the bench to track & field, namely gene transfer technologies.

WADA has inserted gene transfer technologies in the Prohibited List since 2003, under the umbrella of ‘gene doping’. The very act of labelling this type of genetic modification as ‘doping’ is a significant act, clearly connoting an official negative attitude towards the practice. But can gene transfer techniques be classified as doping? Before addressing this question, we need to understand – adopting a similar strategy as the one adopted in the previous chapters – what we are talking about when we talk about gene enhancement from a scientific point of view, distinguishing scientifically feasible from fictional scenarios. Only afterwards can we analyse whether, and on what basis, gene transfer technologies for enhancement purposes can count as doping.

3.1. Gene transfer: the scientific context

Gene transfer aimed at enhancing athletic performance (gene enhancement, or GE) employs the same techniques used in gene transfer used for therapeutic purposes, and is referred to as gene therapy (GT). Gene transfer is based on the delivery to a cell of a gene through a carrier (usually a modified virus, but also a liposomic particle, or no carrier at all), with the aim of compensating an absent or abnormally functioning gene in GT, and with the purpose of reinforcing muscular systems, increasing the number of red cells, or increasing the threshold for pain in GE, as discussed in detail below. Gene transfer differs from other more traditional modes of doping insofar as, instead of giving the doping substance (e.g.
erythropoietin, or EPO) to the athlete exogenously, a gene is administered to the body via a carrier, so that the body itself will produce EPO in higher quantities.

The following are some of the most plausible targets for gene transfer aimed at enhancing athletic performance (hence, only gene enhancement or GE):

- Growth hormone (GH): has a multitude of effects on the body associated with growth, including a well-documented stimulatory effect on carbohydrate and fatty acid metabolism, and a possible anabolic effect on muscle proteins. To note that recombinant GH is already being used as a doping agent in sports. (Baumann 2012)
- Insulin growth factor 1 (IGF-1): stimulates cellular proliferation, somatic growth and differentiation. In 1998, Dr Lee Sweeney (to note, now a member of WADA Gene Doping Expert Group) was the first to conduct in vivo gene transfer studies in mice using IGF-1. (Barton-Davis et al. 1998) The gene transfer successfully increased the strength of the mice, leading the press to dub them as ‘Schwarzenegger mice’. (Bartlett 2003) Macedo and co-authors created a mouse model of gene enhancement based on the AAV-mediated delivery of the IGF-1 cDNA to multiple muscles. (Macedo et al. 2012) This treatment determined marked muscle hypertrophy, neovascularization and fast-to-slow fibre type transition, similar to what happens to athletes during endurance training. In functional terms, IGF-1 transferred mice showed impressive endurance gain, as determined by an exhaustive swimming test. The authors warn against the potential misuses of AAV-IGF1 as a doping agent as a ‘realistic way to achieve a greater athletic performance’. (Macedo et al. 2012)
- Myostatin: is a protein that acts as a negative regulator of muscle mass. Mice in which the myostatin gene has been inactivated show marked muscle hypertrophy (Li et al. 2010) and a recent report described similar muscle hypertrophy in a child carrying mutations in both copies of the myostatin gene. (McFarlane et al. 2011) Therefore, blockade of myostatin action has the potential to allow athlete to rapidly increase muscle mass.
• Erythropoietin (EPO): is a glycoprotein produced by the kidney in response to a low oxygen concentration. EPO expression leads to an increase in red blood cell production and hence an increase in the blood’s oxygen carrying capacity. EPO is one of the most widely used doping agents. (Leuenberger, Reichel, and Lasne 2012)

• Vascular Endothelial Growth Factor (VEGF) and other angiogenic factors: their expression could improve microcirculation in muscle and hence increased oxygen and nutrient supply as well as removal of waste products. (Wells 2008) There are already clinical trials underway or completed employing gene transfer techniques for angiogenesis purposes following an ischemia (peripheral or heart) (http://clinicaltrials.gov/). In a paper co-authored with Mike McNamee and included in this thesis as Appendix 3 we analyse one of these clinical trials employing VEGF and analyse its permissibility from an ethical point of view in a research and professional sport context. (Camporesi and McNamee 2012)

• Hypoxia-inducible factor 1 alpha (HIF-1-alpha): transcription factor activated under conditions of endurance exercise and muscle hypoxia: induces both the endogenous expression of EPO and VEGF. Consequently, increased expression of HIF-1-alpha has the potential to substantially improve oxygen delivery to the skeletal and cardiac muscles. (Borrione et al. 2008)

• Peroxisome-proliferator-activated receptor gamma (PPAR-gamma): the expression of the activated form of this protein in skeletal muscle increased the running endurance of transgenic mice to double that of wild-type littermates. Gene transfer of PPAR-gamma in athletes may improve endurance capacity by increasing the proportion of oxidative slow twitch fibres. (Østergård et al. 2005)

The risks for the health of the athlete are numerous, as they relate both to the kind of vector used (usually a modified virus), and to the encoded transgene. (Harridge and Velloso 2008) As to the former, while gene therapy has proven relatively safe in clinical trials so far (with some major exceptions, such as the death of 18-year old clinical trial subject Jess Gelsinger due to immunoshock to the viral vector in 1998, (Lehrman 1999; Hollon 2000) it is plausible to infer that gene
doping, since outlawed, would be carried out in laboratories with less stringent regulations, therefore posing even more health hazards. Gene doping represents indeed one perfect example of technological determinism as discussed by Agar (Agar 2005) and presented in section 1.4.

As to the latter risks, they are similar to the ones encountered in more traditional doping modes, but in addition both the level and the duration of protein expression are less amenable to control. For example, growth hormone and insulin-like growth factor 1 are both potent mitogen (i.e. stimulate cellular proliferation) and anti-apoptotic (i.e. inhibit physiological death mechanism) agents, which could lead to an increased risk of oncogenesis. Overexpression of EPO caused an increase in haematocrit and this makes the blood more viscous and increases the load on the heart. Potential consequences include blockage of microcirculation, stroke and heart failure. In addition, the uncontrolled expression of the genes may in themselves be harmful. The production of viral vectors requires considerable purification and testing. Adenoviral vectors have been clearly associated with morbidity and in one case death after vascular administration in 1998, as mentioned above.

3.2. Gene ‘doping’: the regulatory context

Gene transfer detection also poses several unique challenges to detection. (Baoutina et al. 2008) To start with, the protein produced through gene transfer will not be different in sequence or structure from the endogenously produced one. Anti-doping techniques aimed at identifying the “markers” of the viral vectors deployed have low probability of success, as the viral vectors may be measurable only shortly after administration, lowering therefore the probabilities of spotting it. In addition, detection would often require tissue sampling, as the administration of the vector would be performed directly into the muscular target tissue. Obviously, muscle biopsies are not an option for the athlete, therefore excluding this mode of detection. (Baoutina et al. 2008)

Alternative modes of detection called “transcriptional profiling” aimed at detecting changes in protein levels compared to the physiologically measured basal
level of the athlete would require simultaneous and repeated measuring of around 1,000 proteins. WADA Director David Howman reported to the Telegraph in 2010 that he was quite confident that gene doping strategies will be able to detect it, (Telegraph Staff 2010) but his optimism seems overly-confident, as while laboratories such as the Drug Control Centre Unit directed by David Cowan at King’s College (http://www.kcl.ac.uk/biohealth/research/divisions/aes/research/drugcontrol/index.aspx) and the one directed by Mauro Giacca at the International Centre for Genetic Engineering and Biotechnology in Trieste (http://www.icgeb.org/molecular-medicine.html) are making efforts to come up with detection strategies, at the same time other laboratories are devising undetectable doping strategies. It is a race, and very competitive indeed. As shown below, WADA is actively building a confident narrative on the possibility of detecting gene doping through ‘shear good-will’ and generous funds. (http://www.wada-ama.org/)

The International Olympic Committee (IOC) established its first list of banned substances in 1967, and in 1999 convened the World Conference on Doping in Sport (also as a reaction to the widespread Tour de France doping scandals in 1998). This event led to the creation on November 10, 1999 of WADA. In March 2003 WADA released its first World Anti-Doping Code (WADC), now in its 3rd revised edition. This new WADA code is expected to come into force in January 2015. (See section 3.5 for a discussion of the revision of the criteria for inclusion of a substance in the Prohibited List). WADA is based on the cooperation between sports organisations and governments, and is financed by sports organisations and governments on an equal basis. The rationale behind the WADC is the harmonisation of anti-doping rules and measures. Nearly all international sports federations have accepted the WADC, and governments support WADA financially (M. J McNamee and Tarasti 2010) In 2001, shortly after the creation of WADA, the International Olympic Committee (IOC) convened the first working group on gene doping. The group’s finding affirmed support for the medical applications of gene therapy but advised taking measures to keep genetic modification out of the realm of sports. Quoting from the official WADA publication, ‘Play True’: 
“We endorse the development and application of gene therapy for the prevention and treatment of human disease. However, we are aware that there is the potential for abuse of gene therapy medicine and we shall begin to establish procedures and state-of-the-art testing methods for identifying athletes who might misuse such technology”. (Haisma and de Hon 2006)

In March 2002, the first workshop on gene doping was organized by WADA at the Banbury Center in New York. ([http://www.wada-ama.org/en/Science-Medicine/Science-topics/Gene-Doping/](http://www.wada-ama.org/en/Science-Medicine/Science-topics/Gene-Doping/)) Shortly thereafter, in 2004, WADA also created a ‘Gene Doping Expert Group’, with Theodore Friedmann as Chair (Friedmann is the Director of the Gene Therapy Lab at the University of California San Diego), and the above-quoted, in the context of IGF-1 research, Professor Lee Sweeney (Professor and Chairman of Physiology, University of Pennsylvania).

As we have seen, WADA has included gene doping techniques in the blacklist of prohibited substances since 2003. The most recent version of the ‘Prohibited List contains the following proscription for Gene Doping:

“The following, with the potential to enhance sport performance, are prohibited:
1. The transfer of polymers of nucleic acids or nucleic acid analogues;
2. The use of normal or genetically modified cells.”
(WADA Prohibited List 2013, 6)

Therefore, as defined by WADA, gene doping includes the non-therapeutic use of genes, genetic elements, or cells that have the potential to enhance athletic performance. This is a very broad definition that encompasses both gene and cellular therapy: WADA wants to make sure that all possibilities of gene doping are covered under the wide umbrella of this definition.

The first documented gene doping case dates back to 2006 in Germany. Thomas Springstein, track & field coach, was found guilty of trying to procure a gene transfer product called Repoxygen to administer to supposedly oblivious athletes. Repoxygen was a viral delivery vector carrying the human EPO gene under the control of a hypoxia response element, based on the principle of increasing the number of red cells in the athlete, therefore increasing oxygen carrying capacity.
(G. Reynolds 2007) (Fantz 2010) It was also an example of a direct bench to track & field transfer of technology (without passing through the bedside), as Repoxygen was at that time in animal studies for a company called Oxford Biomedica. Therefore, at that time, there were no data at all on the effects and possible risks of the use of gene transfer for EPO in humans.

As it will be evident now, even though gene doping had been included under the WADA Prohibited List since 2003, it is only since 2006 and the Repoxygen case in Germany that gene doping has become a documented reality. Foreseeing a massive use of gene doping techniques in the London 2012 Olympics, WADA invested nearly $15 million to support research laboratories to develop methods for gene doping detection since its first investment in 2002. (Daiji World 2013) Among the funded laboratories was the Molecular Medicine-Gene Therapy laboratory at the International Genetic Centre for Genetic Engineering and Biotechnology, which received WADA funding to come up with mouse models of genetic enhancement, as the one we have already mentioned (Macedo, 2011), and subsequently with detection techniques. In London, the King’s College Drug Control Centre directed by Dan Cowan was appointed by WADA as the only laboratory in the UK responsible for gene doping detection and for ‘championing Olympic integrity’. (E. Reynolds 2012) King's College London then partnered up with GlaxoSmithKline (GSK) to enable its world-renowned Drug Control Centre to operate a WADA accredited satellite laboratory during the London 2012 Olympic and Paralympic Games. (E. Reynolds 2012)

At the London 2012 Olympics there have not been scandals of ‘gene doping’ as it could have been expected given the hype built beforehand. There have been, though, speculations on Chinese Swimmer Ye Shiwen, who won the mixed 400 meters setting a new world record in 4’28″, and swimming the last 100 meters faster than the male US swimmer and gold medallist Ryan Lochte. This detail led to the public accusation by John Leonard, executive director of the World Swimming Coaches Association (USA office), that her victory was ‘disturbing’ and that she may have cheated. The British tabloid Daily Mail pounced on the case and speculated about the possibility of genetic modification:
“The astonishing suggestion seems to be that London 2012 may be the first Olympics in which competitors are attempting to cheat by altering their genes to build muscle and sinew, and boost their blood’s oxygen-carrying powers.” (Naish 2012)

Shiwen later tested negative at the anti-doping control, and John Leonard had to deliver a public apology. The result of the anti-doping control did not quench though completely the speculations that China may have undertaken state-sponsored genetic modification experiments to breed athletes. The scenario, though science-fictional, is not too far from real documented experiments of Chinese-based talent scout camps for very young children where traditional modes of talent-scouting have been coupled with new genetic technologies, as presented in chapter section 2.5 and in Appendix 2. In section 3.5 I will discuss a similar accusation of ‘cheating’ raised against another athlete with an exceptional genetic variance that has led to a supposedly unfair advantage in competition. After this brief detour, relevant because it shows that the possibility of GE is not only a science fiction scenario, I return now to the analysis of the ethical arguments at the basis of WADA’s ban on gene transfer.

3.3. Gene enhancement, or gene doping? The ethical context

In the second issue of “Play True”, the official publication of WADA, we can read Theodore Friedmann’s opinion on why gene doping is unethical:

“This technology is highly experimental and completely inappropriate where the goal might be something other than the cure of life-threatening disease like cancer, neurological degenerations and so on. To apply this very immature technology to athletes or to any young, healthy people for the purpose of increasing some already-normal function, in my mind, is unethical and constitutes deliberate professional malpractice.” (WADA Official Publication 2007)

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8 Note that Friedmann is Chair of the expert group on Gene Doping and director of the Gene Therapy Laboratory at UC San Diego, therefore a conflict of interest cannot be excluded.
Note that Friedmann’s concern about gene doping is merely a concern on the safety of the athletes, and while the concern for safety may make, at the present state of knowledge, a persuasive case to prohibit the use of gene modification in sports at a later point in time, this does not seem to constitute sufficient ground to ban it. The most important question, which I will address below, is whether genetic modification is still ethically acceptable in conditions where the technology is sufficiently safe. I will therefore examine and unpack WADA’s position regarding doping, and discuss whether it can be applied to gene transfer technologies.

WADA defines a substance as doping, and therefore prohibits it, if it meets two of the following three criteria:

a) It has the potential to enhance or enhances sports performance;
b) It represents an actual or potential risk to the athlete;
c) It violates the spirit of sport. (WADA Code 2012)

As we can read in the following statement published on WADA’s official publication “Play True”, it is evident that WADA considers gene transfer technologies aimed at enhancing athletic performance as a form of doping as if they meet all the three criteria outlined above:

“Gene doping represents a threat to the integrity of sport [c] and the health of athletes [b], and as the international organization responsible for promoting, coordinating and monitoring the global fight against doping in sport in all its forms, WADA is devoting significant resources and attention to ways that will enable the detection of gene doping”. (WADA Official Publication Play True 2008)

As mentioned above, two of the three criteria are sufficient for inclusion of a substance in the Prohibited List. WADA is now in the process of revising its Code, expected to come into effect with a new version in 2015. I discuss the revisions and the desirability of a shift towards the inclusion of the necessary condition of performance enhancement in a forthcoming co-authored paper. (Camporesi and McNamee 2013a) In what follows, I will focus on the analysis of the third criterion, i.e., the ‘spirit of sport’.
What do we talk about when we talk about the ‘spirit of sport’? Murray defines sport as “the paramount public expression of our embodied humanness” and argues that the achievement of excellence in athletic performance requires a combination of both physical natural talents and of character traits such as “perseverance, dedication, and a willingness to suffer in pursuit of a valued goal”. (T. H. Murray 2009a) Catlin and Murray write that the spirit of sport is about winning “with the best combination of natural ability, stamina, courage, willingness to undergo intense and difficult training, and strategic cunning”. (Catlin and Murray 1996) In 2008’s second issue of “Play True”, Murray writes:

“We need to go back again to a key question: What is sport about? What contributes to its beauty and its value? What gives sport its meaning? I don’t want my children or grandchildren to have to go through genetic enhancement to compete on a level playing field. [...] we can do with the natural talents we have, perfecting them through human excellence, persistent effort and dedication, and not with artificial enhancement and engineering.” (WADA Official Publication Play True 2008)

Sigmund Loland points out that the prospect of gene transfer for enhancement purposes is so disturbing for sports ethics because it forces us to note that the “natural lottery” of genetics is getting less random all the time as our knowledge of human genetics expands. He writes: “It is an individual’s genetic predisposition to develop phenotypes of relevance to performance in the sport in question. The distribution of talent in the natural lottery is a random process”. (Loland 2002, 69) In this sense, gene transfer would undermine the spirit of sport as defined by Murray as above, because genetic interventions would undermine the very ability of sport to distinguish those who passively inherit their talents from their progenitors from those who actively acquired them from their physicians. Sandel has also written about the problem with genetic enhancement as corrupting the spirit of sport:

“The real problem with genetically altered athletes is that they corrupt athletic competition as a human activity that honors the cultivation as display of natural talents”. (Sandel 2004, 55)
Implicit in Murray’s statement and in WADA’s definition of doping is therefore a deeply value-laden interpretation of sport, an ‘intrinsic value’ or an ‘essence’ of Olympism, but neither WADA nor its spokespersons attempt to explain what this essence is. In Camporesi and Maugeri (2011), included in this work as Appendix 5, I apply a deliberative democracy approach to unpack this moral transcendence view underlying Murray and WADA’s statement on doping, by drawing on the report “Beyond Therapy”, (President’s Council on Bioethics (U.S.) 2004) delivered by the former President’s Council on Bioethics (http://bioethics.georgetown.edu/pcbe/reports/past_commissions/). The report discusses explicitly the relation between genetic enhancements and the spirit of sport, and WADA seems to have drawn extensively from it. The Council, appointed by former US President Bush in 2001, chaired at that time by Leon Kass, was charged “to undertake fundamental inquiry into the human and moral significance of developments in biomedical and behavioral science and technology.”

“Beyond Therapy” aims at spelling out what is morally problematic about genetic advancements (the assumption being that there is something morally problematic with it). The Council undertook this task by giving centre stage to the purposes and means of the activities that might be affected by genetic enhancements, or of ‘Superior Performance’ as it is phrased in the relevant section (third chapter) of the report. The main claim of the Report is that the extensive use of enhancing agents (genetic or not) by athletes corrupts the true ‘nature’ of sport. According to the report, although genetic enhancements are not, in absolute terms, utterly different from other kinds of traditional enhancements, they are distinct in a ‘humanly’ and ethically significant way as they would eventually ‘partially alienate’ the athlete from her performance, and dehumanize the essence itself of the athletic activity. (President’s Council on Bioethics (U.S.) 2004)

As argued extensively in Camporesi and Maugeri (2011), (Appendix 5) I agree with the President’s Council’s report to the extent that an appropriate analysis of the ethical justifiability of genetic enhancement in sports must take into account an analysis of the values of sports. However, I think that the Report assumes an ‘essentialism’ in the ethics of sports that is unwarranted. Indeed, it has
to be noted that all talk of purity of sports overlooks that all elite sports are both ‘play and display’, i.e., they thrive both on ‘internal goods’ after MacIntyre (MacIntyre 1984) (such values as commitment, channelled concentration, controlled aggression and power, courage in the face of suffering, dedication, strategic intensity, tenacity, to name but a few of the virtues of sports), and on external goods or rewards, as the achievement of considerable esteem, glory, honour, and wealth. (M. J. McNamee 2008)

In addition, it must be noted how the norms that govern sports are highly heterogeneous among sports, and it should also be clear that we are referring to the practice of elite sports. Therefore, when evaluating the impact of gene enhancement on athletic performance, we should ask ourselves to what extent, if any, genetic technologies enhance or diminish our admiration for human athletic achievements and in relation to a particular sport. Tom Douglas has argued that there are arguments derived from the value intrinsic in the practice of elite sports that make the case for restricting enhancement more heavily in sports than outside sports. Douglas advances a relatively simple thesis: that the case for permitting enhancement outside of sport is often stronger than the case for permitting enhancement in professional sport, and that this distinction depends on how genetic technologies affect the way in which we admire elite athletes and their achievements. (Douglas 2007) Douglas spells out two main models for what it is that we admire most in elite athletes, namely:

a) The ‘Athenian’ model: the value and meaning of sports lies in revealing the natural potential of athletes.

b) The ‘effort’ model: the value and meaning of sports lies in rewarding and praising athletes for hard work and effort.

The adoption of the Athenian model only seems unrealistic, as we normally allow all kinds of external edges to boost/enhance the natural potential, i.e., training/equipment/facilities (eye and knee surgery, training in hyperbaric rooms, and so on). But a position based only on b) does not correspond either to how we normally value and perceive sports. I agree with Douglas that neither of the two models taken alone is a plausible account of what we value in sports, but a more plausible view is one that combines the two and that holds that the outcomes of
sport should be determined by natural ability and effort, and that we value sport because it serves as a test of these two characteristics. For these reasons, I think that a better approach to define the ethical permissibility of a gene enhancement technology is the following, which reflects on how a technology affects a sports practice in a contextualized way:

Technology can be understood as a “human-made means to serve human interests and goals”. (Cooper 1995) Elaborating on this definition, Loland defines sports technology as a human-made means to serve human interests and goals in or related to sport, (Loland 2009) and when evaluating the role of a technology in sports, Murray outlines three possible outcomes in relation to an ethical standard (Murray 2009a, 157–9):

1. A technology may be ethically desirable: insofar as it may, for example, reduce the impact of factors other than natural talents and their virtuous perfection by reducing unequal access to the legitimate means of enhancing performance. Example: hypoxic chamber (levelling the playing field for athletes who because of geography or lack of money, cannot “live high, train low”).

2. A technology may be ethically permissible: they are ethically “neutral” in respect to the relation between talent, virtue and performance. For example, inequalities of access to superb coaching and training facilities are very pervasive. Normally the differential access of athletes due to their geographical and economical conditions to different degrees of coaching and of training facilities is regarded as a tolerable inequality, a status quo.

3. A technology may be ethically prohibited: this should be the case when it undermines the meaning of sport by interfering significantly with the relationship between natural talents, their virtuous perfection, and athletic success. Examples: blood doping, EPO.

The question then becomes: In which of the above categories can we put genetic enhancements? I argue that is a matter of context, and of spelling out the values intrinsic in the practice under scrutiny. In a paper I co-authored with Mike McNamee, we tackle this question using as a case study a real, on-going clinical trial using VEGF gene transfer to increase circulation and tolerance to pain in patients
with limb ischemia, but also plausibly to do so in athletes engaged in endurance races. (Camporesi and McNamee 2012) (Appendix 3) We employ there a comparative strategy to highlight the similarities and dissimilarities between the ethical frameworks used to evaluate the two scenarios, and to reach conclusions regarding the justifiability of the technology, based on how it affects the values specific to the two contexts. It is a matter of fact that different athletes have different baselines and different abilities to cope with pain. While we do try to give people tools to cope better with pain in everyday life, where pain is not seen to be an essential or meaningful part of the activity we are performing, in the elite-sports context we do not give people those tools, as we understand pain (excluding the acute pain related to an injury) as a fundamental part of practising and competing at an elite level. In the paper we argue that, while in the latter context (clinical research) the choice of participating in a gene transfer clinical trial is fundamentally a self-regarding one, predicated on individual autonomy together with a risk/reward calculation as the principal factor determining the ethics of that decision, in the professional endurance sports contexts individual autonomy ceases to play the decisive role in the ethical analysis. In this latter context, the meaning of significance of pain plays an essential role, and consequently pain cannot simply be levelled out, as we do for example by standardizing bikes, or shoes, or swimsuits the athletes compete with. This happens because, if we did level out the ability to endure pain, we would also diminish a substantial part of the meaning of athletic performance, which we understand - following from Murray (2009) - as the combination of physical talents and character traits to try and push one’s own limit. For the full argument see (Appendix 3). I will continue this discussion when critiquing the new International Association of Athletics Federations (IAAF) rules on eligibility of athletes with hyper-androgenism to compete in the female category in the next section.

