The Ethics of the New Eugenics

THE ETHICS OF THE NEW EUGENICS

Edited by
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ABBREVIATIONS AND ACRONYMS

CETS	Council of Europe Treaty Series
CF	Cystic Fibrosis
CNR	Cell Nuclear Replacement
CVS	Chorionic Villus Sampling
DNA	Deoxyribonucleic Acid
Dor Yershonim	'Upright Nation' (Ps.112:2)
ECHR	European Convention on Human Rights
EES	Eugenics Education Society : British Eugenics Society
ES cells	Embryonic Stem Cells (pluripotent)
FISH	Fluorescence in situ hybridisation Analysis
HFEA	Human Fertilisation & Embryology Authority
ICIDH	International Classification of Impairments, Disabilities and Handicaps
IVF	*In Vitro* Fertilization (in the laboratory)
NSC	National Screening Committee
OHSS	Ovarian hyperstimulation syndrome
PES	Preimplantation Embryonic Selection
PGD	Preimplantation Genetic Diagnosis
PND	Prenatal Genetic Diagnosis
RCOG	Royal College of Obstetricians and Gynaecologists
SS	*Schutsstaffel*
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organisation
WHO	World Health Organisation

INTRODUCTION

Selection strategies or decisions aimed at affecting, in manners which are considered to be positive, the genetic heritage of a child, a community or humanity in general have always represented a challenge to human beings from an ethical perspective. That challenge was the inspiration of many popular works of science fiction, such as Aldous Huxley's book *Brave New World,*[1] written in 1932, in which an organized society is deliberately created with different groupings of people designed to fulfil different roles. Another, more recent, example is the 1997 film *Gattaca* in which a utopian society openly discriminates against those who are born invalid (in a natural birth without selecting out biological limitations).

Since the Second World War, however, the word 'eugenics' which describes these selection strategies or decisions has aroused strong emotions, though a clear definition of the term has remained elusive. At the outset of this book, therefore, it is particularly important to clarify what is meant by the expression. The word 'eugenics' derives from two Greek roots, 'eu' (good) and 'genesis' (birth) and denotes the practice of producing human life that is good at birth. This means that eugenics includes selection on the basis of genetic characteristics and stems from the belief that human beings or humanity can be improved by encouraging people with desirable traits to have children and by encouraging people with undesirable traits not to procreate. This belief is itself based on the historical success of selectively breeding in agriculture since scientists realized that human beings, like plants and animals, inherit many physical and behavioural characteristics.[2] The successful selection and elimination of inherited characteristics in plants and animals implied the possibility that similar practices could occur with human beings. The Englishman Francis Galton (1822–1911) coined the term 'eugenics' in 1883 to characterize such a proposal.

On the other side of the Atlantic, similar suggestions were presented at about the same time, with the Harvard biologist Charles Davenport urging the American Academy of Medicine, in 1909, to accept eugenics. Again, the impetus for human eugenics derived from a success with animals, in this case with the elimination of a pernicious virus from selectively bred horses. Drawing the connection even more obviously, in 1917, the American tycoon W.E.D. Stokes penned a book entitled *The Right to Be Well Born, or Horse Breeding and Its Relation to Eugenics.*

These early developments of eugenics reflected the belief that the scientifically directed good birth of plants and animals could have a direct influence on the equivalent practice in human beings.[3] However, in spite of the benefits that eugenics seemed to promise humanity, it did not win universal support as a serious scientific discipline,[4,5] largely because nonscientific and subjective elements characterized much of eugenic practice. The most disputed aspect of eugenics was the diverse understandings of the terms. For example, defining the concepts of 'disorder' and 'benefit' was difficult in the context of an accurate overall assessment of the 'improvement' of the human genetic heritage. Moreover, even though eugenicists were concerned with the elimination of certain inheritable disorders, there were several problems with labelling certain ailments as 'genetic disorders' without any definition of what constituted such disorders.

The highly subjective criteria governing the practice of eugenics also gave rise to expressions that could be considered scientific racism, as seen most insidiously in the atrocities of Nazi Germany in the first half of the twentieth century, including the systematic elimination of people with mental disorders.[6] In light of these crimes, after the Second World War, many eugenic policies were condemned as coercive, restrictive, or genocidal with a number of countries even ultimately banning these practices. For many years the concept of eugenics was then relegated to the outer rim of polite discussions.

Yet as recently as the early 1970s, serious scientists have revisited the possibility of using the convergence of genetic engineering and reproductive technologies to forge a new path in human development. At the same time, the opportunity to improve the human race and its individual members has increasingly been reconsidered amongst some bioethicists as a possible step in the right direction.[7] The old eugenic dream, temporarily discredited by Nazi pursuits of a 'superior race', has been resurrected. Many new procedures that may contribute to a eugenic transformation of humanity are now being considered or predicted. Already, children may be born with improved genetic endowments as a result of the careful screening and selection of embryos carrying desirable genes or to directed genetic change in gametes or embryos.[8] Extrapolating from these developments, some scientists have even predicted that, in the near future, parents may be able to exert precise genetic control over a large number of specific characteristics in their offspring.

Not surprisingly, then, the future of this field remains uncertain. As scientists and futurists return to their investigations concerning new possibilities for humankind, the potential for change seems nearly limitless. At the same time, the ethical values and consequences of potential new developments remain unclear, and the scientific and ethical communities have greeted these predictions with both enthusiasm and alarm.[9] Representative of one such approach, the historical journalist Christine Rosen warns in 2003:

> The question is no longer whether we will practice eugenics. We already do. The question is: Which forms of eugenics will we tolerate and how much will we allow the practice of eugenics to expand? . . . Not all eugenic practices are equal, and often the same practices can have very different meanings when pursued in a different spirit or governed by a different moral purpose. Perhaps some forms of eugenics are sacred and some profane. But we ought never [to] allow good intentions (or claims of holiness) to blind us to moral realities.[10]

The present book will thus discuss not only the potential advantages but also the risks and consequences for society which may arise from these new technologies. It will thereby assist in the examination of most of the ethical concerns related to the development of what can be considered as the new eugenics.

Definitions

Before outlining and evaluating the history of eugenics, a clarification of key terms relating to the concept of eugenics will assist in eliminating ambiguities or misunderstandings. This is being provided even though a generally accepted definition of eugenics does not yet exist in English or on the international stage.[11] These clarifications are, therefore, only informed suggestions, although they will be useful in the discussion of the new eugenics by establishing a common vocabulary. The following list is by no means comprehensive but represents terms that often occur in debates relating to eugenics.

Different Kinds of Eugenics

Communal (societal) eugenics: eugenic strategies or decisions pursued by a concerned community.

Destructive eugenics: eugenic strategies or decisions that involve the destruction of a biological entity.

Dysgenics (cacogenics): the genetic deterioration of a population or the evolutionary weakening of an organism relative to its environment. Also, the study of degeneration. The opposite of eugenics.

Eugenics: strategies or decisions aimed at affecting, in a manner which is considered to be positive, the genetic heritage of a child, a community or humanity in general.[12]

Note: The desirable aims of eugenics may not always be the same for a child, a community or humanity in general. For example, what a community may consider desirable may not necessarily be the same as what parents consider desirable in their child.

Negative (or preventive) eugenics: strategies or decisions with the aim of *avoiding or reducing what is considered to be an undesired* genetic heritage in a child, a community or humanity in general.

Such strategies may include:

a) compulsory sterilization of undesirable persons capable of reproduction;
b) marriage restrictions whereby some people may not be allowed to get married;
c) selecting out undesirable embryos or foetuses because of specific disorders;
d) immigration control preventing certain kinds of people from entering a country;
e) segregation between desirable and undesirable persons; or
f) extermination of certain undesirable persons.

Note: the distinction between positive or negative eugenics is not clear-cut. As mentioned above, some procedures, such as genetic selection of embryos and certain forms of marriage counselling, allow participants to make choices based on genetic characteristics widely held as desirable or undesirable.

Positive (or progressive) eugenics: strategies or decisions aimed at *promoting what is considered to be a desired* genetic heritage in a child, a community or humanity in general.

Such strategies may include:

a) the selection of desirable sperm in a sperm bank;
b) certain forms of marriage counselling; or
c) promoting increased birth rates in couples who are deemed to be biologically desirable parents.

Personal eugenics: eugenic strategies or decisions pursued by concerned individuals. This includes parental eugenics.

Nonvoluntary eugenics: eugenic strategies or decisions that are taken without respecting the principle of informed consent.

Voluntary (or liberal) eugenics: eugenic strategies or decisions that are taken while respecting the principle of informed consent.

Others Terms Used in Eugenic Discussions

Many discussions of eugenic procedures note the difficulty in establishing clear borders between paired terms such as 'healing' and 'enhancement' or 'ability' and 'disability'.[13] However, it may be useful to try to characterize the different terms and the questions they raise in the context of eugenic debates in order to inform the discussion of eugenics in the twenty-first century and beyond. Though these cursory definitions seek to eliminate ambiguities, only universally accepted definitions will ultimately unify the different concepts. Since such unanimity is currently unavailable and unlikely for the foreseeable future, a regular refining of definitions based on common practice remains the only alternative. As in the previous section, the list of terms below is not comprehensive.

Enhancement (or augmentation): an activity (whether biological or not) through which an object is transformed to exceed what is normal to improve its natural state or function.[14] The term 'enhancement' reflects the idea of using technology and science to increase the human functioning of a healthy individual beyond the norm for that person and in the absence of any identified dysfunction.[15]

With respect to biotechnology, it can be defined as an activity designed 'to alter…the 'normal' workings of the human body and psyche, to augment or improve their capacities and performances.'[16]

Enhancement does not include the creation of capacities in new beings that have never previously existed (which may be considered under the concept of transhumanism). The aim of enhancement is to improve upon the norm but not to surpass a preexisting, human, natural state or capacity. This means that enhancement procedures are not geared to exceed the achievement potential of human beings who are at the upper end of the statistical distribution.

Healing: the restoration, preservation, or prevention of human dysfunctions. Equally, healing may be defined as the removal of individual disorders relative to recognized standards of an average healthy human being.[17]

In the past, medicine and biotechnology together have sought to eliminate pathology but have never sought to enhance normality. Though the distinction between the two is admittedly difficult to define, regulatory agencies are generally able to do so in practice.[18]

Health: the World Health Organization defines 'health' as 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity'.[19] Many national legislations in the health field do not explicitly define 'health'. Indeed, health is not always a matter of scientifically demonstrable fact and may be a matter of perception.

Normal: though the concept of what is normal can be interpreted in statistical terms as being 'typical', there is no universal distinction between what is classed as 'normal' versus 'abnormal' because the distinction hinges on societal perceptions of the condition in question.[20] See Health.

Therapy (or treatment): medical intervention that restores human functioning to species-typical norms or that gives abilities integral to the body which are considered to be normal. A therapy thus counteracts a known or an anticipated health deficit.[21] For example, kidney dialysis is a therapy that enables dysfunctional kidneys to filter impurities from the blood in a manner that approximates the properly functioning kidneys of a human being. However, an alteration of the brain that adds twenty IQ points would be considered an enhancement if performed on someone who already has a normal IQ.[22]

As previously noted, distinguishing 'therapy' from 'enhancement' is difficult and depends on the definitions of other terms as well as cultural norms and values.[23] If a society willingly seeks to enhance its members, then what would be considered normal for this community would eventually be altered. Previously normal traits could even be considered as dysfunctional if they no longer attain the new 'norm'. In such an event, these new dysfunctions could begin to be considered for treatment.

Using the Eugenics Term

The concept of eugenics, as already mentioned, does not have any fixed definition, and ever since Sir Francis Galton coined the term 'eugenics' in 1883, the word has had a number of interpretations.[24] Many meanings have been proposed, and even Galton continued to reformulate his own definition until just before his death. At the beginning of the twenty-first century this ambiguity remains and eugenics may mean very different things to different people.[25]

Galton's concept of eugenics also differed from what would later be known as Social Darwinism. While both claimed that traits, such as intelligence, were hereditary, eugenic ideology asserted that new policies were needed to actively change the status quo towards a more 'eugenic' state. Social Darwinists, on the other hand, argued that even if no such specific eugenic policies were established, a balance in society would eventually be obtained based on Darwinian evolution if no welfare policies supporting the disfavoured were put in place.[26] Social Darwinism proposed that the poor may have a greater number of children but would, at the same time, have higher mortality rates, making active eugenic programs unnecessary.[27]

Generally, however, the term eugenics is used when a specific intervention is considered which seeks to improve the genetic heritage of a child, a community or humanity in general. But, in this regard, many who study the ethics of genetic selection prefer to evade the term since they recognize that it was tarnished by the abuses that occurred in Nazi Germany. During this time, widespread, compulsory and state-regulated discrimination took place. Some commentators, such as ethicist Robert Sparrow, have also indicated that it may not only be the means used by past authoritarian eugenic programs that were seen as objectionable but also the goal. In other words, for many people there may be something reprehensibly immoral and arrogant about being able to pass judgement on the quality of human lives.[28]

Thus, by using a new and more acceptable vocabulary there is a wish to avoid the negative connotations of selective decisions which took place in the past because there is concern that any procedure labelled 'eugenic' will garner immediate condemnation.[29] Alternative terminology such as 'human enhancement' or 'selection' is seen as being more appropriate, though the results may be similar and the changes may only be ones of vocabulary. Examples of such transformation of language took place when the *Annals of Eugenics* became the *Annals of Human Genetics* in 1954 and the journal *Eugenics Quarterly* was renamed as *Social Biology* in 1969. Frederick Osborn (1889–1981), a past leader of the American Eugenics Society also stated in 1974 that 'Birth control and abortion are turning out to be great eugenic advances of our time. If they had been advanced for eugenic reasons it would have retarded or stopped their acceptance'.[30] Osborn recognized, in this way, that society would more likely accept eugenic goals and practices if the word 'eugenic' was avoided or omitted.[31]

Thus, there are those who support the benefits of selection and who argue that using the eugenic term is detrimental to recognizing scientific progress and its predictive capacity. As a result, they reject any use of the term if prospective parents undertake the selection decision voluntarily in order to make sure that their prospective child avoids serious suffering.[32] This stance also reflects the fact that concerns over the future genetic heritage of a nation have now generally been replaced by those for private families and how they consider their own selection decisions. Relatedly, in medicine, respect for patients' wishes and the perceived right to reproductive autonomy have become dominant values in contemporary society.[33]

One the other side, however, many see any selection decision as truly meriting the term 'eugenics'. Because of the stigma attached to the word, those who are opposed to the different genetic selection procedures already taking place in society sometimes deliberately make a point of describing such practices as eugenic in order to cast them negatively as being associated to former abuses.[34] They are concerned that the voluntary eugenic practices of parents are still far too similar to the negative selection procedures of the past. Critics are also worried of a sort of 'back-door' eugenics resulting in the collective impact of many voluntarily, autonomous and individual decisions in unregulated fertility clinics.[35,36] It is a eugenic resulting from a free and unrestrained market encouraged by consumer choice and desires as well as unavoidable social expectations.

