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GENETIC SELECTION FOR HUMAN ENHANCEMENT

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Abstract

This paper examines the UK regulatory framework and the ethical arguments surrounding the use of genetic tests, specifically considering how they would apply to selecting for enhanced health characteristics. It discusses the Human Genetic Commission reports on the use of genetic information more broadly, identifying the implied values and concerns arising from their conclusions. It argues that the HGC conflates the concepts of 'best' and 'enhancement' and that this limits the persuasiveness of their moral stance *against* preimplantation genetic selection for nondisease characteristics. Subsequently, the paper develops a conceptual framework of ethical objections related to genetic tests and selection. In response, it is argued that there are good reasons to permit access to genetic tests (preimplantation and postnatal) on the basis that a) it will promote the accumulation of *biocultural capital* and b) the burden of proof deems prohibition to be unacceptable. In conclusion, a number of issues are described as unresolved, such as the lack of clarity over whether postnatal genetic tests should be considered medical interventions and the capacity of a national health care system to provide for enhancement choices. However, it is argued that neither of these factors creates insurmountable problems for the regulation of genetic tests for enhanced health characteristics.

Introduction

Knowledge about the genetic origins of life encounters a mixed reception from a range of social institutions, professions and the public. The science is steeped in fears about the determinism that might arise from the availability of such information.¹ Such views trouble those who are concerned that sociological interpretations of the world will be overlooked in favour of some, presumed, causal explanation of human behaviour and values via genetics.² Yet, for (some) scientists, genetics presents something of a holy grail in the pursuit of knowledge about biology.³ For them, genetics reflects the best possible advance in science to deal with the many causes of disease that continue to baffle scientists.

The coincident mapping of the Human Genome with the turn of the millennium might be seen as having been rather unfortunate, as the *fin de siècle* hype and hysteria seemed to beget a secular faith in the genome's promise, even though successful therapeutic interventions resulting from gene transfer remained few and far between. Indeed, some scientists and bioethicists argue that the attention (and funding) given to genetic science exceeds its capacity to deliver results and that this is morally significant when considering that other areas of science and health care lack funding.⁴ More extreme positions argue that work surrounding the genome can threaten the enjoyment of human rights through, for instance, introducing the prospect of ownership of DNA and products deriving from it.⁵

The use of *testing for* and *selecting out/in* specific genetic predispositions are intimately connected to these debates. Such applications of knowledge about genetics are an imminent prospect for bringing about some form of *designer* human, since selection offers the possibility of shaping individual characteristics without having to modify genetic structures. Yet, the use of such technology has not encountered the same kind of *yuk factor* response that describe some of the discourses surrounding genetic modification.⁶ One might even suggest that there is a moral ambivalence towards genetic selection, perhaps because modification can imply harm to *actual*

¹ Morse A. Searching for the Holy Grail: The Human Genome Project and Its Implications. *Journal of Law and Health* 1998;**13**:219-256.

² Lippmann A. Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities. *Am J Law Med* 1991;**XVII**(1&2):15-50; 1; Nelkin D, Lindee MS. *The DNA Mystique: The Gene as a Cultural Icon*. New York: W H Freeman & Co, 1995.

³ McGee G. Ethical Issues in Genetics in the Next 100 Years. Lecture presented in Kobe, Japan to the UNESCO Asian Bioethics Congress, Kobe & Fukui Japan, November 6, 1997; Hubbard R. Science, Power, Gender: How DNA Became the Book of Life. *Signs: Journal of Women in Culture and Society* 2003;**28**(3):791-799.

⁴ Callahan D. Liberals and their Ill-Liberal Policies. *Bioethics Forum* 2006 May 11. Hypertext document. Available Online at: <http://www.bioethicsforum.org/20060511dcallahan.asp> [Accessed: June 2006].

⁵ Pottage A. The Inscription of Life in Law; Genes, Patents, and Bio-Politics. *The Modern Law Review* 1998;**61**(5).

⁶ Glover J. Eugenics and Human Rights. In: Burley J, ed. *The Genetic Revolution and Human Rights*. Oxford: Oxford University Press, 1999: pp.101-124; Midgley M. Biotechnology and Monstrosity. *Hastings Center Report* 2000;**30**(5):7-16.

persons, whereas selection can imply harm only to *potential* persons. For genetic testing, the legal emphasis has been on the legitimate use of any *information* deriving from such tests and how this might be used to the detriment of individuals or communitarian interests.

Differences between the ethics of *modification* and *selection* might also be due to the ambiguous ethical status of selection processes within society, compared with the *clear* moral obstacles associated with genetic modification.⁷ Unlike genetic modification, many legitimate social structures rely on some form of genetic selection, through the breeding of animals and agricultural techniques. Moreover, mechanisms of selection are relevant measures through which to distribute social goods. Even if adjustments are made to take into account the influence of social determinism, meritocratic systems of justice are a dominant feature of modern, democratic cultures. Thus, the relevant questions surrounding any form of selection process are whether the method is *relevant* and *just*. For instance, selection for employment based on ethnicity, gender, or age is considered illegitimate in law because these are generally irrelevant characteristics through which to evaluate a person's competence to undertake a particular task.

In the context of genetic selection – the selection of specific people for specific tasks based upon a favourable genotype, or the selection of specific embryos that exhibit desirable genetic characteristics⁸ – there remains considerable uncertainty about whether it is possible to define what constitute better or worse genotypes. The Human Genetics Commission (HGC) (2004) includes this second form of selection within their category of 'embryo enhancement' within which they also include modifications to the genome. However, I propose that their categories should be: 'negative embryo selection', 'positive embryo selection' and 'embryonic enhancement'. Indeed, this is why the use of non-therapeutic genetic testing gives rise to such criticisms, as the consequences of testing can give legitimacy to decisions about selection that seem to involve a eugenic claim about which kinds of people are preferable to bring into the world. Such actions are troublesome, in part, because the relevance of the information is contested – gene-environment-lifestyle models are more reflective of current approaches to understanding the role of genetics in our biological constitution. As such, it is not clear whether it would be possible to defend selection on the basis of 'fair discrimination' in a similar vein to the United Kingdom Sex Discrimination Act (1975). On this view, the use of genetic selection constitutes an overemphasis on the relevance of genes in influencing phenotypic characteristics.

⁷ This claim relies on the premise that altering genetic structures involve additional harms to testing for genetic information, the latter of which might involve simply a mouth swab. Admittedly, if genetic tests involved an invasive procedure, then this distinction is complicated, though testing is still not obviously worse than genetic modification.

⁸ This includes administering genetic tests to adults to determine the characteristics they are likely to pass on to their offspring, as a means to informing whether or not they have a child (with a specific person).

Within the United Kingdom, this matter has received some attention already within government advisory structures. In particular the HGC⁹ has spent considerable time discussing the legitimate use of genetic information. Additionally, recent uses of genetic selection for indirect therapeutic purposes such as tissue typing¹⁰, paternity tests¹¹ or sex selection¹² raise questions about the capacity of medical law and ethics to limit lifestyle choices. Discussion about these examples is critical to the development of moral and legal frameworks on the use of non-therapeutic genetic tests. Yet, I will suggest that selecting for *enhanced health* characteristics raises more complex issues than other, nondisease uses, such as sex selection. These debates form the regulatory context for this essay, which attempts to inform an ethical and legal discussion about the supposed ‘unlikely’¹³ prospect that people would use genetic information to make enhancement selection decisions.

The two forms of selection under consideration (postnatal and preimplantation) engage different aspects of medical law, though my intention is to explore their inter-relatedness. Thus, I will argue that the use of genetic selection in reproductive decision making is underpinned by similar, ethical criteria about the value of certain traits over others. Moreover, the use of genetic tests in postnatal circumstances will weaken the relevance of legislation that seeks to prohibit preimplantation selection for enhancement. While this might appear to be characteristic of a *slippery slope*, I will argue that such prospects ought *not* be conceived as either slippery or as a slope.

In sum, my aim is reminiscent of Glover¹⁴ who sought to: ‘diagnose the varied sources of our resistance to genetic engineering, and to see how far they withstand scrutiny when separated.’ I wish to pursue the resistance to the genetic *selection* of enhanced health characteristics rather than *engineering* and demonstrate that it would be unacceptable to prohibit access to – and development of – genetic tests for enhanced health characteristics (pre- and post- natal). Thus, as some response to Glover’s question about what sort of people there should be, I argue that individual decisions to raise the health of prospective people through embryonic selection or through informing life decisions by considering genetic potentialities are both justified and valuable. Moreover, I argue that there are crucial differences that distinguish such choices from previous eugenic practices. In particular, the specificity of genetic selection for enhanced health, and the claim that enhancements are not general categories, are crucial distinctions between arguments on behalf of such liberties and the immorality of eugenics, the former of which are context specific and

⁹ Human Genetics Commission. *Inside Information: Balancing Interests in the Use of Personal Genetic Data*. London, Human Genetics Commission, 2002; Human Genetics Commission. *Choosing the Future: Genetics and Reproductive Decision Making*. London, Human Genetics Commission, 2002; Human Genetics Commission. *Making Babies: Reproductive Decisions and Genetic Technologies*, London, Human Genetics Commission, 2006.

¹⁰ Dyer C. Couple allowed to select an embryo to save sibling. *British Medical Journal* 2004;329:592..

¹¹ Kaebnick GE. The Natural Father: Genetic Paternity Testing, Marriage, and Fatherhood. *Cambridge Quarterly of Health Care Ethics* 2004;13:49-60.

¹² Human Fertilisation and Embryology Authority. *Sex selection: options for regulation. A Report on the HFEA's 2002-03 review of sex selection including a discussion of legislative and regulatory options*. HFEA, 2003.

¹³ Human Genetics Commission, 2006. *op cit*.

¹⁴ Glover J. *What Sort of People Should There Be?* Harmondsworth: Penguin, 1984, p.16.

subjectively derived. Neither of these arguments has been considered in previous literature on this subject.

In short, my position is helpfully articulated via Nozick's¹⁵ metaphor of the genetic supermarket. In my view, *if only* there were a supermarket, then the major moral concerns surrounding genetic testing and selection would *not* arise. The more worrying circumstances arise when there is *too little choice* for people to make – more a convenience store than a supermarket – or where a *blueprint* for future people is instituted (intentionally or not) through legislation.¹⁶ A *prohibition* of genetic selection for enhanced health would constitute such a blueprint and, as such, would be eugenic in principle and intention.¹⁷

To this extent, my approach here is teleological rather than deontological. However, in accordance with a casuistic mode of reflective equilibrium, I draw from the principles implied and explicit within medical ethics, which contribute to the development of exemplary cases. For example, I will consider how the general acceptance of autonomy as an established good within medical ethics might apply in the context of decisions about nondisease genetic testing and selection.

Characterising 'Enhanced Health' Genes

To conclude this introduction, it is necessary to provide some description of the technical aspects of this case, in order to establish its parameters and feasibility as a relevant ethical issue worthy of attention at this time. As I have indicated, I challenge the HGC's¹⁸ claim that deriving ethical guidelines and law in relation to the prospect of using genetic tests and selection for nondisease or, as they term them 'enhancing' purposes, is unnecessary. Indeed, in an era where such organisations as the United States President's Council on Bioethics are investigating the ethics of life extension, genetic tests seem much less radical. This position does not advance a *carte blanche* for the serious consideration of any ethical dilemmas, such as the ethics of grafting wing structures onto humans, which is satirically discussed in Annas'¹⁹ article on 'Perfect People'. Yet, I consider that the use of genetic tests for enhancement purposes is sufficiently imminent as to justify serious consideration. Yet, the HGC's position relies on a claim about the impossibility of characterising enhanced characteristics, which conflates the terms 'best' and 'enhanced.' It is particularly concerned about assertions that some nondisease genes are better than others. It is less clear whether the HGC denies the possibility of identifying characteristics that are preferable from a supra-healthy perspective. While I accept that the science available presently does not offer much opportunity to make choices in this area, there are good

¹⁵ Nozick R. *Anarchy, State and Utopia*. New York: Basic Books, 1974.

¹⁶ The distinctions I draw here are among a) no choice, b) some choice and c) considerable choice.

¹⁷ I will attend to the concerns of runaway individualism and cultural complicity later, which appear to be the dominant concerns of many critics of a permissive approach to consumer-based medicine.