3.4. Exceptional genetic variance and the accusation of cheating

As illustrated in section 3.2, there have been allegations of genetic modification to Chinese swimmer Ye Shiwen at the London 2012 Olympics. The
allegations were not necessarily of the insertion of an exogenous gene through
gene transfer, but possibly broader to include also the possibility of genetic
manipulation at the embryo level to select an individual with a genetic variation
conferring a competitive advantage. The assumption underlying the accusation was
that such advantage would be unfair. In this section I am going to examine the real
case of another athlete who has been accused of a similar charge for a natural
occurring genetic/biological variation. In August 2009, at the Berlin the World Track
Championship, South-African middle distance runner Caster Semenya was accused
of cheating after winning the 800 meter by nearly two and a half seconds over her
fellow competitors, with the chronometric time of 1:55.45. Shortly after her victory,
the International Association for Athletics Federation (IAAF) revoked her gold medal
and prompted an investigation concerning her gender. The assumption was that
Caster derived an ‘unfair advantage’ from some condition related to sex
differentiation which gave her higher than average levels of testosterone. (Smith
2009)

My goal in this section is to challenge the assumption underlying the IAAF
decision, namely that Caster Semenya’s supposedly high levels of hyper-
androgenism conferred her an unfair advantage. My strategy will be two-fold: I will
first challenge the assumption that Caster has a performance advantage; and
secondly, I will argue that even if that were the case, it would not be unfair⁹. I will
also argue for the necessity to put in place a more transparent and accountable
decision-making system for this kind of decision affecting the eligibility of athletes
to compete. In a co-authored paper written in the aftermath of the Caster Semenya
debacle in 2009, Maugeri and I argued that framing Semenya’s case from a medical
perspective alone was largely unsatisfactory, as biomedical knowledge cannot
provide ready-made answers as to where to draw the line on a continuum of sex
conditions, and decisions concerning the constructions of categories in sport need
to be informed not only by biomedicine but also by an ethical reflection on fairness
and the value and meaning of competition. (Camporesi and Maugeri 2010) We
concluded that the debate spurred by Caster’s ordeal would lead us to discuss not

⁹ I would like to acknowledge here Dr Paolo Maugeri for his intellectual contribution to the discussion of
these issues.
only gender categories in sports, but it also demanded reflection on the value
dimension of that ordering and, by extension, of sports in general. In this regard,
the concept of ‘fairness’ appeared to us as one of the keys to reading the debate
and, possibly, to clarifying it. In what follows I will elaborate on the concept of
fairness in the context of elite sport, and on the unfair advantage assumption
underlying the IAAF decision to revoke Caster Semenya’s medal.

“These kind of people should not run with us. For me, she is not a woman.
She’s a man.” This is what Elisa Cusma, a disappointed Italian runner who finished
6th, was reported saying about Caster’s victory in the 800-metre final of the Berlin
World Athletic Championships in 2009. (Kimmel 2009) In Elisa’s words we find
encapsulated the reasons that have long supported sex-segregation in sports
competitions. It would seem therefore that, if women want a fair chance to win,
they should compete with other women, and not with men. Elisa’s words, however,
carry with them also the binary ontology of sex differences (male-female), and the
discriminatory attitude towards bodily entities challenging such dichotomous order,
which forms the basis of the classification system in professional sport. Of course,
this is not the only possibility, as pointed out already well before Caster Semenya’s
case by sociologist Kane who argued in favour of a sport continuum instead of a
binary classification of sport (Kane 1995), or more recently the analysis by Foddy
and Savulescu, who argued in favour of re-evaluating gender segregation in
athletics (Foddy and Savulescu 2010). I will not analyse here though their positions
here as I think it is practically unfeasible, and therefore only of limited interest for a
discussion aimed at exploring the practical implication of ethical arguments such as
this one.

Although decades of multi-disciplinary scholarship in psychology, medicine,
humanities, and social studies have convincingly shown that the anatomical-
biological features of sex do not overlap with, and need to be distinguished from,
gender as a psychological and socio-cultural construct, the bodily dimension of sex
has always been seen as the truly natural marker for establishing who counts as
woman for the purposes of sports. How to identify the marker/s, however, is
recognizably no easy task. As Dreger, among others, points out, for centuries
scientists and clinicians have disagreed about what body parts or anatomical features should count as the natural master properties of ‘masculinity’ or ‘femininity’. (Dreger 1998; Dreger 2010) Chromosomes, gonads, hormones, secondary sex characteristics, external and internal genitalia are all candidates, as noted in Karzakis et al. (2012), however, none of them alone or in combination offers clear solutions for sorting sex out into a nice dichotomy. (Karkazis et al. 2012) In the case of sex differentiation, a broad spectrum of conditions lies between the two extremes ‘male’ and ‘female’, and the number of deviations from statistically normal traits - often referred to as the medicalised term ‘disorders of sex differentiation’ (DSDs) - can be counted in the order of tens and can be classified as sex chromosome, gonadal, and sex hormone deviations. (Yang, Baskin, and DiSandro 2010) About 1.7 % of people have these conditions, of which only a minority are apparent. Indeed, the majority of the individuals affected by DSDs do not discover they belong to this 1.7 % until they decide to have children and find out that they are subfertile or sterile. For the sake of illustration, people with complete androgen insensitivity syndrome (CAIS) are genetically XY (males), have testes and testosterone levels in the normal range of the male population. Nevertheless, these individuals have a thoroughly feminine phenotype, with breast and female typical genitalia, because they are unable to metabolise androgens. If we take their genetics into account, these individuals would classify as males. Nevertheless, their metabolic levels of androgens are on the standard female range and they overwhelmingly identify, and are identified as, women. (Yang, Baskin, and DiSandro 2010) The same difficulties of categorization can be found in the case of ‘hyperandrogenism’ - the condition targeted by the IAAF policy - where genetically female individuals produce levels of androgens in excess of the range typical for females and which can have a variety of causes, among which are congenital adrenal hyperplasia (CAH) – deficiency of enzymes involved in the metabolism of androgens; androgen insensitivity syndrome (AIS); ovotesticular DSD (previously called “true hermaphroditism”); polycystic ovary syndrome (PCOS); and adrenal carcinoma. (Karkazis et al. 2012) Whatever the underlying cause, hyperandrogenism condition confers a number of phenotypic traits typically associated with masculinity such as increased muscle bulk, and increased hirsutism.
These examples already show how great is human physical variance, and how difficult it is to force such a variety into rigidly binary ontologies. The way in which humans group things is not merely a reading of an alleged ‘natural order’; rather it is a complex social activity requiring negotiation and reflection upon the consequences and the purposes of such an ordering. To see what this implies for the discussion of Caster Semenya’s case, let us take a closer look at the IAAF regulations. Following an 18-month long coordinated discussion with the International Olympic Committee (IOC) medical commission, the IAAF issued its policies on hyperandrogenism in early 2011. (IAAF 2011) The policies require female athletes who do not fall within the limits of 100 ng/dL2 of testosterone to undergo androgen-suppressive therapy for up to 2 years to reduce the level of testosterone in order to compete as females. The burden of proof to demonstrate that female athletes with hyperandrogenism do not derive a competitive advantage from the excess testosterone is on the athlete (paragraph 6.6 of the rules).

The policy declared goal, hence, is not to determine whether someone is ‘really’ a woman, but to assess instead whether high levels of androgens (hyperandrogenism) confer any significant advantage to women displaying this condition. The IAAF is hence explicitly trying to provide an answer to an allegedly far simpler ontological question: what is it that makes a woman (and a man) for the purposes of sports competitions? The proposed answer is is also seemingly simple: it is testosterone. As we read in the regulation: “The difference in athletic performance between males and females is known to be predominantly due to higher levels of androgenic hormones in males resulting in increased strength and muscle development” (p.1). Testosterone, hence, becomes the master molecule of ‘athleticity’ and, more importantly for our purposes, the biochemical watershed of ‘masculinity’ and ‘femininity’.

The idea put forward by IAAF that an extremely complex trait like athleticism can be reduced to one single biochemical component did not go without critique. To reiterate just some – illustrated extensively in Karzakis et al. (2012) – there is no scientific evidence showing that successful athletes display higher levels of testosterone than less successful ones. As we read, moreover, in Bostwick and Joyner, although the reference range for testosterone for adult males
is comprised between 300 and 1200 ng/dL and for adult females it does not exceed, on average, 100 ng/dL, it has been observed that testosterone concentrations vary according to several factors like: exposure to exogenous hormones such as estrogen and thyroxine, the time of the day, and the age of the individual. (Bostwick and Joyner 2012, 510) Although interesting, I do not wish to pursue here this line of inquiry further, as I pursued it already in Karkazis et al. (2012). What I would like to do here is highlight the auxiliary assumptions that seemingly prompted the classificatory effort within the IAAF regulation. I will therefore take as premise of my arguments the assumption that higher levels of testosterone confer an athletic advantage and argue that, even on the basis of this premise, the IAAF 2011 policies are unwarranted, and instead of obtaining a level playing field as it is their aim, they achieve exactly the opposite aim of unfairly discriminating against female athletes with hyperandrogenism by excluding them from competition, or subjecting them to unnecessary medical treatment.

In a response letter to Karzakis et al. published in the American Journal of Bioethics, (Bermon et al. 2013) the authors of the policy recognize that drawing a line on such a complex continuum is controversial, to say the least. However, they state that the policy responds well to the ‘limited purpose of providing for fair competition in sport [with regards to possible cases of hyperandrogenism] and that, although bound to be controversial, it is “a vast improvement over previous efforts”, and “responds with sensitivity to possible cases of hyperandrogenization”. (Bermon et al. 2013) Here, I would like to focus on the fourth point addressed by Bermon and co-authors, i.e., that the new policies represent “fairness for female athletes, respect for all”, and point out the necessity of drawing a distinction between advantage and unfair advantage. Write Bermon and co-authors:

“The female former Olympic athletes, who contributed to the creation of the IAAF regulations, agreed that success in sport should be due to the combination of talent and dedication. In events where androgenization provides a powerful advantage, women want to compete against alike, not against women with a degree of hyperandrogenism that gives them a male physiology.” (Bermon et al. 2013)
The rationale underlying the IAAF and IOC policies is that setting a limit on the levels of androgens would compensate for the ‘unfair competitive advantage’ of female athletes with hyperandrogenism, and achieve that ‘level playing field’ that is the ideal of Olympism and essential condition of the ‘spirit of sport’. But is this a plausible scenario in elite sports? As I argued elsewhere, singling out, and setting a limit on, hyperandrogenism from other biological variations that may confer a genetic advantage is – to say the least – an inconsistent policy: there are plenty of other genetic variations that are not regulated by IAAF and, even though advantageous for athletic performance, they are not considered unfair for competition. (Camporesi and Maugeri 2010) Here I will provide only a couple of examples by way of illustration. One famous example is the Finnish athlete Eero Mäntyranta, who at the 1964 Winter Olympics in Innsbruck won two gold medals in cross-country skiing. It was later determined that Mäntyranta had primary familial and congenital polycythaemia, a rare genetic condition characterized by an elevated absolute red blood cell mass and a consequent increase of 25-50% in the blood oxygen carrying capacity. (Mäntyranta 2013; Epstein 2013, 266–81) Certainly, such an increase in red blood cell mass could provide affected individuals, as it did for Mäntyranta, with a competitive edge in endurance races. Notwithstanding, his gold medals were not revoked, contrary to what happened to Caster Semenya (whose advantage, as we have seen, is not as straightforward).

Cases like Mäntyranta’s are hardly rare among elite athletes. Endurance athletes in particular have been shown to have mitochondrial variations that increase aerobic capacity and endurance. (Ostrander, Huson, and Ostrander 2009) Acromegaly, a hormonal syndrome caused by the pituitary gland producing too much growth hormone during development resulting in extremely large hands and feet (among other symptoms), is especially prevalent among professional basketball players. (Clemmons 2008) There have also been speculations that American swimmer Michael Phelps, winner of 8 gold medals at the 2008 Beijing Summer Olympics, has Marfan’s syndrome, a rare genetic condition affecting connective tissues that results in long limbs and flexible joints (an obvious advantage for a swimmer). (Doyle 2008) Another example – this time not only speculated – was Flo Hyman, one of the greatest protagonists of women’s
volleyball, who had post-mortem demonstrated Marfan syndrome. The condition gave her a tall stature and long arms, obviously also providing her with an advantage in volleyball (Bostwick and Joyner 2012) (Marfan syndrome also caused aortic dissection leading to her death during a match). All these examples and many others reviewed in (Ostrander, Huson, and Ostrander 2009) show how elite athletes derive advantages from a range of biological variations. Hyperandrogenism, being also a naturally occurring biological variation is no different in this regard. Why, then, are IAAF policies targeting only hyperandrogenism among all possible ranges of biological variation? I concur with Claire Sullivan, who pointed out how: “[...] the playing field [in elite sports] has never been level. There will always be genetic variations that provide a competitive edge for some athletes over others. We readily accept the genetic, athletic gifts that elite athletes possess without trying to find ways to “level the playing field”. (C. F. Sullivan 2011)

To the best of my knowledge, analysis of the concept of advantage and its distinctions between “fair” and “unfair” are rare, or non-existent in the literature of ethics and sport. The only author that I am aware of and who recently embarked upon an analysis of the concept of advantage is Hämäläinen (2012). Hämäläinen wrote that: “It is often implicitly assumed that the concept of advantage is unambiguous and unproblematic; only the parameters of fairness pose a challenge. This seems to be an unwarranted assumption.” Hämäläinen distinguishes between two kinds of ‘advantage’ in competition: ‘performance’ and ‘property’ advantage. The former is a relationship of superiority between performance numbers possessed by different athletes (or teams) and is defined as follows: “A has a final performance advantage over B if A has a better final performance number than B”. (Hämäläinen 2012) Examples of performance numbers are the number of seconds that an athlete runs a sprint in, or the numerical score that is the result of a football match. The latter is defined as “A has an advantage over B in property X if A has a more favourable amount of this property X than B does”, where properties are “constituent parts of competitors and competition environment”. (Hämäläinen 2012, 317) One of the examples of property advantages offered by Hämäläinen is exactly the property of carrying oxygen possessed by Finnish cross-country skier Mäntyranta already quoted above. Due to his genetic condition, Mäntyranta had a
property advantage against fellow competitors, which in at least two occasions (the two Gold medals won at the Winter Olympics in Innsbruck 1964), and probably many others, contributed to his performance advantage. The fact that Mäntyranta had a property advantage derived from his genetic condition does not necessarily imply, though, that he had a performance advantage, as many other factors contribute to a successful performance.

Following Hämäläinen, we could say that Caster Semenya also may have (under the assumption that a higher level of androgens results in a more athletic body) a property advantage, but that is not a sufficient condition for having a performance advantage. Even if Hämäläinen does not pursue further his analysis to distinguish between fair and unfair advantage, it seems to us that merely possessing a property advantage could not possibly be classified as ‘unfair’, because as we have seen above that does not necessarily imply a performance advantage.

Exceptional biological and genetic variations constitute part of what the elite athlete is, and of what makes sports competitions valuable, namely achieving excellence through combination of talent – the natural endowment of the athlete – and dedication – the effort in training and preparation that the athlete puts forth to maximize what her talent offers. That is also why the IAAF considers all the biological and genetic variations found in elite athletes ethically acceptable, because it is considered part of the meaning of sports and competition to see individuals (elite athletes) with exceptional physical characteristics push their bodies to the limit to win in competitions and achieve world records. Quoting again Bostwick and Joyner: “The existence of such gifted athletes precludes the appealing but unrealistic truism that the playing fields are actually level”. (Bostwick and Joyner 2012, 511)

I find particularly problematic the fact that the IAAF singles out hyperandrogenism from the other biological and genetic variations, the possession of which could also be classified as property advantages, as being outside the ‘ethically acceptable’ limits. I find such singling out unwarranted: for the sake of consistency, either the IAAF would have to ban from competition all athletes who derive a property advantage from biological variations, or let everybody who is “out
of the ordinary,” compete, Caster Semenya – and other athletes with hyperandrogenism – included.

Another point that needs to be noted here is that the IAAF policies not only raise a problem of consistency, but also a problem of discrimination against female athletes. Since the rationale underlying the policies is that they aim to achieve a level playing field by setting an upper limit for a biological molecule that provides a competitive advantage, then the rationale should be applied not exclusively to the female category. Why is a similar threshold not set for male athletes, too? Indeed, Vanessa Heggie already pointed this out in 2010, when she wrote:

“What the sex test effectively does, therefore, is provide an upper limit for women's sporting performance; there is a point at which your masculine-style body is declared ‘too masculine’, and you are disqualified, regardless of your personal gender identity. For men there is no equivalent upper physiological limit – no kind of genetic, or hormonal, or physiological advantage is tested for, even if these would give a ‘super masculine’ athlete a distinct advantage over the merely very athletic ‘normal’ male.” (Heggie 2010)

Thus, the IAAF policies locate the process of eligibility to compete within a discourse of fair play that it is itself situated within a medicalized conceptualization of sex which goes against the same principle of fair play that the policies advocate. The policies deprive female athletes of the essence itself of athletic performance, which, borrowing from Murray (who, to our surprise, was one of the authors of the response letter to Karkazis et al. quoted above), is both a “celebration of and a challenge posed by our embodiment”. (T. H. Murray 2009b, 236) By doing so, we could say that they ‘dis-embody’ female athletes in competition and they not only fail to achieve the ideal of ‘fairness’ they aim for, but they deprive female athletes with hyperandrogenism exactly of the possibility “to test their [bodies’] capabilities and limits, and to integrate them with our will, intellect, and character”, borrowing again from Murray. (T. H. Murray 2009b, 237)

To conclude, I think that on the basis of the arguments highlighted in Camporesi and Maugeri (2010), Karkazis et al. (2012) and here, the current IAAF
policies on the eligibility of women with hyperandrogenism to compete in the female category should be withdrawn, and advocate in favour of a return to the previous status of no policies on sex testing in sports. Rephrasing from (Bermon et al. 2013), the rest of the female athletes will just have to come to terms with the fact that fairness in competition does not imply competing “against alike” (versus “against women with a degree of hyperandrogenism that gives them a male physiology” as put by Bermon et al. (2013)) and open their eyes to the fact that they are already not competing against alike in so many other different respects.

Returning to Ye Shiwen and the accusation of genetic manipulation, the question to ask is not (only) whether her competitive advantage (presumably obtained through genetic manipulation at the embryo level, or genetic screening between different embryos, or through selective breeding among athletes) would be unfair, but whether we want to be living a society where the State (e.g. China), or the individuals, go to such great lengths to increase performance, and what this tells us about the meaning of elite sport today. We need to ask ourselves, therefore, whether such practices would not actually diminish our admiration for elite athletes, and their achievements, demanding therefore a reflection on the significance and the values of sport. In the next and final section of this chapter I consider the current WADC revisions and argue in favour of establishing a framework for research on performance enhancing agents in order to have a better empirical basis for inclusion of substances in the Prohibited List.

3.5 Anti-doping governance and performance enhancement: towards doping under medical context?

Professional sport has always been a laboratory for biomedical and biotechnological innovations regarding the treatment of injury, recovery and training regimes aimed at maximising athletic performance. It is a matter of fact that elite athletes are willing to accept high degrees of risks in exchange for the expected performance enhancing benefits derived from the consumption of
substances, from extreme training regimes or diets, or the experimentation upon themselves of innovative surgeries. It is also a matter of fact that athletes lack information on the safety and effectiveness of the agents they are taking, or of the performance enhancing technologies that they are undertaking.

This happens because the existing WADA Code (now subject to revisions expected to come into effect in January 2015) does not require that a substance has a demonstrably performance enhancing effect for it to be included on the Prohibited List. At present, it suffices that the substance has the ‘potential’ to enhance athletic performance, in addition to meeting one of the other two criteria of the definition of doping already illustrated in section 3.2: that it is harmful (or potentially so), or that it is against the spirit of sport. (WADA Code 2012) Therefore, the lack of information on the safety and effectiveness of the performance enhancing agents that are introduced in the practice of professional sport means that in some cases athletes may be actually taking on the risks of the drugs, without experiencing any performance enhancing effect. In addition, the athletes lack protection against the conflict of interest that can arise in the professional sport context, where short-term gains (such as a swifter return to play after an injury) and the gaining of ‘competitive edge’ are often in conflict with the long-term health of the athlete-subject. (Huizenga 1995; Nixon 1993; Howe 2004)

King and Robeson (2007) were among the first authors to bring to the fore the problematic position of the athlete-patient, situated in a professional sport context where the introduction of performance enhancing technologies can be regarded - in their own words drawing a parallel from the clinical context - as “unregulated clinical research”. (King and Robeson 2007) King and Robeson note how well understood problems in research ethics (i.e., vulnerability, voluntariness, undue influence, full disclosure, equitable subject selections, conflict of interest) become particularly problematic in the elite sports contexts, as opposed to the more typical health, medical and scientific contexts in and through which research is already regulated. They note how, in the current system where performance enhancing substances and technologies are introduced into athletes’ bodies, which
become the locus of unregulated experimentation, three types of potentially serious consequences follow:

“First, the people who receive the innovation lack information about it, particularly about the limits of knowledge about it. Second, they lack protection against the conflicts of interest that can arise when the innovator has more than the individual’s well-being in mind (such as product development). Finally, the safety and effectiveness of the innovation cannot be adequately determined.” (King and Robeson 2007)

Finally, they define athletes as ‘unwitting or unwilling research subjects’, or ‘guinea pigs’ (p.1). In this section, I elaborate on King and Robeson’s paper and discuss whether the current lack of research on performance enhancing agents, and the current revision of the WADC, support a shift towards a more robust empirical basis for the introduction of performance enhancing agents in WADA Prohibited List.

To the best of my knowledge, the only existing, albeit small, review of the few existing studies with substances that might enhance athletic performance has been conducted by Maschke (2009), who points out the tension raised by the necessity to research the performance enhancing effects of such agents, together with the necessity to develop accurate detection tests on the right pool of subjects, and the legitimization that such necessary research would seem to impress on the use of doping agents. (Maschke 2009) This paucity of data is exacerbated as the data on the ‘potential’ performance-enhancing effect of an agent are mostly extrapolated from clinical trials conducted with therapeutic purposes, on a pool of subjects that has little in common with the population that will eventually be prescribed the drug. As Eynon has pointed out it is problematic that: “Much of what we already know on sports genetics and will learn in the future has to be inferred from studies in non-athletic populations”. (Eynon et al. 2011) Green (2009) further illustrates the point of “externality”, or of the unrepresentativeness of the subjects of the study, when he writes of his participation in a study aimed at validating testing to detect recombinant EPO (rHuEPO) (a doping product used to enhance speed endurance) before the 2002 Winter Olympics. (Green 2009) Green notes that one of the criteria for inclusion of volunteers in the study was that volunteers could
not be subjected to drug testing, nor actively competing at a level that would render them a potential subject in a relevant anti-testing pool (this in accordance with WADA Code). Under these circumstances, Olympic athletes who commit an anti-doping rule violation (i.e., return a sample that is positive for doping substances) could challenge the validity of the testing, on the basis that the test was not developed with a representative cohort, and that somehow Olympic athletes metabolized rHuEPO differently from untrained individuals. (Eynon et al. 2011) The rHuEPO case should not be understood as an isolated example, and in so far as there is disagreement as to the extent that valid and reliable methods of detection exist, athletes who test positive may challenge the scientific validity and reliability of results obtained on a different pool of subjects, with different doses of substance, or not obtained at all.

As mentioned above, the WADC is currently under revision, and it appears that the 2015 Code will elevate ‘performance enhancement’ from being merely one of three criteria to a necessary condition of doping, to be supported by either of both of the remaining (now) secondary conditions: harm to health and contrariness to the spirit of sport. (M J McNamee 2012) This would increase the visibility of the substances in the Prohibited List, which at present are not (or at least often not) supported by high quality evidential bases. Having completed two of three consultative phases, it seems that the inclusion of the performance enhancement criterion as a necessary condition in the revised WADC will be widely supported. Nevertheless, as I argue extensively in my forthcoming paper (Camporesi and McNamee 2013a), if the performance enhancing criterion indeed becomes a necessary condition, there should be reasonable grounds for a product’s or process’ inclusion on the Prohibited List – reasonable grounds that, at the moment, do not appear to be evident, as many of the substances included in the Prohibited List are merely presumed to be ergogenic.

Therefore, in (Camporesi and McNamee 2013a), we argue that a proper governance framework would need to be established both to assess the performance enhancing effects of the substances, and the risks to the health of the
athlete.¹⁰ As a disclaimer, I note here that we do not argue in favour of WADA suspending their enforcement power until a certain point in the future when the performance enhancing effects of the substances will be demonstrated, as we agree that one cannot wait until robust evidential basis can be supplied for every substance in the List. We argue instead that the inclusion of the substances in the List should proceed following the precautionary principle, though it should not be used indiscriminately but only where there are reasonable grounds to infer a performance enhancing effect, or risk to the harm of the athlete. (Sandin 2006) We are aware that sometimes it will be inevitable that the inclusion of a substance in the Prohibited List will involve reasonable extrapolation. For instance, there is good evidence to suggest that the use of beta-blockers enhances performance in pistol shooting, (Kruse et al. 1986; M. D. Silver 2001) and that this might be contrary to the spirit of sport, as it infringes the level-playing field which is a necessary condition for fairness equality in competition. (Camporesi and McNamee 2013a) Thus beta-blockers are reasonably banned and considered doping. Yet we dispute that the ban applies not only to target sports - where the inference is reasonable - but also to other sports, where its performance enhancing effects seem less than obvious. To be clear, we would not count as reasonable grounds anecdotal evidence on performance enhancing effects or harmful effects of a substance, such as creatine with (say) a particular population (children). (Calfee and Fadale 2006)

Some may want to challenge our arguments, by saying something along the lines of: ‘Are you advocating legalising doping, or having doping under a medical context?’ Indeed, as shown in section 3.1, the negative connotation of doping practices is a relatively recent acquisition. More recently, there has been a return to those initial arguments, and several authors have argued in favour of legalising doping. For one, see Foddy, Savulescu and Clayton, who argue that doping is not contrary to the spirit of sport (J Savulescu, Foddy, and Clayton 2004), or Andy Miah, who argues that a pro-doping culture will not only be inevitable in the future of professional sports, but that it is also an essential part of what we value in sport

¹⁰ I note here that the problematicity of ‘potential risk to the health of the athlete’ criterion, which, contrary to the potentiality of the performance enhancing effect, is not under discussion in the Code revision process. For further discussion of this problem see ((M J McNamee 2012)).
(and of why we are interested in it), i.e., pushing humanity to its limits and beyond. (Miah 2006) As illustrated in 3.3 and Appendix 3, we do not think that doping should be legalised. Quite on the contrary, we think that the use of genetic technology aimed at enhancing athletic performance is not ethically permissible as it undermines the meaning of sport by interfering significantly with the relationship between natural talents, their virtuous perfection, and athletic success. (T. H. Murray 2009b; Camporesi and McNamee 2012)

In the rest of this section I will instead discuss the charge that our arguments could lead to doping under a medical context, by analysing the perspective put forward by Holm (2007). While Holm’s analysis is antecedent to ours, his arguments represent an instance of a critique that can be raised to the arguments spelled out in Camporesi and McNamee (2013a), in favour of establishing a framework for research on performance-enhancing substances.