That being said, there are those who are not afraid of still using the eugenic tem in a positive fashion. The ethicist Nicholas Agar disagrees with the manner in which those who support human enhancement as an individual choice deliberately camouflage or avoid the term of 'eugenics' in their discourse in order to distinguish themselves from Nazi policies. Agar argues that 'this smacks of Orwellian redefinition.'[37] He continues by defending the use of the term, even employing it in the title of his book, *Liberal Eugenics,* in which he supports the freedom of parents to choose certain characteristics in their children.[38] Notably, many self-defined past eugenicists also believed that in conjunction with widespread education and accessibility, the establishment of a voluntary eugenic system was the ideal way to prevent the birth of people they considered degenerate.[39] Even Francis Galton, who coined the term eugenics, was very much opposed to any coercion in its implementation.[40] The UK House of Commons Science and Technology Committee also supported this perspective, as indicated by its 2005 report *Human Reproduction Technologies and the Law.* In discussing parental choice the committee stated, 'If ensuring that your child is less likely to face debilitating disease in the course of their life can be termed eugenics, we have no problem with its use'.[41] In short, it was agreed that eugenics is about the selection of human persons, regardless of the form this selection takes.

But there is another reason why the eugenic term is sometimes employed, which relates to its warning potential. Indeed, by deliberately avoiding the term and replacing it with new terminology, there is a danger that a cleansing procedure is simply being proposed. Prof. Didier Sicard, Past President of the French National Consultative Ethics Council, warns that the discarding of the word because it is seen as a diabolical term of the past may enable its realisation in all peace of mind[42] instead of it being used and considered as a warning to future generations.

As the bioscientist and physician David Galton indicates in his book entitled *Eugenics: The Future of Human Life in the 21st Century*:

> Call it what you will; but if your aim is to use scientific methods to make the best of the inherited component for the health and wellbeing of the children of the next generation, it is by definition eugenics. Sweeping the word under the carpet or sanitising it with another name merely conceals the appalling abuses that have occurred in the past and may well lull people into a false sense of security.[43]

It is indeed unfortunate that use of the word 'eugenics' elicits a defensive reaction from supporters of selection procedures. Rather than evaluating the legitimacy of the procedures, some supporters invariably articulate deep offence at being compared to Nazi policy sympathizers. But this tack disregards an astonishing but important historical fact that most supporters of such procedures in Nazi Germany were not monsters but normal people influenced by similar contemporary trends, just as people are today. They were not different from the population of any other European nation, and they did not stop the abuses that took place by their government. Thus, taking the moral high ground in suggesting that such unethical and abusive eugenic programs could never take place today indicates a profound lack of humility and sense of reality.

But claiming the moral high ground is not the only strategy for banishing the word 'eugenics' from contemporary discourse. Another option is to tether it immovably to the past. This is unfortunate since in examining the different selection procedures that are presently being considered, it is impossible not to recognize that some kind of eugenic return has taken place which can be considered as a new eugenics. Copious research and painstaking analysis has led the American political scientist Diane Paul to observe in 1998, 'Only a few years ago, it seemed that eugenics had been wholly discredited by its association with race and class prejudice, and in particular with the crimes of the Third Reich. The movement appeared to be dead'. Then, with rhetorical finesse she asks, 'Or was it just sleeping?'[44] Paul's question begs an affirmation that, yes, the old eugenics has slept only to stir and awaken with vigour at the end of the twentieth century. Now, the twenty-first century faces a renewed eugenics that eschews the heinous, outright coercion of an earlier era but nonetheless operates with the undergirding principle that people may (should?) be ethically improved by technological advancements.

By carefully taking into account the lessons that can be learnt from history, it is possible instead to evaluate cautiously all the different procedures which can be characterized as eugenic. This alternative starting point opens the possibility of suggesting that not all procedures are unethical. For example, a woman's decision to choose a certain kind of husband may be unconsciously influenced by considerations such as age and reproductive capability. Strictly speaking, this would be a decision that has a eugenic component, though most worldviews would not consider such a choice as being unethical. Thus, not all forms of decisions which may have an indirect eugenic element need to be considered as inherently unethical. Stephen Wilkinson writes 'if there really are sound eugenics arguments in play then we need these to be clearly and unambiguously articulated. Only then will we know which technologies to ban or restrictively regulate, and understand properly the reasons for doing so'.[45]

In summary, this book allows that all strategies aimed at affecting or deciding the genetic heritage of a child, a community or humanity in general are eugenic procedures. This approach to the term 'eugenic' is broader than a number of past definitions that only addressed the consequences for a whole population.[46] But the approach here is sound, since the principle of eugenic selection is consistent regardless of the subject, whether for a nation, a family or an individual. Still another reason why the term 'eugenic' cannot characterize only programs taking place on the scale of a nation or large community concerns the nature of corporate entities. The accumulation of many single voluntary decisions by parents will eventually have a significant, though unintended, impact on the whole of a population. For example, a majority of parents may choose to avoid disability, and an accumulation of such decisions could have a eugenic impact on a societal group.[47] As the ethicist Cynthia Cohen puts it, 'Individual decisions taken collectively, if promoted and supported as a matter of public policy, could amount to a new form of eugenics'.[48] Indeed, policy options may reflect social propensities.[49]

The practice of eugenics, however, is also related to the broad ethical theory known as consequentialism which is at risk of becoming the highest priority in terms of seeking to increase happiness or wellbeing while trying to reduce suffering in a child, a community or society in general. There are many versions of consequentialism, and different nuances provide slightly different ethical results when applied to the question of the new eugenics.[50] But the underlying maxim of the theory is 'Always do whatever produces the greatest good'.[51] Eugenics is driven by this impulse to maximize what is good, as seen in the relentless quest for health and the avoidance of suffering.[52] So common is the assumption that pursuit of the greatest good equals the ethical good that one industry analyst writes: 'Biotech advocates deploy the priority of good health to deflect concerns about the power of these technologies to reinforce race, gender and other social inequities. They portray health as the unassailable aim of human biotechnologies and insist that it takes precedence over political and social interests'.[53]

The Oxford ethicist Julian Savulescu has been an outspoken advocate for this kind of consequentialist approach to health, arguing that parents are obliged to seek to create the best possible children.[54] At the same time, he recognizes that the fabric of liberal society prevents him from legislating too firmly against the rights of parents. He states that 'we should allow couples to make their own decisions about which child to have' even if that means selecting children with disabilities.[55] In spite of this caveat, though, Savulescu contends that medical technologies should be used to dispense with disability and disease. To put it mildly, this is a common opinion in discussions of selection procedures and human enhancement.[56]

Another prominent ethicist, John Harris offers a particularly lucid and challenging version of this perspective in his 2007 book *Enhancing Evolution.* From the outset, Harris laces polished prose with an overt agenda to convince his reader that abolishing disability and disease is not only desirable but ethically mandatory. 'We ought to want this', Harris writes, referring to the educational utopia he describes in which children are healthier and more intelligent than any previous human beings.[57] As the book continues, though, Harris shows that this hypothetical educational scenario is actually a metaphor for the sweeping technological developments that he envisions will transform humanity. In discussing the ethics of selection procedures, Harris concludes that parents 'have to do their best'.[58]

This consequentialist manner of thinking and its associated choices in relation to the expected health and quality of life of the future child has, therefore, become a dominating emphasis in eugenics. As the legal ethicist Roberto Andorno notes, 'It is precisely when this "quality control" is applied to human procreation, and especially to the fruit of procreation, i.e. children, that it constitutes, by definition, a eugenic practice'.[59]

This book aims to accomplish two tasks. The first aim is to provide an introduction on the selection procedures that constitute the new eugenics. In doing so it will examine and evaluate these contemporary practices within their historical context and present a fresh contribution to the ongoing dialogue about how society can appropriate technological advancements in an ethical manner. A mark of wise and measured progress will be a willingness to understand the present in light of the past. Accordingly, this book does not discard the unpleasant practices of the twentieth century, although it may not always be easy reading. The second aim is to stimulate and galvanize discussion in the public square—not merely in the ivory towers of academia—regarding where to draw a line between what is acceptable and what is not.[60]

The matters considered in this volume extend beyond the tidy books and articles of professionals and reach into the lives of all members of society. Consequently, men and women responsible for societal well-being will have to address these issues, and this book offers a convenient entry point for all interested parties, politician and layman alike. The philosopher Alasdair MacIntyre recognized the importance of public discussion and particularly the role of the politician: 'What we actually do will be determined by what those who hold social and political power more generally decide, for a variety of reasons, it is good to do'.[61] In no small measure the future of human society depends on how legislative bodies delineate between health and enhancement, treatment and eugenics. The editors of this volume, on behalf of the many other hands and minds that have contributed, present the following pages in conviction that questions relating to the new eugenics deserve a studied response.

Notes

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6. W.E. Seidelman. 2002. 'Pathology of Memory: German Medical Science and the Crimes of the Third Reich', in F.R. Nicosia and J. Huener (eds), *Medicine and Medical Ethics in Nazi Germany: Origins, Practices and Legacies,* New York: Berghahn Books, 97.
7. For example, J. Savulescu and N. Bostrom (eds). 2009. *Human Enhancement,* Oxford: Oxford University Press, and J. Harris. 2007. *Enhancing Evolution,* Princeton: Princeton University Press.
8. President's Council on Bioethics. 2003. *Beyond Therapy: Biotechnology and the Pursuit of Happiness. A Report of the President's Council on Bioethics* (Washington, DC), 30–31.
9. Ibid.
10. C. Rosen. 2003. 'Eugenics—Sacred and Profane', *The New Atlantis* 2, 89.
11. D. Wikler. 1999. 'Can We Learn From Eugenics?', *Journal of Medical Ethics* 25(2), 183–94.
12. Note: The term 'eugenics' is not restricted to humanity, but this book will only address human eugenics.
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15. Harris, *Enhancing Evolution,* 9. Cf. British Medical Association. 2007. 'Boosting Your Brainpower: Ethical Aspects of Cognitive Enhancements', Retrieved 27 August 2010 from http://www.bma.org.uk/images/Boosting_brainpower_tcm41-147266.pdf.
16. President's Council, *Beyond Therapy,* 13.
17. Grunwald, 'Human Enhancement', 1–3.
18. For example, prescribing Ritalin for ADHD could be construed as either enhancement or therapy, but regulatory agencies somehow manage to make and generally enforce the distinction between permitting it for therapy and not for enhancement, F. Fukuyama. 2002. *Our Posthuman Future: Consequences of the Biotechnology Revolution,* New York: Farrar, Straus and Giroux, 210.
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21. British Medical Association, 'Boosting Your Brainpower', 5.
22. B. Mitchell. 2009. 'On Human Bioenhancements', *Ethics & Medicine* 25, 133.
23. For some, an intervention may be a therapy, but for others the same intervention may be a clear enhancement, leaving a gray area in between. Moreover, it can be unclear whether therapies, whose primary purpose is curing diseases but which have a secondary potential of improving performance, should be classed as enhancements or treatment.
24. The bioscience commentator David King remarks, "It may be impossible to produce a *definition* that everyone agrees with." In D. King. 1999. 'The Persistence of Eugenics', *Human Reproduction and Genetic Ethics,* 5(2), 32.
25. S. Wilkinson. 2008. '"Eugenics Talk" and the Language of Bioethics' *Journal of Medical Ethics* 34, 467–71.
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49. Similarly the French Conseil d'État indicates that 'Eugenics can be defined as the set of methods and practices aimed at improving the genetic heritage of the human species. It may be the product of a deliberate policy taken by a State which is contrary to human dignity. It can also be the collective total result of convergent individual decisions made by prospective parents, in a society where the search for the 'perfect child', or at least free from many serious disorders, would prevail.' (Translated by Calum MacKellar) Conseil d'État. 2009. *Étude sur la révision des lois de bioéthique,* Paris : Conseil d'État, 30.
50. For example, 'rule consequentialism' mandates that people act according to an internalized code of behaviour. For a concise description, T. Mulgan. 2009. 'Rule Consequentialism and Non-identity' in M.A. Roberts and D.T. Wasserman (eds), *Harming Future Persons: Ethics, Genetics and the Non-identity Problem,* Dordrecht: Springer, 123–27. And, more comprehensively, T. Mulgan. 2006. *Future People: A Moderate Consequentialist Account of Our Obligations to Future Generations,* Oxford: Clarendon Press.
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56. The prolific literature from this perspective prevents a thorough discussion. See e.g., Savulescu and Bostrom, *Human Enhancement,* and J. Savulescu, R. Ter Meulen, and G. Kahane (eds). 2011. *Enhancing Human Capacities,* Oxford: Wiley-Blackwell.
57. Harris, *Enhancing Evolution,* 1.
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THE HISTORY OF EUGENICS

The Development of Eugenics

In examining and evaluating the new eugenics, a useful starting place is the history of eugenic programs.[1] Past attempts to better humanity, whether the individual or whole populations, serve as important mirrors for the present. This section looks, therefore, at how and why past eugenic programs were implemented. Such a tour of humanity's dark past will highlight some of the risks of the present as well as possible directions for the future.

Selective breeding in the human species was suggested at least as early as the Greek philosopher Plato (427 BCE–347 BCE), who believed that human reproduction should be controlled by government.[2] Plato recorded these views in his famous dialogue the *Republic* in which Socrates discusses a number of topics. After observing hunting dogs and noble birds in the estate of Glaucon, a leading man in Athens, Socrates draws an analogy between humans and animals. He asks Glaucon 'if care was not taken in the breeding, your dogs and birds would greatly deteriorate?' Glaucon answers affirmatively, prompting Socrates to suggest that the same principle holds for our species. Through Socrates, Plato then concludes that '[t]he best men must have intercourse with the best women as frequently as possible, and the opposite is true of the very inferior'.[3] Plato also proposed that selection be performed by a fake lottery system so that people's feelings would not be hurt by any awareness of selection principles.[4] However, even prior to Plato, the ancient city of Sparta had, allegedly, developed radical eugenic policies. It reportedly practiced a form of physical selection by leaving babies outside city borders to test their strength. Those who were too weak then died of exposure.[5]

This kind of selection was later generally rejected, however, with the growth of the major monotheist faiths which condemned practices such as infanticide and the intrusion of third parties into the sexual lives of married couples. Of course, many forms of injustices and exploitation, such as slavery, remained, and individuals in society were often seen as 'unequal'. But it was only when the influence of these faiths started to diminish in the West with the discoveries and developments of the enlightenment that the advantages relating to some kinds of human selection, based on the perceived biological quality of individuals, began to be reconsidered.[6]

Eventually eugenics as a specific discipline emerged during the 1860s and 1870s as a combination of a number of different movements. In this regard, the pioneer of modern eugenics, Francis Galton, sought to organize and apply new information about the evolution of man and animals provided by the theory of his cousin Charles Darwin. Influenced by Darwin's book *On the Origin of Species,* Galton noticed that the mechanisms of natural selection were potentially hampered by modern human civilization. He suggested that because many human societies sought to protect the sick and the weak, they were contravening natural selection, which enabled the extinction of the weakest. To remedy what he saw as the decline of civilization, Galton indicated that only by changing these social policies could society be saved from a degeneration towards mediocrity.[7]

In many ways, therefore, it was the principles of natural selection that gave birth to eugenics in a number of countries by suggesting that human beings should not be considered different from other animals. For example, the prominent zoologist Ernst Haekel (1834–1919) in Germany was heavily influenced by natural selection and evolution in his belief that 'the difference between the highest and the lowest humans is greater than that between the lowest humans and the highest animals.'[8] Haekel sent a message to Darwin for his seventieth birthday thanking him for having 'shown man his true nature and thereby overthrowing the anthropocentric fable'[9] whereby humankind believed that it was different from other animals and morally special. Individual human life had lost its inherent worth in the light of the natural selection struggle for existence and evolutionary progress. The lives of the weak, the sick and the handicapped were no longer seen as equally valuable and meriting protection.[10]

As early as 1857, Galton communicated settled opinions about the inherent inequality of human beings in their characteristics, 'I do not join in the belief that the African is our equal in brain or in heart'.[11] In 1865 he also noted that no scientist had rigorously studied the transmission of the different human traits from one generation to another: 'The breeders of our domestic animals have discovered many rules…But we have not advanced, even to this limited extent, in respect to the human race'.[12] Acting on the paucity of research in the field of human heredity, Galton eventually explored his theories in the 1869 book *Hereditary Genius,* noting in the preface that the 1865 article had been a preliminary investigation.[13] The book, according to Galton would show:

> that a man's natural abilities are derived by inheritance, under exactly the same limitations as are the form and physical features of the whole organic world. Consequently, as it is easy, notwithstanding those limitations, to obtain by careful selection a permanent breed of dogs or horses gifted with peculiar powers of running,… so

> it would be quite practicable to produce a highly-gifted race of men by judicious marriages during several consecutive generations.[14]

Galton was interested in reproducing 'eminent men' who are 'well-known to persons familiar with literary and scientific society' and for whom 'the whole intelligent part of the nation mourns when they die'.[15] These remarkable men, Galton suggested, also tended to father children who accomplished equally remarkable feats, whether in literature or politics. Drawing on theories of animal breeding, Galton argued that the children of uniquely talented human beings bore characteristics of the parentage. He argued that '[i]t is in the most unqualified manner that I object to pretensions of natural equality'.[16] Galton believed that many characteristics, such as intellectual, moral and behavioural traits, were hereditary. Consequently he not only proposed that individuals with a desired genetic heritage should reproduce, but also raised the possibility of a society imposing quotas on individuals to reproduce according to their ranking on physical and intellectual tests. Any violation of these quotas would then be punished by fines or even lifelong segregation in specific colonies.[17] Galton was, indeed, distressed to note that the eminent men of society failed to replace themselves adequately through reproduction and that those he deemed less intelligent were out-reproducing the more intelligent in nineteenth-century civilized societies.