¹⁸ Human Genetics Commission, 2006. *op. cit.*

¹⁹ Annas GJ. Our Most Important Product. In: Blank RH, Bonnicksen AL, eds. *Medicine Unbound: The Human Body & the Limits of Medical Intervention*. New York: Columbia University Press, 1994

reasons to presume that such possibilities are on the horizon. As the American Medical Association Council on Ethical and Judicial Affairs²⁰ notes:

As the mapping of the human genome progresses and tests for newly discovered genes are developed, the possibility has arisen that many different testing 'packages' could be administered simultaneously. This latter kind of multiplex testing creates a new level of complexity because the modes of heredity, social implications, and availability of treatment can differ greatly among the conditions tested (p.15).

While this does not imply that Nozick's²¹ genetic supermarket is imminent, it alludes to the possibility that parents could request tests for a range of characteristics, some of which might not be characterised as disease-related traits. Zimmerman²² offers further support for taking this prospect seriously:

While such information would reveal the basis for much current or future pathology, it would also reveal subclinical or non-clinical tendencies or characteristics that not only physical attributes, such as stature, body type, and athletic ability, but personality, intellect, musical and artistic talent, and perhaps even moral character. (p.224)

Indeed, one of the crucial challenges to advocates of genetic tests for only genuine medical conditions is the claim that the concepts of disease/nondisease genes are *too* closely connected, to be meaningfully separated. To this extent, the problem is even more complicated than Savulescu²³ describes:

A disease gene is a gene which causes a genetic disorder (e.g. cystic fibrosis) or predisposes to the development of disease (e.g. the genetic contribution to cancer or dementia). A nondisease gene is a gene which causes or predisposes to some physical or psychological state of the person which is not itself a disease state, e.g. height, intelligence, character (not in the subnormal range). (p.414)

While Savulescu distinguishes nondisease from specific kinds of disease, I am interested in characteristics that could be described as *supra-healthy*. In part, this is because I consider that Savulescu's distinction understates the interconnectedness of those characteristics he seeks to investigate and their role within the promotion of health as a corollary of disease. On this premise, it would be mistaken to characterise any biological information as an exclusively nondisease trait, even if no specific disease is associated with variation in that trait (within a normal range). After all,

²⁰ American Medical Association Council on Ethical and Judicial Affairs. Multiplex Genetic Testing. *Hastings Center Report* 1998; 28(4):15-21.

²¹ Nozick, 1974, *op. cit.*

²² Zimmerman BK. The use of genetic information and public accountability. *Public Understanding of Science* 1999;8:223-240.

²³ Savulescu J. Procreative Beneficence: Why we should select the best children. *Bioethics* 2001;15(5/6):413-426.

there is still a considerable amount that is unknown about human health and evolution.

This characterisation of nondisease might imply that any form of tampering with biology should always be modest. Indeed, such a *precautionary principle* underpins many technological developments in medicine. However, many parts of the world already embrace technologies that disrupt (or attempt to improve upon) an alleged natural form of evolution. For example, the fluoridisation of drinking water or nationwide vaccination programmes are each designed to improve the resistive capacities of humanity. Such interventions might be justified on the basis that they merely correct for earlier environmental damage brought about by humanity. However, this seems even further to weaken the defence for *letting the body be*, since it acknowledges an interactionist model of nature and culture. It is inconceivable that bodies could be left alone, as if they are divorced from the environments they inhabit. Indeed, such a view would make it even harder to claim that biology can be left to its own devices when human suffering is at stake. On one view, medicine is precisely the attempt to enable our enjoyment of culture – seen more broadly as the lived experience of individual choices. Medicine necessarily involves making people well *for something*.

Thus, humanity already tampers with natural structures in an attempt to preserve and optimise the overall health of the species and its individual members. Nevertheless, while this might provide some form of justification for the general practice of altering nature, it does not say very much about what might constitute a nondisease gene. Moreover, it does not indicate why medical practice would entertain testing for such characteristics. Indeed, where medicine is concerned, tampering with human biology involves relieving the kind of suffering that arises from the body in pain, particularly where such pain is indicative of dysfunction, such as a genetic disorder or illness. As such, utilising medicine to tamper with nondisease attributes is already stretching the boundaries of its traditional role.

This characteristic distinguishes medicine from other kinds of social practices. Indeed, while the transfer of new technologies from one human practice – say, the military – to another practice – such as automobile engineering – is common, within medicine, there is greater resistance to the application of medicine to non-medical practices. In part, this is because using medicine for non-medical purposes would often require the skills of a medical professional, as is the case for aesthetic surgical procedures, when such professionals are governed by an ethical code that generally involves repair work rather than enhancement. Yet, it is also due to the regulatory mechanisms surrounding medicine, which are designed to limit the application of a medical technology to the specific context for which it was developed.²⁴ Thus, one way of distinguishing medical from non-medical information involves examining how health *is* operationalised within health care systems (rather than arguing how it *should* be operationalised). To the extent that medicine is generally concerned with relieving suffering, decisions not to approve the use of a medical procedure for a specific purpose would imply that it lacks these critical characteristics that justify the use of

²⁴ Indeed, the terms associated with product liability are an indication of this.

medicine. Consequently, even if we cannot establish what medicine *should do*, we can observe what medicine *actually does* – its ethos perhaps - as some indication of what it should be doing.

In the context of genetic tests and selection, this distinction has been reasonably consistent over time. Traditionally (and still), genetic tests have been used to identify whether an individual is carrying a trait associated with a specific genetic disease, or for screening populations to ascertain trends of carrier status and the implication of this for developing healthcare policy. As such, genetic tests for nondisease or enhanced health related information have not existed. This is not to say that nondisease factors have been absent from the decision making process surrounding genetic tests for specific and known diseases. Indeed, the difficulty with separating disease from nondisease is that knowledge of any health related information for a prospective parent or an individual has a bearing on the decisions made either in terms of the continuation of a pregnancy or the kind of lifestyle one leads. Moreover, the concern of some scholars is that these implications have a bearing on how people give value to specific ways of living. This concern will be addressed later when discussing the ‘Expressivist Objection’.

Testing for enhanced health genetic states does *not* imply a wholly different process of decision-making, compared with testing for genetic disorders, even if different kinds of priorities are evident. Indeed, this is indicated by the HGC’s²⁵ definition of these terms:

Distinguish between Embryo Selection and Embryo Enhancement

Embryo selection refers to the selection of embryos using PGD. PGD is a technique currently used to select embryos without a specific serious genetic disorder or chromosomal abnormality. It has also been used to select for female embryos to avoid an X-linked genetic disorder which is a disorder that will only affect male children. In one case, the HFEA has licensed a clinic to use selection to obtain an embryo that is both free of the relevant genetic disorder (β Thalassaemia) and would be a tissue (HLA) match for an existing child.

Embryo enhancement refers to using techniques to enhance the genetic make-up of a child, and is prohibited. In theory, embryo enhancement might involve either the selection of an embryo with genetic characteristics indicative of desirable traits such as beauty or intelligence, or a process of genetic modification to enhance such traits.

The crucial issue seems to be whether information about nondisease genes – the optimisation of which provides no direct therapeutic benefit – offers too much control over shaping future people or the kinds of lives people lead. Fortunately, there are some relevant examples on which to draw to inform this debate. For instance, the use of sex selection has provoked precisely these questions. In some cases, selecting for sex need not involve a clear therapeutic function. Yet, it is now possible to test for this characteristic and select the desired embryo. This will provide a useful example

²⁵ Human Genetics Commission, 2004, *op. cit.*, p.19.

on which to evaluate the current case, which involves selecting for ‘enhanced health’ (rather than non-health) characteristics.

Selecting for Enhanced Health or ‘Beyond Therapy’²⁶

To conclude this technical summary, the specific case under investigation draws on studies that seek to investigate what ethical and legal entitlements should pertain to using genetic tests for selecting specific embryos or specific people who have the desired genotype. It extends these studies by considering selecting for enhanced health or characteristics that are ‘beyond therapy’. The following list offers some indication of what these characteristics might include:

- Improved respiratory functioning.
- Eyesight greater than 20:20.
- Greater strength and elasticity in tendons, ligaments and muscle tissue.
- Greater capacity to re-form broken tissue (improved healing).
- Resistance to (context specific) illness and disease (e.g to preservation of health in inhospitable environments, such as coal mines or outer space).

To understand how this might function, an example might also assist. Let us suppose that a cycle of IVF involves identifying ten embryos, each of which is tested for a number of health-related characteristics. Fortunately, each of them is deemed to be healthy, yet among the ten, we discover varying ranges of capacities. Thus, the information might reveal that the vision of one embryo is likely to remain *perfect* (functionally healthy) for a few more years compared to others. Alternatively, perhaps one embryo might be shown to have greater respiratory capacities, even if only marginally. Ideally, our case would include embryos that show capacities, which might be described as genetically supra-normal and there are various stories about such people throughout history. For instance, in the 1960s a Finnish skier named Eero Maentyranta won three gold medals and was subsequently found to have a genetic mutation that meant he naturally had 40-50% more red blood cells than the average person. More recently, in 2004 a German boy was born who had double the normal dose of a genetic mutation that causes immense strength.²⁷ Each of these examples constitutes an interesting case of enhanced health characteristics. For now, we will leave aside the complication that these mutations might have the guise of enhancement within only narrowly defined circumstances or that they, nevertheless, will give rise to health complications later in life. As such, my proposition is not of this character but, as stated, involves the aforementioned ten embryos that show variation within a normal range.

Thus, in a situation where there are ten embryos each varying in their likely health characteristics, would it be reasonable to identify a preferable embryo, or are they all equal in their desirability? I seek to establish that selection of the more optimally healthy is consistent with our commitment to health promotion generally and that

²⁶ The U.S. President's Council on Bioethics. *Beyond Therapy: Biotechnology and the Pursuit of Happiness*, 2003.

²⁷ Shuelke M, Wagner KR, Stolz LE, et al. Myostatin Mutation Associated with Gross Muscle Hypertrophy in a child. *New England Journal of Medicine* 2004;350(26):2682-2688.

prospective parents should be allowed to make enhancement decisions when confronted with the choice of selecting among *normal* variation. While this might sound like eugenics, I argue that the legitimacy of such choice is located in conceptualising the decision as similar to the sentiment of hoping that one's child is free from debilitating illnesses and/or suffering.

In none of the debates surrounding genetic testing and selection is this ethical dilemma presented as something that pertains to the difficulties raised by preimplantation genetic diagnosis (PGD). Indeed, most discussions indicate that genetic technology should certainly not be used for 'trivial' purposes, such as selecting for hair or eye colour.²⁸ Rather, organisations like the HGC are struggling to protect the integrity of therapeutic interventions from *slippery slope* propositions, which allude to the use of gene technology for lifestyle applications. Rather, the more frequent challenges genetic testing and selection raises involve the ambiguity of the therapeutic imperative. The principles of these limits were tested in the case involving an American deaf lesbian couple who sought a specific sperm donor that would ensure their conceiving a deaf child. They justified such interests by appealing to the importance of a close relationship between them and the child and by arguing that deafness is not a disability but 'the constitutive condition of access to a rich culture'²⁹. On this basis, the claim corresponds with the HGC's interest to ensure children 'fit' within families.³⁰ This case is interesting because it reveals the ambiguous merit of the therapeutic imperative. Thus, if medicine's limits are defined by clarity over the distinction between therapy and enhancement and yet, the value of therapy is ambiguous, one might also question the fixity of enhancement's *lack* of value. In some cases – perhaps selecting for enhanced health – one might claim that selecting for enhancements is consistent with the therapeutic imperative, insofar as it contributes to the general well-being of a person.

Here, I consider genetic testing and selection in the context of preimplantation circumstances. Thus, the HGC discussions and the ethical objections surrounding selection derive from debates about preimplantation genetic selection. However, I am interested in the common ground between preimplantation selection and the selection of specific people (postnatal) on the basis of genetic information. The regulatory framework for prenatal tests is relatively well established and, I suggest, can inform discussions surrounding the use of postnatal genetic tests by revealing the implied values that are assumed by selection processes generally. There have been nearly no debates about the regulation of non-medical genetic tests involving mouth-swabs or muscle biopsies. Moreover, it is unclear whether such products would even fall within the terms of reference for established regulatory bodies. While there are crucial ethical differences in the implementation of both, the main interest here is to understand the arguments against the use of genetic selection, as a means for optimising individual health, the value of which can be proposed in both sets of circumstances. It is anticipated that understanding the ethics of preimplantation

²⁸ Human Genetics Commission, 2006, *op. cit.* p.11.