Holm spells out the two possible scenarios that would take place were a ban on doping to be lifted, namely a) that athletes could have access to data on the effectiveness and side effects of the performance enhancing substances; and that b) athletes could get impartial advice from the sports doctor about when and how to dope. (Holm 2007) In both scenarios, Holm argues, athletes would still have incentives to cheat, and a two-tiered system of doping under a medical context and of secretive doping would ensue. This would be the case due to the existing deeply intertwined financial and dependent relations between athletes, sports doctors and employers: more often than not, sports doctors act as agents for their employers, and even to the detriment of the long-term health of their athletes-patients. Sports doctors are de facto employees (of the team, of the athletes), and athletes find themselves at the centre of a conflict of interest between the ethical norms of the medical profession (good of the patient first), and the ethical norms of sport medicine (excellence, victory first?), where often short term health goals such as a swift return-to-play as previously mentioned are privileged over long-term health goals. In addition, more often than not the athlete’s income is controlled by his/her employer (e.g. team, sponsor), and the degree of control that the athlete has over the decision to play/to compete is very limited. Finally, another reason why legalising doping would not necessarily turn it into an open and transparent
practice is that athletes have strong incentives to keep doping practices secretive in order to maintain an exclusive use on a drug, and therefore a competitive advantage over fellow athletes. Holm identifies these incentives as an instance of a ‘take and hide’ option that dominates other options in a game-problem. For these two reasons, it is not lifting the ban on doping that will let doping become an open and transparent practice, but:

“It is thus only if the pay-off matrix is changed that it becomes rational to choose to take the doping substance openly”. (Holm 2007, 139)

Holm argues that we could reasonably expect, were a ban on doping to be lifted, a two-tiered situation, where two practices would ensue: a) the open use of well-known drugs, with well-known doping effects (both performance-enhancing, and side effects); and b) the hidden use of other doping methods in order to preserve the competitive advantage over fellow athletes. Even in a legalised doping scenario, controlling systems would need to be put in place to catch and punish those who cheat. This system would in a way reinforce doping control, albeit through different methods from the ones in place in the current scenario of illegal doping. How to avoid this dominant “take and hide” option in this instance of a game problem? As quoted above, Holm thinks that the only way out of the game problem is a drastic change in the economic and financial relations in the sport matrix. Such changes would ensure that sportsdoctors would not find themselves anymore in the position of being employed by a team/a sport association, and that the athletes would consequently not find themselves anymore at the centre of a conflict of interest between their long-term health goals, and short term gains for the team/for the athletic career. Even in this changed sport matrix, though, there would still be incentives to keep at least some doping practices secretive in order to preserve exclusive use and competitive advantage. Therefore, the doping practices, concludes Holm, would not become and open and transparent practice even in the scenario in which doping where legalised, and the sport matrix and financial relations between coaches, sportsdoctors and athletes were changed.
Relevantly for our arguments discussed above and fully elaborated in Camporesi and McNamee (2013a), it needs to be noted that Holm does not think that, if doping were put under medical control, it would be the case that doping substances would be tested more thoroughly than they currently are before being used. (Holm 2007, 142–3) The reasons he advances are two-fold: a) that the pharmaceutical industry would not have an interest in developing and testing doping substances thoroughly (unless the doping substances could also be used outside the professional sport context, which he doubts); and that b) athletes would not have an interest in waiting to use doping substances until they had been extensively tested, because of the ‘take and hide’ option discussed above.

The clash of interests in sports medicine, between services to the athlete-patient and the contracting party is well known, (S. Holm, McNamee, and Pigozzi 2011) but discussions are more frequently framed in terms of return to play issues or enhanced recovery than in terms of necessity to establish a research framework for performance enhancing agents. I would be content with having shown in this section, that the transfer of norms of medical ethics to sport medicine without their re-visioning can be and is problematic, and that there are grounds for legitimization of a research enterprise to measure the enhancement effects of agents. This, I argue, would promote greater visibility and consistency in the context of professional sport currently lacking both, and where athletes may be subjected to an unregulated research system, which poses high risks to their health. While I am aware that the practical implementation of such a proposal would be very difficult, and that probably a two-tiered system of doping as the one envisaged by Holm (2007) would ensue, I do not think that this diminishes the importance of evaluating the ‘unregulated research context’ that is the introduction of innovations in professional sport.

In the next chapter I turn to the analysis of the place of research on enhancement in society, first discussing the case study of adults seeking prescriptions for cognitive stimulants under the rubric of ADHD, then attempting to provide a preliminary justification based on ethical criteria translated from the clinical research context to the enhancement context, and finally discussing what
changes would have to be put into place in society to accommodate research on enhancements, with a focus on the US system.
Chapter 4: The place of enhancement research in society

4.1 Why we need research on enhancements

Following up from the previous section, where I argued in favour of research on performance enhancing agents, in this chapter I tackle the broader question of an ethical justification for research on enhancement (enhancement research or ER). This question is surprisingly neglected in the bioethics literature on enhancement: The leading critics of biomedical enhancement [Kass, Habermas, Annas, Fukuyama] have not addressed directly the issue of ER. However, their statements against enhancement strongly suggest that research and development of enhancements would also be considered unethical from their point of view, on the basis of the argument that ER would promote an unethical practice, and should therefore be banned. As it can be foreseen, I do not concur with them, as I think that even though particular technologies aimed at enhancing human capacities are not ethically permissible in a certain context, it does not follow that research on enhancement per se is also not ethically permissible. To the best of my knowledge, the only authors that have raised the point about the necessity to establish a framework for, and to regulate, ER are Lev and co-authors (2010). They write:

“As with other biomedical interventions, research to assess the safety and efficacy of these enhancements in humans should be conducted before their introduction into clinical practice” (Lev, Miller, and Emanuel 2010, 107)

This is what should happen, but not what happens in practice. There is no system in place to regulate ER, and very little - if any - discussion about it. If this is the situation, it is also obvious that there are no safety precautions for the individuals who want to take on pharmacological enhancements, as there are no regulated trials that spell out the possible risks and harms, and benefits. Should this not be case? Or at least, should there not be a case for it? What could be the ethical justification for ER?
Lev and co-authors seem to justify research on enhancements on the basis of a health-related value:

“Categorically condemning research on biomedical enhancements as unethical is unwarranted, since at least some research on biomedical enhancements is likely to produce significant health benefits. Indeed, under certain circumstances enhancement research would be urgent, as it would address major public health concerns. Therefore, a blanket prohibition on enhancement research is unjustified.” (Lev, Miller, and Emanuel 2010)

While I agree with them that “a blanket prohibition on enhancement research is unjustified”, it is not immediately clear that ER ought to be justified by having health-related social value, even though there might be some cases of ‘dual use’ biomedical interventions, or interventions that can be used both as treatments and as enhancements. (Miller and Selgelid 2007) In such cases any health-related social value can be seen as an added value rather than a prerequisite. In all other cases, while the health of the research participant should of course still remain a primary concern, research on performance enhancing substances should have as its first epistemic goal the validity and reliability of performance enhancement claims. Of course this epistemic goal should be circumscribed by an ethical one, and thus the evaluation of risks and benefits needs to be modified when shifting from the clinical to enhancement contexts. Precisely what counts as benefit and risk in enhancement research need not be identical to what counts as benefit and risk in clinical research (see section 4.3 for a discussion of the criteria for an ethical justification of ER).

As I see it, an analysis of the ethical permissibility of ER should be two-tiered:

a) It should seek a contextual, bottom-up analysis of the ethical justification of research on a particular kind of enhancement;
b) It should try to provide a general ethical justification of ER adopting a translational perspective from clinical research ethics.

Let us now analyse these points in turn.
4.2 Prescribing Ritalin & Adderall under the rubric of adult ADHD

It is an increasingly common trend in the United States to seek requests for medication treatment of cognitive symptoms. Cognitive complaints may include difficulties with concentration, problems with attention and memory, inability to focus, concentrate, or sustain tasks, or an inability to complete tasks. (Richardson-Vejlgaard et al. 2009) In the current US system, requests for medical treatment (prescriptions for Ritalin and Adderall) can be accommodated only through a diagnosis of adult ADHD. While the phenomenon of patients asking for specific medications has existed for decades, and was originally attributed to the erosion of physician authority in the 1980s, advertisements encouraging patients to “talk to their doctor” about a specific medication or condition can be a direct channel for legitimate and less legitimate complaints. (Brett and McCullough 1986) As documented by Kravitz et al. (2005) in the context of depression and anxiety, these requests can be extremely powerful as it is demonstrated that they have a “profound effect” on physicians’ willingness to prescribe medications. (Kravitz et al. 2005)

Published experience in the UK confirms that this phenomenon is common in practice also on this side of the Atlantic: self-referred patients were “upset” if they did not receive the diagnosis of adult ADHD. (Young and Toone 2000) Moreover, there is a clear hierarchy of treatments in the patient’s eye. For example, patients that receive non-stimulant medication treatments for ADHD often feel their complaints have been dismissed without consideration, and frequently express their objection and preference for scheduled stimulant treatment by directly continuing to ask for a stimulant trial, even if they could derive clear benefits from the non-pharmacological treatment. In addition, it must be noted how patients have become increasingly less shy about asking physicians

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11 This section and much of this chapter is focused on the US system. I was thinking and writing about these issues during my period as a visiting PhD student at University of California, San Francisco in 2011/12. I would like to acknowledge Dr Akhil Mehra for his intellectual contribution to the discussion of this issues.
for specific stimulant medications: many seem to expect them. (Galtieri and Johnson 2005) Indeed, another trend that may contribute to adult ADHD presentations is DTC pharmaceutical advertising, which is permitted in the US. Most of these patients have heard of adult ADHD and wonder if their own symptoms may be due to this condition. They often ask their doctor for specific ADHD medications by name, having read about it online, or having tried a friend’s or family members’ medicine that seemed to help. Patients often score high on adult ADHD self-report symptom rating scales, and their past history may reveal some level of dysfunction as child. However, clear age of onset is elusive, and extensive co-morbidity with past mood and anxiety disorders confounds the story of progression of symptoms from childhood to adulthood. Family or school reports from the distant past are unavailable, or when available do not clarify the diagnosis. The clinician might identify some current level of cognitive or executive dysfunction, but often the patient’s complaints are neither convincingly pervasive nor directly observable. What happens in most instances of patients’ requests is that, barring some obvious contraindication, most doctors skip, ignore, or blindly confirm the age of onset criterion and accept current subjective symptoms and the patient’s self-report of dysfunction as the basis of their diagnoses. Patients’ self-reports are then reified by the use of self-report rating scales, (questionnaires about ADHD symptoms) which merely quantify the patients’ self-report, and are subject to what Galtieri calls the “halo effect”, a reporting aberration based on what the patient would like the outcome to be. (Galtieri and Johnson 2005) The patients’ requests eventually result in a trial of Ritalin or Adderall, and a diagnosis of adult ADHD.

Adult ADHD is a relatively new construct, in which a childhood syndrome of hyperactivity and inattention is hypothesized to continue into adulthood, causing significant dysfunction. (Nigg 2001) (McGough 2004) It is recently a popular diagnosis, with an almost 12% year over year increase in prevalence from 2000-2005. (Castle et al. 2007) There have been questions posed about the validity of adult ADHD, from the validity of the childhood diagnosis (from which the adult diagnosis has been extrapolated), to the lack of field studies of the condition in adults, and to methodological problems in defining ADHD in long-term follow-up studies of children with the condition. (Moncrieff and Timimi 2010; Spencer et al.
1998) In addition, the poorly disclosed pecuniary relationship between a small group of prominent ADHD researchers frequently cited in validity studies and pharmaceutical manufacturers of ADHD medication raises legitimate conflict of interest questions in both adult and paediatric ADHD, among other conditions. (G. Harris 2008) Finally, there are criticisms that adult ADHD is a societal construct that requires individuals to perform at unrealistically high levels and that medicalises resulting underperformance. (Conrad and Potter 2000) I will not enter here, though, into the debate on whether or not adult ADHD can be considered a ‘disease’. Let us assume for the moment that it is, and focus instead on analysing the requests for Ritalin and Adderall prescriptions that do not stem from the actual ADHD condition (whatever that means), but from cognitive complaints of individuals being generally not satisfied with their current cognitive capacities.

In our society, there are people who do not perform cognitively as well as they would like to, for many different reasons. Some of these people know about pharmaceutical products that might help them with their cognitive shortcomings. They also know that a certain diagnosis would give them access to these products. Because of their desire to access these pharmaceutical products, some of these individuals start thinking that perhaps they really do have a disorder, and start seeking a diagnosis that would give them access to the pharmaceutical products.

At least in a subset of these patients, a form of self-deception seems to be present, as their belief that they really have a disorder stems from an apparent unawareness of their true motivational states, and of their desires (i.e. having access to stimulant drugs). Self-deception is defined as the acquisition and maintenance of a belief (or at least, the avowal of that belief) in the face of strong evidence to the contrary motivated by desires or emotions, favouring the acquisition and retention of that belief. (Dewese-Boyd 2013) Therefore, in at least some cases of adult ADHD, it seems that self-diagnosis, poor diagnostic reliability, external motivators, and the ubiquity and non-specificity of cognitive symptoms in human experience coalesce in a system in which doctors and patients become co-complicit in a self-deceptive or plainly deceptive system. This system seems problematic from a moral point of view for various reasons:
The medicalization of human cognitive capacities variation under the label of adult ADHD contributes to inappropriate health care expenditures and misallocation of resources, as well as encourages a black market for stimulant medication. According to Inciardi, the United States Drug Enforcement Agency (DEA) estimates that prescription drug diversion, the repurposing of legitimately prescribed medication for sale on black markets, totals $25 billion per year, constituting a substantial shadow economy. (Inciardi et al. 2009) Black markets undermine the doctor-patient relationship, lead to safety and overdose problems, and channel users into the criminal justice system. Accommodations in the school and workplace constitute powerful incentives to seek a diagnosis of adult ADHD, at least in the US, where patients diagnosed with ADHD gain access to the larger category of having a ‘disability’ under the Americans with Disability Act of 1990. This, as pointed out by Conrad and Potter (2000), can serve as “a gateway to potential claims to certain benefits and accommodation” both in education and in the workplace, therefore constituting an additional incentives to seek an ADHD diagnosis. (Conrad and Potter 2000, 574) Among these benefits and accommodations are: “untimed tests, oral versus written administration of tests or instructions, additional time to complete tasks, structured work assignments with written instructions, extra clerical support, more frequent performance appraisals, checklists for multi-stage tasks, diminished capacity arguments in criminal suits, and protection against discrimination”. (Conrad and Potter 2000, 574)

What if, instead of perpetuating this system, we adopted an enhancement model with symptom-based treatment for cognitive complaints? In this model, patients could simply tell their physicians that they wanted a specific medication, because they are unhappy with their cognitive capacities, and physicians could prescribe it without having to diagnose them with adult ADHD or another condition. Note that this would not be a new practice in medicine, contrary to what some claim. As mentioned in section 1.4, already in the early 1900s the US pioneer surgeon Max Thorek was performing ‘therapeutical gonadal implantations’, (i.e., testicular transplants mostly from apes and monkeys, but also from human cadavers) with the aim of elevating the level of male hormones (and supposedly, their sexual function) in the recipients, mostly older patients. (Rothman and
Rothman 2003, 142–44) Between 1912 and 1923, Thorek performed more than 100
testicular transplants at the American hospital in Chicago. Thorek was also among
the first surgeons to perform breast reduction and abdominal excisions (the
antecedents of contemporary plastic surgery practices), and in 1942 he wrote one
of the first textbooks on plastic surgery. Thorek as a doctor is a particularly
interesting figure as he could be seen as a precursor of some of the arguments
being used today in support of pharmacological enhancement. Thorek was also a
convinced champion of the legitimacy of enhancement within the scope of
medicine, as he was convinced that “raising the quotient of patient happiness” was
a legitimate medical task to pursue within the purview of the doctor’s remittal.
(Rothman and Rothman 2003, 142–44) The following quote exemplifies his
thinking: “If the child can be given shapely ears he should have them for his own
happiness; and who is to deny him that happiness if he can attain it?” (Rothman
and Rothman 2003, 143), and also: “If surgery can restore happiness and
enjoyment of life to an individual who has lost them, that is as strong a justification
for its use as restoration to health”. (Rothman and Rothman 2003, 143) This small
detour should therefore serve to debunk the historical inaccuracy of the arguments
that enhancement technologies do not belong to the proper scope of doctor’s
profession (for a more extensive analysis see Scripko (2010)).

Should the prescription of Ritalin and Adderall also be understood within
the purview of medicine as understood by Thorek “to raise the patient’s
happiness”? Many authors have argued that using cognitive enhancements is morally
problematic. These authors have suggested that to use enhancements indicates
weak moral character, because the use of enhancements becomes a substitute for
effort to achieve life’s goals. (Sandel, Michael 2004; President’s Council on Bioethics
(U.S.) 2003; Kass 2002) In this formulation, effort alone has a positive value, and
achievements obtained through effort are considered more morally worthy than
achievements obtained without, *ceteris paribus*. Buchanan, when reviewing, and
opposing, these arguments, terms this reasoning the ‘moral flabbiness’ argument.
(A. Buchanan 2011) In the moral flabbiness argument, a person uses enhancement
as a shortcut for hard work. It thus seems that the ethical accusation of enhancement is that it allows some people not to have to work as hard as others. However, as shown above, the current system where stimulants are prescribed under the rubric of disease is also ethically problematic from several points of view: the existence of black markets; the existence of social benefits and accommodations constituting powerful incentives for self-deceptive, or plainly deceptive behaviours; the undermining of the doctor-patient relationship; the undermining of the validity of ADHD as a valid disease construct, etc. All of these factors strongly suggest that a shift to an enhancement model, characterized by a higher degree of accountability and transparency, would be highly desirable. Legitimate enhancement treatments would also increase the level of accountability of the system, as enhancements would compete against other ‘public goods’ for the distribution of resources through a more transparent and open process of deliberative democracy, rather than entering through the back door under the rubric of diseases as pointed out by Buchanan:

“[…] When a society recognizes enhancement as a legitimate aim, it changes the way deliberations about biomedical enhancements are framed. One of the most important framing shifts is that it signals that biomedical enhancement must compete fairly and openly with other legitimate social goals in the process of allocating resources. In contrast, in a society in which biomedical enhancement comes in through the backdoor, piggy-backing on the treatment and prevention of disease, [italics added] ever-greater amounts of social resources may be devoted to it, but without any opportunity for democratic, scientifically informed decisions about its comparative worth.” (Buchanan 2011, 16–17)

I am aware of the objection that consenting to individuals’ requests for stimulants runs the risk of ‘cultural complicity’ with a society that does not accommodate individuals with different cognitive capacities, or that simply imposes too high performance requests on the individuals. (Little 1998) However, while I recognize the importance of this objection, I believe that eventually in what situations people choose to use enhancements are up to them. These decisions may be morally laden; however, in an enhancement framework, a person’s motivations are not obscured like they are in the current disease framework by the
act of having to obtain the drug. Responsibly expanding access to enhancements would not only have the morally desirable effect of decreasing self-deception in doctors and patients, but would also entail other practical benefits, first of all cutting down on black and grey markets for prescription stimulants.

In fact, adult ADHD is currently understood as a chronic disease requiring daily medication treatment. Thus, when medication is prescribed, an entire month’s or even several months’ supply is released to a patient. However, an enhancement model would recognize the reality that many people who take stimulants for enhancement do not take them chronically, but instead they do so on an as-needed basis (in preparation for an exam, an interview, a challenging task at work or in the private sphere, etc.). (M. E. Smith and Farah 2011) The extra cost of chronic prescription medicine supply must be borne by somebody: frequently, in the disease model, it is borne by an indirect third party, such as an insurance company, or the government. However, to the best of my knowledge, the monetary costs of prescribing expensive chronic medications for adult ADHD has never been challenged. Moreover, although there are generic versions of several prescription stimulants, physicians are increasingly prescribing not cheaper generic drugs, but newer, more expensive, branded versions of stimulants. (Castle et al. 2007) Again, in an enhancement model, it is plausible to speculate that stimulants diversion would be a less severe issue, and that overall the actual amounts of medication dispensed would be at the discretion of doctor and patient, including the freedom to dispense only small amounts for use on an as-needed basis.

Another issue to take into account is the issue of reimbursement for the cost of the stimulants. Currently, in the existing disease framework, insurance companies or third parties pay for physicians’ visits and medications. To the contrary, many elective procedures, like cosmetic or aesthetic procedures, are not covered by insurance companies. The underlying rationale is the T/E distinction as argued for by Normal Daniels and presented in section 1.4. (Daniels 2000) Under an enhancement framework, prescriptions for Ritalin and Adderall would probably be considered along the lines of cosmetic or aesthetic procedures, and not be reimbursed by a third party. Indeed, it could be argued that, if patients had to pay
out of pocket for visits and costs of cognitive stimulants, their current behaviour might change. First, patients might limit themselves to supplies of medication only which they needed. Secondly, patients would have to expend more personal effort and expense in order to obtain the prescriptions, which might cut down on casual requests for enhancement. In any case, the issue of medical reimbursement would need to be more closely analysed.

Finally, another problematic issue in the increasing trend to prescribe cognitive stimulants is that there is very little systematic trial data on the long-term effects of cognitive stimulants. Indeed, most of the information we currently have on stimulant substances has been obtained for studies conducted for therapeutic purposes, therefore having therapeutic and not enhancement endpoints. As pointed out also recently by neuroscientist Barbara Sahakian from the University of Cambridge (UK), it would be necessary to establish clinical trials for enhancement purposes for cognitive stimulants, as currently there are no studies on the long-term effects of stimulants, possible side effects, and actually not even on the demonstrated long-term cognitive enhancing effects of stimulants. (Sahakian and Morein-Zamir 2010) It may very well be the case, therefore, that individuals are seeking stimulants prescriptions for cognitive enhancement purposes while in reality stimulants do not cognitively enhance but only raise the attention awareness or attention span in the short term (in a sort of ‘enhancing misconception,’ drawing a parallel from the ‘therapeutic misconception’ phenomenon described for early clinical trials in clinical research (Appelbaum et al. 1987)).

In conclusion, the current disease model for prescription of stimulants prevents hard reflection about the chasm that sometimes exists between our ambitions and abilities, and prevents a real discussion about the true costs to build the bridge between them. Instead, I think that granting a legitimate place to cognitive enhancement would not open the floodgates to all kinds of enhancements, as is sometimes feared, but would provide society with a framework for a more open debate about the pros and cons of each technology, and with a more accountable system for the allocation of resources. In the next paragraph I attempt to give a preliminary analysis of the ethical requirements to
justify research on enhancements, borrowing a commonly accepted justification of clinical research.

4.3 What could be the ethical requirements for enhancement research?

A widely accepted view is that for clinical research to be ethical, it must fulfil seven requirements: it must (1) have health-related social value, (2) be scientifically valid, (3) use fair subject selection, (4) involve a favourable risk-benefit ratio, (5) be independently reviewed, (6) satisfy informed consent requirements, and (7) respect enrolled participants. (Emanuel, Wendler, and Grady 2000) How do these requirements translate to research on enhancements? Let’s take a closer look at each criterion:

1) Health-related social value: Contra Lev and co-authors (2010), I do not think that research on enhancement needs to be justified by having a health-related social value, even though there might be some cases of ‘dual use’ biomedical interventions, or interventions that can be used both as treatments and as enhancements, for which the health-related social value could be seen as an added value. Enhancement technologies do not have ‘health’ as their goal, but ‘enhancement’. Therefore, the justification should not be based on health, but on the considered legitimacy of enhancement as a goal of our society.

2) Scientifically valid: I think this criterion can be considered quite straightforward, and should translate from clinical research to ER.