At his death in 1911, Galton was the recognized leader of eugenics. He was the founder of the Eugenics Laboratory of the University of London and the honorary president of the Eugenics Education Society. Six months before his death Galton concisely redefined eugenics as 'the study of the conditions of human control which improve or impair the inborn characteristics of the race'.[18] Nearly a half-century of interest in the subject had persuaded him that the future of respectable society depended on the implementation of some eugenic policies. But he observed that such policies would only take root if 'revolutionary changes in public opinion' also took place.[19] As the father of the modern eugenics movement, Galton would not live to see the results of his own work, but because of the large part he played in the pioneering efforts, a eugenics regime emerged with unparalleled force.

Indeed, the history of eugenics reflects the strength this movement had on the relationships between science and politics and between knowledge and values with particular force.[20]

Eugenics and the State

By the early twentieth century, most European countries as well as Canada and the United States had considered or even developed eugenic policies regardless of political partisanship.[21,22] Organized eugenic movements appeared in Germany in

1904, in the United Kingdom in 1907 and in the United States in 1910.[23] It was at the beginning of the 1920s that certain countries developed programs for the sterilization of individuals deemed unfit to procreate with the aim of reducing social degeneration. A few nations, notably Canada and Sweden, maintained large-scale eugenics programs, including sterilization until the 1970s.[24] Similar policies also affected people who were deemed mentally retarded in Australia, Denmark, Estonia, Finland, Iceland, Norway and Switzerland.[25] More recently, in the wake of trying to reduce its population growth, China was another country which was not devoid of eugenic ideology.

Eugenic Programs in Different Countries

Eugenics in China

The selection practices that have arisen in China with the *Maternal and Infant Health Care Law 1994* have given rise to serious concerns both in China itself and abroad.[26] With respect to marriage restriction the law indicates that if a premarital physical examination reveals the possibility for a couple of giving birth to a child with a serious genetic disorder then the couple may only be married if they agree to take long-term contraceptive measures. If the couple is already married and are carriers of a serious genetic disorder, again long-term contraceptive measures must be taken.[27]

There is, however, support for such legislation on the basis that China has a population of about 50 million disabled persons, which it is suggested creates serious social problems. Defenders of the law also propose that it does not have any eugenic aspects.[28]

Eugenics in France

Eugenic policies in France at the turn of the twentieth century, as in many other countries, often had their origins in racism. The French writer Arthur Comte de Gobineau (1816–1882), actually published a book (between 1853 and 1855) entitled *Essai sur l'inégalité des races humaines* (*An Essay on the Inequality of Human Races*) in which he suggested that the Northern Arian race should be developed without any mixing with other races.

The French anthropologist Comte Georges Vacher de Lapouge (1854–1936), however, was probably one of the first persons to espouse eugenic ideals in France. He had very strong views about the present state of his country, suggesting in his writings that the principles of liberty, equality and fraternity resulting from the French Revolution should be replaced with determinism, inequality and selection.[29]

In 1913 the French Eugenics Society was formed[30] with the French 1913 Nobel Prize winner for medicine Charles Richet (1850–1935) becoming its president from 1920 to 1926. Again his beliefs were heavily influenced by racism, indicating in 1919 that:

> [W]hen it comes to the yellow race, and, even more so, with the black race, in order to maintain, and especially to increase our mental powers, it would be necessary to no longer practice individual selection as with our white brothers, but specific selection, resolutely rejecting any mixing with inferior races. In this way, an authority should direct the 'elimination of the inferior races' before that of the 'abnormal'.[31]

Another renowned supporter of eugenics in France was the 1912 Nobel Prize winner for medicine Alexis Carrel (1873–1944). In 1935 he experienced international success with his book on eugenics entitled *L'homme, cet inconnu* (*Man, The Unknown*) in which he advocated enforced selective measures later used by Nazi Germany.

As a consequence of what happened during the Second World War, eugenic selection was rejected as a social policy. Current French Penal and Civil Codes indicate that the implementation of any eugenic practice leading to the organization of the selection of persons is a crime against the human species.[32] However, even though legislation is clear, the position is ambiguous when it comes to implementing the regulations. A number of practices, such as the deselection of foetuses with disorders, such as Down syndrome, are in fact accepted in France.

Eugenics in Germany

As in the United Kingdom and the United States, eugenic ideology was present in Germany long before the National Socialists led by Adolf Hitler were elected in 1933.

A number of German late-nineteenth- and early-twenty-century intellectuals, including the physicians Alfred Ploetz (1860–1940) and Wilhelm Schallmayer (1857–1919) and the philosopher Friedrich Nietzsche, actually promoted eugenic policies in their books, the latter suggesting the introduction of marriage health certificates.[33] The first chair of eugenics was given in 1923 at the University of Munich to the geneticist Fritz Lenz (1887–1976), who had been one of Ploetz's pupils. He was a promoter of what was defined as racial hygiene emphasizing the desirability of Nordic traits while seeking to discourage the existence of those considered inferior. His writings helped support Nazi ideology, and he eventually became a member of this party in 1937.

Thus even before the Nazis came into government, the ground had been prepared for eugenic ideas. Legislation was being proposed for the sterilization of certain kinds of people, such as persons with specific mental disorders, albeit this would have been voluntary.[34] As soon as the Nazis assumed power, however, the infamous eugenic programs began with inexorable force, having as their aim the protection of a 'pure' race through eugenic policies which encouraged 'racial hygiene'.[35] Here, more than elsewhere in the twentieth century, Galton's theories about heredity and eugenics found their logical end.

The first implementation of the Nazi eugenic ideology occurred in July 1933 when previously proposed legislation relating to the legalization of sterilizations was quickly brought into force in 1934. However, the voluntary element of prior legislative proposals was now expanded to include the involuntary sterilization of 'hereditary and incurable drunkards, sexual criminals, lunatics, and those suffering from an incurable disease which would be passed on to their offspring…'.[36] As a result, from 1934 to 1939, the Nazi regime compulsorily sterilized up to three hundred and fifty thousand people whom they viewed as mentally and physically 'unfit'.[37,38]

Another incarnation of the eugenic ideology was the euthanasia program initiated in 1939. The program was code-named 'T-4' after 'Tiergartenstrasse 4', the address of the headquarters of the organization which oversaw the scheme. The order underlying the policy empowered selected physicians to grant 'mercy killing to those deemed incurable according to the best available judgement of their state of health'.[39] The basis for this kind of eugenic ideology had been prepared with the expression *Lebensunwertes Leben* ('life unworthy of life'), which first appeared in the title of the 1920 book by psychiatrist Alfred Hoche and lawyer Karl Binding, *Die Freigabe der Vernichtung Lebensunwerten Lebens,* (*Allowing the Destruction of Life Unworthy of Life*).[40] The concept became an important component of Nazi ideology, and the T-4 staff endeavoured to popularize the idea by commissioning the 1939 propaganda film *Dasein ohne Leben; Geisteskrank* (*Existence without Life; Mentally Ill*). However, economic concerns and the cost of care for the disabled were also important considerations for the Nazis.

The T-4 program officially ended in 1941 but continued unofficially until the collapse of the Nazi government in 1945. This second informal phase was sometimes referred to as 'wild euthanasia' since physicians could now decide by themselves who should die or live without being directed by the Nazi regime.[41] Overall, the program oversaw the euthanasia of some seventy thousand patients in psychiatric institutions. The work of T-4 was clandestine and was often concealed by false declarations of death with false signatures being affixed to death notices.

But this T-4 activity was not the only program of state-sanctioned eugenics. Indeed, an earlier euthanasia program had already taken place that had identified and killed at least five thousand children with disabilities, and another twenty thousand disabled people were euthanized following systematic searches in the concentration camps.[42]

Trying to understand the rationale behind this barbarism is challenging and many questions remain. But the Nazis prided themselves in having, amongst other reasons, a scientific foundation for their policies based on the evolutionary process, racial hygiene and eugenics. This then seemed to have influenced their morality and behaviour.[43] The Nazi-sanctioned euthanasia programs were officially suspended when their existence became public knowledge and gave rise to strong protests in Germany. This included opposition by the Catholic clergy, such as the Bishop of Münster, Clemens August Graf von Galen.[44] In a Sunday sermon, he openly condemned the deportation and euthanasia of mentally ill people. With powerful simplicity he argued, 'These are people, our brothers and sisters; maybe their life is unproductive, but productivity is not a justification for killing'.[45] His reasons were two-fold. He argued that the actions could be considered as murders, thus violating German law, while emphasizing that the eugenic practices of the Reich were a rejection of the laws of God.[46]

The widespread euthanasia of the T-4 program was a form of negative eugenics, a regime of genetic purification by means of elimination. But the Nazi government also sought to implement positive eugenic policies. These included the implementation of measures that sought to reproduce 'racially pure' children under the *Lebensborn* program. In this program, German men, certified as biologically fit and racially pure Aryans, were encouraged to procreate with Aryan women who had volunteered and been selected for the sole purpose of producing superior children. The aim was to develop and propagate the Aryan 'master race'.[47]

At the end of the war, and from November 1945 to October 1946, the Palace of Justice in Nuremburg, Germany, housed the famous trials of Nazi leaders. For the first time, much of the world learned about the shocking eugenic practices that had characterized the Nazi regime.

The breadth and power of the eugenic programs was notorious, not only for its atrocities but for the subtle rhetoric that attempted to justify as science otherwise unthinkable actions. As a result, eugenic ideology became almost universally reviled in many of the nations where it had once been popular. In reaction to Nazi abuses, postwar politicians and members of the scientific community denounced the notion of any inherent inequality between human individuals. More importantly legislative bodies throughout the world sought to learn the lessons from these trials and construct an ethical bulwark preventing the possibility of any further abuses or atrocities. The most notable contribution in this regard arose from the newly created United Nations.

Eugenics in Nordic Countries

At the beginning of the twentieth century, extensive public interest on the topic of eugenics existed in a number of Nordic countries, including Denmark, Sweden, Norway and Finland. At first the debate, which peaked just before the First World War, centred on racial differences and basic forms of inheritance for socially important physical characteristics in society. The second phase, which took place in the 1930s and 1940s, was not so racist in nature and emphasized a more refined understanding of genetics.[48] It was in this second stage that eugenic sterilizations were made possible as an integral part of social welfare.

It should be noted that these sterilizations were also the result of a broad support for a moderate form of eugenics as being necessary with very little public opposition to sterilizations being considered in this context. There was indeed a concern about increasing numbers of mentally disabled individuals in society. Thus several Nordic countries implemented sterilization programs, with Denmark being the first to enact legislation in 1929. These northern countries with Estonia were the only democratic European countries to introduce specific sterilization laws during the 1930s. After the Second World War, however, there was a significant drop of eugenic sterilizations of those with mental disabilities in response to a decline in support for eugenic policies as a whole.[49]

Though the circumstances varied between the different Nordic countries, the situation in Norway and Sweden will be examined in the following section as examples of some of the contexts.

• *Norway*

Public debate concerning eugenics and 'public hygiene' in Norway was already very much present before the First World War though no official governmental policy was ever considered.[50] Sterilization was first mentioned in a report of a government commission for revision of the penal code in 1927.[51] Eventually, Norway enacted the 1934 Sterilization Law based on social indications, including the fact that parents could not look after their children, and genetic indications whereby a hereditary disease could be passed on to a potential child. This law remained in force until 1977 with a minor amendment being accepted in 1961 to emphasize the rights of individuals.[52] It should be noted, however, that at no time was there any official government policy of eugenic sterilizations. Every instance was considered on its own merits and on a case by case basis.

Between 1934 and 1976 nearly forty-one thousand sterilizations had taken place in Norway, though the vast majority were undertaken on persons with full legal rights and on their own application. Nearly 75 per cent of sterilization took place on women.

From 1 January 1943 and until the 8 May 1945, a law 'for the protection of the race' was enacted during Nazi occupation. This wartime sterilization law promoted the importance of biological inheritance, widened the conditions for sterilization and developed regulations for coercion.[53] As soon as the Nazi puppet regime fell, however, the law was rescinded.

In 1977 when the old legislation was abrogated sterilizations in Norway had generally changed from a means of social control to become a means of individual freedom to limit reproduction.

• *Sweden*

Sweden was the only Nordic country with a national eugenics society in the early twentieth century. It was also a country where certain individuals believed that there existed an important Swedish-Germanic type. In a lively parliamentary debate in 1921 concerning the creation of a state institute on race biology, Arthur Engbert, a future minister of education and ecclesiastical affairs, indicated that Sweden was lucky to have a race which was generally unspoiled and characterized by very high qualities. Thus he found it 'odd that while we are so very particular about registering the pedigree of our dogs and horses, we are not at all particular when it comes to trying to preserve our own Swedish stock'.[54]

Discussions concerning the possible advantages of eugenic sterilizations of certain people were also present around this time though many opposing views were expressed. For example, Gunnar Hedrén, who was professor of forensic medicine, indicated in 1922 that if legislation permitting sterilization was enacted, what would be considered as legally acceptable would increasingly be widened. He indicated 'with regard to the right of disposal of the individual, euthanasia, for example, might in time become a lawful measure and perhaps also the taking of life in other instances, whenever it appears desirable for eugenic or other social reasons.'[55]

But despite the concerns raised by some commentators, the Swedish Parliament eventually enacted the 1934 Sterilization Act. The legislation, however, only addressed the possibility of sterilizations without consent of persons considered to be legally incompetent. This law was then updated and broadened in 1941to regulate all sterilization instances: not only persons with mental disabilities without capacity to consent (who could still be sterilized) but also individuals affected by serious physical disabilities of a hereditary nature. There was a sense, therefore, that some of the sterilizations were taking place because they were seen as desirable to the common interest including from an economic perspective.