²⁹ Levy N. Deafness, culture, and choice. *Journal of Medical Ethics* 2002;28(5), p.284.

³⁰ HGC, 2006, *op. cit.* p.16.

genetic selection will elucidate difficulties arising from the use of postnatal genetic testing and selection.

The UK Regulatory Framework

Discussions about the use and regulation of genetic tests began soon after the DNA double helix was identified in 1953. The first prenatal genetic tests developed in the 1960s and their widespread use occurred in the 1980s.³¹ To this extent, it would be misleading to separate discussions about the regulation of genetics tests from similar debates about other medical procedures associated with monitoring health. Indeed, many of the ethical and legal issues arising from genetic tests overlap with other debates in the regulation of medicine. Nevertheless, for some time, the supposed novelty of genetic technology has given rise to a debate about *genetic exceptionalism* – whether genetic information and technology are qualitatively different from other kinds of medical information and, for this reason, whether they should give rise to alternative approaches in bioethics and biolaw.

While many of the stronger claims over genetic exceptionalism rely on the predictive capacities of genetics, it is these attributes that have become more contested as gene-environment models of genetics have developed. Nevertheless, the distinct and particular cultural resonance of genetics indicated by some social scientists might provide a sufficient basis for its receiving special treatment.³² Indeed, the HGC³³ report that ‘people see genetic information as special and as a private matter and we agree that there are sometimes good reasons for this’ (p.4). To this extent, the issues presented by genetics are intimately connected to the range of meanings attached to genes and this has moral weight.³⁴ Today, the prevailing view is that an integrated approach is preferable to an exclusivist or inclusivist position on genetic science. This perspective is reflected in the HGC’s first report in this area, *Inside Information*,³⁵ which, among other things, provides a useful guide for how medical (or personal) information can be evaluated in ethical and legal terms³⁶:

- Sensitive vs. non-sensitive information.
- Private vs. Observable information.
- Low vs. High informational impact
- Recessive vs. Dominant
- Unifactorial vs. Multifactorial

³¹ Condit CM. The meaning and effects of discourse about genetics: methodological variations in studies of discourse and social change. *Discourse and society* 2004;15(4):391-407.

³² Nelkin, D. and M. S. Lindee, 1995, *op. cit.*

³³ Human Genetics Commission, 2002, *op.cit.*

³⁴ This discussion might require an investigation of the cultural as a sub-set of aesthetic value. I will not pursue this here but one might find relevant connections within literary texts, such as the obvious examples of Shelley’s *Frankenstein* or Huxley’s *Brave New World*. In both cases, the aesthetic of the texts is intimately connected to the construction of a moral landscape surrounding scientific modification of life.

³⁵ Human Genetics Commission, 2002, *op. cit.*

³⁶ A similar view is expressed in subsequent legislative guidelines, such as the Australia Law Reform Commission, 2003, *op. cit.*

- Diagnostic vs. Predictive
- Screening (population) vs. Testing/Diagnosis (individual)

These categories suggest ways to justify ethical and legal distinctions between different forms of medical information. For example, if the information revealed is sensitive, then more restrictive measures over testing might be reasonable. Alternatively, if the information is observable, then there is less of a basis on which to assert an entitlement to privacy over that information. In some cases, the information might have a number of indirect, ethically important attributes. For instance, in the context of the ‘informational impact’, it is important to note the influence not just of test results but the *mere* existence of tests on decision-making. Alternatively, if the results of a genetic test are likely to influence, say, decisions about the continuation of pregnancy more than other kinds of tests, then this might be a justification for making a distinction between them.³⁷ Lippmann³⁸ even considers that the existence of a test can give rise to an imperative to use it, which might have special moral significance, though this is also true of non-genetic tests.³⁹ In the context of genetics, Henn⁴⁰ outlines such circumstances when discussing screening for the cystic fibrosis gene:

the molecular genetic proof of heterozygosity can determine the decision of a couple not to have children or to request a prenatal diagnosis in case of a pregnancy. This prospective dimension of genetic diagnosis that goes beyond individual health care may support autonomous reproductive decision making but also bears the danger of external encroachments on parental autonomy.

The HGC model and others like it also help to distinguish between information related to either late or early onset diseases. For the former, it is widely considered that environmental influence on potentialities limits the reliability of the information and that such information might unreasonably influence behaviour.⁴¹ As such, there is a concern that people with late onset predispositions might alter their life dramatically, out of a concern for a condition that might never develop. In this case, the justification for using such tests is less persuasive.⁴² A major impetus for making these distinctions is that there are potential harms associated with discovering information about one’s genetic profile. This is a clear case of how new technology gives rise to new moral dilemmas, new choices to make and the need for new

³⁷ Scott R. Prenatal Testing, Reproductive Autonomy and Disability Interests. *Cambridge Quarterly of Health Care Ethics* 2005;14:65-82.

³⁸ Lippmann, A. 1991), *op. cit.*

³⁹ Cameron C, Williamson R. Is there an ethical difference between preimplantation genetic diagnosis and abortion? *J Med Ethics* 2003;29:90-92.

⁴⁰ Henn W. Genetic screening with the DNA chip: A new Pandora's Box? *J Med Ethics* 1999;25(2), p.200.

⁴¹ Advisory Committee on Genetic Testing. *Report on Genetic Testing for Late Onset Disorders*. Department of Health, UK Government, 1998.

⁴² Indeed, one might argue that any form of genetic testing is currently unjust, since we do not yet have a complete picture of our individual genes. As such, I might have a genetic condition for which there is not yet a test, but the presence of a test for another condition that my friend has might lead some to conclude that he or she is at greater genetic risk than I. Such a conclusion – and any policy based on it – would be an inadequate form of distinguishing genetic risk among people.

approaches to establishing social justice through law.⁴³ Alternatively, information related to a genetic dysfunction has an ambiguous relevance in cases where nothing can be done to alleviate or cure the illness. In this case, beliefs about the condition's inevitability could give rise to a feeling of futility for the potential patient. As McLean⁴⁴ identifies in the context of prenatal genetic screening, some of the concerns involve potential,

loss of self-esteem, affect the way in which the child is treated in the family or the wider community, prevent a later exercise of autonomy by taking the decision about testing out of the hands of the potential adult, and breach current UK policies on the need for counselling before or in tandem with screening.

However, it also concerns entitlement to act on behalf of someone else in a way that might limit their autonomy. For instance, Sevick, Nativio and McConnell⁴⁵ discuss whether parents are entitled to use genetic tests to discover whether their child has a predisposition to a late onset condition, such as Huntington's Disease. After all, it might undermine the child's later autonomy to decide whether they want to have such information. Moreover, knowledge of the test results may not offer any additional benefit to the child.⁴⁶ Indeed, Cohen⁴⁷ notes that knowledge of such predispositions might even lead to the child blaming him or herself for the disorder. Yet, Sevick et al.⁴⁸ note that it can be useful for parents to know about any potential genetic condition that their child will encounter, because it will help them to plan their lives and adjust to the special circumstances they will face.

By identifying what matters about any kind of information, the HGC methodology allows differentiation between, say, somatic or germ-line cell information without entering into complex, speculative debates about altering the future of the gene pool, or discarding the importance of what matters to individuals about the sanctity of life. However, it is important to note that the very same concerns apply for genetic *selection* as for genetic *modification*, since each implies affecting subsequent generations albeit in different ways. Indeed, Harris⁴⁹ discusses genetic selection as a paradigm of genetic manipulation.

The HGC conclusions have particular relevance for establishing the regulatory framework within which discussions about nondisease genetic testing and selection would evolve. For instance, if it were possible to utilise PGD to identify hair colour,

⁴³ Buchanan A, Brock DW, Daniels N, Wikler D. *From Chance to Choice: Genetics & Justice*. Cambridge: Cambridge University Press, 2000.

⁴⁴ McLean SAM. Genetic Screening of Children: The U.K. Position. *Journal of Contemporary Health Law and Policy* 1995;12(1), p.120.

⁴⁵ Sevick MA, Nativio DG, McConnell T. Genetic Testing of Children for Late Onset Disease. *Cambridge Quarterly of Health Care Ethics* 2005;14:47-56.

⁴⁶ Ayabe S, Tan SY. Entering the Age of the New Genetics with Eyes Wide Open. *Hawaii Medical Journal* 1995;54(April):460-463.

⁴⁷ Cohen CB. Wrestling with the future: Should we test children for adult-onset genetic conditions? *Kennedy Institute of Ethics Journal* 1998;8(2):111-130.

⁴⁸ Sevick MA, Nativio DG, McConnell, 2005, *op. cit.*

⁴⁹ Harris J. No sex selection please, we're British. *Journal of Medical Ethics* 2005;31:286-288.

then it might be considered relatively unimportant to prohibit the use of such a test, since this would soon become neither sensitive nor private information. One might compare it to, say, knowledge that a child has two legs or five fingers on each hand. Of course, this latter example alludes to the fundamental problem arising from this issue: whether information about the latter, seemingly innocuous examples would inform the reproductive decision making process. After all, one might question whether it would be a sound decision for prospective parents to consider a termination of a pregnancy if their child was shown to have only four fingers on one hand or perhaps just one leg. Debates about the legitimacy of such choices have arisen in the context of a range of recent cases (such as cleft lip, deafness, Down's syndrome), which have engaged disability activists who claim that such actions constitute a devaluing of people with disabilities and a neglect of society's responsibility to develop structures that include all kinds of people.

More recently, the HGC's *Reproductive Decisions and Genetic Technologies*⁵⁰ considers the use of genetic tests in detail to select for nondisease characteristics, noting the complex issues they raise:

The new insights into inheritance are not confined to health and well-being. Many of our physical and, perhaps, our behavioural characteristics are influenced by the variation in the genes we inherit. Choice in these cases would have nothing to do with health, but with something far more subjective and, in the eyes of some, far more problematic: choice about the "sort" of children we want. Are there further choices that we will be pressed to consider in the years to come – intelligence, appearance, sporting or musical abilities?

In the context of genetic testing and selection, the HGC is still reasonably assured that the ethics of selecting for nondisease or enhanced health is of limited concern to law presently. When discussing the use of PGD for such purposes it states that,

Even if all the genes involved were to be identified, prediction of the required characteristics would remain uncertain and the limited supply of embryos available for selection would make the finding of particular gene variant combinations very unlikely. The anxiety that PGD lies at the top of a slippery slope leading to the possibility of a wide range of potential enhancements, such as intelligence or beauty, is misplaced (p.15).

There are two important, but overlapping characteristics of this rejection of nondisease PGD issues. The first involves a claim about the scientific feasibility of PGD and its capacity to yield information about nondisease states. The other involves a response to the presumed view that permitting therapeutic PGD would initiate a slippery slope towards PGD for enhancement. Some brief responses are necessary before more fully considering the arguments related to selecting for nondisease or enhanced traits. The first is to indicate that the HGC's position involves a claim over

⁵⁰ Human Genetics Commission, 2006, *op. cit.*, p.3.

a *technical* slippery slope, rather than either a *logical* or *empirical* slippery slope.⁵¹ The Commission states that the technology does not allow for enhanced genetic selection and so it is legitimate to dismiss its consideration. However, it does not address the development of an expectation that science should work towards delivering such choices for people – the so-called *empirical* slippery slope. This lack of engagement with the social science of slippery slopes requires further attention on its part. Indeed, it is surprising that there has not been any investigation of this phenomenon within the literature surrounding the public understanding of science.⁵²

The HGC⁵³ alludes again, to, Jonathan Glover's⁵⁴ questioning over what sort of people there should be and makes a clear distinction between people who are born at the precise desires of their parents and those who are selected to avoid serious disability. It also indicates that it is acting on behalf of the voting population to the extent that people who are concerned with reproductive decisions regarding the health and wellbeing of their children are uninterested by the idea of genetic selection for enhancement purposes. In the context of donated egg and sperm they state:

38. A number of our respondents were worried that selective donation might also be used to enhance traits such as intelligence or sporting ability. In fact, there is very little evidence that such selection is of concern to parents choosing donors. Parents' main interest is in a child who would fit into the family. We believe that choice based on the information provided in the current donor information form precludes anything that might be described as eugenics and that current arrangements should be continued.