3) Use fair subject selection: as above, I also think this criterion should translate. In fact, the protection of ‘vulnerable’ subjects as research participants is one of the concerns of my analysis of current modes of participation in clinical research, and I analyse it in detail in my open peer
commentary (Camporesi and Mameli 2012) included in this thesis as Appendix 4. In this short paper we discuss the COMPAS trial (NCT00466947) as an instance of suboptimal study design, and of the increasing tendency of pharmaceutical companies to run clinical trials in low and middle income countries. The COMPAS trial is a very controversial study and reached the headlines in 2008 due to the unclear, and possibly trial-related, cause of the death of more than ten infants in 2008. In the paper, though, we focus our analysis on the trial as an instance of a ‘mutually advantageous transaction’ (Wertheimer 2011) for individuals who live in disadvantageous geographical and economical conditions, and that qualify as ‘vulnerable’ by not having any other way to access some kind of healthcare other than participating in exploitative research. The paper raises several important issues: a discussion of matters of exploitation in the outsourcing not only of clinical research but also of drug manufacture; a discussion of contemporary modes of participations (the exploitation of individuals in LMICs as research participants, and the exploitation of individuals belonging to un(der)insured fractions of population in high-income countries as serial participants in trials with no therapeutic benefit); a discussion of the post-trial obligations of clinical research in LMICs; and the triggering of a thorough analysis of all aspects of the COMPAS trial. See Appendix 4 for a full argument.

4) Involve a favourable risk-benefit ratio: This criterion could also translate from a clinical research context to an ER context, but it would need to be spelled out what would count as benefit, and what as risk, in ER, and how they are evaluated. For the purposes of this work, I will not come up with my own personal take on the matter, but instead only remark how this criterion seems to be a plausible one which could withstand translation from a clinical research context to an ER context, but that of course would need to be modified, as the meaning attached to the concept of risk and benefit in a different context would also be modified.
5) Be independently reviewed: I am quite confident to speculate that what Lev and co-authors (2010), being US-based scholars, probably have in mind when including this criterion is the existence of IRBs (Institutional Review Boards) as they are established actors for the approval of clinical research in the US. However, as recently pointed out by Laura Stark (2012), the *modus operandi* of the IRBs is a) historically contingent, and b) ethically problematic from several viewpoints, starting from the way decisions are reached devoid of any transparency or personal accountability. The IRBs function as ‘expert bodies’ and reach only consensus decisions. In *Behind Closed Doors. IRBs and the Making of Ethical Research* (Stark 2012), Stark shows how IRBs produce decision in a setting characterized by low public exposure (hence, “behind closed doors”) and low accountability. In such a setting, a consensus is often reached on the basis of subjective experience, or the use of “local precedents”, i.e., exemplary cases that function as ‘shared warrants’ that guide the IRB decision regarding the approval, or not, of a protocol. This leads to the fact that different IRBs never seem to agree on how research should be conducted, and indeed different IRBs in the US more often than not reach different decision on the permissibility of the same protocol. This becomes a real and problematic issue since the same clinical trial often falls within the jurisdiction of several IRBs. The IRBs are unitary social actors that reach a decision through a unanimous consensus, and by doing so they erase completely the accountability of the individual members. For these reasons and others illustrated in Stark’s book, (Stark 2012) I am not persuaded that the translation of the existing process of review understood as IRBs from clinical research to ER would be a good idea, but I am more inclined to think that other models could be devised that would satisfy the requirements of independent review. To sum up, I think the ‘form’ of the 5th criterion spelled out by Lev and co-authors (2010) could hold, but its substance would need to be revisited\(^{12}\).

\(^{12}\) While I do not intend to pursue this in my research in the near future, I am content to acknowledge/point out here the originality and relevance of Stark’s new book.
6) Satisfy informed consent requirements: I think this criterion should translate. I will not dwell upon the subtleties of informed consent, though as pointed out already in relation to the analysis of expressivist arguments raised by individuals with disabilities (section 2.3) I recognize the increasing importance of the patients’ stories when thinking about informed consent issues. (see (McCormack 2002) (Corrigan 2003)).

7) Respect enrolled participants: This criterion would also transfer to the ER context, and goes back to the problem of ‘vulnerability’ mentioned in relation to the third criterion above of fair subject selection.

In replacement of the ‘health-related social value’ criterion, I think it would be necessary to add a criterion of ‘accountability’, which would increase the transparency of the decision making process in regulating research (see point 5 above) and in prescribing enhancing drugs. Buchanan, already quoted in the previous section, also stresses the advantage of having a regulatory system of research on enhancement in place in a society that becomes more accountable about the allocation of scarce resources. (A. Buchanan 2011) It is important to note here that even assuming that ER could be justified in general from an ethical point of view, on the basis of the seven criteria spelled out above, this would not imply that all research on enhancements would be immediately justified: individual cases would still need to be reviewed and justified - or not - on a case by case basis. In the next section I will consider what changes would need to be put into place in society to establish a proper regulatory framework for ER, by attempting a first look at the policy changes required by ER.

4.4 What changes would be needed to accommodate research on enhancements?

To the best of my knowledge, the only existing analysis of the type of regulations that would need to be put in place in society to regulate enhancements
has been carried out by US law and bioethics scholar Hank Greely (2011). Greely reviews the policy tools available in the US, and shows how not necessarily new regulatory frameworks or systems would have to be invented, but that in the most probable scenario existing regulation could accommodate biomedical enhancements. (Greely 2011). This is the case because:

“FDA regulation already covers enhancements. If a firm were to seek approval to sell a new drug for enhancement purposes, no new safety regulation would be needed in the United States. The company would have to conduct serious clinical trials and to demonstrate to the satisfaction of the FDA that the drug was safe and effective for the intended use”. (Greely 2011, 510)

Greely proceeds then to identify two main issues that would need careful consideration to assure the safety of enhancements, namely the regulation of off-label use for enhancement purposes of the pharmaceuticals, and possibly the increased regulation of dietary supplements. As it is plausible to speculate, many and probably the vast majority of biomedical enhancements would be approved to treat disease and used off-label as enhancements. The off-label practice of use for pharmaceuticals is already a widespread practice in the US, so from this point of view the introduction of enhancements would not be substantially new.

What is off-label use? In the USA, after a drug’s approval, the FDA works with the manufacturer to create a drug label that contains information about the drug, how it should be administered, and the indications for which it has been approved. Since the FDA itself does not regulate “the practice of medicine”, off-label use of FDA-approved drugs is a legal and common medical practice: after approval, a licensed doctor can use a drug for any indication he/she consider appropriate. (R. Sullivan et al. 2011) I find the widespread use of off-label drugs in the US very problematic, to use an euphemism: what is the purpose of having in place a huge bureaucratic and financial apparatus (i.e., the FDA) to regulate clinical research, if then the doctor is free to prescribe any drug without any evidential basis that the drug works in a context different from the one for which it was tested? Greely seems to concur with me on this point when he writes that:
“Drugs can be approved as safe and effective for one use against one disease, based on clinical trial evidence, but then prescribed off-label for uses in people without that disease, or perhaps any disease, without any proof that the drug is either safe or effective for the prescribed use”. (Greely 2011, 511)

Contra very strong libertarians such as Harris or Savulescu, I do not think that the current off-label system promotes liberty, or individual freedom of choice (note that this is indeed the rhetoric underlying so many proponents of DTC advertising), but that the patient-consumer needs and deserves some protection from the market’s free reign. While in theory the arguments advanced by Harris or Savulescu could work, in practice the intricate financial ties between pharmaceutical companies, lobbies and politics in the US create markets where there is no legitimate demand, and lead to ethically problematic situations such as the case of prescriptions for Ritalin or Adderall discussed in section 4.2. For all these reasons, I do not think that the entry of enhancements in society through the ‘off-label’ system would be desirable. It would be equivalent as entering society ‘through the back door’ – to borrow an expression from Buchanan (2011) – as they are now, and once again that would happen without the appropriate regulation and demonstration of effectiveness and risks/harm data, and without any accountability whatsoever.

Another issue that needs to be taken into account when thinking about the regulation of access of enhancements in society is the necessity to tighten up regulations regarding dietary supplements. In the US, regulation of such supplements is minimal according to the Dietary Supplement Health and Education Act (DSHEA), which defines the FDA’s power to regulate them. The manufacturer neither has to prove that the supplements are safe, nor that they are effective, in order to get approval to enter the market. On the contrary, the burden of proof rests on the FDA to prove to a court that a supplement is unsafe in order to remove it from the market. (Greely 2011) The only requirement for the manufacturer is that “that product label information is truthful and not misleading”, and even that minimum requirement is often not respected. As a way of illustration of this trend, consider “Think Gum”, a chewing gum marketed in the US as a dietary supplement
as the “brain boosting chewing gum.”¹³ According to the product website (http://thinkgum.com/), the chewing gum improves memory by 25 %, as demonstrated by a ‘peer reviewed study’ (of course, there are no data on the peer-reviewed study whatsoever). It is interesting to note how the motto for the gum is “stop cheating, start chewing”, therefore going contra one of the commonly raised arguments against using enhancements, namely that they are a way of cheating!

The system in place for regulation of dietary supplements in the US seems therefore to be a very fruitful terrain for attempts to fraud scientifically or medically naïve individuals.

Therefore, it is plausible to speculate that biomedical enhancements which are manufactured as pills could also reach the market, at least in the US, as dietary supplements, therefore evading completely the purview of FDA. Even if they were marketed as pharmaceuticals to treat diseases, though, we have seen how they could still be used off-label without having to demonstrate either the safety or the efficacy for that particular use. The possibility of pharmacological enhancement to enter the market in this way seems to me particularly frightening. Instead, I think that a much better – and more accountable – way for enhancements to gain entry to society would be to put in place a regulatory system for clinical research, and for prescription of performance-enhancing substances outside the current disease (including off-label prescriptions) model, as I argued for in section 4.2. I am aware that this is only a preliminary discussion, and that much more work would be required before to implement this system.

In the next and final chapter I will consider the policy implications of the enhancement technologies that I have discussed so far, and spell out a possible shift of the debate to the level of political philosophy, which could provide a way out of the current stalemate between libertarians and conservatives.

¹³ For this example I am also indebted to Greely (2011)
Chapter 5: Conclusions and way forward

5.1 A deliberative democracy approach to escape ethical incommensurability

In this thesis I have discussed different topics related to enhancing human capacities through a case studies approach: from genetic interventions aimed at choosing traits in embryos, to genetic interventions aimed at scouting children’s talent in order to give them a competitive advantage in life, to discussion of the application of gene transfer technologies for enhancement purposes in sport, to the discussion of the ethical justifiability of the practices of prescribing cognitive stimulants under the rubric of ADHD.

In each of these cases I first provided a scientific, accurate analysis of the enhancement technology under discussion, and then tried to analyse the context of its practice, and its relevance for the ethical discussion by adopting a casuistic approach employing different ethical frameworks and tools. In the last chapter of this work I would like to attempt to spell out a possible way forward for the discussion of the ethical justifiability of enhancement technology by analysing their impact on society, and taking into account the necessity to reach policy decisions. This will necessarily include a shift from an abstract ethical level to a policy level which includes the discussion of public health goals and issues. I will first analyse the approach spelled out by Matty Häyry (2010) and then by Michael Selgelid (2009, 2012), and then try to combine the two with a deliberative democracy approach which I apply in Appendix 5 to the case of genetic enhancements in sport as a possible way forward for a too often polarized and possibly stalled debate. I am aware that this is a very difficult shift to undertake, and that I can offer at best only a preliminary discussion, and point to a possible fruitful direction of research.

Matty Häyry identifies three competing approaches used by scholars in the debate on the ethics of genetic technologies (what he refers to as ‘genethics’). (Häyry 2010) The three competing approaches are the following:
1. consequentialism (outcome and utility directed)
2. teleology (purpose- and virtue-oriented ethics)
3. deontology (rule- and duty-based ethics)

As argued by Häyry, these three approaches are ‘incommensurable’ because they respectively define a) persons, b) traditions, and c) principles as the entities that matter in the ethical debate. Häyry writes:

“In current bioethical debates participants often avoid revealing their views [...]; how they believe things are in the world; how they think impacts should be optimised; and what entities matter to them.” (Häyry 2010, 47)

Along similar lines to what is argued by Parens in terms of ‘authenticity’ implicit in the enhancement debate (discussed in section 1.5), Häyry also argues that in practice the ethical judgments about the ethical permissibility of a technology depend ultimately on the choice of world-views, attitudes and ideas about what counts in the moral discussion. Therefore, if assumptions about the entities (persons, traditions or principles) that matter are not made explicit, it is going to be impossible to really have either a productive discussion, or any progress in the debate. In fact, if we do not agree on the ‘unit of measurement’ itself of discussion, then the “outcome calculation cannot be helpfully compared or combined”. (Häyry 2010, 194) For Häyry, the three approaches can all be simultaneously valid, and the only necessary condition for their validity is that they be internally coherent/consistent. Häyry also argues that the comparison between the three different approaches (or, how he refers to them, competing “rationalities”) can be possible only in the spirit of “reflective equipoise”, a concept drawn with a parallel from the “clinical equipoise” concept in clinical research, which is defined as a “a state of genuine uncertainty on the part of the clinical investigator regarding the comparative therapeutic merits of each arm in a trial”. (Freedman 1987) In a “reflective equipoise” perspective (assuming that this concept can be valid), it is impossible for the philosopher (paralleled here with the clinical investigator) to know which of the three approaches is better, unless the
philosopher decides *a priori* which ‘unit of measurement’ to use (i.e. persons, traditions or principles), after which he/she will be able to judge an ethically problematic case from a certain ethical perspective.

I agree with the analysis by Häyry to the extent that I think assumptions about the entities that matter morally in the debate often remain implicit, therefore jeopardizing the debate, but I do not agree with his analysis on the second point, insofar as he argues that all the approaches can be simultaneously valid and there is no way to argue that one is better than another. Indeed, in a co-authored paper (Camporesi and Maugeri 2011) already introduced before, and included in this thesis as Appendix 5, I analyse the different ethical frameworks, or “moral rationalities”, that underlie the arguments at the basis of the debate, in particular in reference to a case study (genetic enhancements in sports) and bring to the fore the implicit assumptions underlying the different positions. In the paper we discuss the case of genetic enhancements in sport, which is a very useful case study as it allows us to unpack and spell out the values underlying the competing ethical frameworks used when discussing such a controversial topic as the application of gene transfer technologies to enhance athletic performance (see section 3.3). It is also a case study of particular interest as it relates to a regulated activity (i.e. sport), and therefore its discussion demonstrates the necessity to move beyond the discussion of the internal consistency of different ethical perspectives, or even of the pros and cons of each ethical framework, but demands that a reasonable though provisional consensus should be reached to inform policy making and regulation, for example regarding the inclusion (or not) of genetic transfer technologies under the WADA Prohibited List. In the paper we also argue that there is need to distinguish the moral and legal levels, and to shift from an analysis based in applied ethics to political philosophy, and initiate a discussion at the level of deliberative democracy to find ways to reach a solution acceptable by all parties in society, even though provisionally, in the next section.
5.2 Shifting the enhancement debate from the ethical to the political level

As I hope to have shown in many instances in this thesis, the debate on the application of new genetic technologies often intersects and overlaps with the debate on the ethical justifiability of enhancement technologies. Indeed, many genetic technologies are explicitly enhancement-oriented, for example pre-implantation genetic diagnosis aimed at choosing desired traits, or genetic technologies aimed at giving children a competitive advantage, or genetic technologies eliciting the spectre of eugenics as discussed in sections 2.1 and 2.2. As noted by Buchanan (2011, 2012) among others, the application of enhancement technologies is often seen – *pace* Harris - as a positional and not an intrinsic good. The differential access to enhancement technologies is likely to exacerbate the existing inequalities in society, and therefore poses a problem of justice. Michael Selgelid adds that the value of liberty (explicated often as ‘reproductive liberty’) in the enhancement debate is often given too much weight in comparison to the value of equality, or of utility, understood as social utility of a particular technology. (Michael J. Selgelid 2013) Along similar ways to what is done by Häyry, Selgelid spells out the three main approaches used in the enhancement debate to try to – unsuccessfully – resolve controversies regarding the particular application of an enhancement technology, namely utilitarianism, egalitarianism, and libertarianism. (Michael J Selgelid 2012; Michael J. Selgelid 2013) As each perspective tends to place absolute or overriding weight on the values they emphasize, consequently, the current approach to the enhancement debate is not able to make any substantial progress. Selgelid also points out how questions about the ethics of enhancement either turn on unresolved empirical questions and on unresolved philosophical questions. For example, there are unresolved empirical question about the extent of inequality that would likely result from an unrestricted practice of human enhancement, and the overall impact that an unrestricted practice of human enhancement would have on human wellbeing. To obviate the current misbalance in debate between the value of liberty and other important values (such as equality and utility), Selgelid argues in favour of a contextual approach that
spells out, and tries to reach balance, between them by shifting the focus of the
debate on enhancement towards the analysis of how to reach a ‘fair’ trade-off
between the different values, the conflict of which is often intensified (or at least
they seem to be so at a first glance) by enhancement technologies. Selgelid also
argues that the only possible way to make tangible progress in the enhancement
debate is to address the controversial issues through a rigorous empirical analysis
and a case by case contextual approach. This is exactly what I strived to do in this
thesis, and the included papers. Therefore, for Selgelid, the way to resolve disputes
about enhancement is not, though, the polite-bystander view to which the
philosopher is relegated as suggested by Häyry, but a fourth approach, which he
refers to as a “moderate pluralistic approach to public health policy and ethics”.
This approach would provide a principled way of striking a balance of making trade-
offs between liberty, equality and utility in cases of conflict.

What would Selgelid’s moderate pluralistic approach entail in practice?
First, it would start with the aim to promote the three values of liberty, equality and
utility as independently legitimate social goals, without any of them being by
default overriding the other. Secondly, it would aim to strike a balance and make
trade-offs between the values in cases where they conflict, with the assumption
that no value has priority over the others.(M. J. Selgelid 2009) One potential
problem with Selgelid’s “moderate pluralistic approach” that Häyry could raise, for
example, is the apparent incommensurability of the values of liberty, equality and
utility. Hence, questions such as “How much utility outweighs how much liberty
(or vice versa) in a particular case?” seem not to make any sense. Selgelid is aware
of this issue, which may be irresolvable from a general, abstract philosophical
viewpoint. Not so, however, when the level of analysis is that of policymaking, and
when decisions need to be taken regarding the ethical justifiability of a particular
technology, and the ethically justifiability limits – for example – on personal liberty
in favour of equality or on equality in favour of utility and so on and so forth. At the
level of policymaking, the analysis of the relative weight of each value will be
context dependent, as – he argues – there is no magical formula or number that
can resolve such complex decisions. (Michael J Selgelid 2012; Michael J. Selgelid
2013) This is also in line with the approach spelled out by Wolff in his analysis of the
relations between ethical theories and real public policy, highlighted below. (Wolff 2011)

Another possible way out of the dilemma between apparently irresolvable conflicting values can be indicated by creative thinking about ways to promote all the three values at the same time, instead of privileging one over the others. One of the examples offered by Selgelid is that of ultra-resistant strains of tuberculosis and the consequent coercive measures of isolation and quarantine (obviously, liberty-limiting) that have been imposed and are imposed in the US and South Africa and elsewhere on infected individuals in order to avoid the diffusion of the ultra-resistant bacteria strain, and that are implemented every time the risk of a potential pandemic due to a new virulent influenza strain arises (M. J. Selgelid 2009) In such cases, a creative approach entails the recognition that the causes of infection resulted from a combination of factors rooted in the disadvantaged social conditions of the individuals, (Wolff and De-Shalit 2007), and that a ‘global ethics’ approach would prevent the reoccurrence of untreatable infections and consequently more cases of unnecessary liberty-restricting measures. Of course, such a global ethics approach would not solve the issue of what to do in the particular case of the already affected individual – for which a heavily liberty-restricting measure may be the only thing to do – but would require that such an ethically problematic decision regarding that individual would be coupled to other broader decisions thinking about similar cases that could arise in the future. In this way, such an approach would promote the liberty of future individuals, the social utility of the measure and the equality between different populations in the world.

Finally, Selgelid notes – and I agree with him – that often in the hardest ethical cases – the ones that seem to entail the most irresolvable conflicts between values – there would not be only one possible route, or one possible ethically justifiable route, for policymaking. There would instead be a “moral spectrum” of decisions going from ethically justifiable to morally problematic from which the policy makers would have to fish out their decision. (M. J. Selgelid 2009) The criterion to use when deliberating about such decisions would be proportionality, and the decision would be ethically justifiable, or ethically problematic, to a matter of degree. The task for philosophers, with the aid of social
scientists to answer the empirical questions necessary for the contextual analysis, would be to identify the area of the moral spectrum on a case by case analysis by weighing the different principles. In the next and final section of this thesis I continue this discussion and spell out what I think the role(s) for the philosopher would be in the enhancement debate, at the intersection with policymaking.

5.3 Which role(s) for the philosopher in the enhancement debate?

In order to avoid the ‘polite bystander’ impasse described by Häyry, in the paper (Camporesi and Maugeri 2011) (Appendix 5) I suggest a possible way out of the stalemate of the ‘genethics’ debate based in the deliberative democracy (DD) approach spelled out by Gutmann and Thompson (Gutmann and Thompson 2004) and applied to genetics by Farrelly. (Farrelly 2009) On this view, “first-order” ethical frameworks (i.e. deontology, utilitarianism, virtue ethics) try – unsuccessfully – to resolve moral disagreement regarding a particular technology by demonstrating why that particular ethical theory is superior to another. This approach anyway is deemed to fail since as pointed out by Häyry different ethical frameworks are incommensurable as they use different ‘unit-values’ (person, utility, good, wellbeing, etc.), or along similar lines as spelled out by Parens (2005) they rely on different notions of ‘authenticity’ that are left implicit in the debate. The choice of which ethical framework to adopt in the first place is guided by the preference of the individual for one ‘unit-value’ over another. Though, while individuals may prefer one first order theory to another, they may agree that questions raised by the intersection of genetics and society demand public answer, and therefore that confrontation needs to take place at the societal and public level.

Rather than adopting a ‘polite bystander’ view such as the one suggested by Häyry, I think that a more productive way forward in this discussion could be based on an approach, as the one proposed by Gutmann and Thompson, that deals with the moral disagreement residual of first-order theories and seeks a resolution by adopting a dynamic conception of political justification, aimed at reaching a mutually binding (to all parties involved) consensus achieved through principles of
reciprocity, publicity, and accountability on mutually justifiable reasons. (Gutmann and Thompson 2004) The consensus reached would be provisional, and would try to achieve a trade off between the values of liberty, equality and utility identified out by Selgelid as the important ones to consider when discussing the place of enhancement in our society.

I concur with Selgelid’s point on the necessity to incorporate discussion of the values above, but would add that the decisions would of course differ depending on the political system in place in that particular context, the healthcare system, the political party in power at the moment, etc. In a deliberative democracy perspective, the role of the philosopher would not be that of a “polite bystander”, but of a thinker involved in society whose task is to first “try to understand enough about the policy area to be able to comprehend why it generates moral difficulties”, and in a second place to “connect those difficulties or dilemmas with patterns of philosophical reasoning and reflection”. (Wolff 2011, 9) This approach would run opposite to the approach spelled out by Häyry, who argues that the only possible way to reach a conclusion regarding an ethically problematic decision is from within a certain ethical perspective, or the even less alluring option of just standing “at the border of the field of play” and watching the others compete, i.e., only evaluating the internal consistencies and coherencies of an ethical theory. As pointed out by Wolff, while radical philosophical arguments can play a vital role in the debate, on their own they will not lead to settling any discussion, as the example of choice in the context of pre-implantation genetic diagnosis (PGD) discussed in section 2.3 shows. While it may work well in a philosophical setting to argue that using PGD to avoid ‘disabilities’ does not discriminate existing individuals with disabilities because it would be a logical fallacy to infer so, in practice – as argued by Holm (2008) – individuals with a disability have a right to make such an inference, and only policy oriented decisions, for example, at a fair allocation of resources, could reach a balance between the reproductive liberty of individuals who want to avoid having disabled children, and disabled individuals who wish to live in a society that respects and includes them. Including the writing of people with disabilities, and of individuals outside philosophy who write about disability, is a necessary step to understand their claims and do justice to them. As pointed out again by Wolff,
appeals to inconsistencies or logical fallacies while they may work well in the seminar room, do not work so well in public policy: you do not “win” if you show that your opponent’s position is inconsistent – unless it is blatantly so – with another policy, as laws are compromises between different people with different interests, and are the product of different times and contexts. While philosophers thrive on minute differences – and it is part of our job to show successfully how one’s theory differs in minor respect, and is better than, other existing theories – public policy strives to reach a consensus (or at least a large majority), therefore eliminating or not giving too much weight to differences that are deemed irrelevant.