During the debate in the Swedish Parliament relating to the 1941 Sterilization Act, arguments promoting the protection of the healthy Swedish race were still being heard. Minister of Justice K.G. Westman emphasized that the legislation was 'an important step in the direction of a purification of the Swedish stock, freeing it from the transmission of genetic material which would produce, in future generations, such individuals as are undesirable among a sound and healthy people.'[56] It should be noted, however, that the 1941 legislation also covered noneugenic motives such as the sterilization of women for medical reasons who were already overwhelmed with large families living in socially challenging settings, so that they could avoid any further pregnancies.[57]

Though the legislation officially prohibited coerced sterilization of those who were legally competent, this still occurred to some extent because a certain amount of persuasion could take place which did not always fulfil the requirements of free and informed consent. For example, at the beginning of the program, sterilization was often a precondition for certain mentally disable individuals being released from their institutions or for permission to get married.

Thus, from 1935, when sterilizations were often being undertaken for eugenic reasons until 1975 when they were generally being considered for medical reasons and the legislation was eventually overturned, Sweden sterilized nearly sixty-three thousand persons. Up to a quarter of these persons were mentally disabled. Though there was never a systematic sterilization program of mentally disabled individuals on the basis of political decisions or administrative instructions, the sterilizations seemed to develop on their own in the context of what was allowed.

More than 90 per cent of these procedures were undertaken on women, but many individuals considered as having an antisocial way of life also felt the effects of somewhat coerced sterilizations.[58,59]

Eugenics in the Soviet Union

Following the catastrophic and protracted conflicts stemming from the 1917 communist revolution, Russia saw a drastic reduction in its population, with Moscow alone losing about half of its inhabitants. At this time the Russian biologist and eugenicist Aleksandr Serebrovskii, like his British counterparts, was concerned for the wellbeing of his society. In 1929, as a remedy for the population decline, he recommended the widespread introduction of artificial insemination with the proviso that quality sperm was used. He stated: 'With the current state of artificial insemination technology…one talented and valuable producer could have up to one thousand children…In these conditions, human selection would make gigantic leaps forward. And various women and whole communes would then be proud… of their success and achievements in this undoubtedly most astonishing field – the production of new forms of human beings.'[60] However, Joseph Stalin eventually rejected such proposals, becoming convinced that eugenic policies contradicted Marxist ideology by claiming that human characteristics were determined through biology rather than through social and economic realities. In the end, and because of their perceived threat to communism, many geneticists in the Soviet Union were put to death or imprisoned while others fled the country.[61]

Eugenics in the United Kingdom

In the early 1900s, British demographics swung against the middle and upper classes, as entrenched poverty increased and the birth rates of those considered as the elite fell. This change provided a strong incentive for eugenic policies. In 1907, the eugenicist Sybil Gotto, concerned for the future of the nation, founded the Eugenics Education Society (EES)[62] to voice the concerns of the elite and develop responses to the perceived demographic problem. As already noted, the elderly Francis Galton served, a year later, as the first honorary president of the EES, significantly influencing the direction of the EES and the social thought of the United Kingdom.[63] The EES perceived the poor classes as having few positive qualities worth reproducing. The contempt for the poor classes by the EES was so marked that it labelled them as the 'residuum', that is, the unwanted leftovers. Following Galton's work on heredity, the Society also saw low intelligence as directly linked to the underprivileged. As a solution to the burgeoning sector of unintelligent people, one of the first proposals of the EES was to reduce the relatively high birth rate of the lowest classes in society so that the poor would be gradually eliminated. The result would be an improvement of the whole of society as the middle and upper classes eventually regained a majority of the population.[64]

Pushing past Galton's theories, the EES offered other practical proposals for reaching this goal, including an attempt to increase the number of children from middle classes and the enforced isolation of individuals whose reproduction could threaten the positive social goals the EES had charted for the United Kingdom. These suggestions eventually resonated amongst some UK politicians. In 1910 Winston Churchill wrote to a now unknown recipient that the socially inept persons in Britain 'should, if possible, be segregated under proper conditions so that their curse died with them and was not transmitted to future generations'.[65] Three years later, and following the *Royal Commission on the Causes and Control of the Feeble Minded,* the UK Mental Deficiency Act of 1913 legalized the compulsory detention of people labelled idiots, imbeciles, feebleminded or morally defective. The aim, in part, was to control their reproduction by segregating them into special colonies, asylums, sanatoriums and hospitals.

Eugenic concerns for the wellbeing of society remained and even increased after the particularly high death rate among officers in the First World War. Consequently, the promotion of eugenic policies in the 1920s continued to develop in the United Kingdom. In doing so, a wide consensus took hold of British society and beyond, that behavioural and personality traits as well as moral qualities were largely determined by inheritance. Galton's influence remained a force that shaped British thinking.

With the success of its educational programs in the 1920s, the EES initiated a campaign to legalize sterilizations at the end of the decade. However, the campaign failed while opposition to eugenic proposals began to increase in both volume and tenacity. By the 1930s social and political activity resulted in a strong antagonism to eugenic ideologies in the United Kingdom, an opposition which was encouraged from the marginal evidence that the characteristics so central to the eugenic programs were inherited.[66]

External resistance also neutralized the EES campaign. In 1930 Pope Pius XI issued the encyclical *Casti Connubii* addressing issues related to marriage, including procreation. Alarmed by eugenic proposals, such as the EES sterilization campaign, Pius XI strongly supported the freedom of marriage which was being debated in countries such as the United Kingdom. He denounced eugenics as 'that pernicious practice' and unequivocally declared the inappropriateness of any civil body attempting to regulate human reproduction.[67] In particular, he stated, 'Public magistrates have no direct power over the bodies of their subjects; therefore, where no crime has taken place and there is no cause present for grave punishment, they can never directly harm, or tamper with the integrity of the body, either for the reasons of eugenics or for any other reason'.[68] Thus one of the main grounds behind the reluctance of the UK government to introduce policies, such as eugenic sterilizations, was the strength of the Catholic lobby and the reticence of those in power to run the risk of adopting controversial and contentious legislation.[69]

The EES did, however, have some success in recruiting prominent members of British society. These included the past prime ministers Arthur Balfour, who gave the opening speech at the first international conference on eugenics in 1912, and Arthur Neville Chamberlain.[70,71] In 1926 the EES changed its name to the (British) Eugenics Society and, in 1989, eventually to the Galton Institute, which is still in existence.

In more recent times, commentators, such as the legal ethicist John Keown at Georgetown University, have suggested that the decriminalization of abortion in the UK Abortion Act 1967 may also be partly the result of a campaign to eradicate the disabled and the unwanted based on eugenic ideology. For example, Janet Chance, who chaired the Abortion Law Reform Association (ALRA), indicated in 1938 that it was in the name of racial improvements and because abortion may be a useful instrument for the development of eugenics that its liberalization should be considered.[72] Similarly the academic jurist Glanville Williams, who was president of ALRA, argued that abortion, amongst other possible eugenic procedures, would be of obvious social importance in 'preventing the birth of children who are congenitally deaf, blind, paralysed, deformed, feeble minded, mentally diseased, or subject to other serious hereditary afflictions'.[73] This was because he believed that society was already burdened by a large number of undesirable persons[74] and that giving birth to such individuals was a horrible evil and an offence to society.[75]

Keown also indicated that the Human Fertilisation and Embryology Act 1990 could be considered as allowing certain forms of eugenics. Warnings were even given during the passage of the act that it would allow abortions for even minor abnormalities such as cleft lip and palate. At the time, these concerns were dismissed as ridiculous and as scaremongering with those presenting such warnings being accused of deliberately misleading parliament. However, these fears have since been validated with abortions having taken place for these specific disorders without any prosecution.[76]

Eugenics in the United States

While the modern eugenics movement was born in the United Kingdom with Francis Galton, it first flourished as a scientific endeavour in the United States, which had one of the largest eugenic movements in the late nineteenth and early twentieth centuries. The first recorded eugenic experiment was the selective breeding of human beings which took place in the Perfectionist Community of Oneida, New York. The leader of the community, John Humphrey Noyes, was a Christian theologian and utopian visionary who believed that Christians had a responsibility to promote moral perfection. Key to this mission was the propagation of human beings who had attained an approximation of perfection. Noyes was influenced by Darwin's *Origin of the Species* as well as Galton's early work on human heredity in spearheading what he termed 'stirpiculture', the cultivation of high-quality human stock.[77] Between 1869 and 1879, he organized a campaign encouraging high-quality members of the community to reproduce. The result was the creation of fifty-eight 'stirpicults', or cultivated children. Community members involved in this program were selected on the basis of numerous characteristics, including intelligence, physical traits and commitment to Noyes's vision. Noyes himself fathered ten of the stirpicults.[78] The children born from the program were carefully studied and judged to be superior in their physique and intellect.

Noyes, however, was not the only Christian to embrace eugenic ideology. Many prominent Protestant clergymen taking part in the early development of the movement exercised their religious convictions and authority in support of what they considered a superior humanity. In 1912 the Reverend W.T. Sumner, dean of the Episcopal cathedral in Chicago, refused to marry couples who lacked a medical certificate proving that they were both mentally and physically healthy. This particular proposition being subsequently endorsed by another two hundred fellow clergymen with many more accepting the policy as desirable even though they would not implement its rigors.[79,80] The aim was to stop families which were seen as being trapped in criminal and social destitution, such as the infamous Jukes family in nineteenth-century United States, from having descendants.

A number of US states also enacted eugenic marriage laws restricting certain types of people, such as those deemed 'epileptic, imbecile or feeble-minded' from marrying.[81] Similarly, the state of Connecticut prohibited, in some circumstances, women over the age of forty from marrying, since their age significantly increased the risk of bearing less than perfect children.[82]

Even on the national stage, eugenic concerns emerged as a topic for debate and policy implementation. For example, a 1917 government statute excluded from immigration to the United States 'all idiots, imbeciles, feebleminded persons, epileptics, [and] insane persons'.[83] The intersection between eugenics and immigration reappeared during the 1924 session of the US Congress. To limit the influx of purportedly inferior humans from Eastern and Southern Europe, Congress passed the Immigration Restriction Act as a result of the influential testimony of expert advisers (read: eugenicists).[84] This landmark legislation reduced the number of undesired immigrants to the United States by 15 per cent compared with previous years. In an attempt to maintain the genetic heritage, it also strengthened existing laws prohibiting race mixing.

Overall, during the first seven decades of the twentieth century, eugenic policies affected up to sixty-four thousand Americans. But this happened primarily through measures such as forced sterilization programs.[85] The 1907 Compulsory Sterilization Law of Indiana was the first to enact such legalization, though the public at large, was generally unaware of this initiative.[86] According to this law, every institution that housed 'confirmed criminals, idiots, rapists and imbeciles' could authorize medical personnel 'to perform such operation for the prevention of procreation'.[87] This legislation was replicated by other states to such an extent that, by 1927, an estimated twenty-four states had enacted similar laws. Of these, the state of California was one of the most active, performing 4,636 sterilizations and castrations between 1907 and 1925, reaching a total of 9,930 by 1935.[88]

In 1927 a woman named Carrie Buck eventually challenged the law in the state of Virginia when a leading physician decided that her sterilization was for the good of society. When the high court of Virginia denied her claim, Carrie Buck appealed to the US Supreme Court in the notorious case of *Buck v. Bell.* The 8–1 decision against her was a watershed moment in the history of eugenics. In presenting the majority opinion for the court, Justice Oliver Wendell Holmes Jr. famously ruled that Virginia could legitimately require Ms. Buck to be sterilized since she was a threat and danger to the genetic stability of society. Justice Holmes indicated that:

> We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes.[89]

Holmes concluded with the now infamous phrase, 'Three generations of imbeciles are enough'.[90] Though this declaration understandably offends modern sympathies, equally striking is the language of imposed self-sacrifice. Holmes concluded that Carrie Buck's duty to society was to accept sterilization, lest she bear more 'feeble-minded' children like herself. With the case of *Buck v. Bell,* a eugenic ideology had fully captivated the United States.

Following the decisive ruling of this case, American sterilization policies and practices continued with little opposition until the 1974 case of *Relf v. Weinberger.* The impetus for this case was the malicious, undesired sterilization of sisters Mary Alice and Minnie Relf. Ruling in favour of the plaintiffs, the US District Court in Washington DC concluded that 'legally competent adults must give their "informed consent" to sterilization'.[91] However, it was not until 1981 that this ruling became standard practice, and its implementation owed primarily to public and legal pressures rather than judicial rulings.[92] Ultimately, formal acknowledgement of the ethically unacceptable abuse of sterilizations in the United States only came in 2003.[93]

The international influence of American eugenic policies should not be underestimated. The Nazi government in Germany regularly cited a publication that touted favourable results of the sterilization policy in the state of California as evidence that wide-reaching sterilization programs were both feasible and humane. At the Nuremberg trials following the Second World War, Nazi administrators accused of war crimes actually justified the mass-sterilization of hundreds of thousands of people in less than a decade by referencing the United States success as their inspiration.[94]

Ironically, by the end of the Second World War, news of the Nazi atrocities contributed to the retreat of the American eugenics movement with involuntary sterilizations declining in the 1940s.