Yet, the Commission's argument relies on the stability of the claim that parents are not interested or on the narrowness of that interest (ie. strictly health related and fitting into the family). I am interested in what form of regulatory structure would operate in a world where prospective parents *are* concerned about these matters in the same way that they are concerned about what food their children eat, who they socialise with, where they go to school and what leisure entertainment they enjoy. While I will not make any attempt to justify the parents' *authority* to influence such characteristics, I will assume that there is a great probability that such entitlements will be asserted, once the technology arises. This view is also present in the US President's Council on Bioethics⁵⁵ publication in this area, which states:

⁵¹ Burg W. The Slippery Slope Argument. *Ethics* 1991;102(1):42-65. Actually, the HGC response appears to characterise genetic selection for enhancement as the 'apocalyptic' version of the slope, discussed in Burg where the lower end of the slope is presented as a set of horrific circumstances that nobody could ever possibly want. To this extent, their brief response to the slippery slope argument is peculiar, as they both appear to dismiss the very idea of one, but also employ the rhetoric of the apocalyptic slope.

⁵² Perhaps the closest is Mulkay, M. Embryos in the News. *Public Understanding of Science*, 1994, 3: 33-51; Mulkay, M. Changing Minds About Embryo Research. *Public Understanding of Science*, 1994, 3: 195-213.

⁵³ Human Genetics Commission, 2006, *op. cit.*, p.16.

⁵⁴ Glover, J., 1984, *op. cit.*

⁵⁵ The U.S. President's Council on Bioethics, 2003, *op. cit.*, p.41-42.

...we think it would be imprudent to ignore completely this approach to “better children.” More and more people are turning to assisted reproduction technologies (ART): in parts of western Europe, roughly five percent of all births involve ART; in the United States, it is roughly one percent and climbing, as the average maternal age of childbirth keeps rising and family size keeps declining. More and more people are using IVF not merely to overcome infertility but to screen and select embryos free of certain genetic defects. Women who plan to delay childbearing are being encouraged to consider early removal and cryopreservation of their own youthful ovarian tissue, to be reintroduced into their bodies at sites easily accessible for egg harvesting when they decide to have children.... Once more and more couples start screening embryos for disease-related concerns, and once scientists have identified those genes that correlate with various admirable traits, the anticipated expansion of improved and more precise screening techniques might enable users of IVF to screen for “desirable genes” as well.

Crucially, at stake is a claim about whether it is possible to characterise the *best* children, which, as was noted earlier, is quickly dismissed by the HGC as an impossible and unjustifiable term to institutionalise through legal entitlements. I will discuss a position that negotiates this problem offering a way of establishing a permissive environment for enhanced health genetic selection, while avoiding the concerns associated with engineering perfect people. To inform this conclusion, it is first necessary to develop a conceptual model for the various resistances to nondisease genetic selection.

Ethical Objections

As was noted earlier, the subject of this paper emerges in the context of the HGC inquiries, which have been accompanied by extensive debate within the medical ethics and law literature on the use of genetic technologies in reproductive decision making. It must also be remembered that our present case is not limited to testing for reproductive purposes, but extends to the general use of nondisease genetic tests in order to learn about a number of predispositions. To this extent, the hypothesis under inquiry claims that the HGC conclusions do not satisfactorily address the nuances of decisions associated with genetic technologies, since they underestimate the complexity of the technical and ethical distinction between therapy and enhancement. In part, this problem is compounded by their conflation of the terms ‘best’ and ‘enhanced’.

I agree with the HGC that the choices facing parents who rely on reproductive interventions does not leave much scope for its considering anything other than how to bring about as healthy a child as science allows. However, its conclusion identifies a set of social circumstances that explain rather than justify why this should be so. If one could foresee a situation where parents are presented with choices about how best to optimise their child’s health then, I suggest, this is likely to appeal. The HGC report is informed by a range of literature that establishes why the use of genetic information might give rise to a number of ethical issues. However, it will be useful to

identify some of these arguments in order to explain why permitting access to such tests or, indeed, promoting their development is not straightforward.

The following section provides a conceptualisation and reworking of the various ‘Objections’ to *nondisease* genetic selection, which then is applied to the specific case of selection for *enhanced health* as a series of ‘Responses’. A number of other authors have attempted to derive a classification of arguments surrounding selection.⁵⁶ As such, this overview of objections to nondisease genetic selection also constitutes an attempt to synthesise these various, but related, arguments into some coherent structure.

- The Incomplete Knowledge Objection
- The Competitive Logic Objection
- The Specific Child Objection
- The Prejudice Objection
- The Diminishing Openness Objection

The Incomplete Knowledge Objection

This first objection was alluded to earlier when discussing what kind of biological information might be characterised as non-health-related. While it is generally uncontroversial to claim that variation in some specific biological attributes has no major health-related impact, it is a harder task to dismiss them as relevant to the general health of a person. For instance, we would not identify predispositions to particular hair colours as having a particularly high-impact on health or, at least, not something that would be characterised as a disease.⁵⁷ Yet, one can envisage a range of modifications to hair colour, which provoke mixed responses to the question of whether it is likely to affect health generally. Thus, using a colour dye on hair might not be significantly harmful, even if prolonged colouring – perhaps bleaching – can damage the hair. However, if it were possible to genetically select hair colour, then there might be less certainty about the safety of such interventions. In part, this is because of the phenomenon of *pleiotropy*: the idea that single genes have multiple effects. After all, the condition of hair is often indicative of general states of health.⁵⁸

The lack of specificity in the relationship between genotypic and phenotypic characteristics constitutes one kind of a critique of attempting to make decisions on the basis of such information. Thus, de Melo-Martín⁵⁹ asks, in a world where we can select specific genes, ‘What do we select for?’, outlining the nature of the problem:

suppose we have to choose between embryo A that has a predisposition for physical strength but has normal height and embryo B that will be taller but will have normal strength. Or, a little more difficult, and also a more plausible scenario for the kinds of choices that parents might have to make, will give us

⁵⁶ Scott, R., 2005, Prenatal Testing, Reproductive Autonomy and Disability Interests *op. cit.*

⁵⁷ Yet, the condition of hair might also be an indication of health.

⁵⁸ Bayliss F. The Inevitability of Genetic Enhancement Technologies. *Bioethics* 2004;18(1):1-26.

⁵⁹ de Melo-Martín I. On our obligation to select the best children: A reply to Savulescu. *Bioethics* 2004;18(1), p.78.

embryo A that is more likely to have physical endurance, be prone to stress and ulcers, high intelligence, hearing problems, blue eyes, and very fair skin, and embryo B that will be more likely to be tall, have good memory, food allergies, brown eyes, physical beauty, and early hair loss.

This position appears in a number of other works including the HGC 2006 report and Glover's⁶⁰ seminal text and can be described as *The Incomplete Knowledge Objection*. It states that it is impossible to construct a meaningful claim over how one might bring about the best kinds of people through merely selecting for specific kinds of genes. This is because it is impossible to know what constitutes being the best kind of human due to the incompleteness of our knowledge about biology. For instance, in the context of selecting for intelligence, this view would claim that we do not know what constitutes the entirety of intelligence, so cannot know how best to select for it. At most, we have a partial understanding of neurobiological processes, which, in some way, explain variations in human cognitive capacities.

If this argument is applied to the present case of selecting for 'better than well'⁶¹ genes, or genes that are particularly valuable for a given pursuit, then various difficulties arise. First, for the claim to be sensible it would be necessary to show that there is a connection between the specific genetic characteristic and variation in the particular characteristics associated with the given activity. While this is difficult to establish, there is growing evidence to support the claim, so we will assume that this connection is demonstrable. Second, it would be necessary to justify whether the specific requirements of what is optimal for a given lifestyle – say, becoming an elite athlete or a surgeon - compromises any broader enjoyment of health. For instance, if an athlete is a sprinter and selection for fast-twitch muscle fibres was the target, then would such selection compromise any health requirements during, say, maturation or even old age? Finally, one might need to show that such positive selection would not affect the functioning of other biological processes. From the perspective of this Objection, one of the more fundamental problems relates to authorising a decision about what constitutes the best. In the context of PGD to select optimal genes, such decisions direct the future benefits for that person in a way that eliminates the possibility of reversal. In short, selecting for one type of characteristic is likely sometimes to imply an irreversible loss of another characteristic. Alternatively, selecting specific persons on the basis of such information would fail to account for the gene-environment interactions that a person encounters in the process of becoming exceptional at something.

The Competitive Logic Objection

De Melo-Martín⁶² provides a second criticism of attempts to select the best children, which can be described as *The Competitive Logic Thesis*. This argument claims that the rationale for selecting the best characteristics relies on the capacity of those

⁶⁰ Glover, J. 1984, *What Sort of People Should There Be?* *op. cit.*

⁶¹ Kramer, P. 1994. *Listening to Prozac*. London, Fourth Estate.

⁶² de Melo-Martín, 2004, *op. cit.*, p.78.

characteristics to offer a competitive advantage for the individual. For instance, there is only value in being tall if one is taller than the average height of a population and, even then only up to a point, for to be terribly tall (or short) can be disabling. Thus, if one aims to select a particular kind of best child because it will be socially advantageous, then freedom to do so would make sense only in a climate of inequality – one can benefit only in a world where others do not have such advantages and only up to the point where the social conditions within which that person lives enable the flourishing of that advantage.

Parens⁶³ and Brock⁶⁴ offer a similar argument, the latter of whom concludes that, *nobody gains* when everybody has the same competitive edge. In this sense, it could appear to be contrary to social justice to permit such actions, since only those who are first to utilise the technology will benefit. Others will merely slowly recover their equal status, though even this seems unlikely.⁶⁵ Moreover, it would be an ultimately self-defeating process, if one assumes that all such selections would gradually become accessible to all. In this potential future, the selected trait would cease to have value, since all people would have it. Importantly, Buchanan et al.⁶⁶ do not consider that such a response is valid in the context of therapeutic interventions:

The kinds of self-defeating effects we observed for cases in which everyone pursues a trait that confers competitive advantage are not present for treatments. If everyone pursues elimination of departures from normal functioning, the outcome is not self-defeating. (We ignore the very special case of antibiotics losing effectiveness after widespread use or overuse.)...There is a fairly broad consensus that it is important to restore to the status of "normal competitors" those whose opportunities are diminished by disease and disability. Consequently, the healthy do not (or at least should not) feel a sense of loss when their competitive advantages over the sick or disabled are thereby lost.

In any event, De Melo-Martín⁶⁷ acknowledges that this *competitive logic* objection makes sense only for those selections that are conceived as competitively advantageous and it relies on the assumption that an opportunity to select nondisease characteristics will illicit precisely those kinds of choices.

The Specific Child Objection

A third criticism of selective practices for nondisease characteristics can be described as the *Specific Child Objection*. This argument objects to the procreative liberty to

⁶³ Parens E, ed. *Enhancing Human Traits: Ethical and Social Implications*. Washington, D.C.: Georgetown University Press, 1998.

⁶⁴ Brock DW. Enhancements of Human Function: Some Distinctions for Policymakers. In: Parens E, ed. *Enhancing Human Traits: Ethical and Social Implications*. Washington, D.C.: Georgetown University Press, 1998: 48-69.

⁶⁵ This assumes a Rawlsian approach to social justice, which deems that the natural lottery should not be corrected, but that societies must address the resulting inequalities.

⁶⁶ Buchanan A, Brock DW, Daniels N, Wikler D. *From Chance to Choice*, 2000, *op. cit.* p.187.

⁶⁷ de Melo-Martín, 2004; *op. cit.*

select nondisease genes, since such liberty or right does not extend to such *specific* claims as individual genetic characteristics. As Mahowald⁶⁸ explains, this argument ‘erroneously assumes that the right to reproduce implies the right to reproduce a child of a specific kind.’ On this view, one might legitimately claim a negative freedom not to have one’s procreative freedom obstructed, but one cannot claim a positive freedom to bear specific kinds of children. Rather, the right is more general.⁶⁹ Thus, one cannot defend a moral or legal right to have a child with blue eyes, although I can defend a general legal right to wanting to give birth to a child who is free from severe disability.⁷⁰ Buchanan et al.⁷¹ offer further justification for this by discussing *general purposes means*. On this view, therapeutic selective decisions are justified on the basis that they enable the achievement of a number of *general* life plans, whereas nondisease selection decisions are directed towards *specific* life plans. In the context of the previous example, the claim would be that it is acceptable to select for a child that has the capacity of vision, but not for one that has blue eyes, because, unlike the capacity to see at all, eye colour is not a relevant factor in the establishing of general life plans.