To conclude, what is the role for the philosopher in the enhancement debate at the intersection with policy making? I think it is at least on two levels, following the direction pointed out by Wolff (2011): the first level is to help spell out the relevant and implicit values that generate moral disagreement in a particular case of impact of science and medicine or society. Philosophers should help ‘make distinctions’, as philosopher Mary Anne Warren instrumentally showed in the debate surrounding abortion by drawing the distinction – that was not apparent before, and became afterwards – between human beings and persons. (Warren 1973) At a broader level, they should “set out arguments and visions of other ways of doing things that might hope to shape the values that people hold”. (Wolff 2011, 195) For example, they should stress the value of social equality when discussing the permissibility of an enhancement technology, together with the value of responsibility towards future generations, and what kind of human beings we want to leave to the future. These are arguments that often are neglected in the enhancement debate, and that need to be brought in from neighbouring fields, for example from discussions regarding sustainability and environment. Hence, the value of an interdisciplinary discussion that takes in arguments from the sciences as a necessary premise for an empirical based discussion, and from the social sciences to include the views of the participants and all the stakeholders of the discussion, and to understand how decisions were reached and came into being in the past (thus, the value of a historical perspective, for example in relation to eugenics).
A reshaping (and possibly resizing) of the goals of the debate will be necessary when attempting to reach a decision at the public policy level, as often the only realistically achievable goal will be a kind of “inter-subjective” and provisional agreement between all the parties involved, for in the public policy arena there “seems to be little to be gained by asking whether values are ‘objective’ or ‘subjective’” (Wolff 2011, 196), and decisions will need to be revised as new empirical data are produced. The discussion never really ends, and if the philosopher insists that “truth has been found and the debate is finished, he or she is likely to find the debate continuing without them”. (Wolff 2011, 194) By distancing myself from these types of premature conclusions, I hope to continue to be part of the discussion on enhancement technologies, and in general the discussion of the implications of science and medicine on society. Borrowing from Italian essayist and political activist Elio Vittorini,14 I think that the philosopher – and ideally, every citizen at some level – needs to engage with ‘other, higher duties’ (“altri, più alti doveri”), and that there needs to be a discussion about our “offended world” (“il mondo offeso”), namely about what kind of responsibilities we have towards future generations, what kind of society we want to leave to our children, with what kind of disparities, and to what extent; in short, what kind of planet.

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14 Elio Vittorini, Conversation in Sicily, 1941
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Appendix 1

Appendix 2

Appendix 3

Appendix 4

Appendix 5
Choosing Deafness with Preimplantation Genetic Diagnosis: An Ethical Way to Carry on a Cultural Bloodline?

SILVIA CAMPORESI

Introduction

Consider the theoretical possibility of screening to ensure that only a disabled child would be conceived. This would surely be monstrous. And we think it would be monstrous because we do not believe it is just as good to be born with a disability.

These words were written by ethicist Jonathan Glover in his paper “Future People, Disability and Screening” in 1992.¹ Whereas screening and choosing for a disability remained a theoretical possibility 16 years ago, it has now become reality. In 2006, Susannah Baruch and colleagues at John Hopkins University published a survey of 190 American preimplantation genetic diagnosis (PGD) clinics, and found that 3% reported having the intentional use of PGD “to select an embryo for the presence of a disability.”² Even before, in 2002, a controversy was generated by the case of Candace A. McCullough and Sharon M. Duchesneau, a lesbian and deaf couple from Maryland who set out to have a deaf child (then, Gauvin) by intentionally soliciting a deaf sperm donor.³

The whole debate on using PGD in order to choose what kind of children to bring into the world has been monopolized by the discussion of the different notions of “disability” and by the related topic of the treatment–enhancement distinction. In this debate, different definitions of “disability” seem to imply different normative judgments about parental reproductive choices.

I here adopt a different perspective, as I shift the debate from the level of “disability” to that of “impairment.” Indeed, I take as premises the definitions of “disability” and “impairment” given by the social constructivist scholar Michael Oliver and contend that it is still possible to claim that choosing deafness with PGD is morally wrong, without claiming that deafness is a disability.

I frame the issue in terms of justice toward the future children and limitation of a reasonably broad array of different life plans. I also support my view in terms of the balance between self-determination of parents within their sphere of reproductive freedom and their determination of future children.

In the conclusions I mention the regulatory issue and some consequences of a consistent application of my line of reasoning.
Different Regulations

Deafness is the most common sensory disorder, present in one of every 500 newborns. With almost 50 genes implicated in nonsyndromic hearing loss, it is also an extremely heterogeneous trait. The most frequent genes implicated in autosomal recessive nonsyndromic hearing loss are GJB2, the gene for connexin 26 (Cx26), followed by SLC26A4, MYO15A, OTOF, CDH23, and TMC1. A Cx26 mutation can be detected in ~30% of sporadic cases of prelingual hearing impairment. The likelihood of detection of a Cx26 mutation increases to more than half of the families with identified autosomal recessive transmission. Up to 95% of deaf children are born to parents with normal hearing.4

Countries have adopted very different legal approaches to the regulation of PGD. The United States has no federal regulation at all, but PGD issues are regulated by professional standards. In Canada, apart from a prohibition against nonmedical sex selection in the Assisted Human Reproduction act, regulations regarding the use of PGD are yet to be promulgated. In Australia, PGD is regulated partly by state legislation and partly under the National Health and Medical Research Council guidelines on the use of assisted reproductive technology (NHMRC ART Guidelines).5 Europe is very heterogenous in this respect, as laws range from prohibitive (PGD is not allowed in Germany, Austria, Ireland, and Italy) to restrictive (where PGD is permitted only in cases of screening for disorders or in cases of tissue typing, as in Scandinavian countries, Spain, Belgium, and France). The lack of harmonized regulation at the European level has resulted in an increasing number of couples crossing borders seeking PGD.6 The U.K. approach is certainly the most liberal, as PGD is allowed also for tissue typing and for screening for disease susceptibilities. In the United Kingdom, PGD is licensed by the Human Embryology and Fertilization Authority (HFEA) for around 50 conditions, including cystic fibrosis, familial hypercholesterolemia, blood disorders such as thalassemia and hemophilia, muscular dystrophy, deafness, achondroplasia, Down syndrome, Huntington’s Chorea, X-linked mental retardation and other X-linked disorders, and so forth.7

In spring 2008, the debate on choosing children with a “disability” surfaced again in the United Kingdom on Clause 14(4) (9) of the draft Human Fertilization and Embryology Bill, which stated that “embryos” known to have a genetic abnormality “with a significant risk of transmitting a serious mental or physical disability, serious illness, or any other serious medical condition . . . must not be preferred to those that are not known to have such an abnormality.”8 A petition was filed to drop the clause 14(4) (9) of the HFE bill, and was rejected on August 20, 2008, on the ground that “[i]t is in the best interests of the child not to prefer embryos that have a significant risk of developing a serious medical condition.”9 The still ongoing debate revolves around the interpretation of the clause and its relevance for the deafness case, because, according to one interpretation, it could imply that a deaf couple undergoing PGD would not be able to choose embryos carrying a gene associated with a genetic hearing impairment.

The Impairment–Disability Distinction

Do we need to define “deafness” as a disability to argue that it is morally wrong to choose deaf children with PGD? And do different definitions imply different
normative judgments about the ethical acceptability of parental choices regarding genetic traits?

I will try to provide an answer to the first question and make some suggestions relevant to the second one.

There are several notions of disability: a purely medical definition such as the one given by the World Health Organization (WHO), a purely social definition such as the one formulated by Michael Oliver, and a “harmed-condition” account of disability by John Harris. In this paper I do not want to argue in favor of a particular notion of disability, but I will take for granted a particular notion and then shift the discussion to the level of “impairment.” As also Jonathan Glover has recently argued in his book Choosing Children. Genes, Disability and Design, it is time to abandon the “unfruitful” disability debate.

On the one hand, “disability” is defined as the possible functional consequence of impairment (e.g., inability to hear certain sounds or inability to speak clearly). This definition is close to the commonsense notion of disability and impairment. In what follows I adopt a more philosophically elaborated one, namely, the definition given by Oliver, the main theorist of the social model of disability, which does not refer explicitly to any notion of “normality.”

On the other hand, the 2001 revision of the WHO’s International Classification of Functioning, Disability and Health defines “impairment” as “an abnormality of a structure or function of the body” that can be congenital (present at birth) or acquired, through disease or trauma.

According to the definition by Oliver, impairment is “lacking part or all of a limb, or having a defective limb, organ or mechanism of the body” whereas “disability” is defined as “the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.” Therefore, impairment has to do exclusively with the body; disability also necessarily involves other factors.

As defined by Oliver, impairments often result in disabilities, but need not. A disability is inherently relational: being disabled is being unable to do something, to perform some significant range of tasks or functions that individuals in some reference groups (e.g., adults) are ordinarily able to do.

How do these notions of “disability” and “impairment” relate to the deafness case? Being deaf in a deaf community is not a disability understood in these terms, but is still an impairment. However, one can have a physical impairment without being disabled, for example, a person in a wheelchair living in a town devoid of architectonic barriers. For this reason someone’s ethnicity (e.g., being Black) is not a disability under a social constructivist approach, precisely because all its disadvantages are socially imposed.

In what follows I argue on the basis of Oliver’s definition and contend that it is still possible to claim that choosing deafness with PGD is morally wrong.

Deafness as a “Variation”?

Empirical research suggests that deaf people often have a degree of preference for a deaf child, and a rather smaller number would consider acting on their preference with the use of selective techniques. It turns out that such parents do not view certain genetic conditions as disabilities, but as a passport to enter into
Choosing Deafness

a rich, shared culture. They see being deaf as defining their cultural identity and sign language as a sophisticated, unique form of communication. Parents contend that not hearing is just a form of human variation, as being Black or gay, and that one that has given rise to a culture of its own, with members who want to see their community continuing into the future.\textsuperscript{17}

Darshak M. Sanghavi, a pediatric cardiologist at the University of Massachusetts Medical School, wrote in favor of their reproductive freedom:

Controlling a child’s genetic makeup, even to preserve what some would consider a disease, is the latest tactic of parents in an increasingly globalized society where identity seems besieged and in need of aggressive preservation. Traditionally, cultures were perpetuated through assortative mating, with intermarriage among the like-minded and the like appearing. … Viewed in this context, the use of PGD to select for deafness may be merely another ritual to ensure that one’s children carry on a cultural bloodline. (italics mine)\textsuperscript{18}

According to deaf parents, deafness is a condition that opens up as many and as valuable options as it closes down. In this sense, they argue, deafness is analogous to “Blacksoness,” as both minorities suffer socially imposed disadvantages because of their condition. The analogy goes on to say that, as deaf people, also Black people, on average, do worse than their White (hearing) peers, but (according to the parents) due to social discrimination, not to their skin color (hearing defect).

But is it plausible to claim that not hearing is just a variation as being Black or gay? I contend that it is not, on the ground that deafness (and not Blackness) is an impairment that limits a broad array of different life plans, independently of the societal context.

Let us, then, imagine how Oliver’s definitions would be applied if we were in a very advanced and nondiscriminatory society. Of course, it is true that different shades of disability could go with certain impairment, depending on the social context, but the hearing impairment would still be limiting the person in some activities even in the most advanced societies, whereas the social constraints imposed on other kinds of minorities (e.g., Black or gay) would vanish because they are completely socially determined. Thus, under Oliver’s account, being deaf would still be an impairment in any kind of society, because of the underlying asymmetry of this trait.

Therefore, even accepting a social constructivist model of disability and defining deafness as an impairment that does not necessarily go with a disability, the question remains whether it is morally wrong to choose children with a physical impairment.

Let us elaborate a bit more on this and think of two groups of people in an ideal society with no societal barriers toward deaf people: the only differences between the two groups would be that one group can hear and the other cannot and that one communicates with sign language and the other with a verbal, spoken language. Notwithstanding what the prospective parents assert on this point, the relationship between the two groups would still be asymmetrical, because hearing people could be part of the “shared and rich” deaf culture by learning how to communicate with sign language, but not vice versa.\textsuperscript{19} Of course, to this it can be objected that being born genetically deaf is not the same thing as learning
to be deaf and learning the sign language. I can concede this point, together with the point that the deaf culture may have its compensations that hearing people cannot fully experience, but the fundamental point here is that deaf parents do not need to choose to exclude their children from the hearing world in order to include them in theirs (however, imperfectly include them, as parents may counterargue), because both worlds and languages are open to their children: both the hearing and the not hearing worlds, both the verbal and the nonverbal languages.

Sanghavi also wrote that “[t]he small number of PGD centers selecting for mutations doesn’t bother me greatly. After all, even natural reproduction is an error-prone process... I’ve learned to respect a family’s judgment. Many parents share a touching faith that having children similar to them will strengthen family and social bonds... But it’s not for me to say.”

While conceding that parents have good intentions concerning the future of their children, is it tenable to claim an equivalence between natural reproduction being an “error-prone process” and deliberately choosing to have a deaf child with PGD? And, if it is not for Sanghavi or for the discretion of individual practitioners to decide (and I agree with him on this point), does it follow that it is for nobody to decide? In other words, is there still ground to argue that parental reproductive freedom should be regulated?

It is now time to go back to the question posed by John Harris:

> Some apparently decent deaf people do in fact wish their children to be deaf like them and resist therapies to improve the hearing of their children. They suggest that there is a distinctive deaf culture which is in some senses better than that available to those with hearing. Perhaps the test here is whether or not we would feel a deaf parent justified in deliberately taking steps to ensure that any future child would be conceived with deafness genetically guaranteed in order to ensure that it had secured to it the benefits of deaf culture. (italics mine)

Because this thought experiment by Harris has become reality in some PGD centers in the United States, I will attempt to answer this question on the basis of three main arguments.

**Why It Is Morally Wrong to Choose Deafness with PGD**

Framing the issue in terms of justice toward the future children avoids not only the thorny discussion of what a disability is but also the related and somewhat underlying discussion of the treatment–enhancement distinction. Such a distinction has been strongly criticized and forces us to treat relevantly similar cases in dissimilar ways, by making some “morally arbitrary” ad hoc assumptions. As Buchanan and coauthors also argue, such a distinction should not play a moral role, because it is useless in helping us to draw both an obligatory/nonobligatory boundary and a permissible/impermissible boundary.

In our society, there is a presumption in favor of not interfering with parents’ decisions, and they are allowed a big degree of discretion in choosing what is good for their children (e.g., education, religion). Some scholars argue that, indeed, it should not be so (and parents should be licensed by the state, as it is required from people applying for an adoption). More recently, other scholars have made the less extreme case for compulsory parental education.
Reproductive freedom is one of the fundamental rights of the person and finds its justification (at least in part) in the democratic presumption. According to this principle, citizens should be free to live according to their own values, and the state should not interfere with their freedom unless there is a direct danger to other citizens or to society in general. To note, it is not sufficient that other people disagree with the choices of a person or find her values “fastidious” or “disgusting” for a limitation to freedom; otherwise all our fundamental freedoms of speech, expression, religion, sex, and reproduction would vanish together with the very concept of democracy.

This said, I believe that in case of parents choosing deaf children with PGD, the condition of a “direct danger to other citizens” (i.e., future children) is satisfied, and the state (through some authority such as HFEA in the United Kingdom) could, and indeed should, interfere with the parental reproductive freedom. The direct danger to the children would be the restriction of a broad array of possible, future life plans due to deafness. The extensive character of the hindrance makes the case for the limitation of the democratic presumption and therefore of the reproductive freedom, whereas it does not make the case (other arguments would be needed to support such a claim) for limiting parental freedom in more general terms.

Along lines of reasoning similar to those by Buchanan and coauthors, I believe that a certain degree of neutrality must be expected from parents toward different conceptions of the good for their children. Parents, qua persons, can, of course, have a particular conception of the good and lead their lives according to it (which brings us back to the democratic presumption), but parents, qua parents, should maintain a certain degree of neutrality toward different conceptions of the “good” for their children. In other words, parents should not be allowed to make their children suitable for only one particular conception of a good life that the parents happen to have, such as the conception of the rich and shared culture of the deaf community. Any intervention that would greatly restrict this range of choices, as a hearing impairment would do, would be unjust to the child.

Finally, the notion of “self-determination” is one of the values that determines the moral importance of reproductive freedom (together with individual well-being, equality of expectations, and opportunities). Self-determination can be understood as the interest in making significant decisions about one’s own life for oneself, according to one’s own values and conception of a good life. John Rawls has characterized this interest as based on people’s capacity to form, revise over time, and pursue a plan of life and conception of the good. This said, the impact of peoples’ actions on others (i.e., future children) must be understood as a competing moral consideration that can, and must, place a limit on self-determination and, therefore, on reproductive freedom. Shaping the nature of children is not primarily a matter of individual self-determination but as well, and more importantly, the determination of another.

To note, I am not questioning here the motivations of the parents reported and interpreted by Sanghavi. Such parents may all have good intentions—and thinking to choose “the best” for their children—when choosing to have a deaf child, but considerations of justice suggest to us that parents should not maintain their currently accorded discretion toward such broad scope capabilities such as hearing, because this means to determine the lives of others.
Of course, I am aware that an important problem of threshold is looming in the background here, namely: Where should the threshold be set, and when could reproductive freedom be limited, on the basis of justice considerations and the limitation of a reasonable array of different life plans?

The discussion of where to put the bar would lead us to the above mentioned debate on compulsory parental education and parental licensing, which I can only hint at in this paper. Nevertheless, I believe that the deafness case is not a borderline case and that it can be successfully argued in favor of limiting parental reproductive freedom.

The Social Construction of Impairment

So far, my arguments were based on the definition of disability and impairment given by Michael Oliver.

Some scholars, such as Philippe Cole, could object on the basis of the more radical claim that impairment also is socially constructed.\(^3\) Cole argues that disability arises always in a particular social context and that the “social structure + impairment” cause the disability. So far, I could agree with him. But then he goes too far, as he wants to take one of the two factors (namely, impairment) out of the causal relationship that gives rise to disability, and leave all the blame on the social structure. To claim this he stretches his arguments to the point of writing: “Certainly, the disability is the product of the interaction between bodily impairment and social context, but it is the social context that gives the action or ability its form and context.”\(^3\)

In the end, Cole concludes that “it is the political idea of disability that determines what counts as bodily impairment,” because persons wearing glasses (as do Cole, long-sighted, and myself, short-sighted) to correct some minor eyesight defect have an “eyesight that is impaired to some extent” (at least he concedes this point!) but we “would not want to describe them as bodily impaired.”

Why not? We could reply (and Philippe Cole would probably object something along these lines) that it is so because there exists something so simple and readily available as wearing glasses to correct the minor eyesight defect, and there is no need to use the power of thought to correct it. So, from one point of view, we (people wearing glasses) are “impaired,” but from another (and the only one relevant, according to Cole), we are not. Who chooses the relevant point of view, or what makes it relevant? Indeed, Cole proceeds and spells out the reasons why this is so, namely, that from a “purely philosophical approach”: “There is no good reason why a defect in eyesight should not count as bodily impairment, but politically, there are very good reasons why it should not count.”\(^3\) These “very good reasons” are taken for granted to a good extent.

I would like to remark on two points touched upon by Cole that are useful for the discussion of the deafness case. The first revolves around the issue of the normativity of definitions. Cole aims at defining “deafness” or “blindness” as “something less than an impairment,” as a “mere inability,” with the purpose of deriving a normative judgment about the permissibility of making some kinds of parental choices or of society adopting certain kinds of policies. But the derivation of ethical prescriptions from a definition cannot be taken as straightforward, as it would need to be justified and argued for. As a consequence, we can decide to accept Cole’s point that under some circumstances deafness is not
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an impairment, but from such a definition no ethical judgment of PGD screening permissibility would be automatically derived.

This brings us to my second and more general remark, namely, that I do not think it is necessary to define “deafness” as disability or impairment or inability to infer some kind of ethical judgment on the parental choices. We can still reason on a case-by-case basis, even if some kind of broader, normative definition that could be applied to different cases (e.g., blindness, deafness, dwarfism) would be useful. But, to repeat, it is not necessary to possess such a kind of normative definition to claim that choosing deafness with PGD is morally wrong.

Indeed, it can still be argued that it is wrong to choose deafness with PGD even if it is not an impairment on the ground that there is an underlying asymmetry and that not hearing is a broad limitation of the future child’s life plans (as I did in the previous paragraph) or on the basis of other arguments (e.g., an “impersonal concept of ‘harm’” as developed, among others, by Buchanan and coauthors to deal with “non-identity” problems such as this one35).

As for the consequences of my line of thought concerning parental freedom in molding the nature of their children, I cannot dwell on them here, but I will at least mention this issue in the concluding paragraph.

Conclusions

In this paper I focused on the existing case of parents choosing to bring deaf children into the world with PGD screening.

The discussion concerning the moral acceptability of choosing deafness with PGD has been traditionally framed in terms of disability and of the treatment–enhancement distinction, without reaching any satisfying conclusion on either side of the debate. I here abandoned such a loaded perspective, shifting the debate from the issue of disability to the more objective and less controversial issue of impairment.

I took for granted the definitions of “disability” and “impairment” given by the social constructivist scholar Michael Oliver and showed that it is still possible to claim that choosing deafness with PGD is morally wrong, without contending that deafness is a disability.

I framed the issue in terms of justice toward the future children, as I argued that choosing deafness with PGD is unjust toward them because it is a broad limitation to a “reasonable array of different life plans.” I also supported my view in terms of the balance between self-determination of parents within their sphere or reproductive freedom and their determination of future children.

As defined by Oliver, deafness remains an impairment, even if in some societies, and in deaf communities, it may not count as a disability. Parents who choose to impose on their children their idiosyncratic vision of the good, in terms of the richness of the deaf culture, are acting unjustly toward the future child, who should have a sufficiently large array of opportunities to decide on her own what is good for her later in life. Moreover, the advantages of being part of a deaf community are asymmetric, as also a hearing person could learn the sign language and be part of it (even if only “imperfectly,” if we concede this point to the deaf parents).

To those scholars, like Philippe Cole, who view “impairment” as socially constructed, I replied that we could abandon the quest for a normative definition
valid for several traits (e.g., deafness, dwarfism, blindness) and reason on a case-by-case basis. In other words, we can decide to call deafness just “deafness”: Is it or is it not “not being able to hear”? If we agree on this, then we should agree that it is a limitation on the future of the child, and not a minor one, as it is a general hindrance for a vast array of plans of life. It is obviously not the same thing as “being Black/White/boy/girl,” contrary to what the parents assert, as being deaf is an asymmetrical condition in respect to hearing, and even the most advanced and nondiscriminatory societal context would not abolish the limitations of this trait.

What are the consequences of my claim? Should parental reproductive freedom in terms of PGD choices be regulated from a legal point of view? What about parental discretion for other kinds of choices? Where should the threshold be put, if we decide that one has to be put (as I argued)? And who decides?

I cannot here respond fairly to these complex questions and will only suggest two possible directions to elaborate in the future.

For what concerns regulation, the issue here is subtle and manifold: As Sanghavi has rightly noticed, in the past people were mating the “alike” (physically and mentally) to have children like them. I believe this kind of reproductive freedom should not be constrained, as we do not want to live in a paternalistic society where deaf couples are discouraged from having children for the “good” of future generation or for improving the gene pool, as was done with forced sterilization back in the old eugenic times. Somehow different is the case of the lesbian couple who sought a deaf donor to have a very high probability (although not a certainty, because of the heterogeneity of the trait) to have a deaf child, as Candace and Sharon McCullough did. Can this still be considered a kind of assortative mating? I doubt it.

The case is even more straightforward for those parents who choose PGD to be “sure” (medical errors not considered) to have a deaf child. Unlike Sanghavi, I do think that there is a morally relevant difference between the natural errors of reproduction and the intentional choice to have a deaf child. This morally relevant difference makes the case for the justified natural assortative mating, but it does not make it for cases of PGD screening for deafness or of couples soliciting a deaf donor.

Who would be entitled to limit parental reproductive freedom? Sanghavi does not feel entitled to choose, and I agree with him on this point. Such a decision should not rest on the shoulders (and discretion!) of individual practitioners. Exactly for this reason the U.S. system of having unregulated PGD clinics and complete nondirectiveness in genetic counseling should be modified. Other countries have developed different institutions to regulate such issues, as the HFEA in the United Kingdom.

As for the consequences of a consistent application of this line of thought, I am willing to accept them. This is to say that, in a different paper, I would argue in favor of further limitations on parental discretion concerning other kinds of interventions (not necessarily genetic) that could limit a reasonable array of different life plans of the future children.

Decisions in terms of education (e.g., parents belonging to the Amish community requesting to withdraw their children from school at 14 years, 2 years before the normal age limit for compulsory education 36), religion (e.g.,
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should parents be allowed to impose compulsory Catholic education on their children, as is still common practice in Italy?), and healthcare (e.g., Jehovah’s Witnesses opposing blood transfusions) could fall within those that need to be regulated.

Notes

7. For a complete list, see Preimplantation Genetic Diagnosis (PGD): Conditions licensed by the HFEA; 2009; available at http://www.hfea.gov.uk/docs/List_of_PGD_conditions.pdf (last accessed on 10 Apr 2009).
15. See note 11, Oliver 2006:22.
20. See note 18, Sanghavi 2006.
31. See note 18, Sanghavi 2006.
34. See note 32, Cole 2004:175.
The recent boom of direct-to-consumer (DTC) genetic tests, aimed at measuring children’s athletic potential, is the latest wave in the ‘pre-professionalization’ of children that has characterized, especially but not exclusively, the USA in the last 15 years or so. In this paper, I analyse the use of DTC genetic tests, sometimes coupled with more traditional methods of ‘talent scouting’, to assess a child’s predisposition to athletic performance. I first discuss the scientific evidence at the basis of these tests, and the parental decision in terms of education, and of investing in the children’s future, taken on the basis of the results of the tests. I then discuss how these parental practices impact on the children’s right to an open future, and on their developing sense of autonomy. I also consider the meaning and role of sports in childhood, and conclude that the use of DTC genetic tests to measure children’s athletic potential should be seen as a ‘wake up’ call for other problematic parental attitudes aimed at scouting and developing children’s talent.