International Developments

In 1948, the United Nations adopted the *Universal Declaration of Human Rights* in response to the crimes against humanity perpetrated during the Second World War. As expressed in the Declaration's preamble, the underlying concern was to protect all human beings, without exception, from prejudice and injustice. With this aim, the Declaration rejected both the atrocity of genocide but also any eugenic ideologies that would deny basic human rights such as the right to have a family. Thus, for example, in Article 16, the Declaration affirmed that '[m]en and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family'.[95]

However, the framers of the Declaration did not succeed in totally eliminating the pervasive influence of eugenics. As already noted, eugenic practices legally continued in the United States until well after the Second World War. Moreover, many pre-war eugenicists covertly maintained their beliefs while at the same time excelling in their respective fields.[96] In 1962, an international group of distinguished biologists met at the Ciba Foundation in London to consider 'Man and His Future'. Among those in attendance was the biologist Julian Huxley, the president of the British Eugenics Society from 1959–62 who was also the first Director-General of UNESCO. At this meeting Huxley suggested that:

> The improvement of human genetic quality by eugenic methods would take a great load of suffering and frustration off the shoulders of evolving humanity, and would much increase both enjoyment and efficiency…The general level of genetic intelligence could theoretically be raised by eugenic selection; and even a slight rise in its average level would give a marked increase in the number of the outstandingly intelligent and capable people needed to run our increasingly complex societies. How to implement eugenic policy in practice is another matter. The effects of merely encouraging well-endowed individuals to have more children, and vice versa, would be much too slow for modern psychosocial evolution. Eugenics will eventually have to have recourse to methods like multiple artificial insemination by preferred donors of high genetic quality… I confidently look forward to a time when eugenic improvement will become one of the major aims of mankind.[97]

While the British Eugenics Society lost some support after the Second World War, it continued to attract prominent scientists, including some geneticists, well into the 1980s. Throughout this postwar period the society advocated eugenic policies that allowed for voluntary participation in procedures such as contraception, insemination with donor sperm, genetic-carrier detection of Mendelian diseases and prenatal diagnosis.[98] For example, in 1983, in conjunction with its seventy-fifth anniversary, the British Eugenics Society focused its discussion on the eugenic and ethical aspects of new reproductive and genetic technologies. At the centre of the conversation was the sperm bank created by the American millionaire businessman Robert Graham, who founded, in 1980, the Herman J. Muller Repository for Germinal Choice. The Repository was a sperm bank that only accepted samples from Nobel Prize winners or men with demonstrably high qualities. The discussion ultimately concluded that, although controversial, a case could be made on eugenic grounds for choosing donors who exceeded normal levels of intelligence.[99]

The eugenic movement also had a profound effect on the development of clinical genetics in the postwar era, with increasing attempts to separate the genetic counselling of prospective parents from eugenic policies. This may be seen, for instance, in the emphasis on nondirective counselling for procedures such as terminations in contrast to the provision of directive advice that characterizes other clinical treatments.[100]

Notes

1. See also: A. Bashford and P. Levine (eds). 2010. *The Oxford Handbook of the History of Eugenics,* Oxford: Oxford University Press.
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3. Plato, *Republic* V.
4. Plato, *Republic* V.
5. W. Berns. 2001. *Making Patriots,* Chicago: University of Chicago Press, 12, 'and whose infants, if they chanced to be puny or ill-formed, were exposed in a chasm … and left to die'.
6. See also Christopher Irmscher. 2009, 'Proto-Eugenic Thinking Before Galton', *Bulletin of the German Historical Institute* 44, 83–88.
7. F. Galton. 1885. 'Typical Laws of Heredity', *Nature* 15, 492–95, 512–14, 532–33. Galton's parade illustration of this reversion is the rarity of giants. 'Giants marry much more rarely than medium men, and when they do marry they have but few children. It is a matter of history that the more remarkable giants have left no issue at all' (492).
8. E. Haeckel, 1866. Generelle Morphologie, 2 vols. II, Berlin: Verlag von Georg Reimer, 435.
9. E. Haekel to Charles Darwin, 9 February 1879, in G. Uschmann. 1983. *Ernst Haeckel: Biographie in Briefen,* Gütersloh: Prisma Verlag, 156.
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11. F. Galton. 1857. 'Negroes and the Slave Trade', *The Times,* 26 December, D10.
12. F. Galton. 1865. 'Hereditary Talent and Character', *Macmillan's Magazine 12,* 157.
13. F. Galton. 1869. *Hereditary Genius,* London: MacMillan and Co., v.
14. Galton, *Hereditary Genius,* 1.

15. Galton, *Hereditary Genius,* 5, 11.
16. Galton, *Hereditary Genius,* 14.
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21. V. Mottier. 2007. 'Eugenics, Politics and the State: Social-Democracy and the Swiss Gardening State', *Studies in History and Philosophy of Biological and Biomedical Sciences* 39, 263–69.
22. See also D.J. Galton. 2002. *Eugenics: The Future of Human Life in the 21st Century,* London, Abacus; New Ed edition. S. Kuhl. 2002. *The Nazi Connection. Eugenics, American Racism and German National Socialism,* Oxford: Oxford University Press. H. Bruinius. 2007. *Better for All the World. The Secret History of Forced Sterilization and America's Quest for Racial Purity,* New York: Vintage Books. V.F. Nourse. 2008. *In Reckless Hands. Skinner v. Oklahoma and the Near Triumph of American Eugenics,* New York: WW Norton. P.A. Lombardo. 2008. *Three Generations, No Imbeciles: Eugenics, The Supreme Court, and Buck v.Bell,* Baltimore: Johns Hopkins University Press.
23. Paul, *Controlling Human Heredity,* 6.
24. The 1996 film *The Sterilization of Leilani Muir* presents the Canadian situation. For Sweden, L. Lennerhed. 1997. 'Sterilisation on Eugenic Grounds in Europe in the 1930s: News in 1997 but Why?' *Reproductive Health Matters* 5(10), 156.
25. See for example, G. Broberg and N. Roll-Hansen (eds). 1996. *Eugenics and the Welfare State: Sterilization Policy in Denmark, Sweden, Norway, and Finland,* East Lansing: Michigan State University Press. Also, Paul, *Controlling Human Heredity,* 72.
26. X. Mao. 1998. 'Chinese Geneticists' Views of Ethical Issues in Genetic Testing and Screening: Evidence for Eugenics in China', *Am. J. Hum. Genet.* 63, 688–95.
27. Ibid.
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29. R. Weikart. 2004. *From Darwin to Hitler: Evolutionary Ethics, Eugenics, and Racism in Germany,* New York: Palgrave MacMillan, 89.
30. A. Carol. 1995. *Histoire de l'eugénisme en France,* Paris: Seuil, 79.
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32. French Penal Code, Sous-titre II du Titre I du Livre II, Article L 214-1; Civil Code, Article 16-4.
33. R. Weikart. 2004. *From Darwin to Hitler: Evolutionary Ethics, Eugenics, and Racism in Germany,* New York: Palgrave MacMillan, 48–49.
34. Müller-Hill, 'Lessons from a Dark and Distant Past', 133–41.
35. Wikler, 'Can We Learn From Eugenics?', 183–94.
36. 'Sterilisation of the Unfit, Nazi Legislation', *The Guardian,* 26 July 1933. Retrieved 26 July 2011 from http://century.guardian.co.uk/1930-1939/Story/0,6051,126942,00.html.
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42. German National Ethics Council, *Self-determination,* 33.
43. R. Weikart. 2004. *From Darwin to Hitler: Evolutionary Ethics, Eugenics, and Racism in Germany,* New York: Palgrave MacMillan, 227.
44. German National Ethics Council, *Self-determination,* 33. Also, J.A. Emerson Vermaat. 2002. 'Euthanasia in the Third Reich: Lessons for Today?', *Ethics & Medicine* 18(1), 21–32.
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51. Roll-Hansen, *Norwegian Eugenics: Sterilization as Social Reform,* 169.
52. Roll-Hansen, *Norwegian Eugenics: Sterilization as Social Reform,* 172–76.
53. Roll-Hansen, *Norwegian Eugenics: Sterilization as Social Reform,* 178–79.
54. Quoted in G. Broberg and M. Tydén. 2005. 'Eugenics in Sweden: Efficient Care', in G. Broberg and N. Roll-Hansen (eds), *Eugenics and the Welfare State: Norway, Sweden, Denmark, and Finland,* East Lansing: Michigan University Press , 87.
55. Quoted in G. Broberg and M. Tydén. *Eugenics in Sweden: Efficient Care,* 104.
56. Quoted in G. Broberg and M. Tydén. *Eugenics in Sweden: Efficient Care,* 107.
57. G. Broberg and M. Tydén. *Eugenics in Sweden: Efficient Care,* 108–11.
58. B. Müller-Hill. 1994. 'Lessons from a Dark and Distant Past', in A. Clarke (ed.), *Genetic Counselling: Practice and Principles,* London: Routledge, 133–41.
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62. After 1926 the EES became known as the British Eugenics Society and after 1989 as the Galton Institute.
63. Wikler, 'Can We Learn From Eugenics?', 183–94.
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65. Quoted Black, *War Against the Weak,* 215.

66. Nuffield Council, *Genetics and Human Behaviour,* 15.
67. Pope Pius XI. 1930. *Casti Connubii,* sections 68–71.
68. Pius XI, *Casti Connubii,* section 70.
69. G.R. Searle. 1979. 'Eugenics and Politics in Britain in the 1930s', *Annals of Science* 36, 159–69.
70. D.J. Kevles. 1995. *Au nom de l'eugénisme,* Paris: Presses Universitaires de France, 88.
71. D.J. Kevles. *Au nom de l'eugénisme,* 162.
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73. G. Williams. 1958, *The Sanctity of Life and the Criminal Law,* London: Faber & Faber, 82.
74. Williams, *The Sanctity of Life and the Criminal Law,* 83.
75. Williams, *The Sanctity of Life and the Criminal Law,* 212.
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78. Carden, *Oneida,* 63.
79. Paul, Controlling Human Heredity, 10.
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    See also: Christine Rosen. 2004. *Preaching Eugenics: Religious Leaders and the American Eugenics Movement,* Oxford: Oxford University Press.
81. Black, *War Against the Weak,* 146.
82. M. L. Ricci. 2009. 'Assisted Procreation and Its Relationship to Genetics and Eugenics', *Human Reproduction and Genetic Ethics* 15, 10.
83. Black, *War Against the Weak,* 188.
84. In this context Senator Ellison DuRant Smith of South Carolina indicated during the discussions on the Immigration Act of 1924: "Thank God we have in America perhaps the largest percentage of any country in the world of the pure, unadulterated Anglo-Saxon stock; certainly the greatest of any nation in the Nordic breed. It is for the preservation of that splendid stock that has characterized us that I would make this not an asylum for the oppressed of all countries, but a country to assimilate and perfect that splendid type of manhood that has made America the foremost Nation in her progress and in her power, and yet the youngest of all the nations."
    Speech by Ellison DuRant Smith, 9 April 1924, *Congressional Record, 68th Congress, 1st Session, 1924,* Washington DC: Government Printing Office 65, 5961–62.
85. By 1940, 35,878 men and women had been sterilized and castrated in the United States, Black, *War Against the Weak,* 123.
86. Black, *War Against the Weak,* 67.
87. State of Indiana. 1907. *Acts 1907 – Laws of the State of Indiana, Passed at the Sixty-Fifth Regular Session of the General Assembly,* Indianapolis: William B. Burford, 377–78.
88. Black, *War Against the Weak,* 122. Cf. Galton, 'Greek Theories on Eugenics, 263–67.
89. *Buck v. Bell* [1927], 274 U.S. 200. For piercing analysis see: P.A. Lombardo. 2008. *Three Generations, No Imbeciles: Eugenics, the Supreme Court, and Buck v. Bell,* Baltimore: Johns Hopkins University Press.
90. *Buck v. Bell* [1927], 274 U.S. 200.

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94. D. Kevles. 1985. *In the Name of Eugenics: Genetics and the Uses of Human Heredity,* Berkeley: University of California Press, 169. Also Black, *War against the Weak,* 400.
95. Universal Declaration of Human Rights, Article 16.
96. For the general changes in views towards genetics and race after the Second World War: E. Barkan. 1992. *The Retreat of Scientific Racism: Changing Concepts of Race in Britain and the United States between the World Wars,* New York: Cambridge University Press.
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98. Nuffield Council, *Genetics and Human Behaviour,* 16.
99. C.O. Carter. 1983. *Developments in Human Reproduction and their Eugenic and Ethical Implications. Proceedings of the Nineteenth Annual Symposium of the Eugenics Society,* London: Academic Press.
100. Paul, *Controlling Human Heredity,* 125–29. Also, Nuffield Council, *Genetics and Human Behaviour,* 16.

GENERAL INTRODUCTION TO EUGENIC PROCEDURES

The topic of eugenics is generally perceived as being multifaceted, with different procedures being considered in both positive and negative ethical lights. The present moral distinction among these eugenic practices being made all the more difficult because of the abuses which took place in Nazi Germany which gave all forms of eugenics a very bad press. But some indirect eugenic practices, such as the selection of a partner, are generally seen as being acceptable by society even though they may not be recognized as having a eugenic component.

However, some eugenic procedures in contemporary society do still receive negative attention. These often relate to the ability to screen and select or deselect biological entities with specific genetic traits that have been created randomly, such as gametes, embryos and foetuses. Genetic improvements may also eventually be possible through genetic manipulation of gametes, embryos and foetuses but also human beings after birth.

In theory, selection procedures enable scientists and prospective parents to control the genetic make-up of potential children by (1) eliminating the unwanted, (2) selecting the desirable, or (3) redesigning and improving those entities or children who already exist. However, it should be emphasized that even a successful genetic selection or manipulation may not always produce the desired results since most traits of interest to parents seeking better children are heavily influenced by the environment. Moreover, these procedures are not equally feasible and vary in the frequency of practice though each activity raises its own ethical questions.[1]

This chapter will scrutinize eugenic procedures which may affect future children. Examples of each practice will clarify exactly what is at stake, as well as demonstrating the relevance of the discussion for the twenty-first century by presenting three components:

(1) The procedure will be clearly described in lay language without compromising scientific accuracy.

(2) The method in question will then receive an ethical analysis. This examination engages a number of serious arguments in favour and against the procedure and demonstrates that ethical judgements are not straight forward.
(3) Each section will finally present relevant regulatory provisions including pertinent legal data. This will mainly be in addition to the following international legislation from bodies such as the United Nations, UNESCO and the Council of Europe while also addressing the United Kingdom legal framework as a typical example of a regulatory context in a large Western state that has an advanced expertise in reproductive procedures.

In summary, the legislation and recommendations provided in this book validate the need to ethically address the various procedures being presented in the following sections since they demonstrate that each issue has already been considered to be far more than just science fiction.

General Legislation Concerning Eugenic Procedures

Before discussing the ethical perspectives relating to the different procedures which may be considered as eugenic practices it is important to set the scene with regards to legislations which have been implemented especially since the Second World War. When the different eugenic procedures will be discussed in the following sections, these legal instruments, which are of a general nature, should be kept in mind since they can be considered as foundational legislation.

United Nations

The Universal Declaration of Human Rights (Adopted and proclaimed on 10 December 1948)

> Article 1:
> All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.
>
> Article 3:
> Everyone has the right to life, liberty and security of person.

United Nations Education, Scientific and Cultural Organization (UNESCO)

Universal Declaration on Bioethics and Human Rights (Adopted by acclamation on 19 October 2005 by the 33rd session of the General Conference of UNESCO)

> Article 11 – Non-discrimination and non-stigmatization:
> No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms.

Universal Declaration on the Human Genome and Human Rights (Adopted on 11 November 1997)

> Article 6:
> No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.
>
> Article 11:
> Practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted. States and competent international organizations are invited to co-operate in identifying such practices and in taking, at national or international level, the measures necessary to ensure that the principles set out in this Declaration are respected.

Council of Europe (Forty-seven Countries)

Convention for the Protection of Human Rights and Fundamental Freedoms (CETS No.: 005, Entered into force on 3 September 1953)

> Article 14 – Prohibition of discrimination:
> The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (CETS – No. 164, Entered into force on 1 December 1999)[2]

> Article 11 – Non-discrimination:
> Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.

European Union (Twenty-eight Countries)

Charter of Fundamental Rights of the European Union (Proclaimed in Nice on 7 December 2000)

> Article 3 – Right to the integrity of the person:
> 2. In the fields of medicine and biology, the following must be respected in particular: … the prohibition of eugenic practices, in particular those aiming at the selection of persons.

United Kingdom Legislation

Disability Discrimination Act (1995)
Under this Act, a disability is defined as 'a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out

normal day to day activities'. 'Impairment' is not defined, but regulations clarify certain exclusions. The Disability Discrimination Act protects disabled people (children and adults) from discrimination and less favourable treatment for a reason relating to their disability.