The Prejudice Objection (The Expressivist Objection)

Perhaps one of the most frequent criticisms of selection for nondisease traits is the claim that it would devalue specific kinds of individual. As Edwards⁷² notes, the ‘practice of prenatal screening for disability is sometimes objected to because of the hurt and offence such practices may cause to people currently living with disabilities.’ This argument has arisen in the context of selecting for sex or sexual orientation.⁷³ Yet it has also received considerable attention in the context of traits that are recognised as disabling or disease based. From this position, even the use of genetic selection for avoiding disease traits has received criticism. As such, one might wonder what kind of response the expressivist view would take to nondisease traits. However, before elaborating on this, it will be useful to outline this objection through examples. Over the last five years, the prospect of using genetic tests to select for sex has emerged, particularly for couples who seek to avoid passing on a sex-related genetic dysfunction to their offspring. This possibility, nevertheless, has given rise to broader discussions about the conditions in which sex selection might more widely be used.

One of the concerns about selecting for sex is the prospect that it might show a positive valuing towards a particular sex. More specifically, commentators have noted that in some cultures, the social pressure to give birth to a boy might exacerbate gender inequalities within society. Thus, in an era where feminist approaches to bioethics have drawn attention to the dominant patriarchal values of health care, the

⁶⁸ Mahowald MB. Reverse Sexism? Not to Worry. *American Journal of Bioethics* 2001;1(1), p.15.

⁶⁹ This is accurate in both the Human Rights Act (1990) and the European Convention on Human Rights (1950).

⁷⁰ The Abortion Act, 1967.

⁷¹ Buchanan et al. *From Chance to Choice: Genetics & Justice*. 2000, *op. cit.*

⁷² Edwards SD. Disability, identity and the 'expressivist objection'. *J Med Ethics* 2004;30, p.418.

⁷³ Stein E. Choosing the sexual orientation of children. *Bioethics* 1998;12(1):1-24.; Conrad P, Markens S. Constructing the 'gay gene' in the news: optimism and scepticism in the US and British press. *Health and Human Rights* 2001;5(3):373-400.

anticipated positive evaluation of male children arising from a permissive environment for sex selection has received considerable support.⁷⁴ Strong objections to genetic selection also arise in the context of selecting out disabling characteristics. Expressivist objectors advocate a social model of disability, which emphasises the view that the disvaluing of disabilities is due to inadequacies within the social environment to accommodate varying needs, rather than because of some inherent lack of value that impairment entails. As such, to omit selection of potential lives that exhibit abnormalities simply condones the view that the lives led by people with disabilities are less preferable. In contrast, Shakespeare⁷⁵ argues that this evaluation is a product of social circumstances, rather than an indication of anything inherent about disability. Moreover, the burden should be on society to change the disvaluing of disability, rather than permit individuals to avoid the creation of such people through genetic selection.

In the context of selecting people for specific tasks based on their genotype (postnatal selection), the potential for discrimination in a number of spheres, such as employment or insurance, has also been highlighted.⁷⁶ In this case, resistance is more broadly accepted on account of the potential harm to specific people it would create. In contrast, legislation against prenatal selection on this basis does not affect specific people directly, but more the community of interests of specific groups of people. Yet, the expressivist objection indicates that such choices to *not* bring into the world people with disabilities will, nevertheless, eventually harm specific people with disabilities through *loss of support*, both political and financial, for their special needs.⁷⁷

The Expressivist Objection is particularly interesting when considering prenatal and postnatal selection for enhanced health characteristics, as it shifts the discourse somewhat. Whereas *negative* prenatal selection for specific genetic disorders or abnormalities (selecting-out disabling characteristics) might constitute a harm to people who live worthwhile lives despite such conditions, *positive* selection for enhanced health (selecting-in enhanced characteristics) does not engage any specific group. In short, there is no community of interests that is at stake in this case, other than humanity itself. Indeed, embarking on choices to select enhanced health characteristics would involve conceptualising the whole of humanity as disabled, since medically 'normal' characteristics would still be considered below the optimal level.

⁷⁴ Holm S. Like a Frog in Boiling Water: The Public, The HFEA and Sex Selection. *Health Care Analysis* 2004;12(1):27-39.

⁷⁵ Shakespeare T. Choices and Rights: eugenics, genetics and disability equality. *Disability and Society* 1998;13(5):665-681.

⁷⁶ Cook DE. Genetics and the British insurance industry. *J Med Ethics* 1999;25(2):157-162; Rothenberg KH. Genetic Information and Health Insurance: State Legislative Approaches. *Journal of Law, Medicine & Ethics* 1995;23:312-319; 1. Sandberg P. Genetic Information and Life Insurance: A Proposal for Ethical European Policy. *Social Science Medicine* 1995;40(11):1549-1559; Wolf SM. Beyond 'Genetic Discrimination': Towards the Broader Harm of Geneticism. *Journal of Law, Medicine & Ethics* 1995;23:345-353; Wong JG, Lieh-Mak Felice. Genetic discrimination and mental illness: a case report. *J Med Ethics* 2001;27:393-397.

⁷⁷ Scott, R. Prenatal Testing, Reproductive Autonomy and Disability Interests, 2005, *op. cit.*

Perhaps the most common objection to selecting for specific characteristics is that it would create distinct classes of people. This prospect is neatly characterised in the science fiction movie *GATTACA*⁷⁸, which articulates the relative social value of the ‘designer human’ and the ‘in-valid’. For postnatal selections – such as using genetic tests to select the athletes with the best genes – the objection is also more complex. The Australian Law Reform Commission⁷⁹ considers that permitting such tests could legitimise unreasonable discriminatory practices. Yet, some scientists consider such information to be an accurate way of informing the process of talent identification and selection. The crucial issue seems to be whether the information derived from such tests is relevant to the specific requirements of the task for which the person is selected. Again, the complexity of most social practices – including sport – has provoked considerable resistance to the claim that genetics should be a significant factor in any form of selection process.

*The Diminishing Openness Objection*⁸⁰

Finally, one can oppose a rights-based claim to nondisease genetic testing and selection by applying a modified version of Feinberg’s⁸¹ thesis on the value of an ‘open future’. This position can be described as the *Diminishing Openness Thesis* and asserts that a child’s right to an open future prohibits choices by parents that *might* diminish that openness. Feinberg explores the legitimacy of selection by considering whether one could justify selecting for characteristics that are often described as disabling. The context of his analysis relates to the interest from within the deaf community in selecting positively for deafness. He argues that it would be morally unacceptable to positively select for disabling characteristics, because the rationale for such a choice fails to optimise the openness of the prospective child’s future.

Moreover, Feinberg discusses our obligation to *maximise* such openness. Thus, positive action to bring about someone’s incapacity to hear is to partake in diminishing the openness of their future. Importantly, the claim is not that this would constitute harm – since this would require taking a stance on whether it is preferable to lack or have the capacity to hear. Rather, it is to identify the range of opportunities a person might face in life and identify which might be a preferable set of circumstances if one were, perhaps, behind a ‘veil of ignorance’⁸².

An additional challenge from this objection is that selection exerts an unjustified (and unnecessary) substituted judgment over what might be best for someone. The

⁷⁸ Niccol, A. (dir.) (1997). *GATTACA*.

⁷⁹ Australia Law Reform Commission, 2003, *op. cit.*

⁸⁰ The choice of the word ‘diminishing’ is deliberate. It is not enough to say ‘diminished’ openness, as this would encounter the difficulty of having to establish how diminished a life must become before it is less valuable. Instead, the word diminishing offers a general moral stance on actions that diminish in any capacity. Thus, on this view, a life that is more diminished than it otherwise could have been is considered to have been harmed.

⁸¹ Feinberg J. The Child's Right to an Open Future. *Freedom and Fulfilment: Philosophical Essays*. Princeton: Princeton University Press, 1980/92: 76-97.

⁸² Rawls J. *A Theory of Justice*. Cambridge Mass: Harvard University Press, 1971.

alternative of not denying the possibility of hearing might not be a better kind of life, but, critically, the individual could decide for themselves what might be best – a life with or without the capacity to hear. In this sense, deliberately removing capacities thus, oversteps the authority of any prospective parent. Schonfeld⁸³ makes a similar claim in the context of genetic enhancements of the potential child, which he considers violates ‘the parent’s fiduciary responsibility’. He goes on to claim that,

Given that we do not know what interests the child will develop, genetic enhancements impose particular values on the child. This is at least partly because enhancing certain abilities and opportunities diminishes others.⁸⁴

Schonfeld offers a sporting example to make his point, considering Sarah, a young girl who wants to be a successful soccer player.

So, we also enhance Sarah’s genome with the “increased quickness and dexterity” trait prior to her birth. Assuming that the science is perfected by then, there is a strong likelihood that Sarah will be a successful soccer player, which would open up other opportunities for her—perhaps playing the sport professionally, or even simply ensuring her entrance into an Ivy League university, which would give her a chance to develop other skills and talents, both those genetically enhanced and those not. It seems, then, that enhancing both Sarah’s intelligence as well as her quickness and dexterity is acting for her benefit and would be at least permissible according to our fiduciary role, if not specifically required by it.⁸⁵

He goes on to state that harms might arise if Sarah decides, at some point, that she does not like soccer any more and that this might give rise to incredible pressure to continue, despite her own wishes. Moreover, he proposes that changes to a person’s physical constitution provoke a ‘physicalization of value’⁸⁶, which encompasses the development of ‘dubious social and cultural ideals’.

Extending Feinberg’s position, one might argue that positive selection for enhanced health characteristics also limits the openness of the child’s future, though the effectiveness of this argument relies on two components, a) the specificity and b) irreversibility of the selection. Thus, if the selection is too specific, then this might diminish the range of opportunities to pursue other life choices. Also, if the selection is irreversible, the child will be unable to undo the actions of the parents who made the choice about what is best for the child.

⁸³ Schonfeld T. Parents of Unhappy Poets: Fiduciary Responsibility and Genetic Enhancements. *Cambridge Quarterly of Health Care Ethics* 2003;12, p.411.

⁸⁴ *ibid.*

⁸⁵ *ibid* p.413-4.

⁸⁶ *Id*, p.415.

Other Objections?

This framework of objections is unlikely to be exhaustive of all forms of objection. However, it does attempt to structure the range of objections that have been made in relation to genetic selection. Moreover, it establishes – by omission – which forms of objection are indirect or which mask more deeply founded objections. For instance, the objection from eugenics is, I suggest, more accurately conceived as an Expressivist Objection. Yet, it is often used as an end point of an objection – the possibility that something is eugenic in principle is often considered a sufficient basis on which to disqualify it as a legitimate choice. Alternatively, the ‘slippery slope’⁸⁷ argument is not an objection in itself, but only because it leads to a situation that is objectionable for one of the reasons I have specified.

It is also useful to note that these arguments constitute a framework of objections, which means that they are not intended for use in isolation from each other. For instance, the relationship between the Diminishing Openness and Incomplete Knowledge objections is critical. Thus, because our knowledge about human biology is incomplete, we cannot claim much certainty over what selections widen or narrow the openness of a potential child’s future. Other objections have not been mentioned in great depth, such as the resource costs associated with providing genetic tests for nondisease or enhanced health characteristics. Indeed, the HGC notes that genetic profiling on a national scale for genetic disorders is unlikely to be affordable for at least 20 years.⁸⁸ This argument relates closely to medical necessity as a basis for determining what can be offered from medicine.

In the case of prenatal genetic selection, I also omit objections in relation to the moral status of the embryo. In part, this is because there are no novel circumstances posed by this prospect. The same ethical issues arise for enhanced health selection as for IVF more generally. Even the crucial difference advanced in relation to nondisease selection does not apply with the same strength here, as the characteristics of selection are those that confer some health-related benefit. Thus, it is assumed that the minimal rights of the embryo make permissible the use of such practices.⁸⁹

The case against prohibition

Clarity over the regulatory framework for genetic selection for nondisease traits has developed considerably over the last ten years. Yet, the HGC’s⁹⁰ terminology fails to distinguish between genetic testing and selection for various purposes. These distinctions might be summarised as follows,

- a) Avoiding a disease or disability.
- b) Selecting a nondisease trait (such as sex or intelligence).
- c) Selecting for enhanced health.
- d) Modifying aesthetic characteristics.

⁸⁷ Daniels N. It Isn’t Just the Sex. *American Journal of Bioethics* 2001;1(1):10-11.

⁸⁸ Human Genetics Commission, 2006, *op. cit.*, p.76.