KEYWORDS DTC genetic tests; children; sports; talent; pre-professionalization; open future; autonomy; practice

1. Introduction

‘Bend it like Beckham’ is the title of a 2002 Golden Globe-nominated movie by British director of Indian origin Gurinder Chadha. The movie features a young talented girl named Jess (Parminder Nagra), who dreams of becoming a professional soccer player, but she is not allowed by her parents to join a team because of her double identity as female, and Indian. After much family fighting, Jess finally escapes traditional conceptions of Indian femaleness to flee to the USA where she is able to play with a college scholarship at Santa Clara University, CA. It seems to me that the title of the movie encapsulates well the parental desires and motivations underlying the recent boom (especially in the USA) of direct-to-consumer (DTC) genetic tests aimed at measuring athletic potential (Chang 2009; Macur 2008; Stein 2011). Parents aim to gain an early advantage (a ‘head start’) which would allow their children to turn already at an early age into professional athletes, and continue on a hoped-for chain of events
from college scholarship to success, fame and money. What, if anything, is problematic with this?

I have argued elsewhere that parents should not be allowed to resort to pre-implantation genetic diagnosis (PGD) to choose to have deaf children like themselves, on the basis of the rights of the children to a/an (sufficiently) open future and on the limits of parental reproductive freedom (Camporesi 2010). In this paper, I consider another kind of intervention that may at first sight appear much less ‘radical’ than intervening at the level of PGD to mold children’s futures. This would be the use of genetic tests, sometimes coupled with talent scout camps, to assess the child’s predisposition to athletic performance. I first discuss the scientific evidence at the basis of these tests, and the parental decision in terms of education and investing in the children’s future taken on the basis of the results of those tests. I then discuss how these parental practices impact on the children’s right to an open future (ROF), and on their developing sense of autonomy, and consider the meaning and role of sports in childhood.

2. Genetic Tests for Athletic Performance

In the USA, there are at least seven companies that sell DTC genetic tests for sports performance or related traits, probably more (Roth 2012). The prices for these tests are quite affordable, thanks to the constant lowering of the costs of genome sequencing, and vary from approximately $80 to $200. Among these companies feature ‘Sports X factor’, ‘Atlas Sport Genetics’, ‘Athleticode’, ‘Geneffect’, and ‘Warrior roots’. Since such data is proprietary, it is not clear exactly how many parents and coaches are using these tests, but based on the number of companies thriving on the market, we can speculate that hundreds of parents and coaches are using them (Brooks and Tarini 2011). Note that since these tests are available on the Internet, the market is not limited only to the USA, but potential customers in the UK, Europe or rest of the world could order the test online, and only have to pay higher shipping expenses for the test-kit.

Sometimes, these tests are coupled with more ‘traditional’ methods for talent scouting, as a story published by the CNN shows (Chang 2009). The story tells of a camp set up in Chongqing, a major city in south-west China. In the so-called ‘Children’s Palace’, about 30 children between the ages of 3 and 12 were selected to participate in an innovative programme that combined traditional methods of talent scouting with genetic testing with the goal of giving Chinese children ‘an effective, scientific plan [of development] at an early age’ as put by Director Zhao Mingyou. The Chinese Government then takes care of implementing this ‘effective, scientific plan’. I will not consider in this paper the role of the government in education, as I want to restrict my analysis to the role of parents; but it is interesting to note that talent scout camps like the one in Chongqing are a possible future in the West.

2.1. What are these Tests Testing for, and What is their Predictive Value?

Most companies test for a panel of what they call ‘performance enhancing polymorphisms’ (PEP), a few only for one. All of them test for the alpha-actinin 3 (ACTN3) polymorphism, which I will describe in detail below. Although many genes and
gene sequence variants have been tentatively associated with performance-related traits, few if any have risen to a level that would be called conclusive. As Roth (2012) recently pointed out: ‘This is not a judgment against the existing science, but rather a recognition of the infancy of the field of exercise and sports performance genomics’. Not only is the field of genetics of sports performance in its infancy, but the DTC genetic tests take data obtained in one pool of subjects (i.e. elite athletes) and apply them to a substantially different one (i.e. children, teenagers) in what Eynon et al. (2011) refers to as the problem of ‘externality’.

As an example, I will focus on the test for ACTN3 polymorphism, which has the most robust scientific basis: ACTN3 was the first PEP to be demonstrated to have an association with skeleto-muscle formation and function, and is offered by all the companies available on the market. Therefore, any criticisms directed against this test will be valid also—even more so—against the other tests.

In 2003, Yang et al. found a significantly higher frequency of the functional 477R genotype in the ACTN3 gene (where R stands in place of an arginine ‘R’ rather than a stop codon) in both male and female elite sprinters (Yang et al. 2003). Alfa-actinin is an actin-binding protein, where actin is an integral component of the protein superstructure that generates contractile force within muscle fibers. Polymorphism in ACTN3 are thought to contribute to the heritability of fiber-type distribution in muscle, where the Type I are slow-twitch fibres that metabolise aerobically and are used in endurance races, while Type II are fast-twitch fibres that metabolise anaerobically, and are used in sprints (Ostrander, Huson, and Ostrander 2009).

The test for ‘ACTN3 Sports Gene’ is sold as a genetic ‘Power/Speed performance test’, and as we can read on the website of Atlas Sports Genetics (one of the companies that offer the test) with the aim to give ‘parents and coaches early information on their child’s genetic predisposition for success in team or individual speed/power or endurance sports’ (http://www.atlasgene.com/). We can also read that the results of the tests will be ‘valuable in outlining training and conditioning programs necessary for athletic and sport development’ (ibid.).

The patent exploitation of the infancy of this field of research by the companies has been referred to by Caulfield (2011) as ‘scienceploitation’, or the ‘exploitation of legitimate fields of science and, too often, patients and the general public, for profit and personal gain’. A case in point for scienceploitation: the tests for ACTN3 variant claim to assess the predisposition to athletic ability and prowess, while the ACTN3 gene accounts for only 2% of total variance in muscle performance (Eynon et al. 2011). The rest of the variation is determined by a wide range of genetic and environmental factors, most of which (particularly the genetic factors) are very poorly understood.

In addition, as pointed out by McArthur (2008) (note that McArthur is one of the authors who demonstrated the higher frequency of the ACTN3 polymorphism in elite sprinters), the fact that there is a higher frequency of ACTN3 polymorphism in elite sprinters does not mean that the test is actually predictive of athletic performance, as muscle performance (of which the ACTN3 variation accounts for only 2%) clearly does not equate with athletic prowess, notwithstanding what the companies are claiming.

Finally, these tests pose a potential problem with false negatives, as the parents will act upon the results of these tests and the claims made by the companies and actively discourage their children from a particular kind of sports for which they allegedly do not have a genetic predisposition. For example, the company Geneffect

Following a classification by Caulfield (2011) of DTC genetic tests into the three partially overlapping categories of: (a) the clearly preposterous; (b) the marginally pertinent; and (c) the vaguely predictive, we could say that, in a charitable interpretation, DTC genetic tests offered by companies such as Atlas Sports Genetics, Sports X Factor, or Geneffect would be classified as marginally pertinent, while in a less charitable interpretation, they could be classified as clearly preposterous.

Note that I do not think that the inability of DTC genetic tests to predict children’s athletic performance is a matter of contingency in science or the infancy of the field. I am persuaded that DTC genetic tests will never be able to predict something as complex as athletic talent, even if the association were replicated in larger population samples and, therefore, strengthened. I am not interested in discussing the ethical implications of ‘GATTACA-like’ science fiction scenarios where genetic tests are able to predict intelligence or other complex character traits. I think that athletic excellence is simply too complex a trait to be possibly pinned down to single or even multiple genetic associations in a deterministic fashion. This said, it is a matter of fact that information framed in terms of genetic knowledge is charged with an extra ‘authoritative aura’ that seems to be intrinsic in the G, A, T and C bases of the deoxyribonucleic acid. It is also a matter of fact that these companies market their tests, and that at least some parents accept their results, as if they were deterministic in nature, and as if they were really able to predict the talent of their children. Therefore, parents act upon these tests and make decisions on the basis of the results that involve investing in their children’s future. By doing so, these tests acquire a causal significance in the lives of these children.

The rest of this paper will analyse the ethical permissibility of the parental practices independent of the above criticism on the scientific validity of the claim. As I see them, DTC genetic tests are a new instance of a wave of criticizable parental approaches to childrearing, and they should function as a ‘wake up call’—borrowing an expression from Davis (2009)—for other current practices of directive childrearing that deserve a closer scrutiny, and critical analysis.

3. Parents Scouting their Children’s Talents

Brad Marston, father of nine-year-old prospective soccer player Elizabeth, is a satisfied customer and a testimonial for Atlas Sport Genetics. His story can be read on the company website (http://www.atlasgene.com/index.php?do=testimonial):

Atlas Sports Genetics testing was very informative and the process was quite simple. Although my daughter is only 9 she now knows that she has the ‘Sprint, Power, & Strength advantage’ which we can use to market her athletic career and hopefully a wonderful scholarship from this process.

Brad Marston does not represent the emergence of a new kind of parent. On the contrary, he represents a new instance of an old kind of parent: parents who employ all
kinds of methods to encourage or steer their children towards a life of athletic, musical or other professionalism. Parents have always done so: from submitting their children to heavy training schedules, to intensive summer camps, to hiring private teachers and tutors, and so on and so forth. While these practices are occasionally subjected to criticisms for their strictness, it is generally accepted that it is permissible within the parental role to steer children even aggressively in a particular direction. These kinds of attitudes can be reinforced by the consequences, i.e. if the child later in life is actually successful in her sport or music activities, her success seems to confirm the ‘rightness’ of the childrearing parental behaviour, in a kind of retroactive approval, or consent that takes the form of: ‘See, it was worth it’ or ‘I was right in the end’, etc.

DTC genetic tests aimed at measuring the athletic potential of a child can be seen as the latest tool available to parents to steer their children’s future, and their investments, with the expectation that their efforts will be—quite literally—‘paid off’. Is it justifiable for parents to do so?

Feinberg (1980) has defined the child’s ROF as a ‘vague formula that describes the form of the particular rights in question but not their content’. The rights in question are ‘rights in trust’, or anticipatory autonomy rights: they look like adult autonomy rights, except that the child cannot exercise her choice until later. The violation means that when the child is an autonomous adult, certain key options will be already closed to her, undermining her capacity for self-determination (which Feinberg sees as a necessary condition for self-fulfillment in life). As already noted by Dixon (2007), Mills (2003) objects to Feinberg and argues that not only is it impossible to actually have an open future due to the finitude of our lives, and to the inevitable closure of possibilities that takes place every time we make a choice, but also that it would not even be a desirable option. For Mills, parental approaches that aim to leave their children with an open future consequently expose them to a frenetic ‘smorgasbord’ of activities, and end up being detrimental to a vision of more profound and authentic experiences of the life of a child. This more profound vision would encompass also a meaningful ‘idleness’, a time for play that is not necessarily goal-directed (success, fame), and that privileges the child hic et nunc vs. the successful and possibly burnt-out adult that the child will grow into.

I find the analysis by Mills very compelling: it seems true to me that some parents are constantly projecting into the future of their children, and do not give a proper value to the present child that they have in front of them. What was once ‘free time’ from school and homework has become time devoted to activities x, y, z, which by virtue of being activities that are goal-directed (talent-scout, talent-development directed) lose their value of free time, of idle time that is supposed to act as a counterbalance to the already many compulsory activities that a child has to undertake early on in her life. But, this is only part of the story, as Lotz (2006) has correctly pointed out. Lotz, while recognizing the validity of some of the worries raised by Mills against the smorgasbord approach adopted by some parents, shows that such criticisms are not really directed to Feinberg’s, but to current trends of childrearing and educating driven by excessively competitive parents. In other words, striving to protect a child’s ROF does not commit parents to the problematic ‘smorgasbord attitudes’ described by Mills. Indeed, if we look at the original source, we can see that Lotz is right in her analysis, and that Feinberg is well aware of the inevitable narrowing of options in parenting:
Simply by living their own lives as they choose, the parents will be forming an
environment around the child that will tend to shape his budding loyalties and habits. (Feinberg 1980)

This narrowing of possible futures is inevitable in the practice of parenting and especially so in the case of talented children, but does not necessarily violate the child’s ROF, provided that the child’s input is taken, whenever possible, into consideration. How is that possible in practice?

4. What it Means to be a Child and Discretionary Domains of Autonomy

Archard (2004) argues that parents cannot avoid (nor would it be desirable if they tried) forming their children’s characters to some extent. He writes: ‘It would be a caricature of ideal liberal parents to imagine them zealously striving to avoid the creation of any particular personality in their children’ (Archard 2004, 56–57). Archard acknowledges that the choices made by parents concerning their children’s rearing and education have an ‘opportunity’ cost for their children, namely the absence of some other upbringing, but this is unavoidable. Moreover, self-determination of the child is not the only value to take into account when evaluating upbringing. A good upbringing should realize the child’s talents, and these may be realized sometimes only to the detriment of self-determination, and, therefore, of the child’s open future. Talented children are particularly difficult cases, as the nurturing of a precocious musical or sport talent may lead to a successful adult (concert soloist, Wimbledon tennis player, etc.), but that will have been achieved at the expenses of other skills (possibly, all other skills except that particular one which was nurtured) and of the person’s self-determination. How is it possible to preserve the child’s budding sense of self-determination, while also nurturing her talents? As said above, Feinberg’s analysis of the children’s ROF is that of a ‘right in trust’, i.e. a right to be saved for the child until she becomes an adult. I will move now to the analysis of what it means for a child to become an adult, and what implications this process has on the development of the child’s autonomy.

Schapiro (1999) addresses a very important but fairly neglected question: what is a child, such that it could be appropriate to treat a person like one? In tackling this question, Schapiro is addressing also the following two related questions: (a) When is a parent justified in preventing a child from acting according to her own will? and (b) When is a child entitled to make her own choices?

Schapiro draws a parallel between children being provisional, passive members of the political community with children also being provisional, passive members of the ethical community. Their status of passivity is provisional because of their liminal and ever-changing status, and their condition of moving towards adulthood. Indeed, as children at different stages of development differ from one another in the extent to which they have hegemony over themselves, they also differ in the relative status of their passivity as members of the ethical community. Children gain access to the ethical community once they gain autonomy and sovereignty, as put by Schapiro, by developing increasingly broader ‘domains of discretion’. Once they have achieved sovereignty over some domain of discretion (e.g. being able to eat without being fed, being able to get dressed alone and so on and so forth), parental obligation would
require that children be left to decide and exercise autonomy over that domain. In this way, writes Schapiro, the child is forced to come up with provisional principles of deliberation that function as starting points, as anchors, for ‘ever widening domains of discretion’. Along similar lines, Feinberg also writes: ‘The child can [and should, I would add] contribute towards the making of his own self and circumstances in ever-increasing degree’ (Feinberg 1980, 736). This contribution to her own self-determination entails, I think, also exercising her autonomy over the sport she (the child) wants to play, or does not want to play.

The parental practices exemplified by the use of DTC genetic tests to provide children with a ‘head start’ in life are deeply problematic because—as put by Wall (2010)—they interpret children ‘only through the lens of what they are not yet, namely adults’ (Wall 2010, 144) and do not take into account the *in fieri* moral agency of the child. Borrowing again from Wall, while it may seem an obvious goal that the main purpose of a family and of parenting is ‘helping children to grow up into adults’, this practice ‘obscures the ethical sense in which children are diverse and other moral agents in and of themselves’ (Wall 2010, 144). Children should expect from their parents to be equipped with a range of broad skills that will enable them to make autonomous decisions and choose their path in life. On the converse, being equipped with very specific skills (like playing pre-professionally soccer, football, volleyball and so on) very early in life and having a life plan spelled out for them would constitute a brake on their development, and relegate them to being passive receivers of education. In addition, by depriving children of the possibility to exercise their budding self-determination, it relegates them to being passive members of the moral community. The possession of a ‘life plan’ early on in life has been defined by Slote as both ‘unnatural’ and ‘unfortunate’ (Slote 1989, 40–41). ‘Life-planfulness’ as a character-trait is seen by Slote as a virtue with a temporal aspect, i.e. a ‘positively good thing in individuals mature enough […] to decide upon a career or profession’, but becomes an obstacle for development in children, a ‘brake’ to the existence itself of their, although limited, autonomic domains of discretion.

What about children with talents? Slote recognizes that an early start can be necessary for the fulfillment of that talent, as he writes (though he writes it in a footnote, so he must not have considered their case too important):

> All this [considering a life plan a bad thing in children] is consistent with allowing that those who make premature life plans concerning careers are sometimes very successful in those careers. But such premature choices are typically the result of parental pressure, and those who yield to, and succeed under, such pressure can hardly help being emotionally scarred by it as well. (ibid., 47)

An example that comes to mind is Andre Agassi, the American Hall of Fame tennis player whose father allegedly tied a tennis racket to Andre’s hand when he was only three years old, and obliged him to hit tennis ball after tennis ball that were being literally spit out by a dragon like-machine built by his father specifically for that purpose (Agassi 2010). In his autobiography, Andre Agassi is very resentful towards his father and the education he was submitted to: even though Andre grew up to be one of the world’s most famous tennis players, he achieved that at the expenses of all other skills, including basic school education (Note that both Andre’s older siblings, being also talented
children in tennis, were submitted to a similar education, but never made it to a professional career).

As said above, talented children are tough cases exactly because they embody the tension between nurturing talent and the self-determination capacity of the child, both of which are considered two duties of a good parent. Indeed, it can be plausible to argue that the particular kind of precocious and ‘absolutist’ upbringing necessary to nurture the child’s talent was the only possible way to achieve success in a domain where early training and early gaining of a competitive advantage is essential. It seems, therefore, that parents must strive both to realize the child’s particular talents and to safeguard her ‘open future’, walking along what we could call a kind of ‘imaginary fence’ and trying to keep a difficult balance between the good of this particular child (realising the present) and the good of the adult that the child will grow up to be (the future). The tension between these two goals will be exacerbated when these goals are defined in maximizing terms, i.e. the Andre Agassi or the concert soloist at Royal Albert Hall and so on and so forth. In the next paragraph, I will consider what role and significance sport should play in childhood.

5. The Meaning and Significance of Sport in the Child

As noted by McNamee et al. (2009), if it is appropriate to say that the research field of ‘sports ethics’ is in its infancy, then it could be said that the research field of ‘sports medicine ethics’ is neonatal. The analysis of genetic tests for athletic performance falls within this ‘neonatal’ realm. Note also that the comment by Roth (2012) on the infancy of exercise and sports genomics falls along the same lines. Within the infant field of sports ethics, Mathias (2004) has written a rare and well-argued review of its history. Mathias defines both (elite) sports and medicine as goal-directed activities: the former as having ‘victory’ as one of its goals, the latter ‘health’. Both ‘victory’ and ‘health’ are regarded as goods by the subjects involved in the activities, and these goals may very well be, and often are, in contrast in elite sports (e.g. return to play decisions). As noted by Mathias, ‘the history of ethics in sports medicine has been driven by the general tension between the demands of sport and the demands of health’ (Mathias 2004, 196), and, therefore, we should ‘not be surprised to find in the field where they come together, sports medicine, signs of this tension occur in the form of persistent ethical problems’ (ibid.). It needs to be noted though that the aim of sports in children need not necessarily be ‘victory’, quite on the contrary.

What is the role played by sports in children? I argue that it should not be a goal-directed activity (directed to victory), differently from what it is for the athlete who is engaged in a professional, elite sport. Sport in children could instead be understood as a ‘practice’, defined by MacIntyre (1984) as a coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity (MacIntyre 1984, 186). In this sense, sport as a practice in childhood becomes defined both by goods internal to the practice (e.g. to stay healthy, enjoy the company of friends, enjoy the discovery of the possibilities of one’s own body, learn how to relate with a team, learn the importance of rules, etc.) and by the standards of excellence of the practice (i.e. nurturing and developing talent). Going back to Slote and his analysis of the
temporality of virtues, we could also say that some goods are inherent/intrinsic to
crudelty of virtues, we could also say that some goods are inherent/intrinsic to
childhood (including engaging in a sport as a practice, and not as in a competitive
profession directed to victory) and should be preserved exactly for that reason.

Therefore, parents could, and should, expose children to a variety of sport activi-
ties (and other non sport-related activities) compatible with their financial situations,
and their own preferences and ways of living. In this sense, I think that parents could
and indeed should be free to live ‘their own lives as they choose’, as put by Feinberg
(quoted above), as long as they ‘do not isolate children intentionally from other ways of
life, and make sure that children learn of the variety of ways of life’ (Lotz 2006, 541). If,
for instance, a set of parents love hiking, then they will expose their children to outdoor
sports, while other kinds of parents may expose their children to more indoor activities,
like music, or team sports that are played indoors. This seems to be perfectly reason-
able, as long as the other option is not completely cut off from the child’s horizon.
What seems unreasonable is to expose the child to one and only one sport, and actively
discourage any other.

6. Conclusions

In this paper, I have analysed a new tool that parents have to steer their
children’s education and develop their talents: DTC genetic tests for athletic potential.
After analysing their scientific and medical basis of their predictive value for the most
widespread test (ACTN3), I showed that in the best possible scenario they are only
marginally pertinent, with gross misrepresentation of their predictive value in the
marketing claims of the companies. I have framed the issue as a new instance of the
debate of the Feinberghian children’s ROF, but complemented it with arguments on
what it means to be a child (in an ethical way), the time preference of certain character
traits and the meaning of sports in children as a ‘practice’. In particular, I argued that
Schapiro’s analysis of the child’s autonomy in terms of ‘domains of discretion’,
combined with Slote’s temporality of the character trait of ‘life-planfulness’, can be
useful lenses to analyse parental approaches of childrearing, and complement classical
arguments of the child’s ROF.

Within the children’s domain of discretion falls the choice of which sport (if any)
to play, which I argue should be free from talent-related reasons (as there are many
other values in sports for a child) and from any life plan that the parents may want to
impose on their children. Parental violation of the child’s domain of discretion is not
only a violation of the child’s ROF, but also a violation of the child’s actual preferences.
In this sense, I take into account Mills’ concerns and value the autonomy of the present
child, as much as the autonomy of the adult that the child will grow into.

In the end, I recognize the existence of an unavoidable tension between the goal
of maximizing children’s talents and nurturing their self-determination, but I am inclined
to view the latter as more important. Nonetheless, I recognize the impossibility and
non-desirability of non-directiveness in childrearing, and I find the criticism by Mills of
‘smorgasbord’ parental attitudes quite appropriate and resonant with current Western
trends of parenting.

These arguments form my two-pronged rationale to object to the parental use of
DTC genetic tests to (supposedly) measure their children’s athletic potential, and to
steer their education towards an early start to a professional sports career. I am aware
here of two possible challenges to my arguments, namely that my dismissal of the ‘success stories’ argument derives from not being myself one of those success stories; and that I am not qualified in my critical analysis of parents’ childdrearing practices being not yet a parent myself. These are true. Points taken. But, as for the first point, I would like to underline that only a very small per-cent of the totality of children who underwent an ‘absolutist’ upbringing devoted only to nurturing one particular talent become stories of success, while all of them are raised to the detriment of a complete development of the person, of her self-determination, and possibly of all other skills, and with ‘no small emotional scars’, as put by Feinberg. As for the second point, I will be happy to take on the challenge again in—maybe—a few years.

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Gene Transfer for Pain:  
A tool to cope with the intractable, or an unethical endurance-enhancing technology?

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Introduction
In this paper we consider two plausible scenarios in which an individual is seeking treatment with gene transfer tools to cope better with pain. In the first scenario the individual is a patient; in the second an athlete. The general question explored is whether it is ethically justifiable for the individual to seek an experimental gene transfer treatment in order to raise his/her tolerance to pain. We employ here a comparative strategy to highlight the similarities and dissimilarities between the ethical frameworks used to evaluate the two scenarios, and to reach conclusions regarding the justifiability of the potential practice.

Gene transfer for pain
Untreatable pain represents an enormous problem to society. As estimated by current statistics, approximately 20 per cent of the adult population suffers from chronic pain, and the financial cost to society is estimated at more than €200 billion per annum in Europe, and $150 billion per annum in the USA³. Treatment options are limited, with many patients either not responding to them or having incomplete pain reduction.⁴

In the last decade, several translational clinical trials have been carried out that employed gene transfer tools to try to overcome this medical need. Gene transfer trials certainly qualify as translational trials, as they are designed to bring to the bedside the tools developed at the bench of a molecular biology laboratory. We performed a search with keywords ‘gene transfer’ and ‘pain’ on the National Health Institutes clinical trials directory, which revealed 20 clinical trials that are either completed or in recruitment.⁵ To date nine clinical trials have been completed.⁶ Some of these trials are aimed at treating intractable cancer pain, some at treating pain associated with angina pectoris, others at epidermolysis bullosa (a heritable condition where connective tissue disease causes painful blisters in the skin and mucosal membranes), and others to treat the pain associated with peripheral arterial occlusion (a mini-stroke in the leg which causes the necrosis of muscular tissue leading to impaired functionality and chronic pain). This last kind of pain, and the related clinical trial, serves as a case study for our comparative evaluation between a medical context and a sports context, where the former is a traditionally conceived therapeutic intervention, and the latter is one where the intervention rests in the grey zone between therapy and enhancement – or as it has been labelled, therapeutic enhancement.⁷ We set out the two scenarios below and evaluate them ethically according to two different frameworks.
Scenario a): The medical context (the patient)

In scenario a), in the US TV series *House MD* the protagonist, Dr Gregory House, has suffered from peripheral ischemia to a leg, which has left him limping and with intractable chronic pain, due to the extensive necrotic muscular tissue in his thigh muscles. He is seeking an alternative solution in a gene transfer clinical trial. Dr House can perhaps be seen as a contemporary instance of the archetypical mythological figure of the “wounded healer” Chiron, who is able to heal others but unable to heal himself. After having tried many standard and less standard treatments unsuccessfully, our protagonist is now seeking experimental treatments, i.e. treatments that are currently being tested in clinical trials and not yet approved by national regulatory bodies such as the US Food & Drug Administration (FDA) or the European Medicines Agency (EMA), and are unavailable on the market. Among the gene transfer trials currently active or recruiting, one study stands out as the perfect match for a patient like Gregory House.