Human Fertilisation and Embryology Act 2008
In the United Kingdom it is not legal to specifically select persons or embryos for disability in reproduction. Section 14 (4) of the Human Fertilisation and Embryology Act 2008 states that 'Persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop a serious physical or mental disability, a serious illness, or any other serious medical condition, must not be preferred to those that are not known to have such an abnormality'.

Selection through Migration

In the past, and especially at the beginning of the twentieth century, a number of countries implemented selection procedures on the kind of people they wished to accept as immigrants. This kind of selection would conform to the definition of a eugenic practice, namely, it would be a strategy or decision aimed at effecting, in a manner which is considered to be positive, the genetic heritage of a child, a community or humanity in general.

As already indicated, an example of such a practice happened in 1917 when the US government excluded from immigration 'all idiots, imbeciles, feebleminded persons, epileptics, [and] insane persons' on the basis, amongst other factors, that they may be detrimental to the heritage of the United States.[3] In 1924, the US Congress also accepted the Immigration Restriction Act, which was strongly influenced by eugenic considerations, to restrict immigration to certain ethnic makeup. This was followed, in 1929, by the implementation of national origins quotas in US immigration policies.[4]

At present, some modern governments still have restrictions in place in the kinds of professional persons who can be accepted as immigrants. These are generally people who are considered to be an asset to the country, though these individuals are not selected on the basis of biology or at least not directly.

Some governments, on the other hand, are trying to encourage specific sections of their societies, including certain nationalities, to emigrate back to their countries of origin with financial inducements. These are usually people who are not usually seen as a benefit to the country in which they are presently resident. Again this encouragement is not based on biological origin, though it may play a small indirect part.

Selection of Reproductive Partner

In many countries, relationships that lead to procreation usually begin by a mutual attraction which represents a whole set of reasons. A couple does not generally come together just because the relationship may bring forth children. But it is likely that a person selects a partner because of at least some perceived suitability as a parent, even if this perception is unconscious. Suitable qualities for a parent include specific characteristics that a person considers to be positive and desires to see in his or her future children. For example, a woman may choose a healthy man whom she finds physically attractive for his eye or hair colour and strong features, but the attraction may also arise because she (even unconsciously) desires similar or complementary characteristics in her children. At a more fundamental level, selection may occur based on the phenomenon known in genetics as 'assortative mating', that is, the reality that people often choose partners who are like them. There is often a positive correlation between husbands and wives on IQ scores and in specific cognitive abilities. Thus, it can be argued that all decisions to have a child involve some kind of selection to varying degrees, and as a result, natural conception is not entirely a random exercise.

Another limitation in the randomness of selecting a partner arises when issues of consanguinity or closeness are expressed with respect to incest. Indeed, a lot of discussion has arisen concerning the origins of any prohibition for persons selecting reproductive partners who are too near or similar to themselves. In this regard there is often an unfortunate combination between the origins of the prohibition relating to incest and the reasons for its maintenance long after the grounds for its existence have ceased to exist. It should also be noted that incest was not always prohibited, as in Pharaonic and Ptolemaic Egypt as well as in ancient Iran.[5,6]

When prohibitions in sexual and matrimonial relationships did take place, these were not usually based on a wish to have healthy children but on a dislike of sexual partners who were not different enough on a biosocial level. In other words, they were too close consubstantially in that, for example, the persons derived from the transmission of the same body substances between generations or between the conjugal couple, or as a result of consuming the same foods.[7] In many Muslim communities, individuals who shared the same wet-nurse as infants were barred from having any sexual union later on in life since they were considered as 'milk-siblings'.[8]

The social scientist Enric Porqueres i Gené and historian Jérôme Wilgaux explain the wish for nonsimilar spouses in that:

> Before the nineteenth century, incest prohibitions were explained by the respect due to relatives, by the need to create ties between families through marriage, by the necessity of avoiding the concurrence in the same person of more than one genealogi-

> cal position, by the sexual indifference created by a common residence and, more or less explicitly, by the link of physical sameness or shared physical substance – which explains not only the prohibitions between blood relatives but also between those linked by marriage or sexual intercourse.[9]

It was only in the nineteenth century that the reasons for incest prohibitions were generally given on biomedical grounds with a development of understanding of genetics and inheritance.[10] In this regard, national legislations still often prohibit the marriage between a man and a woman who are blood relatives to prevent, amongst other factors, the creation of a child with a serious biological disorder. This type of legislation acknowledges that the offspring of consanguineous relationships are at greater risk of certain genetic disorders. Since blood relatives share many genes, there is a higher likelihood that a man and a woman who are blood relatives will both be carriers of the same genetic disorder. In turn, the children of the couple would be at risk of inheriting both sets of defective genes with the more closely related parents producing a higher risk of genetic disorder. In an incestuous relationship between siblings, the risk of a genetic disorder arising in a possible child is relatively high since the two parties share about half of their DNA. In a relationship between second cousins, on the other hand, the two parties share only about 1/32 of their DNA, and the risk is considerably lower (although still greater than if the parents were unrelated).

Of course, the classification of consanguinity varies by context. Many cultures and worldviews define a degree of consanguinity within which sexual interrelationships were historically regarded as incestuous. For example, in the Christian faith, which very much influences European legislation, marrying a close relative was strictly forbidden.[11]

In the Roman Catholic Church, unwittingly marrying a closely consanguineous blood relative was grounds for an annulment.[12] The Church's ban on marriage within the fourth degree of relationship (first cousins) lasted from 1550 to 1917. Dispensations were available, but were increasingly more difficult to obtain the closer the relationship between the couple. It is likely, however, that the basis for this prohibition on consanguinity was not a concern for eugenic considerations. The condemnation of affinity, such as marrying a stepdaughter (canon 1092) and marrying an adopted child or sibling (canon 1094) implies that these codes were again drafted on the basis of avoiding sexual relationships between people who were considered too similar or who had something overly 'in common'.[13] The prohibition against marriage went so far as to even include godparents in some Christian communities because such parents had a strong spiritual involvement with a child.[14] For the Christian church the commands in the book of Genesis was for a man to leave that which was close and familiar to him (i.e., his father and mother) and seek a completely different person (i.e., a woman from outside his usual habitat) to establish a new 'one flesh' couple formed from their differences.

This is expressed in Leviticus 18:6, which indicates that no one is to approach any close relative to have a sexual relationship. This is because it involves a sexual merger with someone who is already too similar on a familial level.

The Christian tradition also sought to protect close relationships from sexual corruption and abuse. These sexual restrictions were not, therefore, drafted to protect progeny from inheritable disorders but were similar to those that prevent relationships between teachers and their pupils or doctors with their patients.[15] These relationships were prohibited even though it may have been certain that no child would ever be born.

Methods for Selecting Reproductive Partners

The following paragraphs present a few specific programs in which the selection of reproductive partners has occurred. Two common features mark these programs. They are restrictive, affecting only a small segment of society, and they have generally occurred voluntarily, though not always, as the first example shows.

Nazi Germany

A nonvoluntary program was established in Germany at the end of December 1931 when Heinrich Himmler, Reich-führer (National Leader) - SS and Chief of the German Police, decreed that men in the SS could marry 'solely if the necessary conditions of race and healthy stock were fulfilled'.[16] Either Himmler himself or the RuSHA (Rasse und Siedlungshauptamt – Race and Settlement Main Office) had to approve the marriage. But before this could be considered, both the SS member and his fiancée had to demonstrate the quality of their stock by completing a RuSHA questionnaire and passing a comprehensive physical examination administered by an SS doctor. The application for marriage also required photographs of the man and woman in bathing suits taken from three angles as well as proof of Aryan ancestry dating to 1800 for most candidates and to 1750 for officers.[17] These requirements for marriage found further expression in the laws Hitler proclaimed in 1935, now known as the Nuremberg Laws. The first of these laws underscored that Jews and (Aryan) Germans were not permitted to engage in sexual relations, even in marriage. The goal of using marriage as a means to create a pure race extended to prohibiting Jews from hiring German housekeepers under the age of forty-five, lest a child were created from an illicit liaison.[18]

Premarital Certificates in Cyprus

Epidemiological studies in the 1960s and 1970s in Cyprus found that roughly 15 per cent of the population were unaffected carriers of the autosomal–recessive genetic disorder beta-thalassemia. This disorder reduces the production of haemoglobin (the iron-containing protein in the blood that carries oxygen to the body's cells), leaving affected carriers at high risk of anaemia and numerous internal disorders. As an autosomal-recessive disease, it only affects people who have both copies of the genetic code for the illness. Thus, if both parents are carriers of the defective gene, they have a one in four chance of conceiving a child with beta-thalassemia. The study in Cyprus also suggested that, on average, 2 per cent of all couples were expected to be joint carriers of this recessive disorder.[19] In response, the World Health Organization sponsored a program to screen for the disease and thus help both the health and the economy of Cyprus. Estimations had indeed suggested that, barring intervention, the cost for treating those affected by the disorder would eventually consume the country's entire health budget.[20]

Another response came from the Christian church in Cyprus. In 1983, it supported the introduction of premarital certificates that detailed a person's carrier status. The reasoning was that, theoretically, disclosing carrier status would enable people to select partners with whom they could have children unaffected by beta-thalassemia, with the ultimate aim of curtailing the spread of disease. Healthy carriers could also, of course, decide to marry in any case with the possibility of a prenatal diagnosis and the eventual termination of an affected pregnancy.

Evidence that the premarital certificates (or other procedures) were effective in reducing the number of affected persons in Cyprus is largely anecdotal.[21] Nevertheless, the response of the Christian church to the crisis on the island shows that screening reproductive partners has sometimes been met with approval even amongst some religious conservatives.

Dor Yeshorim (Hebrew for 'Generation of the Upright')

Since the 1980s certain Jewish communities have benefited from advances in human genetics to make decisions about the selection of reproductive partners. The primary impetus for these decisions has been the prevention of Tay–Sachs disease, a fatal, incurable degenerative disorder that affects children with death occurring by the age of about four years. Like beta-thalassemia in Cyprus, the disorder is inherited in an autosomal recessive manner,[22] with some specific Jewish communities being more at risk than others. Amongst Ashkenazi Jews (of Central and Eastern European descent) Tay–Sachs carrier frequency is around 1 in 25 to 1 in 30, whereas in the general population carrier frequency is about 1 in 250 to 300.[23]

To address the onslaught of Tay–Sachs disease in this community, Josef Ekstein, an American ultra-Orthodox Rabbi, decided in 1983 to use new developments in human genetics to set up Dor Yeshorim (Hebrew for 'Generation of the Upright'). Ekstein knew the sorrows of Tay–Sachs personally, having already lost four of his own children to the disease. The purpose of the organization was to help prospective couples avoid a genetic disorder by enabling them to assess their genetic compatibility.[24]

Dor Yeshorim operates with simple procedures. Representatives of the organization visit Orthodox high schools and draw blood samples from pupils, issuing a number to each student. The samples are then screened for genetic disease and the results filed. When the students reach a marriageable age and receive a recommendation about a potential mate from a *shadchan,* a matchmaker in the Orthodox community, they (or their parents) contact Dor Yeshorim for advice. The organization retrieves the assigned numbers for each partner in the potential couple and checks whether they are carriers of genetic disease. If both the man and woman are positive, Dor Yeshorim then advises against the marriage.[25]

To date, more than 330,000 young people have been tested by Dor Yeshorim throughout the United States, Europe, Canada and Israel. As a result, the number of children born with Tay–Sachs disease in the Jewish community in the United States and Canada has dropped from about thirty or forty to between about four or five per year.[26] In addition to Tay–Sachs, the program now tests for a number of other genetic diseases.[27]

In a way, every participant in Dor Yehshorim who eventually declines marriage on the basis of a genetic test makes a eugenic decision to prevent an insidious disorder. In this regard, it might be supposed that such a decision would meet universal acclaim, but as discussed below, several objections have been made of Dor Yeshorim because of a number of concerns.

Arguments in Favour of Selecting a Reproductive Partner

Support for selecting a reproductive partner on eugenic grounds ultimately rests on a complex foundation. Put simply, however, the eugenic characteristics of potentially procreative relationships are related to preventing a serious congenital disease. The aims and successes of Dor Yeshorim illustrate this outcome. By screening and advising members of the Jewish community, this organization has strongly advocated the implementation of both positive and negative eugenics: positive, because the genetic counselling of Dor Yeshorim has promoted a specific genetic heritage, and negative, because this genetic inheritance is marked by the absence of Tay–Sachs and other genetic disorders.

The eugenic selection of a reproductive partner may, as a result, benefit certain individuals in a number of different ways. (1) The procreative couple may benefit from the procedure since they obtain peace of mind when genetic screening reveals no carrier genes for a disorder. Conversely, if tests do reveal a genetic disorder, the couple may opt against marriage with the settled conviction that the match may have resulted in the perpetuation of a disease.[28] (2) Detection of carrier genes may avoid the birth of a potential child with a disorder, provided of course that the individuals decide not to marry or to remain childless.[29] Thus, the work of Dor Yeshorim and other similar organizations prevents the creation of lives affected by congenital disorders.[30]

But the success of selecting a reproductive partner for eugenic reasons depends on the shared principles of a community, such as its responsibilities towards the next generation and its deference to elders in choosing a spouse. This is clear in the selection process that Dor Yeshorim facilitates among the Orthodox Jewish community which also affirms the inviolability of human life and thus welcomes an alternative to abortion. In short, shared principles are essential if a community wishes to practice eugenically directed partner selection.

Arguments against Selection for Reproductive Partners

While eugenic programs for selecting a reproductive partner may have advantages, as noted above, there are also two primary arguments which raise concerns. Firstly, practices such as those advocated by Dor Yeshorim are uncomfortably similar to past eugenic social programs which were rejected for ethical reasons. As David Galton indicated concerning the screening of young Ashkenazi Jews: 'However humane the intention of this programme may be it must be considered as a socially controlled rather than a voluntary eugenic plan.'[31] Opponents of Dor Yeshorim fear that widespread acceptance of partner selection on eugenic grounds could reawaken the discrimination of earlier years. This includes Nazi Germany's notorious promotion of genetic considerations in reproduction by discriminating against all who did not match their genetic criteria. On the other hand, differences are noted in that Dor Yeshorim does not seek to decrease the number of carriers of a defective gene but only the number of children who are affected by a genetic disorder.

A second objection to partner selection concerns the status of gene carriers and the possible stigmatization of an affected community or even a specific carrier.[32] Studies reveal that identified carriers and high school students in affected communities regularly report increased anxiety about their carrier status. Nearly half of all carriers reported feeling worried about their future.[33] Of course, it is possible to argue that the scientific discovery of the genetic basis for a certain condition should neutralize its associated stigma since individuals will realize that it is not their 'fault' if they are affected by dysfunctional genes. But when a specific group is associated with a negative genetic trait, a stigma may still be applied to the entire ethnic population, with almost certain negative consequences.[34] Interestingly, the dramatic decline in the number of Tay–Sachs cases amongst Ashkenazi Jews may also actually increase the stigma associated with the disease in the community since carriers of the Tay–Sachs gene are a small minority and thus more liable to discrimination for a disease that has become relatively rare.