⁸⁹ Fleming L. The Moral Status of the Foetus: A Reappraisal. *Bioethics* 1987;1(1):15-34.

⁹⁰ Human Genetics Commission, 2006, *op. cit.*

The last of these categories appears to correspond with the HGC's definition of enhancement, but it is not particularly clear what the HGC considers would be enhanced by making such a choice. In contrast, one might claim that selecting for enhanced health is a morally universal good, at least in so far as the HGC characterises therapy in this way. Some of these nuances of terms are teased out in the following responses to the theoretical objections.

The Incomplete Knowledge Objection: While it seems reasonable to accept that humanity still does not know everything (or enough) about biology to know which genetic characteristics are optimal for health, there are clearly some characteristics that are valuable in specific contexts. Forgetting genetic tests for one moment, the observable characteristics of young athletes or musicians who appear talented means that we can know something about who might be best without having to know everything about the person's health. For instance, within sport, there is some evidence for presuming that the athletes who make it to the champion's podium did so on the basis of some talent, even if this was accompanied considerably by expertise support systems, such as technological artefacts or scientific knowledge. Thus, the present systems of talent identification are likely to be meaningful. To this extent, basing choices about selection on a claim about what we currently know to constitute athletic excellence is some rationale for extending these methods to genetic selection. So, if it is common for sprinters to exhibit a high proportion of fast-twitch muscle fibre types, then it is unlikely that a genetic test for such characteristics will require any further details in order to verify the claim.

The more difficult problem arises in the context of prenatal genetic selection for enhanced health characteristics. In this case, decisions would not be made in relation to a specific life plan – such as being an athlete or a musician. Rather, it would require adopting a 'view from nowhere'⁹¹ from which to assert what might be valuable for a particular (but unknown) future person. Nevertheless, a number of sensitivities might reasonably be described that could be valuable to cultivate or avoid, such as body leanness or non-obesity.

Competitive Logic Objection: The competitive logic position does not take into account the inherent value of raising all peoples' capacities, which is enabled by selecting for enhanced health. Thus, even if the competitive advantage of any such enhanced capacity were normalised over time, humanity would still find itself better-off by its being comprised by people who are more capable than they would otherwise have been. Thus, if we select for intelligence, one presumes that, eventually, the overall standard of intelligence of people within the world will improve.⁹² Alternatively, if it is possible to select for enhanced speed, then there are a number of day-to-day functions that could be made easier.

⁹¹ Nagel T. *The View From Nowhere*. Oxford: Oxford University Press, 1986.

⁹² It is tempting to engage with the conceptual meanings associated with intelligence. For instance, what is the difference between intelligence and wisdom, or different forms of intelligence, such as emotional or computational? However, this would stray too far from our present inquiry.

The Specific Child Objection: This Objection has met some challenges in relation to sex selection where some authors claim that it should be of no concern to governments to legislate for the selection of *trivial* characteristics or, if the reasons for selecting specific characteristics are trivial or 'morally neutral'.⁹³ Others have claimed that, precisely because the sex of a child is trivial, it should not be important to have the freedom to select for such a characteristic. Such a view has been expressed in relation to sex selection for *family balancing*.⁹⁴ Yet, Savulescu⁹⁵ notes that this trivial request has personal importance to those families who seek to act upon their strong preference. Moreover, he indicates that the circumstances of these choices are reasonable: 'In the US, 90% of couples wanting sex selection wished to balance sex within the family. Parents were in their mid thirties, had two or three children and only wanted one more' (p.374). However, the HFEA⁹⁶ notes that the majority of people would still be against such freedom, even in the case of family balancing, which constitutes the least objectionable use of sex selection. Moreover, Ruddick⁹⁷ identifies that such permission could also be regarded as harmful to unbalanced families; it espouses the view that the preferable or ideal state for families is balanced. The consequences of this can be a weakening of the procreative rights afforded to people who do not live by such standards.⁹⁸ In response to Robertson's⁹⁹ defence of sex selection for such purposes, Ruddick notes that: 'Robertson's proposals and underlying analyses have heterosexist constraints he should wish to avoid' (p.14).

Clearly, a number of different views underpin the desire to balance a family. For many parents, family balancing might not be an appropriate term to describe the interest. For instance, if a parent or parents have two children of one sex, the desire to have a child of a different sex might be because one of the parents would like to have a child of their own sex. Again, such views could be similarly innocuous and reasonable¹⁰⁰ –as described in Savulescu's example – to the extent that it is generally reasonable for parents to have such feelings and that this is not objectionable.

Yet, even for family balancing purposes, views on the legitimacy of sex selection remain divided. As such, it is unlikely that it would be used for any other social purpose. However, this is where the case for enhanced health selection offers slightly different considerations. The major concern surrounding sex selection – from the perspective of the specific child objection – is that it overstates the breadth of parental rights. In contrast, selecting for enhanced health would be consistent with promoting

⁹³ Harris, J. No Sex Selection Please, We're British, *op. cit.*, p.286.

⁹⁴ Leather, cited in Holm, S. Like a Frog in Boiling Water, *op. cit.*, p.30.

⁹⁵ Savulescu J. Sex selection: the case for. *Medical Journal of Australia* 1999;171:373-375.

⁹⁶ HFEA, Sex Selection: Options for Regulation. 2003, *op. cit.*

⁹⁷ Ruddick W. Prejudice Against 'Unbalanced' Families. *American Journal of Bioethics* 2001;1(1):34-36.

⁹⁸ Sutherland EE. 'Man Not Included' -- Single Women, Female Couples And Procreative Freedom In The UK. *Child and Family Law Quarterly* 2003;15(2):155.

⁹⁹ Robertson JA. *Children of Choice: Freedom and the new reproductive technologies*. Princeton: Princeton University Press, 1994.

¹⁰⁰ Benn, P. The Sex Selection Question. *Spiked-Online*. London. 2001 (16 November). Hypertext Document. Available Online: <http://www.spiked-online.com/Articles/00000002D2D1.htm>. [Accessed: 8 December, 2002].

‘general purpose means’, as required by Buchanan et al.¹⁰¹ For example, consider a predisposition to developing asthma. Savulescu¹⁰² uses this example to argue in favour of selecting an embryo that has no such predisposition on the grounds that having asthma reduces quality of life. Now, let us consider being able to select for particularly efficient respiratory capacities. The specific form of this selection is not necessary to establish here, but it might, for instance, involve selecting for genes associated with endurance capacities.¹⁰³ In this case, the claim on behalf of such choice would be that this selection would not be specific in the sense that it limits other capacities, but would be generally health promoting. Such capacities might allow one to enjoy endurance activities even more and promote healthier living. Thus, the Specific Child Objection is not engaged by this type of genetic selection.

The Prejudice Objection: Edwards¹⁰⁴ argues that the Expressivist Objection is not morally sound because it ‘require moral agents to place the obligations not to harm others above their wishes to enact their autonomous choices, and their choices to avoid avoidable harms.’ Even accepting the identity claim of the expressivist objection – that disability is constitutive of identity and that, therefore, the selecting out of these characteristics is an affront to the identity of disabled people – Edwards concludes that it is not compelling on account of three factors:

... [it] does not follow from this that it is right to place the obligation not to harm others above the right to have one’s own reproductive autonomy respected...one can consistently hold two views: (a) prenatal screening is justified; and [b] disabled people should be supported....acceptance of the expressivist objection seems to lead to a *reductio ad absurdum*....it will apply in cases where disability is caused in some other way – for example, by illness or physical trauma (as – for example, in the case of Christopher Reeve).¹⁰⁵

In the context of genetic selection for enhanced health characteristics, each of these arguments also holds. Moreover, the claim that this would be a challenge to the whole of humanity – as well as characterising all people as disabled – perhaps would not diminish support for disabled people. Indeed, if one envisages that medicine will develop multi-packaged genetic tests, then a higher proportion of people might identify themselves as potentially disabled. In turn, this could lead to greater support for the interests of disabled people.

Alternatively, the argument that such selection practices would be an affront to human dignity itself lacks substantive content. It is unclear why human dignity should be challenged at all, since there is no proposition that individuals will lose any of their autonomy in making decisions about the choices they make. However, perhaps this

¹⁰¹ Buchanan et al. *From Chance to Choice: Genetics & Justice* 2000, *op cit.*, p.167.

¹⁰² Savulescu, J. *Procreative Beneficence*, *op. cit.*

¹⁰³ Yang N. et al. ACTN3 Genotype Is Associated with Human Elite Athletic Performance, 2003, *op. cit.*

¹⁰⁴ Edwards, S. D. *Disability, Identity and the 'Expressivist Objection*, *op. cit.*

¹⁰⁵ I do not see that the identity claim is engaged by this final argument, which might invalidate its relevance. Nevertheless, the first two arguments seem adequate to refute the expressivist objection.

requires further clarification on what is meant by the word *dignity*. Edgar¹⁰⁶ notes three different conceptualisations of dignity that should be present in order to ensure dignity is not challenged:

- dignity of the body (dignity is challenged through loss of bodily control).
- dignity of merit (dignity is challenged by being obstructed in forming social roles).
- dignity of moral status and identity (dignity is obstructed by infringements to freedom of expression through language).

In each of these cases, there is no obvious challenge posed by the use of genetic selection for enhanced health. For the prenatal life, any *control* that is exerted over the body exists prior to a claim of autonomy and, thus, the child that is chosen could not claim to have been affected. For the postnatal use of enhanced health selection, the objection from dignity might be less clear. One could foresee genetic tests being used to the detriment of individual liberties. Yet, there is nothing particular about genetic tests for enhanced health, compared with disease or nondisease traits here.

The Diminishing Openness Objection: A response to the diminished openness objection is found in part from the conclusion of the previous response. Scholars have pointed out that an embryo selected on the basis of its having or lacking specific characteristics cannot claim to have been harmed, as it could only ever have been born in this way. This is the view advanced by Derek Parfit's¹⁰⁷ 'non-identity problem'. The other embryos – those not selected – will also never come into existence to find themselves subject to the harms of this action. As such, there is no harm, because the alleged harm is towards a *non-identity*, which cannot be harmed. To elaborate on this, Gavaghan¹⁰⁸ offers a useful example from the film GATTACA. One of the leading characters, Jerome, is troubled throughout his life, as he feels unable to live up to the achievements of his genetically perfect brother. Gavaghan claims that Jerome has no such recompense or justification for feeling that he has been harmed by not having been made genetically perfect, since he could not have been any other person. Indeed, one might argue merely that Jerome finds himself in the same situation as many non-selected children, who wrestle with the expectations others have of them to succeed. In the same way that one cannot claim to have been harmed by having parents with high-expectations, one cannot claim to have been harmed by having one's genes selected.

Thus, the child who is born with an enhanced genetic potential just because her embryo appeared to be the healthiest would have no basis on which to claim that any harm had been done. Moreover, it is unlikely that this choice will have diminished the opportunities she might encounter throughout life. To return to the example of Sarah

¹⁰⁶ Edgar A. A Response to Nordenfelt's 'The Varieties of Dignity'. *Health Care Analysis* 2004;12(2):83-89.

¹⁰⁷ Parfit D. *Reasons and Persons*. Oxford: Clarendon Press, 1984.

¹⁰⁸ Gavaghan, C. Off-the-Peg Offspring in the Genetic Supermarket. *Philosophy Now*, 1998 22(Winter). Hypertext Document. Available Online: <http://www.philosophynow.org/archive/articles/22gavaghan.htm> [Accessed: May 2005].

the soccer player, Schonfeld's¹⁰⁹ concerns do not apply because Sarah would never have been designed for soccer specifically. Instead, those characteristics of 'increased quickness and dexterity' will have been useful for a whole range of life plans or, at least, other plans will not be inaccessible just because these capacities have been optimised. The same is true for other characteristics. For instance, let us suppose that we select positively for perfect musical pitch (non-tonedeafness) or leanness (non-obesity), both of which are considered by the US President's Council on Bioethics.¹¹⁰ In neither of these cases is the selected capacity likely to diminish other capacities in any way that could be seen as unreasonable or harmful.