The trial (Identifier # NCT00304837)\(^8\) is a Phase 1 study that seeks to transfer the DNA codifying for the Vascular Endothelial Growth Factor (VEGF) protein into the legs of patients with peripheral artery disease (PAD). PAD encompasses a range of conditions presenting with blockages in the arteries in the limbs. The nature of the disease is progressive, so that it frequently leads to patients presenting with claudication or critical limb ischemia (CLI).\(^9\) It is this former manifestation of PAD that we are interested to discuss. Most Phase 1 studies are aimed at testing the safety of a new pharmaceutical or treatment in a restricted number of patients, after the treatment has proved efficacious in laboratory testing and animal models, but some – like this one - may also test the efficacy of the agent under study. According to the trial protocol, the DNA codifying for the VEGF protein is injected into the affected legs of the trial subjects on three separate occasions, each two weeks apart. The DNA codifier then directs the cells of the artery wall to increase production of VEGF, which has been shown to cause new blood vessels to grow around the blockages in the leg arteries.\(^10\) It has also been demonstrated that increased VEGF expression through gene transfer techniques improves microcirculation in muscle, and hence increased oxygen and nutrient supply, as well as removal of waste products.\(^11\) Kim et al have observed evidence of growth of new collateral vessels, relief of ischemic pain and ulcer healing in patients with CLI.\(^12\) The trial we are analysing aims not only to test the safety of VEGF-gene transfer, but also to relieve pain and/or heal the ulcers caused by PAD.\(^13\)

Generally speaking, safety concerns about gene transfer are related both to the kind of carrier/vector being used (usually a modified virus) and to the encoded transgene. In our case study, the former are eliminated by injecting the DNA coding for the VEGF protein directly into the patients’ leg muscles, without any viral or non-viral carrier, thus eliminating the risks inherent in the vectors and common to many other gene transfer trials. As to the latter risks, it has been shown that overexpression of VEGF causes haemangiomas (benign tumours characterised by an increased number of normal or abnormal vessels filled with blood) in skeletal muscle in mouse animal models.\(^14\) In addition, angiogenesis, can have detrimental consequences in non-target
tissues. In particular, the theoretical risk of facilitation of tumour vascularization (and therefore, increased growth) or plaque angiogenesis in non-target tissues must not be ignored. Transient peripheral edema (swelling) due to increased local perfusion is a relatively common and mild side effect.

More serious adverse effects have been rarely observed and are mostly related to the use of viral vectors, therefore are not pertinent to the trial we are discussing which injects DNA in the form of a plasmid (a circular molecule of DNA). A recent study conducted by Muona et al and aimed at assessing the long-term side effects (10+ years) of local VEGF gene transfer to ischemic lower limbs found that adenovirus or plasmid (our case) or liposome mediated intravascular local gene transfer does not increase the risk of malignancies, diabetes or any other disease in the long term. The authors also identified as a key element to safe gene transfer the local delivery to the treatment side (as in our case), which reduced the risk of systematic spread of the vector, as well of adverse side-effects to other organs. This suggests that the technique described here could be safely applied both in trial subjects and in healthy individuals (which is pertinent to Scenario b), below).

As noted by Mughal et al, PAD cannot be attributed to one specific genetic cause, and greater therapeutic efficacy could be obtained by targeted gene transfer using multiple growth factors. Indeed, angiogenic gene transfer strategies such as VEGF-gene transfer are by no means the only ones being explored in the treatment of chronic pain but appear to be among the most advanced at the clinical level, while other strategies are still at the level of animal studies. As a general remark, while we are aware that a certain degree of speculation is necessary when applying our case study to the second scenario (the elite sports context), we think there is sufficient scientific and medical evidence to argue that gene transfer for pain has very plausible applications for enhancing athletic performances.

Scenario b): The sports context (the elite athlete)

In scenario b), the would-be protagonist is an elite athlete competing in an endurance event, such as cross-country skiing, marathon running, tour cycling, triathlon, or an event of similar extended duration, seeking VEGF-gene transfer in order to cope better with the pain inherent in the event as a primary outcome, and as a secondary outcome to perform better as a result. The growth of blood vessels in the limbs, as demonstrated by the clinical trial described above, is likely to aid the athlete in his/her performance by increasing the oxygen-carrying capacity to the limbs (nutrient supply) and the removal of waste products.

It is also obvious that an athlete feeling less pain could perform better, ceteribus paribus, than other athletes experiencing a greater degree of pain.

Comparing the scenarios

How are we to understand the similarities and differences these contexts present, and to what extent will the context determine whether it is ethically justifiable for an individual to seek an experimental gene transfer treatment better to cope with pain?
To what extent is the ethical permissibility of the practice dependent upon or independent of the context of gene transfer? We respond to these questions by spelling out two ethical frameworks that might be adopted in order to analyse the two scenarios.

**Framework a): Ethics of translational research**

With a few relevant exclusions, we do not normally regard pain as an essential or valuable part of our lives. On the contrary, we take measures to diminish or even eliminate pain from our daily lives, and from the lives of those who are dear to us. Even in illnesses where pain is present, we try to eliminate it, although it may not be possible to cure the patient of the underlying cause. Palliative care, which we consider an essential part of treating a sick human being with dignity, is predicated on such an understanding.

The first framework we use to analyse the scenarios is the ‘ethics of translational research’ approach recently developed by Kimmelman. Kimmelman develops the new concept of ‘translational distance’, which refers to the space created between cutting-edge biomedical research and clinical applications. It may not be possible in the first in-human studies to apply the concept of ‘clinical equipoise’, defined by Friedman as “a state of honest, professional disagreement in the community of experts about the preferred treatment”. The level of uncertainty is so high in first-in-human research employing gene transfer techniques that robust epistemic thresholds required for clinical equipoise cannot be secured. In its place, the concept of translational distance is a useful and insightful kind of ‘epistemic heuristics’ to understand the bidirectional flow of knowledge between the bench and the bedside.

While traditionally the value of early clinical trials has been regarded only in terms of their ‘progressive value’ towards later Phase 2 and Phase 3 studies, such a framework is not applicable when evaluating the social value of first-in-human research as in our case study. In Kimmelman’s model, Phase 1 translational studies in between the ‘bench and the bedside’ are loaded with value if they stimulate preclinical research or if they stimulate further clinical development. In addition, adopting a translational distance model with a non-progressive epistemic value for these trials would help to dispel the ‘therapeutic misconception’ widespread among (often desperate) first-in clinical trials volunteers. Therapeutic misconception arises where subjects misinterpret the primary purpose of a clinical trial as therapeutic, and conflate the goals of research with the goals of clinical care. As shown in a study of consent documents of gene transfer clinical trials, 20 per cent of consent documents for gene transfer trials fail to explain their purpose as establishing safety and dosage, while only 41 per cent of oncology trials identify palliative care as an alternative to participation. Moreover, the term gene therapy is used with twice the frequency of the term gene transfer.

As defined by Kimmelman, the concept of translational distance “is intended to prompt researchers, review committees, and policy-makers to contemplate the size of the ‘inferential gap’ separating completed preclinical studies and projected human
trial results”, and should inform both the design of the studies (that need to incorporate endpoints that make it possible for the knowledge produced to have an impact in terms of further research), and the ethical approval of the trial, that needs to take into account the concept of translational distance rather than that of clinical equipoise. We agree with Kimmelman that the translational research model better captures the reality of how information flows in translational research. As for the individual seeking to be enrolled in such an experimental trial, we recommend that researchers spell out the potential risks and benefits of the experimental procedure to the would-be volunteer; researchers should evaluate the severity of the pre-existing condition in the subject and its refractoriness to other standard treatment; and they should evaluate the subject’s decisional autonomy, which will be predicated on reasonable comprehension (and voluntariness) in relation to the foregoing.

Returning to our fictional protagonist, we can see that in this particular case the risks inherent in gene transfer trials due to the viral vectors are eliminated by injecting VEGF directly into the leg muscles of the patients, and therefore the translational distance between the bench and the bedside can also be considered a modest ‘inferential gap’. In addition, the pre-existing condition of chronic pain caused by peripheral artery ischemia is severe and refractory to standard treatment. And finally, Dr Gregory House seems to be in a position to make an autonomous decision, one not clouded by therapeutic misconception. As autonomy plays a fundamental role in the ethical framework describing the medical context, there would need to be strong reasons to justify interference with the patient’s self-regarding and autonomous choice to participate in the trial, even recognising as we do that the patient may have no available option (apart from palliative care) other than participating in the trial, due to the severity of his condition and the unavailability of therapeutic options. Provided all the above conditions were met, we might reasonably reach the conclusion that his informed consent to participating in the VEGF-clinical trial would be valid.

Framework b): Ethics of sports enhancement

How should we frame the request of an athlete seeking VEGF-gene transfer for the purposes of better coping with pain during a competition? In the first instance, his participation might look like a case of what we could call ‘physician-assisted doping’.

The World Anti-Doping Agency (WADA) sets out three criteria used in the decision to call a product or process ‘doping’. These pertain to (i) the (potential) performance-enhancing effects; (ii) the potential harm to health; the (potential) health risks. Only two criteria need apply for a product or process to be prohibited. The Anti-Doping Code recognises the rights of athletes to secure healthcare and that this right supersedes anti-doping regulations. This does not, however, allow the patient-athlete carte blanche. Prior to utilising banned products or processes athletes on a registered testing pool (who are on notice that they may be randomly tested) must submit a Therapeutic Use Exemption (TUE) Certificate signed by a relevant medical authority. This certifies that the therapy is necessary for the athlete’s condition and that no non-doping alternative is available. Clearly, the process is open to abuse. Moreover, in
Paralympic sport, where elite athletes have at least one disabling condition, the problem is even more complex.\textsuperscript{27}

Leaving aside for the present the added complexities of unethical behaviour, let us assume that the athlete is asking for a TUE from the relevant authority. In addition to the World Anti-Doping Agency, this might be an International Federation, such as the International Association of Athletics Federations (IAAF), or the Union Cycliste International, or the International Triathlon Union, or an event organiser such as the International Olympic Committee (IOC) or the International Paralympic Committee, who (interestingly) take exclusive charge of in-competition testing during the Olympic and Paralympic Games. There is very little to suggest that a TUE would be achievable in this scenario. Despite TUE precedents for beta-blockers in relation to cardiac patient-athletes in target-accuracy events (such as archery), it is highly unlikely that it would be given for mere pain relief where that pain is simply a marker for injury (and where there may be performance enhancement side effects). The deputy director of the World Anti Doping Laboratory in Cologne, widely recognised as one of the premier testing laboratories, recently remarked upon the practice of using analgesics as analogous to doping:

"It is a grey zone. In my opinion pain killers fulfil all requirements of a doping substance because normally pain is a protection mechanism of the body and with pain killers you switch off this protection system."

Given the longstanding routine use and abuse of painkillers in elite sport\textsuperscript{29,30,31} it might be argued that the introduction of VEGF would represent merely an extension of everyday practice. In both the first and also in this second scenario, consideration would have to be given to the autonomy of the decision-making of the individual in arriving at ethically justifiable interventions. In the second scenario this would be thought necessary, while in the first scenario this might be thought both necessary and sufficient, provided that the conditions for a modest translational distance were met, as they are in our case-study. Why then is it insufficient in the context of elite sports? Well, in addition to determining the conditions of consent, additional factors regarding the ethical permissibility of VEGF-gene transfer in an athletic context must be considered,

In contrast to scenario a), pain can be seen as an essential, integral part of endurance sports. Performing at an elite level in endurance sport and not experiencing pain are mutually exclusive. Indeed, an athlete’s ability to tolerate pain is one of the fundamental characteristics that determine athletic performance and provide competitive advantage. Five-times Tour de France winner Lance Armstrong called the event “an exercise in pointless suffering”.\textsuperscript{32} He and others have talked insightfully about wanting to take opponents (metaphorically) to places that they could not endure. The capacity to endure high levels of pain over significant time (ie suffering) is a highly prized trait in multi-day/week Tour event cycling.\textsuperscript{33} Indeed one may refer to them as “communities of suffering”.\textsuperscript{34}
Not only is it the case that we must distinguish the experience of pain from suffering in sports but in addition there are, of course, different kinds of pain an athlete can experience in competition. One is the acute kind that can be defined as an intense and specific pain that occurs suddenly, often as a result of injury, often experienced by athletes competing in football or other contact sports. Moreover, one can experience such pain in endurance events too — the cycle crash, the herniated disc in running, and so on. VEGF-gene transfer treatment would be meaningless for this kind of pain so it is irrelevant to this discussion. Rather, we wish to discuss the kind of pain that occurs with endurance exercise. This may include muscle soreness or a burning sensation in the lungs, the feeling that one’s heart will explode if the same level of intense effort is maintained much longer, and so forth. The strength of these sensations can range from unpleasant to what is typically thought of as unbearable pain. This second kind of pain is typical of endurance sports such as marathons, triathlon, long distance swimming and cycling, cross-country skiing, and so on. Among athletes, the former kind of pain is often referred to as a ‘bad’ kind, as it impairs the ability of the athlete to continue playing or competing, while the latter is referred to as a ‘good’ kind of pain, as it pushes the athlete to compete and perform at a higher level. Indeed, many athletes regard this second or ‘good kind’ of pain as an achievement and as an essential part of their life and identity as elite athletes.

The level of physical training of an athlete can raise the level of pain that he/she is able to endure, and make a difference in his/her performance. Athletes also report that the level of their ‘mental toughness’ makes a difference in their ability to cope with pain. Different individuals, though, start from very different baselines in their abilities to endure pain, and this one of the factors, among many other biological and environmental factors, that affect an athlete’s performance. Among these are: their birth place (contrast pre-athletic life at altitude and how this affects phenotypic factors with competitors born at or near sea level); wealth and other non-athletic factors that can enhance the possibilities of success (contrast athletes or teams with and without sports psychological services, or sponsorships that improve equipment access), genetic conditions that may confer an advantage over fellow athletes by increasing the amount of erythrocytes and oxygen supply to muscle cells (consider for example the case of Finnish skier Eero Mäntyranta who won two gold medals in cross-country skiing at the 1964 Winter Olympics. It was later discovered that he had primary familial and congenital polycythemia (PFCP), which causes an increase in red blood cell mass and haemoglobin due to a mutation in the erythropoietin receptor (EPOR) gene).

There is no absolutely agreed upon standard or trigger as to when sports administrators or regulatory bodies like WADA try to even out genetic and biological differences to reach a sufficiently ‘level playing field’ for all athletes: some inequalities are systematically excluded, while others are ignored. What happens in practice is that we do not usually try to level biological and genetic factors affecting athletic performance, even where we know those factors confer an advantage (as with Mäntyranta), although there is currently a controversy about new IAAF and IOC rules which exclude women athletes with hyperandrogenism from competing in women’s events on the basis of a supposed unfair advantage derived from increased levels of
testosterone. Typically, philosophers generally agree that the question centres around notions of fairness and equal opportunity, or what Loland calls Fair Opportunity.

Let us think counter-factually here: if we were to try to equalise all the starting conditions (of which tolerance to pain is, again, merely one example) we would move in the direction of having all athletes crossing the finish line at the same point, and then what would be left of the meaning of sport and athletic performance? After all we are precisely interested in distinguishing among excellent performers and performances. Only in certain circumstances, such as horse racing, do sports institutions initiate handicapping systems. And this, it might reasonably be argued, is to keep the competition tight and promote gambling interests. In other scenarios, where a league system – heavily underwritten by commercial media interests – has an incentive to prolong interests and more broadly spread opportunities to win, we find systems like the lower teams gaining access to the best new potential players in a draft system (such as in American Football). But in the main, we would not normally level out the effects of the genetic lottery in sports. If an athlete is 1 metre 40 we steer them away from high jump. If they are 2 metres tall, we do not encourage them to pursue a career as a professional jockey, and so on. Furthermore, a few US companies have started to sell online direct-to-consumer (DTC) genetic tests that aim to exploit the genetic lottery as early as possible, channelling children towards the most ‘profitable’ athletic future as predicted by the results of the tests.

As mentioned above, different athletes have different baselines and different abilities to cope with pain. While we do try to give people tools better to cope with pain in everyday life, where pain is not – with certain noted exceptions - seen to be an essential or meaningful part of the activity we are performing, in the elite-sports context we do not give people those tools, because pain, as described above, is a fundamental part of practising and competing at an elite level.

Pain can be distinguished from non-relevant inequalities, as for example the kind of shoes or swimsuits or bikes the athletes run, swim or cycle with, which do not impact upon the mental and physical qualities that are the source of our admiration for athletes and which are instrumental to the securing of victory. For these sorts of products, however, we can and do insist upon degrees of standardisation. Thus, in baseball, cricket, or tennis there are regulations regarding the size and composition of the striking implement and the ball. Curiously, in Formula 1 racing there are prizes for both the best driver and the best constructors: the best supporting team of engineers and technologists. But even here there are strict rules about engineering variations. In European football, there are even suggestions that there should be financial fair play, so that team owners cannot “buy” victory by purchasing sufficiently large numbers of the talent pool.

We cannot, however, ‘level-out’ the capacity for enduring pain in endurance events without usurping or compromising a key psychological variable inherent within the test. By levelling the ability to endure pain, we would also diminish a substantial part of the meaning of athletic performance, which can be understood as trying to break
one’s own limits given the starting conditions one has. That is why the toleration of pain qualifies as a relevant inequality that serves inter alia to demarcate athletic merit, and we consider that genetically based therapy for pain should not be permitted as it undermines the meaning of sport by interfering significantly with the relationship between natural talents, their virtuous perfection, and athletic success.\textsuperscript{46} In other words, our view of the athlete’s capacity for pain tolerance could be seen a relevant inequality and essential for the meaning of competition. In the model developed by Loland and Hoppeler that combines a biologically based approach with a Fair Opportunity principle, the use of VEGF transfer could be understood as a way to go beyond human phenotypic plasticity\textsuperscript{47}, and thus to go against the Fair Opportunity principle and the idea of the virtuous development of talent.\textsuperscript{48}

**Conclusions**

The differences between the two scenarios we have presented are many and varied. We have focused only on the existence of a fundamental difference between a medical and an elite athletic context of VEGF-gene transfer to tolerate pain. In the latter the choice is fundamentally a self-regarding one, predicated on individual autonomy together with a risk/benefits calculation as the principal factor determining the ethics of that decision. A cautionary note must be struck here. One must be mindful of the areas of uncertainty, the limited evidential base in relation to the experiment\textsuperscript{49} and its hoped-for outcomes in scientific and clinical terms. Nevertheless, in elite endurance sports contexts individual autonomy ceases to play the decisive role in the ethical analysis. Sports have traditionally incorporated paternalistic practices regarding the health of competitors but also the fairness of the structuring of competition in order to produce admirable victors. The context of gene-transfer matters for the evaluation of the ethical desirability or permissibility of the experimental practice we are analysing: while in an everyday life scenario, pain does not play a meaningful role (with some noted exceptions), pain does play a meaningful and constitutive role in endurance athletic competition, along with a range of other anatomical, physiological and psychological factors. By increasing the capacity for pain-tolerance, or even subtracting it altogether from the sports picture, we would inevitably subtract also a fundamental part of the meaning of that picture.

We conclude, therefore, that while we would not interfere with the decision of Dr House to be enrolled in a trial for VEGF-gene transfer, we could not justify the request of the athlete seeking VEGF-gene transfer to increase his/her tolerance to pain. As a tool to cope with the intractable pain that visits afflicted patients, VEGF-gene transfer is ethically justifiable and desirable. In endurance sports, the use of VEGF-gene transfer as an endurance enhancement technology is not merely ethically unjustifiable; it compromises an element essential to the activity itself.

What does this comparison tell us about the relationship between the ethics of clinical research (scenario a) and the ethics of sports medicine (scenario b)? We might note that, while the field of clinical research ethics is more established and has a longer history, the field of ethics of sports medicine is a relatively young one, and reflects the underlying tension between the goals of medicine (health) and elite sports (athletic...
excellence). But the ethics of first-in-human studies, including gene transfer studies, are still largely under-explored. Indeed, Kimmelman’s analysis of translational distance is the first and only attempt, to the best of our knowledge, to fill in the void left by the impossibility of applying the concept of clinical equipoise in first-in-human gene transfer studies, which are characterised by a level of uncertainty that is simply too high (as we have shown above). Both fields are young and relatively under-explored, and a comparison between the two may highlight insightful similarities, and shed light on problematic aspects of each.

Acknowledgement

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5 Search on Clinicaltrials.gov for “gene transfer AND pain” clinical trials (accessed October 12, 2012). It should be noted that this is accurate at the time of press though the figure appears to be rising sharply month on month.
6 Ibid.
10 Ibid.
17 Ibid.
18 Mughal et al, op.cit note 9.
20 There are individuals and religions/sects, which regard pain as having a high intrinsic value.


25 Kimmelman, op. cit. note 21, p. 118.


46 Murray, op cit. Note 42, pp. 141-159.

47 Defined as the capacity of a single genotype to exhibit variable phenotypes in different environments, and therefore as the capacity to adapt to different environments.


49 Kimmelman, op. cit. note 21.


According to Wendler (2012), pediatric clinical research that offers no therapeutic benefits to the participating children can be justified—provided that the risks for the participants are low—on the basis of two considerations: (i) Participating in clinical research is contributing to a valuable project and (ii) contributing to a valuable project is in any child’s broadly conceived interests.

We find Wendler’s argument unsatisfactory in that it fails to consider the context of clinical research. By context we mean the conditions in which participants find themselves and, more specifically, the kind of access to health care that they have. In order to provide a concrete example, we focus on the recent COMPAS-Synflorix trial (COMPAS 2011). This is an instance of a trial in which the participants were taking part in research in exchange for access to health care resources that would otherwise not be available to them. In such circumstances, in our view, the fact that participants “contribute to a valuable project” by participating in the research cannot by itself provide a proper justification for the ethical permissibility of the research, notwithstanding low risks involved in participation.

The so-called offshoring of clinical research to low- and middle-income countries (LMICs) has been steadily increasing in the last 15 years (Petryna 2005; 2009; Petryna, Lakoff, and Kleiman 2006). COMPAS (which stands for Clinical Otitis Media & Pneumonia Study) is the name of the clinical trial that was designed to test the efficacy of Synflorix, an experimental pediatric pneumonia vaccine developed by GlaxoSmithKline (GSK). The aim of the study was to compare the new vaccine with an existing vaccine for other diseases such as diphtheria, tetanus, and hepatitis.

The trial can be seen as an instance of a “mutually advantageous transaction” as defined by Wertheimer (2011). According to Wertheimer’s “Permitted Exploitation Principle” (PEP), one should not try to prevent—on the contrary, one should try to positively enable—those transactions that are beneficial to the disadvantaged and to which the disadvantaged consent. Stopping transactions like those involved in the COMPAS trial would not only not benefit anyone, but would actually harm some individuals, that is, the (prospective) participants. It would harm them by taking away from them the possibility of taking part in the trial and thereby the possibility of having access to important health care resources. Thus, in this view, as the offshoring of clinical research can potentially result in mutually advantageous consensual transactions, such offshoring should not be stopped. Interfering with such studies would be wrong, since the individuals involved (who in some cases are children in LMICs) have a comparative advantage in serving as participants, given the nonideal (and far from ideal) conditions of care in their country.

The Permitted Exploitation Principle is in some respects attractive. But this principle fails to recognize that some mutually advantageous and consensual transactions can be unfair. This is the moral justification, for example, in favor of there being a minimum wage: the fact that some extremely poor individuals may accept to be paid very little for their work does not make any mutually beneficial consensual transaction between employer and employee morally unproblematic. As this example shows, differences in power (and thereby in available options) between the two parties can result in unfair mutually advantageous consensual transactions, though such transactions can also be generated through other mechanisms.