As more genetic disorders, such as those for breast and colon cancers, are discovered among Ashkenazi Jews or other communities, both the positive aspects and negative aspects of the screening may be heightened. The balance between advantages and risks needs careful consideration. For example, in the broader Jewish population, mental illness carries more stigma than cancers. But, as Christine Rosen reports, 'in the Orthodox Jewish community, cancers related to reproduction, such as breast or ovarian cancers, are stigmatized because they are linked to the reproductive value of women in that community'.[35] The relationship between eugenic partner selection and a community is thus relatively complex and, consequently, something of a microcosm for the entire subject of selection procedures.

In summary, it is when the quality of life of a possible future child becomes the primary basis for selecting a reproductive partner that eugenic issues begin to appear. This, however, is not usually the case when couples decide to come together, even though some unconscious reasons may exist relating to the kind of children that may be procreated with the prospective partner. This can then be seen as an innocuous form of unintentional eugenics or a secondary outcome in a kind of 'double effect' situation.

Interestingly, there is also no condemnation, at present, by society of couples who know that they have a high risk of having children with serious disabilities, but decides to have children anyway. Perhaps society operates with an understanding that the child is the fruit and representation of the love that exists between the partners and should, therefore, always be welcomed in that love.

Legislation

In promoting the equality of all members of humanity, regulations have been drafted to protect against discrimination on the basis of genetic heritage. Two of the most wide-sweeping legal texts are noted below to illustrate that, while partner selection may have advantages for limiting the spread of disease, it does not constitute grounds for marginalizing persons.

United Nations
The Universal Declaration of Human Rights - *(Adopted and proclaimed on 10 December 1948)*

> Article 16
>
> 1. Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.
>
> 2. Marriage shall be entered into only with the free and full consent of the intending spouses.

Council of Europe (Forty-seven Countries)
Convention for the Protection of Human Rights and Fundamental Freedoms - *(CETS No.: 005, Entered into force on 3 September 1953)*

> Article 12 – Right to marry
>
> Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right.

Note: The above two provisions ensure that no restrictions should exist with respect to choosing a partner in order to form a couple as long as it is according to national laws.

Legislation in the United Kingdom

The Sexual Offences Act 2003 (England, Wales and Northern Ireland) indicates under Section 64 and 65 (*sex with an adult relative*) that a person aged sixteen or over commits an offence if he or she has a sexual relationship with a relative who is a parent, grandparent, child, grandchild, brother, sister, half-brother, half-sister, uncle, aunt, nephew or niece.

In the United Kingdom, the mixing of donated sperm and eggs between relatives in fertility treatments is not addressed in specific legislation. However, no mixing between close relatives, such as brother and sister or father and daughter has been reported. Fertility clinics would not agree, moreover, to such procedures, since they have a responsibility to prevent treatments which may result in serious harm to any future child.

Selecting to Have Many, Few or No Children

The definition of eugenics presented at the beginning of this book encompasses numerous practices. The focus now turns to examine decisions about children. Some parents may opt to have many children, motivated by a willingness to pass on their own positive traits. Other parents may opt for few or no children if the children are likely to be at risk of a serious genetic disorder. These choices are eugenic under the definition presented at the beginning of this book because their aim is to create life that is considered positive at birth.

Selecting to Have Many Children

In the past, some communities or even whole countries have implemented eugenic policies that have encouraged certain individuals to have many children with the aim of improving or strengthening their corporate genetic heritage. In every case, the community determined a desired genetic standard, identified individuals meeting that standard, and then encouraged them to procreate prolifically.

A stark example of this process is clear in a number of the social policies of Nazi Germany. Heinrich Himmler, Reichsführer (National Leader) - SS and Chief of the German Police, expected his biological elite to have large families. Through the use of propaganda and indoctrination, Himmler urged and cajoled genetically pure Germans to reproduce and thereby to build the master race. In 1936 Himmler's desperation to purify the genetic heritage reached an astonishing climax as he declared that only SS men between the ages of twenty-five and thirty were permitted to marry. In the end, Himmler's efforts failed, as the SS birth rate was little different to that of the overall population.[36] On the whole, the practice of having more children for eugenic reasons found little widespread support beyond Nazi Germany. The experiments of the nineteenth-century Oneida community are a notable exception. As previously indicated, the Oneida community in New York only encouraged people selected for their intelligence, physique and other characteristics to procreate. This took place with the full collaboration of the individual couples who became the parents of the children.

Selecting to Have Few or No Children

While some couples may practise a form of positive eugenics by having many children, other couples may decide to have few children or not to reproduce at all, practising a form of negative eugenics. This may arise for a number of reasons, including from information obtained from preconception genetic testing which examines individuals to determine whether or not they are carriers of a genetic condition. The practice often takes place in a two-stage program including:

(1) A screening step which enables individuals in a whole population group to be tested. This often happens when the population is known to be at increased risk of a genetic condition. But individual members of the population are at no higher risk than other members of the group.[37]
(2) A genetic testing step which determines the presence or absence of a genetic biomarker in an individual, regardless of the context in which the test is commissioned or performed.[38]

By using preconception genetic testing, prospective parents can learn whether a genetic condition could be passed on to a future child even before he or she is conceived. In this regard, the prevalence of a significant genetic disorder arising amongst the general public is roughly 2 to 3 per cent.[39]

Preconception genetic testing is also useful for identifying population groups or individuals who suspect that they may be at risk of passing on a disease. Of course, not all persons who may benefit from preconception genetic testing actually undergo the procedure for a number of different reasons, including the fact they may not want to know the results. Others may even be unaware that the tests are available.[40] Generally, however, the decision not to reproduce is based on the perception that there is a substantial risk that a child could be affected by a serious genetic disorder.[41] Strictly speaking, even though the decision not to have a biological child 'of their own' may receive widespread support, the decision is still a form of negative eugenics because the couple have abstained from reproduction to avoid an 'undesired' genetic heritage.

Interestingly, this form of negative eugenics has been supported by commentators for some time, including by the American ethicist Paul Ramsey, who indicated in 1970 that 'If the fact-situation disclosed by the science of genetics can prove that a given person cannot be the progenitor of healthy individuals (or at least not unduly defective individuals) in the next generations, then such a person's "right to have children" becomes his duty not to do so, or to have fewer children than he might want (since he never had any right to have children simply for his own sake).'[42,43] But even if one or both partners are affected by a very serious genetic disorder, they are under no obligation to refrain from having a child, as the legislation outlined previously affirms. It is generally accepted, with few exceptions, that the couple have a right to have a child even if it has a very high risk of disability or ill health.[44] In this sense, there is, a categorical difference between couples deciding whether to have children in the first place and determining, once this initial decision is made, what kind of child to have (which is a decision which may be based on eugenic concepts). Couples may indeed have all sorts of noneugenic reasons for not having children including the fact that they know that they could not care alone for a severely disabled child and that they will not get any support. In this case, the decision is not based on selection *between* children or possible future children. Had the parents decided to have a child, they would have been prepared to have *any* child. In other words, the emphasis here is on the parents and their situational background and not on the child's characteristics or quality of life, as such. But once parents (who are capable of looking after a disabled child) make a decision to have a child but then decide to go back on their decision because of the biological quality of their prospective child, eugenic influences are present.

As developed later, there is also a crucial ethical difference between (1) deciding whether or not to procreate a child based on eugenic values and whether he or she is affected by a disorder and (2) welcoming him or her into existence, whoever he or she is, as an equal member of society. For example, if two people have a high risk of passing on a serious genetic disorder to a future child and they still decide to pursue conception without screening the disease, then it might be argued that what they are doing is ethically rational. In effect, the couple will be prioritizing the mere existence of a child over any other features of the child's life. In this way they show unconditional acceptance for him or her and thereby acknowledge that all life is worth living for its own sake and has an equal value. For these parents, a person's length of life or possible suffering does not invalidate his or her inherent worth and dignity.

On the other hand, if the couple decides not to procreate because one or both partners carry a serious genetic disorder that may be passed on to their possible future child, even though they may be capable of looking after him or her, they are making a eugenic decision. In this regard, they may also indirectly communicate the message that persons with serious disorders are less welcome in society. This would be an implicit message that individuals, who already live with such disorders, may receive with consternation and worry about discrimination. For this and other reasons, some worldviews consider that every sexual act should have procreative potential.[45] The idea undergirding this thinking is that in a sexual relationship, both partners should be willing to accept a child whoever he or she may turn out to be as the outcome of each act of sexual union.

Wrongful Life and Wrongful Birth

The choice whether or not to have children may be associated to additional more complex issues, as is made clear in recent lawsuits regarding 'wrongful life' and 'wrongful birth' which have been taking place across the world.

In a wrongful *life* lawsuit, a child sues his or her parent(s) and/or other people for having allowed him or her to be born with what he or she considers to be a disability. The child then demands compensation on the grounds that his or her life is 'wrongful'. The underlying issue is that the child believes that life is so difficult that it would have been better for him or her never to have been born in the first place. In some cases, the child may also sue the medical practitioners for failing to provide appropriate information to his or her parents that would have prevented his or her birth.[46]

In a wrongful *birth* case, parents sue other people, such as medical practitioners, to claim compensation for the burden of raising a disabled child whose disability was misdiagnosed due to professional negligence or malpractice. For example, parents may sue for faulty contraceptive advice or mistaken genetic diagnosis when an embryo or foetus is inaccurately diagnosed as not having a disability, i.e., when the embryo or foetus is actually affected by a disorder. Parents emphasize that if they had been aware of the foetus's or embryo's true condition, a termination would then have been a distinct possibility.

Not surprisingly, issues of wrongful birth and wrongful life swirl in controversy. Some believe that it is generally in the interest of the prenatal child to be born rather than to be terminated, even if the child may have a serious genetic condition that could result in an early and/or painful death or a lifetime of medical interventions. United Kingdom legislation supports this position since it does not permit a child to argue that he or she would have been 'better off' dead or to not have existed.

The wrongful life dilemma also introduces the nonexistence problem which is further developed in this book in the section on 'Conditional and Unconditional Acceptance'. The nonidentity problem is a philosophical puzzle that recognizes an inconsistency in claiming that a person with a disability would be better off if he or she had not been born. This is because had the child not been born, the lawsuit would not have been filed, and if the child had been born without the disability, then he or she would have been a very different child from the one affected by the disability. It would have been a different child with another existence. In wrongful life cases suing for compensation would only be legitimate when a comparison is possible between an existing situation where no injury is present and one in which damage is present. But in these cases, the comparison is impossible because one cannot compare the very existence of one child to that of another child or calculate whether a theoretical nonexistent life has less or more value, dignity or worth than an actual life. This important principle is one of the reasons why the French government eventually changed the law after the family of a young man called Nicolas Perruche sought wrongful life damages on his behalf. The Perruche case gave rise to indignant protests from disability rights groups, members of the general public and health care professionals who emphasized, amongst other things, that this case could lead to some lives being seen as having less value or dignity than others. Eventually, the law in France was changed in 2002 to indicate that no one can sue for damages for the simple fact of being born.[47]

An increase in number of court cases of children (or parents on behalf of their children) suing healthcare professionals because they were born with a disability have also arisen in Israel. In this regard, ethicists and physicians are very concerned about the psychological consequences for the children when they hear their parents state, in these cases, that it would have been better for these children if they had not been born. In addition, there is a worry that the increasing number of lawsuits arising because of the birth of disabled children is encouraging the perception that existing disabled people should, in a similar manner, not have been born.[48]

The problem of nonexistence also becomes relevant in wrongful life cases in that it is not philosophically possible to compare nonexistence to existence no matter how much this existence may be pleasurable or difficult.

As the philosopher David Heyd indicates, 'Non-existence is neither good nor bad nor neutral to anyone, since good and bad can be ascribed only to metaphysically identifiable individuals.'[49] Thus, because no comparison is possible, a court case seeking damages cannot be rationally supported.

Legislation

United Nations

The Universal Declaration of Human Rights - (Adopted and proclaimed on 10 December 1948)

Article 16

1. Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.

Council of Europe (Forty-seven Countries)

Convention for the Protection of Human Rights and Fundamental Freedoms - (CETS No.: 005, Rome, 4 November 1950)

Article 12 – Right to marry

Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right.

Note: The above two provisions ensure that no restrictions should exist with respect to parental choice concerning whether or not to have children and the number of children in a family.

Legislation in the United Kingdom

Children born alive have the full protection of the civil and criminal law with legislation such as the Children Act 1989 for England Wales and Northern Ireland and the Children (Scotland) Act 1995. This imposes the enforceable duties of the 'welfare principle' on those tasked with parental responsibility, i.e., they must feed, clothe and bring up the children in accordance with the children's best interests. Further, the law requires that all persons must neither harm nor injure the child, and once a child is born alive, the common law grants some property or inheritance rights not accorded to a baby in utero.

In England, Wales and Northern Ireland the Congenital Disabilities (Civil Liabilities) Act 1976 enables a child to sue for injuries which he or she obtained in utero if these resulted from a contravention of duty towards his or her parents. This means that claims for wrongful birth that seek compensation to cover the additional costs of raising a disabled child continue to be recognized.[50] However, common law in these parts of the United Kingdom does not allow a child to sue for compensation for the simple failure to terminate the pregnancy. Jurisprudence indicates that such a 'wrongful life' assertion is contrary to the important notion reflected in the inherent human dignity of a person and cannot be sustained in public policy. In other words, it is impossible to consider that life itself, even with a severe disability, is an injury for which one can seek redress in the courts.[51,52] Compensation could only be based on a comparison between existence in a disabled state and nonexistence. But such a calculation is logically impossible since a subject cannot be considered in a nonexistent state.

In the United Kingdom Human Fertilisation and Embryology Act 1990 as amended in 2008, it is indicated in Section 13(5) that 'A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for supportive parenting), and of any other child who may be affected by the birth.' This means that a licenced clinic can, in certain circumstances, refuse to provide fertility treatment if it has a good reason for doing so. This may prevent a person from having a child, but the decision is unlikely to be for eugenic reasons.

Selecting Children through Adoption

At first glance, eugenics and adoption may seem to have little in common. Nonetheless, the role of *choice* in adoption procedures provides a relevant connection. If prospective parents were able to adopt an embryo or a child with specific characteristics in mind, a form of selection could occur in conformity to the definition of eugenics outlined at the beginning of this book. Of course, the genetic heritage of humanity in general would not be affected since the embryo already exists or the child is already born. But the adoption of a certain kind of embryo or child fulfilling certain criteria may still influence the genetic heritage of a community or family. This would only happen, however, if the adoption process was undertaken in an unregulated manner and the welfare of the embryo or the child was not established as a priority.

Selection in Adoption of Embryos

It is possible, sometimes, for couples to consider the adoption of surplus embryos from IVF. In some countries, such as the United Kingdom and the United States, there are hundreds of thousands embryos left over from fertility treatment, and some eventually become available for adoption. Organizations such as the Embryo Adoption Awareness Center (www.embryoadoption.org) in the United States are even prepared to assist or give information about such an alternative.

Because embryo adoption is a relatively new procedure and the adoption rate is still relatively low, no real discussion on this procedure is possible, especially from a eugenic perspective. However, it is probable that many of the questions relating to eugenic embryo selection may be similar to the ones concerning selection in adoption of children who are born. These include whether or not the agencies providing the embryos enable a selection to take place by the parents.

Selection in Adoption of Children Who are Born

Adoption is often a poignant experience both for the child and the potential parents. For example, the child may experience very intense emotional and psychological consequences because of his or her separation with his or her biological parents. The biological parents may also experience intense emotions as they release their child for adoption and grapple with their choice, often borne out of an inability to provide adequately for the child. The adoptive parents also undergo intense emotions as they find the dreams of parenting realized.