The case for permission

The previous sections find only limited strength in the arguments against using genetic tests to select for enhanced health. However, they do not constitute a positive case for non-medical genetic selection generally and selecting for enhanced health specifically. Initially, I developed a distinction between a range of concepts that are often conflated in the discourses surrounding non-medical genetic selection, pointing out that the regulatory definitions within the UK do not separate different forms of enhancement – nondisease, aesthetic modifications or enhanced health. In this capacity, the argument makes no particularist claim about what would constitute the *best* children, beyond enabling the healthiest characteristics to be chosen. This is different from the arguments made by Savulescu, whose approach is directed towards nondisease more broadly. However, I have argued that Savulescu's conceptualisation and the HGC's definitions conflate various terms associated with genes and their functions. For instance, the HGC seems particularly concerned with positive selections that amount to *aesthetic* evaluations, rather than *enhancements*. In contrast, Savulescu attempts to show why selection for nondisease genes would be socially innocuous and why, as such, there would be no justification to interfere with parental or individual freedom to use such tests.

Within this section, I wish to more fully advance the positive case for genetic selections for enhanced health. Again, Savulescu¹¹¹ is useful here insofar as his case for selecting the *best* children involves a claim about selecting the *healthiest* children. He justifies this using some of the arguments we have already encountered. For instance, Savulescu talks about selecting children that are likely to have the most prosperous future, which is similar to Feinberg's¹¹² claim that we have an obligation to optimise the openness of a child's future. In his defence of Robertson¹¹³, Savulescu argues on behalf of the general permissibility of selection for nondisease genes. However, his thesis does not extend to other nondisease parameters. Instead, Savulescu's thesis relies on a general concept of betterment that requires further interrogation. Moreover, his focus on improving intelligence does not assist his

¹⁰⁹ Schonfeld, T. *Parents of Unhappy Poets*, 2003, *op. cit.*, p.413.

¹¹⁰ The U.S. President's Council on Bioethics, 2003, *op. cit.*

¹¹¹ Savulescu, J. *Procreative Beneficence*, 2001, *op. cit.*

¹¹² Feinberg, J. *The Child's Right to an Open Future*, 1980/92, *op. cit.*

¹¹³ Robertson JA. Preconception Gender Selection. *American Journal of Bioethics* 2001;1(1):2-9.

position, insofar as the development of intelligence is a fiercely contested concept. Moreover, the range of values associated with intelligence itself is contested. For instance, one might question the value of a world populated by rationally intelligent people who lack, say, emotional intelligence or wisdom. These two terms have clearly different qualities and beg the question as to what is expected to improve as a consequence of selecting for greater levels of intelligence or, indeed, how this might be measured. More specifically, Savulescu's broad theoretical position on enhancement invites a critique from casuistry, since specific applications lead to quite different interpretations of the legal and moral claim to one's entitlement to enhance.

Enhancement as the accumulation of Biocultural Capital

One of the crucial difficulties with Savulescu's argument is the contested status of the word *best*, which implies a number of eugenic connotations. Such a view often invites criticism about the impossibility of establishing what might be the best child. Again, the Specific Child Objection applies here. In response, I argue that the term *best* need not involve any normative claim. Indeed, an argument on behalf of selecting the best children should not involve any claim about what might be the perfect human. Rather, the claim is more particular and involves complex 'strong evaluations'¹¹⁴ about what might be valuable characteristics for particular persons to embody (ie. *my child*, rather than *children generally*). For instance, the HGC discusses selection choices to improve beauty and I have indicated that this does not constitute enhancement. Thus, if the claim is that genetic selections for beauty should be considered as enhancements, then this is both mistaken and, potentially, eugenic. It implies the construction of a blueprint for an ideal human. However, I doubt that this is how most people think about the meaning of beauty. Rather, a more reasonable and representative explanation of beauty is found in the HGC report, which indicates that most families are concerned with their child 'fitting in' to the family. While such a concept is difficult to clarify, presumably, it might involve wanting a child to have the same ethnic origins as other members of the family. Alternatively, it might involve an expectation of enjoying familiar means of communication with one's child. Indeed, this principle is what makes the claims of the American deaf lesbian couple who sought a deaf sperm donor difficult to dismiss, because there is something that appears consistent with how one imagines a *beautiful* relationship between parents and children.

Importantly, this position does not constitute an argument for permitting the couple to positively select for deafness, as this would violate the Diminishing Openness Objection. Yet, the claim about *fitting into a family* and, for instance, wanting a child that has the same ethnic origins as the parents, would be inextricable from this particularist definition of beauty. Moreover, the reverse might also be true – a couple might seek a child of different ethnic origin on the basis of some claim about the value of diversity within families. In both cases, the beauty one sees in a child is intimately connected with one's own identity and values – whether this is identity in

¹¹⁴ Taylor C. *Source of the Self: The making of modern identity*. Cambridge: Cambridge University Press, 1989, p.7.

physical appearance or character.¹¹⁵ The value implied by seeking to make such choices is not a general normative one, but a particular and relativist claim, which amounts to what I will characterise as a statement towards the accumulation of *biocultural capital*. This term derives from Bourdieu's¹¹⁶ notion of cultural capital, which is usefully explained by Rojek¹¹⁷:

The term 'cultural capital' refers to the knowledge of and skills in the discursive realm relating to society, the arts, leisure, sport, science, politics and all the other elements recognised as 'culture' in society at large.'....'[Bourdieu's] interest is in how society evaluates this cultural capital through visible and tacit systems of reward and punishment.

Bourdieu considers extensively the role of the body in this accumulation of cultural capital and even talks of the body as an unfinished product, but does not allude to the role of biological modifications in this accumulation. As Shilling¹¹⁸ notes,

[Bourdieu] displays a clear interest in the unfinishedness of the body, and maintains a more comprehensive view of the materiality of human embodiment than those theorists who focus exclusively on language, consciousness, or even the body as flesh. Bourdieu recognises that acts of labour are required to turn bodies into social entities and that these acts influence how people develop and hold the physical shape of their bodies, and learn how to present their bodies through styles of walk, talk and dress. Far from being natural, these represent highly skilled and socially differentiated accomplishments which start to be learned early in childhood. As it develops, the body bears the indisputable imprint of the individual's social class (Bourdieu, 1984).

I suggest that the accumulation of *biocultural capital* is ambiguously placed in relation to these claims. While claims about how biological modifications might give rise to the accumulation of cultural capital - for instance, encouraging a child to wear braces on his or her teeth – one cannot readily identify a social system that is implied through such alterations (unlike choices about education). Perhaps a useful example is cosmetic surgical interventions, such as breast reduction or enlargement. How would such an example fit within my proposed defence of genetic selection for enhanced health? First, it is critical to note that it is generally permissible to seek such alterations on the basis of personal taste or well-being. Yet, critics of trends towards such modifications might question whether any valued benefit accrues or, indeed, whether the aesthetic choice resonates with some higher concept of beauty. Moreover, critics identify cosmetic interventions as a basis for claiming that people will generally select the same kinds of enhancements and that this amounts to *cultural*

¹¹⁵ Indeed, one might further claim that these two attributes are also closely related. Consider a smile for instance. It is not easy to separate the appearance of a smile from the character implied.

¹¹⁶ Bourdieu P. *Distinction: A Social Critique of the Judgement of Taste*. London: Routledge, 1984.

¹¹⁷ Rojek C. *Decentring Leisure: Rethinking Leisure Theory*. London: SAGE, 1995, p.68.

¹¹⁸ Shilling C. *The Body and Social Theory*. London: SAGE, 1993, p.128.

*complicity*¹¹⁹ or *personal eugenics*¹²⁰, which would give rise to a less diverse society. Perhaps even more seriously, the claims extend to dismissals of such choices on the basis that such people's lives will not be any better fundamentally.

In response, the biocultural capital argument refutes the moral claim that rejects such choices, on the basis that it constitutes an appeal to an aesthetic value.¹²¹ A suitable comparison arises in the context of aesthetic appreciation more generally. Thus, over the last few years, it has been common for the popular press to rubbish such artistic competitions as the Turner prize on account of a presumed question about whether the competitors' exhibits can legitimately be described as art. This positioning of aesthetic appreciation is a good example of the politically necessary relativising of aesthetic preferences. However, it does not constitute a claim about the value systems within which those judgements are made. Similarly, my justification for genetic selection for enhanced health involves permission to accumulate biocultural capital where this involves two expectations: a) selection as an expression of deeply valued preferences and tastes and b) as a mechanism for social mobility.¹²²

By implication, I also claim that permission to utilise genetic tests and select for this purpose can disrupt social hierarchies and power structures, since, unlike education or indeed complex medical procedures, the financial requirements to access information specific to enhanced health characteristics would be reasonably low. Of course, the costs of PGD itself remain prohibitively expensive for most people. Moreover, the complexity of the process is unlikely to appeal to couples who have no difficulties with procreating without assistance. However, the crucial claim is that – where PGD is used, it should also be used to select for enhanced health characteristics and this need not imply any significant greater costs. Additionally, the argument applies also to postnatal genetic testing and selection, which need not encounter these burdens. Such choice offers the chance for individuals to take decisive actions that can directly affect the prospects their children or themselves might face. To use a metaphor, if birth by natural means is characterised as a *lottery*, then utilising genetic selection transform the game into something like *poker*, a game where the outcome is attributable, in part, to individual decisions.¹²³

Locating the Burden of Proof

While the previous argument might go some way to establishing the value of using genetic tests to make enhanced health selections, it does not establish how this would function as a legal entitlement and what responsibilities this might imply on legislative authorities to regulate the practice. Perhaps first it is useful to outline what principles of justice are maintained by this permissive argument. One of the key

¹¹⁹ Little MO. *Cosmetic Surgery, Suspect Norms, and the Ethics of Complicity*. In: Parens E, ed. *Enhancing Human Traits: Ethical and Social Implications*. Washington, D.C.: Georgetown University Press, 1998: 162-176.

¹²⁰ Morse, A. *Searching for the Holy Grail*, 1998, *op. cit.*, p.243.

¹²¹ A useful adjunct to this is the literature that describes the 'Yuk Factor' associated with genetic enhancement and other biotechnological interventions.

¹²² Indeed, these two elements also correspond with Edgar's analysis of dignity.

¹²³ I will avoid any claims about the relative virtues of people who tend to play poker, compared with those who play the lottery!

principles at stake in the discussion over how medicine is regulated involves locating the burden of proof. As McCarthy¹²⁴ notes, in a free society, there is a ‘presumption in favour of liberty’ and that, echoing Mill, the ‘burden of proof is on the opponents to show that those whose liberties they propose to restrict cannot reasonably reject this restriction.’ (p.306). Pursuing this further in the context of sex selection, McCarthy identifies three grounds on which broad reproductive liberty could be challenged:

1. if they ‘interfere with the basic liberties of others’
2. if they involve ‘harm, or the risk of harm’ (to the child or mother)
3. if there are ‘broader social costs’ (threat to the sex ratio, resource costs, too much choice, slippery slope)

When considering genetic selection for enhanced health it is reasonable to foresee considerable disagreement over these various harms. Yet, one crucial difference might arise that is different from McCarthy’s investigation in the context of sex selection. As was noted in the Competitive Logic Objection, a range of tests for enhanced health characteristics might not involve gaining a competitive edge, but still could give rise to a coercive environment. Indeed, the same logic applies here as was noted earlier in relation to therapeutic genetic tests, where Lippmann¹²⁵ identifies that the mere existence of a test gives rise to an imperative to use it.¹²⁶ Yet, in our case, there still might be considerable disagreement about the relevant merits of such tests – indeed, such disagreements emerge in the context of therapeutic tests as well. Thus, some parents are likely to disvalue selecting for certain characteristics over others in the same way that they might have specific feelings about different forms of education (state, private, single-sex, home learning, etc). Nevertheless, if a coercive environment does emerge, it still does not imply a restriction of liberty, but a more informed, deliberative practice of having children. One might even argue that opportunities to think carefully about the kinds of characteristics a child might benefit from having would bring about a greater commitment to the parenting process. Moreover, the claim that such tests would give rise to *too much choice* is easily countered by arguing in favour of informed action, rather than leaving outcomes to chance, which parents might, nevertheless, identify as blameworthy. Again, the presumption should remain in favour of autonomy.

Conclusion

This paper sought to explore the ethical arguments and UK regulatory discussions surrounding the use of genetic tests and selection. It has been argued that the ethical objections to genetic selection for enhanced health do not establish a persuasive or sound justification for its prohibition. Moreover, there are reasonable arguments that urge for a permissive approach to genetic testing and selection for enhanced health characteristics. The objections to genetic selection rely on a confused

¹²⁴ McCarthy D. Why Sex Selection Should be Legal. *J Med Ethics* 2001.