According to Wertheimer, the mutually advantageous and consensual nature of the transactions involved in the clinical trials conducted offshore—where subjects participate in exchange for access to health care—is sufficient for arguing in favor of a noninterventionist stance. But he fails to consider that some of these trials might involve transactions that are at the same time (i) consensual and mutually advantageous and (ii) unfair, or at least sufficiently unfair.
to make a noninterventionist stance morally problematic. In some of these trials, there is the real danger that the sponsor takes unfair advantage of the participants. We are not claiming here that this is actually true of the COMPAS case. We are just offering the COMPAS case as an example of the kinds of trials that are in danger of involving unfair transactions. The mutually beneficial and consensual nature of the transaction, while being a morally relevant factor, is not the only morally relevant factor, as the context in which research takes place is also morally relevant. Thus, additional arguments are needed, for example, to justify the suboptimal design of the trial or to make such suboptimal design morally acceptable.

While we agree with Wertheimer that interventions aimed at stopping the occurrence of trials in LMICs are misguided, since such trials can certainly benefit participants, we think though that it is important to make sure that the relevant transactions are fair enough, that is, that the participants get enough in exchange for their participation in trials with suboptimal design.

We think that the preceding discussion is relevant for a proper evaluation of Wendler’s attempt to justify pediatric research on the basis of a broader concept of what is in the interest of the child to do. Wendler’s arguments may be appropriate when thinking about paediatric research in HICs where children have proper access to health care resources. But the fact that participating in research constitutes contributing to a valuable project does not seem enough to justify pediatric research of the kind that Wendler has in mind in contexts where there is the danger of unfair exploitation on behalf of the pharmaceutical companies.

It is worth noticing that such danger can be present in HICs too. Even in such countries there can be poor fractions of the population where basically the same considerations that apply to LMICs apply. For instance, the large portion of U.S. citizens who are uninsured or underinsured constitutes a pool of research participants for pharmaceutical companies. Some of these companies are creating the narrative that it is rational for these uninsured or underinsured individuals to participate in clinical research in order to access health care (Fischer 2008).

But even accepting the narrative that it is rational for these individuals to participate in clinical studies, by itself this does not make these trials morally unproblematic. Again, one needs to make sure that the mutually advantageous and consensual transaction is also (sufficiently) fair.

To conclude, the context of the research matters, and Wendler fails to see that in some contexts the considerations he presents—the fact that participating in research is a contribution to a valuable project and thereby is in some broad sense in the interest of the participant—fail to provide a proper and satisfactory justification of pediatric clinical research that offers no therapeutic benefits to participating children.

REFERENCES

On Wendler’s New Justification for Pediatric Research

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David Wendler (2012) argues that needed developments in pediatric research are incompatible with the widely accepted belief that such research is unethical if it offers no possible clinical benefit to the children participating in the research. Consequently, in order to justify exposing a child to research risks, we must identify some other benefit for the child that can be tallied against those risks. At first glance, this task seems easy and straightforward—we simply compensate the child financially for participation. Wendler, however, does not consider this sort of benefit,
Reviews of philosophical books run the risk of being either excessively and unconstructively critical or superficially praiseworthy. To avoid both these risks, we test the approach outlined by Häyry in his book *Rationality and the Genetic Challenge: Making People Better?* by applying it to an eighth genetic challenge, namely, a variation of the genetic enhancement challenge discussed by Häyry as it applies to sports. We assess whether genetic enhancement in sports should be conceived as an eighth wonder or an eighth cardinal sin that stems from the interaction between genetics and society, question whether Häyry’s nonconfrontational approach is really useful for dealing with these issues, and discuss how his method can be improved.

In his book, Häyry analyses three ways to deal with what he considers the challenges posed by genetics to society, which he refers to heuristically as neo-consequentialism, neo-virtue ethics, and neo-deontology. A genetic challenge is defined as a “set of questions raised by the engineering of political and medical solutions to the original threats posed by nonhuman and human nature” to which “we cannot readily agree on what our reactions should be and on what grounds.”

As the subtitle of the book suggests, genetic challenges are understood as possible ways to “make people better.” Häyry provides an extensive overview of the state of the field by analyzing seven case studies, namely, preimplantation genetic diagnosis (PGD), the possibility to design children, savior siblings, reproductive cloning, embryonic stem cell research, gene therapies, and considerable life extension techniques. As depicted by Häyry—even though such labeling may not be correct, as John Coggon and John Harris suggest—the first framework (“neo-consequentialism” or “rational tangibility”) focuses on persons and how they value life and is represented in the works of John Harris and Jonathan Glover; the second (“neo-virtue ethics” or “moral transcendence”) puts the emphasis on traditions and is exemplified by Michael Sandel and Leon Kass; and the third (“neo-deontology”) focuses on principles, with Jürgen Habermas and Ronald Green given as examples, reaching very different conclusions in terms of the ethical acceptability of the genetic challenges presented above.

Although the central part of Häyry’s book is devoted to the description of the state of the art concerning the seven wonders (or sins) of genetics, the most innovative chapter is the second, where Häyry spells out his methodological approach and the aim of the book. Häyry’s original contribution to the discussion is the claim that it is not possible to conclude with philosophical tools which of
the three frameworks is best for assessing the ethical justifiability of a new biotechnological practice, as the three approaches differ in the fundamental values and principles they employ. Häyry tests the internal coherence of each position, but claims that it is not possible to assess the superiority of any position over another on philosophical grounds. In his words:

If different approaches (or rationalities or methods of genethics) cannot be universally graded and put into order, as I am saying, then conflicting normative views cannot be put into one rational order, either, and we have no philosophical way of telling once and for all whether we should or should not engage in procreative selection, reproductive or therapeutic cloning, genetic engineering, or considerable life extension. Häyry analyzes the three approaches only on the basis of internal consistency, advocating what he labels "a non-confrontational notion of rationality":

A decision is rational insofar as it is based on beliefs that form a coherent whole and are consistent with how things are in the world; and it is aimed at optimising the immediate or long-term impacts on entities that matter. According to Häyry, there are many divergent rationalities, all of which can be simultaneously valid. As a consequence, there are many rational moralities. We do not agree with Häyry that there are many divergent rationalities, but only that there are many different moralities that can be rationally supported. However, we do not want to dwell on this distinction. What is interesting, instead, is the "polite bystander" proposal that he generates from it. According to this perspective, all ethical principles and judgments have respectable support if they meet the criteria of internal consistency and if in each case the combination of principles and judgments is a stable balance from the author’s point of view (a so-called reflective equipoise).

By presenting the main arguments for and against the genetic challenge, Häyry’s book turns out to be a valuable kind of textbook and an exhaustive picture of the state of the field. In this regard, the book is extremely engaging both for the clarity of the arguments presented and for the insightful indications it gives to readers for the articulation of their own views. But, if Häyry’s arguments are correct and ethical theories cannot be preferred on rational grounds, what are we readers left to do with his polite bystander view? As Häyry himself puts it at the end of the book: "Do we have any role in genethics, if all this [the content of the book] is to be believed?" In the last pages of the book, he lays out the work for the philosophically informed readers, when he writes that there are at least 72 stances that could be critically examined by the philosopher, resulting from the multiplication of three viable methods of ethics, three normative strands, and eight topics. Although Häyry has covered 10 in his book, he generously leaves quite a lot of work for us and other philosophers! But we do not think that focusing our attention on such a nonconfrontational experience would necessarily be an improvement over the actual state of the field and over the recognition of the existence of moral disagreement concerning questions raised by the genetic challenges.

What should we do with Häyry’s nonconfrontationalism then? Should we take it as a claim about diverse methods in ethics, or rather as an insightful plea to confront views at another, more appropriate level? We think that confrontational ethics is still important in many respects and that, if properly framed, can inform...
debates and, hopefully, help at reaching the right conclusions. To show what we have in mind, we critique an eighth wonder (or sin) that Häyry does not take into account in his book, but which has been at the core of radical disagreement between neo-consequentialists such as Harris and Glover and neo-virtue ethicists such as Sandel and Kass: the problem of genetic enhancement in sports. This will demonstrate the problem faced when we move from a level of complete abstraction, where we simply want to know if something makes sense on its own terms, to a level of practical application, where we need to decide what can and cannot be done. As it relates to a regulated activity, the discussion of sport demonstrates the need to go beyond mere deference to distinct perspectives, even if they are internally coherent. We therefore go on to suggest a deliberative democracy as the direction that analysts in the field of genethics may want to take into account when they deal with the complexities of moral disagreement in the realm of legal and political decisions.

Nonconfrontation and Genetic Enhancement in Sports

In this section we assess the ethical permissibility of genetic enhancements in professional sport competitions. We analyze approaches to the ethics of sport in order to demonstrate both the strengths and the limitations of Häyry’s philosophical methodology. Sport allows important insights into the way that Häyry’s approach can be combined with a good deal of confrontational ethics. Professional sport is highly technological, as athletes nowadays are able to improve their performances with a larger array of aids than in the past. Of these aids, genetic enhancements are of particular relevance. Genetic enhancement, or gene doping as it is also called, is banned by international sport institutions. It is perceived as a threat to traditional core values constituting sport activities and shared by many people. It is the source of many ethical disputes and provokes the articulation of many contradictory “rationalities.” Using it as a case study, we test Häyry’s methodology and his claims about the role of philosophers in this aspect of the genetic challenge. We argue that philosophers are not left completely unable to assess the rationality of alternative approaches and go on to consider the necessary confrontation when a moral position underpins a practical decision. We begin by describing and evaluating the World Anti-Doping Agency (WADA)’s ethical position by reference to the internal consistency of its “rational” underpinnings.

WADA considers any substance or method to be doping, and thus prohibited, if

1) It has the potential to enhance or enhances sport performance
2) It represents an actual or potential risk to the athlete
3) It violates the spirit of sport.

Enhancements, genetic or otherwise, are thus prohibited because they would go against other competitors, against the athlete herself/himself, and against sport itself. What is interesting in WADA’s definition is its implicit emphasis on a deeply value-laden interpretation of sport. As it says in the first pages of the WADA code:

Anti-doping programs seek to preserve what is *intrinsically valuable* about sport. This intrinsic value is often referred to as the “spirit of
It is the essence of Olympism; it is characterized by the following values: ethics, fair play and honesty, health, excellence in performance, character and education, fun and joy, teamwork, dedication and commitment, respect for rule and laws, respect for self and other participants, courage, community and solidarity. Doping is fundamentally contrary to the spirit of sport.

What these values really amount to and why certain kinds of enhancement actually threaten them are left to the readers’ intuition, as WADA does not explicate them in detail, nor does it give a single argument in support of its conclusions. Nevertheless, the conclusions reached by WADA are shared by a broad part of the public.

However, do WADA’s rulings and people’s opinions tell us something relevant as to whether genetic enhancements in sport are ethically acceptable? Some argue it does and that the sheer existence of moral rejection of doping “is sufficient for it to be taken seriously and given moral weight, even if the perspective is inconsistent and conceptually flawed.” As we argue below, there is an important distinction to be made in approaches to “genetic challenges” between a philosophical level of analysis, in which evidence and arguments in support of any claim must be put forth, and the political level of analysis, in which people’s moral views need to be taken into account. Let us tackle the philosophical level first.

Although a thick description of sport—one that takes into account both its purposes and ends—might be important for a correct understanding of the values at stake in it, a convincing rational tangibility argument still needs to be made to show how these values would be undermined by genetic enhancements. What is wrong with genetic enhancement? And why should it impair the essence of sport? The way WADA deals with the notion of the spirit of sport is certainly too sketchy for the purposes of philosophical analysis. However, its reference to deep values characterizing this activity leads us to categorize it, in Häyry’s terms, as a kind of moral transcendence view. To philosophically unpack the moral transcendence view on sports we draw on the report Beyond Therapy, delivered by the President’s Council on Bioethics. The Council, appointed by former U.S. President Bush in 2001, chaired by Leon Kass and having Michael Sandel as one of its members, was charged “to undertake fundamental inquiry into the human and moral significance of developments in biomedical and behavioral science and technology.” Beyond Therapy aims at spelling out what, if anything, is morally problematic about the genetic advances. The Council undertakes this task by giving center stage to the purposes and means of the activities that might be affected by genetic enhancements. The problem of enhancement in sport—or of “Superior Performance,” as it is phrased in the relevant section of the report—is a case in point. The claim is that the extensive use of enhancing agents (genetic or not) by athletes would corrupt the true nature of sport. The Council recognizes that one of the fundamental aims of sports, especially professional sports, is excellence. However, according to the writers of the report, the struggle for excellence depends on, and can be achieved through, several means. Some of these are natural talents, such as the genetic endowment of an athlete. Others depend on the athlete’s moral strength, such as perseverance in training. Others still have to do with the kind of external edges that help improve those characteristics, such as training in good facilities by good coaches, good
equipment, balanced diets, and so forth. Among the external edges athletes can use are the so-called gene enhancement methods.¹⁷

What, if anything, is the ethically relevant difference between these methods and other more traditional means to achieve better performances? According to the report, although genetic enhancements are not, in absolute terms, utterly different from other kinds of traditional enhancements, they are distinct in a “humanly” and ethically significant way. Genetic enhancements would eventually “partially alienate” the athlete from her performance.¹⁸ The ethical salience of the distinction pertains to the special relationship that the athlete establishes with her discipline or, to use the report’s terminology, the way in which the “doer” connects with the “deed.” Within this context, those improvements achieved by active training have to be seen as prominently human and honorable for the peculiar way in which they bring about a “connection between effort and improvement, between activity and experience, between work and result.”¹⁹ It is this combination of talent and moral character that defines superior performances as peculiarly human. Hence, according to the report, although the difference between genetic enhancements and more traditional ways to achieve better performances might be one of degree, it is one that matters on ethical grounds. The former would, in fact, appear to the agent as a kind of magic because, by introducing an external edge to the athlete’s body, it would improve her performance at the cost of dehumanizing the essence of the activity.

We agree with the President’s Council’s claim that an appropriate analysis of the meaning of sports cannot be reduced exclusively to performances and must take into account profound values. The report mentions aspiration, effort, activity, achievement, and excellence, but one could add more to the list, for instance, joy, respect, and solidarity. These values need to be balanced to find solutions to the questions concerning the admissibility of genetic or other kinds of enhancement.²⁰ Any philosophical analysis that underestimates these aspects would fail to capture the intricate ethical dimension of sports. However, the President’s Council fails to demonstrate that genetic enhancements would threaten sport and its values up to the point of dehumanizing it. The Council provides inadequate argument that values like those listed above will no longer be required to become excellent athletes. Furthermore, if there is a continuum between genetic and other kinds of performance enhancers, such as diet and training, it is difficult to claim that there is something special, or exceptional, in genetic interventions. Environmental factors such as diet and facilities can influence an athlete’s performance at least as much as the modification of a gene involved in a multifactorial trait such as athletic performance. Although many are inclined to view genetic contributions to ourselves as something exceptional, something that determines identity, this is not scientifically correct. Indeed, diet and nutrition affect a person’s performance through epigenetic mechanisms that also play a fundamental role in shaping a person’s capacity.²¹ Thus the moral distinction between genetic and nongenetic enhancement collapses. The continuum between genetic and nongenetic enhancements does not give principled grounds to claim that some important values we ascribe to sport would be lost were genetic enhancement techniques safe and liberalized. The positions outlined in the Council Report are based on the presumption that there exists a clear-cut distinction between genetic and nongenetic enhancement and on the notions of human nature and human dignity, which are never thoroughly specified. The
absence of such a distinction and the lack of an explicitly elaborated metaphysics are fatal to the arguments outlined in the Report itself.

This analysis of the ethics of sports case demonstrates the utility of Häyry’s nonconfrontational approach. It shows that nonconfrontational analysis can be useful in assessing, and in this case denying, the internal consistency of the neo-virtue ethics position applied to the ethics of sports. Indeed, turning the issue upside down, we note how a philosophical analysis focused on virtues might still make a substantive claim objecting to the idea that gene doping would dehumanize sports activities. Savulescu, for instance, has argued that genetic enhancements will not dehumanize sports but may instead prove useful to rehumanize it by providing a further layer at which important human virtues, such as ingenuity, effort, and so on, can be expressed. One can further argue that it would run against the spirit of sport not to allow people to challenge their limits in new ways.22

Questions about the proper ends and values of sport are, and will probably remain, a matter of discussion, and certainly more can be done to spell out what values are common to all sports and what are specific only to certain activities.23 Nevertheless, beyond nonconfrontational analysis, confrontational philosophical tools—evidence and arguments24—are necessary to assess the ethical permissibility of genetic enhancement in sports. In this regard, we agree with Häyry that “different approaches (or rationalities or methods of genethics) cannot be universally graded and put into order.”25 From this, however, we do not draw the conclusion that “we have no philosophical way of telling once and for all whether we should or should not engage in procreative selection.”26 As we have briefly shown here, the arguments Häyry would categorize as belonging to the rational tangibility approach seem to be superior to those put forward by supporters of the moral transcendence view, at least in this case. Are they thus right once and for all? Probably not. Nevertheless, we maintain, they are right insofar as someone will bring about new arguments and evidence as to show they are wrong. Moral disagreement in society will persist, no matter what philosophers may say. This, however, is not an indication of the fact that all views in the field of philosophical ethics are equivalent or incommensurable. Rather, it highlights how, in practice, we face a political problem. In this context, the deliberative democracy tools seem to be appropriate, as we sketch out in what follows.

A Moral Consensus to Everybody’s Satisfaction?

The example of sports ethics suggests a practical problem that must be overcome if we want some sort of moral position to guide activity in a situation where we are faced with competing “rationalities.” This practical problem does not allow us simply to acknowledge that moral positions differ and then nonconfrontationally to concern ourselves with ironing out internal inconsistencies. Rather, it demands a shift in focus from classical philosophical ethics to the realm of political philosophy. Of course, it would be naïve to expect from Häyry’s work a straightforward solution to the problem. Nor would it be legitimate to criticize Häyry’s work for being a book in ethics and not in political philosophy. Nevertheless, the book’s claims seem to be suspended between these two realms, and we are left wondering how the private considerations of individuals can play
a role in the solution of real-world political problems. As an example, consider the following argument from Häyry’s book:

Philosophical considerations can show that some arguments are flawed and others open to discussion, but they cannot prove to everybody’s satisfaction the rightness or wrongness of selection, cloning, or new treatments.27

In this passage the kind of difficulties we were alluding to are manifest. Here Häyry is conflating two issues that should be kept distinct for analytical purposes. One issue is whether philosophical considerations, or arguments, can prove the rightness of anything at all. Quite another is whether they can prove it to everybody’s satisfaction. The first is a question about moral relativism, the second one of political pluralism, that is, the claim that there exist different, and sometimes hard to reconcile, values in society. Let us tackle the first problem first. If Häyry’s main claim were about moral relativism, then there would be several ways to spell it out that he does not attempt in his book. For instance, why is it impossible to say that something, say one of the genetic challenges, is ethically justifiable or not? Is it because there is no such thing as objective moral truth? Or, more simply, is it that, even if objective morality existed, it would be unreachable by ethical thinking? Whereas the former would be an ontological claim, the latter would be an epistemological one.

Häyry’s position seems to be orthogonal to all these options. What he really seems to say is that there are different ways of doing ethics, none of them being illegitimate, at least as long as they are internally consistent and in some accordance with how things are in the world. As Coggon puts it, “a claim in support of simultaneous, non exclusive, yet competing rationality is a claim about the rightness of pluralism in ethics.”28 Accepting Häyry’s position may mean that each of the three methods he outlines has contradictory claims that cannot be undermined by other approaches, thus giving rise to irresolvable disagreement. For example, does the fact that Sandel/Kass-like conclusions are drawn by appeals to traditional values render them invulnerable to critiques by the rational tangibility approach of Harris and Glover and vice versa? In the previous section about genetic enhancements in sports, we have shown this is not the case. However, Häyry does not provide an answer to this problem. He only shows how some important philosophers, more or less loosely associated with a school or method, have happened to disagree on specific foundational issues.

As for the second issue we mentioned, namely, political pluralism, the absence of agreement on a particular issue poses the question of how to reach a reasonable consensus, even if provisional or revisable, in the polis. People may maintain their private rationalities or rational moralities on the basis of philosophical arguments, but reasonable people may think that it is still worthwhile to reach a consensus in order to make decisions at the policy level. The question at stake, therefore, is not so much one of politeness (referring to the polite bystander view proposed by Häyry) but is one of indicating at what level each kind of rationality can effectively prove insightful and, as a consequence, at what level confrontations should take place. At least three levels ought to be distinguished here:

1) the nonconfrontational philosophical level described by Häyry, which is useful for assessing the internal consistency of each ethical position
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2) the confrontational philosophical level, which takes into account other ethical perspectives (after they have been assessed for consistency with the first approach)

3) the decisionmaking political level, in which moral disagreement is dealt with in practice.

The genetic challenges as described by Häyry are public questions requiring, ideally, public answers. It is in this regard that we do not see Häyry’s approach as exhaustive. Indeed, we believe that practical questions such as who should decide cannot be answered solely by reference to internally consistent rationalities. On the contrary, we think that, by following the route indicated by Häyry, we run the risk of ending up with a cornucopia of ethical perspectives, each internally consistent but providing mere philosophical amusement. If genetic challenges are to be taken seriously, as concrete instances of moral disagreement in the real world—as we think and as also Häyry seems to think—then certain real-world questions concerning whose interests are challenged and how these can reasonably be reconciled cannot be escaped or masked behind the polite façade of Häyry’s nonconfrontational notion of rationality.

As an alternative, we suggest that the problem of “everybody’s satisfaction” could be better addressed by engaging (confronting, if you like) the different ethical perspectives in a process of public reason giving in the spirit of deliberative democracy (DD), as defined by Gutmann and Thompson and applied to genetics issues by Farrell. On this view “first-order” theories are ethical perspectives that seek to resolve moral disagreement by demonstrating that alternative theories and principles should be rejected. First-order theories “measure their success by whether they resolve the conflict consistently on their own term. Their aim is to be the single theory that resolves moral disagreement.” In Häyry’s book, first-order theories can be assimilated to the three ways he describes to deal with the genetic challenges. Whereas Häyry’s polite bystander view claims that the validity of first-order theories should be assessed only internally and not confronting one theory with another, a fruitful way forward in the discussion of the genetic challenge is a second-order theory approach like that proposed by Gutmann and Thompson, which deals with the moral disagreement residual of first-order theories that cannot be resolved at a first-order level or by appeal to any such theory. DD seeks a resolution to the moral disagreement by adopting a dynamic conception of political justification, which is both morally and politically provisional.

Within this DD perspective, the resolution of first-order moral disagreement needs to respect the DD principles of reciprocity, publicity, and accountability and seeks a mutually binding (though provisional, therefore, at a specific time) decision, on the basis of mutually justifiable reasons. Such a DD approach is not morally neutral, nor does it claim to be. Indeed, the quality of moral neutrality is both undesirable and unattainable according to the authors. If we accept this direction, we could read Häyry’s polite bystander view as a claim about first-order theories, to which we could add as a natural, subsequent step our steering toward the realm of political philosophy.

How can a second-order DD approach build on the confrontational analysis of first-order theories applied to genetic enhancements in sports that we discussed above? The details of this process in the context of decisionmaking in sports
would, of course, need to be spelled out in practice, but in this regard we can say that the current process of decisionmaking in sports is unsatisfactory at best. Consider, for example, the ruling made by the International Association of Athletics Federations (IAAF) concerning the admissibility of the runner Caster Semenya to compete with women after charging her of not belonging properly to the category, which was neither transparent nor respectful of her privacy. Furthermore, the reasons for Semenya’s banning and subsequent readmission were never made public, though not respecting the criteria of publicity that is fundamental in the DD approach. In the context of decisions surrounding the ethical justifiability of a gene enhancement (or other kind of enhancement) practice in sports, we envisage a DD process that gives reasons to all the moral constituents involved in the field, where moral constituents is understood as all “those who are in effect bound by the decision, even though they may not have [but maybe they should have, as we argue] a voice in making them,” therefore including at least, but not only, the athletes.

Conclusions

To sum up, our criticisms of Häyry’s book were twofold. First, we raised a critical point concerning his nonconfrontational approach, as applied to an eighth genetic challenge, namely, genetic enhancement in sports. We demonstrated that ethical confrontation is still necessary in assessing the ethical justifiability of this practice. Second, we commented that Häyry’s polite bystander view could, and indeed should, be brought forward to the political philosophy sphere and suggested DD tools as proposed by Gutmann and Thompson could be a fruitful direction to pursue when dealing with moral disagreement at the policy level. In making this claim, we are not saying that Häyry should have written a different book, only that our own view concerning the book requires that questions about genetic challenges need an interface with political philosophy and that, when this is taken into account, whole new perspectives open up that have not been considered by Häyry.

As a general remark on the book, we believe that Häyry’s work is of fundamental importance for anyone who wishes to join the debate or just be clearly informed about the problems arising at the interface between genetics and society. The book is challenging for young philosophers as well, because it provokes them to enrich their professional toolkit and to look at the complexities of genethics with fresh eyes. It is in this spirit that we have tried to “articulate our own view” on the matter.

Notes

4. See note 1, Häyry 2010:238.
5. See note 1, Häyry 2010:43.
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7. See note 1, Häyry 2010:238.
8. See note 1, Häyry 2010:239.
20. Consider, for example, Oscar Pistorius’s case and the surrounding ethical debate on disability and superability, Camporesi S. Oscar Pistorius, enhancement and post-humans. Journal of Medical Ethics 2008;34(9):639.
22. For an argument to this effect, see note 9, Savulescu 2007.
27. See note 1, Häyry 2010:238
33. For a discussion of the criteria of reason acceptability, see note 29, Gutmann, Thompson 2004:Chap. V.