¹²⁵ Lippmann, A. Prenatal Genetic Testing and Screening, 1991, *op. cit.*

¹²⁶ National Childbirth Trust. *The stress of tests in pregnancy*. 1997.

conceptualisation of the manner in which decisions to select for enhanced health would arise. The positive case for selecting enhanced health characteristics does not imply selecting for all nondisease purposes, such as intelligence. Neither does it rely on a claim about what might constitute the best kinds of people. Rather, the argument from biocultural capital accumulation allows for an individualist and particularist notion of betterment. Such a view would be sufficiently diverse so as to avoid the hubristic connotations of seeking perfection, which is often used to justify the curtailment of such freedoms. While my position does not deny the influence of global market structures on decisions to select for preferred characteristics, it does not reduce individuals to mere consumers. Neither does it suppose that people will take decisions to make such selections lightly. Nevertheless, it will be critical to take into account the dependence of the public on advice from genetic counselling and its capacity to be overly directive.¹²⁷

To this extent, the argument undermines the major concerns of the HGC on the limits it places on genetic selection. Thus, decisions to select for enhanced health will be neither trivial, nor meaningless. Rather they will constitute a careful and deliberate attempt to improve upon the limitations of the natural lottery. Importantly, my argument does not confer an *obligation* to utilise genetic tests in order to bring about the ‘best’ children. Rather, it explains the value in extending selection to include enhanced health characteristics when genetic testing is in use. For instance, the position argues on behalf of selecting for enhanced health characteristics for circumstances where parents are faced with the possibility of having to utilise PGD. In short, I have argued that the opportunity should be taken to optimise health rather than merely to return it to a *normal* state. Admittedly, my position is vulnerable to a claim that freedom to make such choices will give rise to an imperative to test. However, this imperative need not result in similar decision making, since people are sufficiently diverse so as to have different views about what might be worth improving upon.

There remain important questions about how societies might implement the use of genetic tests for enhanced health. It has already been noted that it would be a number of years before the National Health Service could afford medical genetic testing. As such, the likelihood of preimplantation genetic tests extending to enhanced health or even nondisease traits would appear remote, since it would be difficult to justify on a social welfare scheme of health care provision. However, this does not discount the need to establish guidelines for privately funded tests or indeed, the possibility that postnatal genetic tests might be used for similar purposes. It has not been shown that privately funded genetic testing would be contrary to principles of social justice. Neither is it obvious that the use of such (postnatal) tests would be unreasonably expensive. However, it is necessary to remain vigilant over the possibility that information deriving from genetic tests will be sought for socially divisive ends. Fortunately, some work in this area already establishes the major ethical issues arising from the use of postnatal tests and the implications for regulation. For instance, postnatal genetic tests have already provoked the interests of insurance companies,

¹²⁷ Ngwena C, Chadwick R. Genetic Diagnostic Information and the Duty of Confidentiality: Ethics and Law. *Medical Law International* 1993;1(1):73-96.

which have made claims over entitlement to access the information they reveal. In this case, the core concerns involve privacy and confidentiality of information. Importantly, this claim cannot extend to requiring clients to undergo a genetic test. Of course, insurance companies are already entitled to know the state of health of their clients and the possibility of accessing genetic information is, in one sense, merely an extension of this entitlement. Moreover, it is possible to understand the basis of such entitlement, given that insurance is understood as a contract between two parties. Thus, if one party (the client) has knowledge about a dangerous medical condition (such as a genetic disorder) and the other party (the insurer) is not privy to such information, then the client is able to capitalise on that knowledge by requesting a more extensive insurance policy.

However, there is less clarity over how society should treat individuals who have bad genetic luck. Burley¹²⁸ suggests that ‘society at large should share the costs of the bad genetic luck that its individual members suffer’ and that, therefore, there should be some requirement for insurance companies to offer a minimal degree of protection for all, despite knowledge of the predisposition. While this might be seen to disadvantage other clients of the insurance company, it is mistaken for such clients to consider that they are different from the genetically disadvantaged. Instead, they might merely describe themselves as technologically (rather than genetically) fortunate, since science has not yet revealed their own genetic vulnerabilities. For characteristics of enhanced health, the additional benefit arises that all people will be characterised as lacking in some way. To some extent, this might alleviate some of the stigma associated with disability and advance a more diverse notion of what it means to be human.

Another concern involves the *ephemeral or permanent* character of the information derived from genetic tests. It is possible that individuals would seek postnatal tests to inform specific lifestyle decisions. For instance, the ALRC¹²⁹ mentions a genetic,

... test for the apolipoprotein E e4 gene compulsory for boxers seeking a licence under the Professional Boxing Control Act 1985 (Vic)...Research suggests that this gene, which is connected with late-onset familial and sporadic Alzheimer’s disease, may also be associated with an increased risk of chronic traumatic encephalopathy (CTE), or ‘punch drunk’ syndrome, in boxers. It has been suggested that a milder form of this condition can occur in players of rugby, soccer and other sports associated with repetitive blows to the head.

In this case, two issues arise. First, the merits of the test were not under discussion as a test that an athlete might wish to use, but rather as one that they would be *required* to undergo in order to obtain a license to box. As such, one question concerns whether the boxing authority (or an athlete’s personal insurance provider) is entitled to make such a request. The second issue is somewhat broader and asks whether knowledge of such information might have wider implications for the athlete. For instance, would

¹²⁸ Burley J. Bad Genetic Luck and Health Insurance. In: Burley J, ed. *The Genetic Revolution and Human Rights*. Oxford: Oxford University Press, 1999, p.56.

¹²⁹ Australia Law Reform Commission, ALRC 96: *Essentially Yours*, *op. cit.*, p.964.

the athlete be required to disclose this information to third parties, such as insurance companies and, in the process forsake their liability? If so, then the existence of (and requirement to take) the test might imply additional burdens on the individual. In effect, this might result in individuals choosing not to enter a profession on the basis that they are unable to assume the financial risks implied by entering such a pursuit. Thus, the information arising from genetic tests can take on a life of its own beyond the specific interest of the individual in the information.

In part, it was the threat of litigation that informed the Victoria Boxing Board's choice not to proceed with using genetic tests to detect predispositions. Yet, this example is only partially helpful for our purposes, since it, again, concerns information that would be considered medically relevant. How would this apply for an enhanced health characteristic? It is likely that enhanced health information would imply a range of other related information that would be of interest to third parties. Consequently, an athlete who decides to undergo a test for muscle fibre type might discover that she has a legal responsibility to disclose this information to interested parties. Indeed, in all likelihood, the increasing political will behind anti-doping programmes might soon require all athletes to undergo extensive genetic testing to support such work. Again, this raises profound ethical and legal questions that have received nearly no attention.

A further concern arises in respect of the age at which individuals might request the use of tests. In the context of sport, such tests are likely to be most useful during various stages of a child's maturation, yet it is unclear whether a child could consent to their use. Moreover, concerns over genetic determinism provide some reason to avoid the use of enhanced trait genetic tests early in life. However, as McLean¹³⁰ notes, the Family Law Reform Act 1969 (England and Wales) and Age of Legal Capacity Act 1991 (Scotland) provide only for people over the age of sixteen years. For children younger than this, McLean indicates that the ruling in *Gillick v West Norfolk and Wisbech Hospital Authority* would apply. This suggests that young athletes could request such tests for themselves. However, in this regard the limits of medicine's proper role needs clarification, since it is not even clear that postnatal tests would qualify as medical treatments, particularly if they involve little more than a mouth swab.¹³¹ Indeed, McLean notes that even medical genetic screening does not easily fit within the category of therapy, since often no therapy is available.

In any case, it seems reasonable to conclude that it would be harmful to institutionalise such tests as a general practice of talent identification. Importantly, the harm is not necessarily that the child's situation will be made worse, but that the child will be unable to ensure that the information deriving from such tests is not used to his or her detriment. Thus, it is unlikely to harm a 12 year-old child to be told they do not have the enhanced health required to become an elite swimmer. Indeed, they will learn to live with the process of selection arising from competition itself. Yet, these two forms of selection are different insofar as the latter is entered into voluntarily. In

¹³⁰ McLean, S. A. M. Genetic Screening of Children, 1995, *op. cit.*

¹³¹ Levitt M. Let the consumer decide? The regulation of commercial genetic testing. *J Med Ethics* 2001;27(6):398-403.

contrast, implementing genetic screening for young athletes offers limited control to the child over their subsequent involvement with the sport. This position would also restrict the use of genetic tests as part of an anti-doping programme, which is a critical position given the increased sympathy for high-school testing in some parts of the world.

A final concern offers some additional challenges to the conclusions developed in this analysis. As McLean¹³² notes, one of the novel aspects of genetic information is its capacity to offer information that concerns relatives of the individual. This gives rise to new burdens on patient-doctor confidentiality.¹³³ Ethical questions arise over whether family members or reproductive partners have a right to such information and whether physicians are duty bound to inform them.¹³⁴ The HGC notes that,

In some cases a person may wish to disclose confidential information if he or she feels that is necessary for reasons of public safety. We believe that in exceptional cases it should be permissible to reveal personal genetic information in order to avert substantial harm to others (p.66).

In response, some authors have advanced a *relational* theory of medical ethics, which challenges the liberal model of autonomy.¹³⁵ Yet, one of the difficulties with the relational model for medicine is that it might appear to invalidate a number of established ethical codes within which individual autonomy is enshrined. For instance, it is difficult to imagine how a pregnant woman might maintain autonomy over her bodily integrity, if her unique circumstances must take into account the affect on others should she wish to seek an abortion. Indeed, some authors would resist any compromising of the mother's rights. In the context of genetic tests for enhanced health, the relational model of autonomy might require that wider burdens of responsibility are taken into account before allowing individuals to claim an entitlement to such technology.

¹³² McLean, SAM Genetic Screening of Children, *op. cit.*

¹³³ Juengst ET. Genetic testing and the moral dynamics of family life. *Public Understanding of Science* 1999;8:193-205.

¹³⁴ Häyry, H. and T. Lehto Who Should Know About Our Genetic Makeup and Why? *20th World Congress of Philosophy*, 1998, Hypertext Document. Available Online: <http://www.bu.edu/wcp/Papers/Bioe/BioeHay1.htm> [Accessed: September 1998]. Häyry H, Takala T. Genetic Information, Rights, and Autonomy. *Theoretical Medicine* 2001;22:403-414; Parker M. Genetics and the Interpersonal Elaboration of Ethics. *Theoretical Medicine* 2001;22:451-459; Sarangi S, Clarke A. Constructing an account by contrast in counselling for childhood genetic testing. *Social Science and Medicine* 2002;54:295-308; Vehmas S. Just Ignore it? Parents and Genetic Information. *Theoretical Medicine* 2001;22:473-484.

¹³⁵ Donchin A. Reworking autonomy: Toward a feminist perspective. *Cambridge Quarterly of Healthcare Ethics* 1995;4(9):44-55; Mackenzie C, Stoljar N, eds. *Relational autonomy: Feminist perspectives on autonomy, agency and the social self*. New York: Oxford University Press, 2000; Meyers D. *Self, society, and personal choice*. New York: Routledge, 1989; Sherwin S. A relational approach to autonomy in health care. In: Sherwin S, ed. *The Politics of women's health: exploring agency and autonomy*. Philadelphia, PA: Temple University Press, 1998.

In conclusion, McLean¹³⁶ notes that ‘legal issues are frequently more difficult to distinguish from ethical ones’ (p.123) and the subject matter of genetics makes this all the more apparent. I have concluded that the use of genetic tests for general purpose enhanced health promotion is permissible, but only within certain conditions. Specifically, I have argued against the institutionalisation of such tests for selective or discriminatory purposes, but in favour of individual choices to utilise such tests.

To return to our sporting example, this would mean that Sarah can take a genetic test once she achieves something like Gillick¹³⁷ competence, but that her coach can’t administer one to her or request the results as part of a selection practice. Moreover, specific codes of practice should be delivered to ensure that such activities do not take place. One might argue that even the best attempts to persuade people that genes are only one component of performance achievements will be inadequate to curtail determinism. As such, any policy decision must take into account the probability that people will make assumptions about individual capacities based merely on the results of genetic tests. However, this point merely reminds us that the advances within the public understanding of science are still reasonably recent.

¹³⁶ McLean, SAM. Genetic Screening of Children, 1995, *op. cit.*

¹³⁷ *Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 WLR 830 (HL).

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