In the best of circumstances, an adoption procedure should go smoothly with the interests and welfare of the child throughout his or her life being seen, by the adoption agency, as having priority over any other interests, including those of the prospective parents. This precedence of the child's interests is crucial since he or she already exists and it is the responsibility of the state to look after him or her in the best possible manner.[53] If the adoption process is carefully implemented, the parents will also put the interests of their prospective child first, not only their own, and the child will be valued and welcomed for who he or she is.

Ethical problems arise, however, when the paramount consideration in the adoptive process is not the child's welfare or best interest. This would happen when the adoptive parents' desired characteristics in their future child become the most important factor. In other words, when the perspective of parental selection returns in the adoption process and the child's interests become secondary.

Parental choice may also complicate an adoption, not least because of the seemingly limitless number of children to be adopted be it on a national or international stage. This may include a very real difficulty in trying to make a choice relating to a prospective child's biological characteristics such as age, ethnic background or special needs. In some circumstances, adoptive parents may even feel a real sense of guilt if they begin to question their own motivations, worldviews and values in seeking to have a child.[54]

In contrast, these feelings are not usually present in parents giving birth to their own biological children since they generally have little choice about their child's characteristics. The feelings and experiences facing these adoptive parents may, therefore, be considered as foreshadowing or reflecting what parents of the future may experience if other selective procedures eventually permit increasingly more parental choice for eugenic selection. The kinds of difficult choices that parents seeking to adopt a child of their choice may already be experiencing can be summarized as follows:

The Sex of the Child

This is probably one of the most important decisions for adoptive parents having crucial consequences for the rest of their lives. But it may also be biased in certain circumstances with a certain amount of selection already taking place towards adopting children of a specific sex in some societies. These choices, however, and their consequences are similar to sex selection in procreation which will be examined in more detail in the next chapter.

The Racial or Ethnic Background of the Child

Adoption agencies often seek to match a child as closely as possible to the racial and ethnic background of the adoptive parents. There is generally an agreement amongst social workers that ethnic background should be one factor, amongst many others, in making the adoptive decision.[55,56] As the anthropologist Judith Modell indicates:

> Social workers take the matter of resemblance seriously, and decisions about an adoption support the adage of blood's thickness. Throughout the twentieth century, the practice of matching dominated placement decision: the baby to be placed in an adoptive home should 'match' the parents in that home. Match in race and in religion, of course, but also in physique, intelligence and temperament.[57]

Interestingly, the biological traits considered in adoption may include attributes that vary among specific ethnic groups such as hair, eye and skin colour, size and other features. This is because some parents prefer to look as similar as possible to their adoptive children for reasons of 'social inclusion' and the manner in which the children may be seen by those around them.

The Genetic Health of the Child

In the process of adoption the parent-child dynamic is somewhat different to the natural one, primarily because the prospective child does not have a biological relationship with his or her parents, which generally supports a relationship of mutual belonging. Since these strong biological bonds do not exist, the question then arises whether prospective parents would be willing to accept a disabled child who could require more resources and thus create more challenges for the parents.

In this regard, the United Kingdom hosted one of the more surprising developments concerning the selection of children through adoption in a number of British towns. Indeed, in addition to the usual battery of medical examinations that routinely collect medical data from children waiting to be adopted, a number of further genetic tests were required for some children. These genetic tests examined whether a child carried a late-onset disease, that is, a disease such as Huntington's that exhibits no symptoms until after childhood. The test results, together with any other available medical information, were then given to the prospective parents so that they could decide whether they wished to adopt a child with certain late-onset disorders.[58] When criticism of such genetic testing eventually received public attention in the United Kingdom, local authorities pursued court orders to ensure the testing could continue. They claimed that it was their responsibility to seek the best adoptive parents for the children in their care, in spite of the ambiguity and awkwardness arising from the testing. Eventually, however, the United Kingdom High Court ruled, in 2013, that it was not in the interests of children waiting to be adopted to be tested for possible future serious genetic disorders. While recognizing that the decision may make it more difficult for some children to be adopted, the judge explained that this could not offset the risk of serious psychological harm in the children if the genetic tests proved positive.[59]

Deciding Whether or Not to Adopt Children Who are Born

As already indicated, the adoption process is useful in considering some of the factors that may arise in other eugenic selection procedures, since adoption distinguishes the parental decision whether or not to have a child from a decision about what kind of child to adopt. In considering adoption, as in procreation, parents are under no obligation to have or not to have a child; they are entirely free to make this choice for themselves. This is a decision which they often make through a combination of compassion for the possible future child and a recognition of their own capabilities to adopt or not to adopt a child.

Deciding to Adopt

If parents do decide to adopt a child with a responsible adoptive agency, then as previously mentioned it is the interests of the already existing child that have priority over the wishes of the prospective parents. It is the independent adoptive agency, and not the parents nor the child, that decides on the adoptive match. The agency then plays a role that is similar, in a way, to the one played by chance in natural reproduction, though a few parental preferences may be taken into account, such as age and nationality. Of course the agency may base its final decision on some of the biological characteristics of the child, but these will always be seen as secondary to the child's best interests and cannot generally be considered as being based on eugenic considerations. Interestingly, in this regard, the unconditional acceptance that adoptive agencies demand from prospective parents is increasingly at odds with the kind of eugenic quality control of children that is gradually creeping into the new reproductive procedures.[60] Indeed, this quality control would be similar to countries where no strong adoptive regulations exist and where parents enjoy the freedom to choose the kind of children they want from a large number of options.

Deciding Not to Adopt

A parent's decision not to adopt is not eugenic when motivated by contentment with the current number of children or a conviction of inadequacy as a parent. These motivations concern the parent and not any characteristics in the child. However, if a decision to adopt a child is clearly made and subsequently retracted because of concerns relating to the health of the child being suggested by an adoptive agency, or any other characteristics, then the reasons behind this resolution may have an ethical perspective. The selective 'quality of life' decision becomes a priority over the decision to have a child, and eugenic concerns return.

This happened, for example, in Norway when two kinds of adoption were made legal in 1935. The first could be termed as 'strong adoption', whereby it was impossible to revoke the decision to accept the child and all legal ties with its biological parents were broken. However, it was also possible for parents to consider a form of 'weak adoption', whereby they could decide to return the child if he or she proved to be 'unsatisfactory'. As such, the legislation was generally based on meeting the needs of a certain class of parents instead of those of the children. In 1944 a revised law made it possible also to bring back the child if he or she was found to be chronically ill or disabled. Many adoptive parents were indeed very concerned about the genetic quality of their adopted children and were forever watchful for any eventual deficiencies they may discover in their child.[61] As social anthropologists Marit Melhuus and Signe Howell indicate, 'This … must be viewed in relation to debates about eugenics and "racial hygiene" that were prevalent in Norway during the first half of the twentieth century.'[62]

As already noted, adoption is a complex process, so a closer look at eugenically motivated adoption may clarify misunderstandings. In this case, two scenarios can be considered: (1) If parents have the means (financial, mental, physical, etc.) to care for a child with serious health problem but opt against adopting such a child because of the health concerns, then the interests of the child would not be prioritized. The child's characteristics (his or her health problems) would be perceived as the sole reason for the refusal to adopt. In this scenario the parents may demonstrate certain ethically questionable values in their decision making. But as with many other similar choices, the decision can only be fully ethically weighed up by the parents themselves. (2) In another scenario, parents may refuse to adopt a child with serious health problems because they lack the means to care for the child. In this scenario, the parents would prefer to adopt without selective considerations and adopt any child, regardless of his or her characteristics. But they only refuse because they lack the means, including social support, to do so properly. In many ways, this would reflect a failure by:

(a) the adoption agency to fully take into account, or enquire about, all the different parental factors in addition to the best interest of the child and
(b) the parents to fully consider all the possible outcomes before making a decision to adopt.

In this second scenario, the parent's decision to refuse the child with serious disability would not be eugenic in nature since it would still prioritize the best interest of the child because the parents have recognized their own inability to accept him or her in an appropriate manner. The emphasis would not so much be on the characteristics of the child as on the parents' own limitations or unworthiness to adopt such a valuable person, suggesting thereby that the child deserves a better couple than themselves.

Selection for What Could be Considered as a Disability

As seen in a later chapter of this book, the concept of disability is a minefield that requires finesse for navigating its various avenues. Even defining the term 'disability' is tricky, and consensus often eludes commentators. In relation to adoption, disability is no less complicated. Indeed, some parents may extend their desired characteristics for their adoptive child to attributes that society may generally categorize as disabilities. For example, deaf parents may specify a preference for adopting a deaf child to create social inclusion. In doing so, these parents may view deafness as merely a social marker analogous to skin colour or education. In countries such as the United Kingdom, the process of adoption would be the only way parents could ensure they had a deaf child since United Kingdom legislation prohibits the intentional procreation of a child with a physical condition that falls under a broad definition of disability.[63]

Legislation

Council of Europe

European Convention on the Adoption of Children (Revised) (CETS No.: 202, Entered into force on 1 September 2011)

> Article 10 – Preliminary enquiries
>
> (1) The competent authority shall not grant an adoption until appropriate enquiries have been made concerning the adopter, the child and his or her family. During such enquiries and thereafter, data may only be collected, processed and communicated according to the rules relating to professional confidentiality and personal data protection.
> (2) The enquiries, to the extent appropriate in each case, shall concern, as far as possible and inter alia, the following matters: … e) the personality, health and social environment of the child and, subject to any limitations imposed by law, his or her background and civil status; … f) the ethnic, religious and cultural background of the adopter and of the child.

United Kingdom Legislation

The Adoption and Children Act 2002, which covers the whole of England but with only some sections being relevant to other parts of the United Kingdom, indicates that 'The paramount consideration of the court or adoption agency must be the child's welfare, throughout his life'. It also adds that 'In placing the child for adoption, the adoption agency must give due consideration to the child's religious persuasion, racial origin and cultural and linguistic background'.

Sex Selection

Selecting the sex of a future child enables parents to implement a form of positive eugenics, if the definition at the beginning of this book is used.[64] Generally, however, choosing the sex of children is not considered a choice for a 'desired genetic heritage' since the only biological characteristic at stake is a child's sex. That said, the central tenet of eugenics is the pursuit of desired genetic characteristics. This means that sex selection may be seen as coming under the definition of eugenics in the limited but significant sense of selecting what one desires. As the philosopher Stephen Wilkinson indicates, '[S]ex selection (with the exception of selection to avoid sex-linked genetic disorders) is a reasonably clear case in which *parental desire or preference* [emphasis original] is the immediate motivation, rather than considerations relating to the health or welfare of the future child.'[65] This is especially true in those cultures that privilege or prefer one sex (usually male) over the other. In other words, in choosing a child of the preferred sex, parents endeavour to satisfy their own aspirations for what, to them, is the preferred outcome either for medical or other reasons.[66]

Methods of Sex Selection

From a scientific perspective, the sex of offspring is determined by the chromosomes (carrying genes and DNA) that are present in the nucleus of nearly every cell in the body. Generally, human cells contain forty-six chromosomes: twenty-two pairs (one of each pair coming from each parent) plus two 'sex chromosomes' denoted as X and Y. An egg produced by a woman during her monthly cycle contains twenty-three chromosomes including an X chromosome, and the sperm produced by a man contains twenty-three chromosomes including either an X or a Y chromosome. Thus, in normal circumstances, when a sperm fertilizes an egg to produce an embryo, the resulting embryo will have forty-six chromosomes including either two X chromosomes (female) or one X and one Y (male).[67]

At present, three different procedures are available for selecting the sex of a child corresponding to three different stages in procreation:

1. *Preconception,* where sperm cells are sorted according to chromosomal indicators to distinguish the sperm cells' capacity to produce male or female embryos.
2. *Preimplantation,* where embryos created by in vitro fertilization (IVF) are selected on the basis of gender and transferred to a woman in order to establish a pregnancy.
3. *Postimplantation,* where termination of a pregnancy is used to halt the development of a foetus that is of the undesired sex.

Preconception Sex Selection

Recent developments in embryology have led to clinical procedures that allow the sorting of sperm carrying the X chromosome from those carrying the Y chromosome. The sorted samples are then used for IVF or artificial intrauterine insemination, which is much less invasive than IVF, to increase the likelihood of producing embryos of the desired sex. The comparative noninvasiveness of sorted sperm procedures is likely to make these procedures attractive to a wider group of people.[68] In addition, it is likely that individuals opposed, on principle, to the destruction of unused embryos may support these procedures since it reduces the risk of creating and subsequently destroying embryos of the undesired sex.[69]

Despite these apparent advantages, two factors suggest caution in embracing the technique wholeheartedly. Firstly, health risks for the future child may be associated with the procedure itself, and further research is required to identify these risks more fully. Secondly, the level of efficacy or error rate must be considered since none of these techniques is guaranteed to sort sperm with complete accuracy. This error rate, however, is likely to decrease as the technology is further developed.[70]

While there are variations, there are at present two types of preimplantation sex selection procedures, namely, the gradient methods and flow cytometry.

Gradient Methods

Selection with gradient methods is based on the different constitutions of the X- and Y-chromosome-bearing sperm; X sperm having on average, marginally larger heads, necks and tails, higher dry mass, and 2 to 3 per cent more DNA than do Y sperm. However, because human sperm exhibit a large degree of variation, this difference is a less reliable guide than in some other species. With the gradient methods, live sperm is mixed with a liquid and typically spun in a centrifuge to separate X from Y chromosome sperm. The larger, heavier X chromosome sperm spin out of the solution, permitting scientists to collect differentiated samples. This centrifuge procedure may be combined with 'swim-up', where the sperm swim through a differentiating medium.

The composition of gradient solutions can vary, which gives rise to different results.[71] For example, albumin gradients typically appear to have a 70 to 85 per cent success rate in separating sperm, but most of the reports of success have come from clinics that offer these methods on a commercial basis, and their results have not been independently corroborated.

Whilst there is very little information on the health risks of using gradients in sperm sorting, there is currently no evidence to suggest that the risks to women or offspring would be significantly increased by the use of this technique since the procedure is similar to that routinely used to prepare sperm samples prior to IVF treatments.[72]

Flow Cytometry

In flow cytometry, a fluorescent dye binds to the DNA in the chromosomes of a semen sample. The sperm cells are then sorted using a laser light to measure and distinguish sperm as either carrying X or Y chromosomes. Based on genetic testing of embryos conceived following the use of this procedure, it is suggested that a success rate of about 70 to 90 per cent can be achieved.[73]

Tests on domestic animals have revealed no health concerns related to flow cytometry, though preliminary results suggest that high-speed flow cytometry puts sperm under high pressure and may contribute to a lower success rate.[74] However, further testing on human sperm samples will confirm whether the fluorescent dye used for sorting the sperm presents any long-term risk of malformation or reproductive dysfunction for human use.[75] There is also some concern that the laser energy used to measure the fluorescence of the sperm cells could damage DNA.[76]

Preimplantation Sex Selection

While sperm sorting offers significant advantages over competing methods of sex selection, it may lack reliability, as the success rates suggest. A more reliable method, with less than 1 per cent failure rate, is a procedure called preimplantation genetic diagnosis (PGD).[77] The technique typically involves four steps.

1. The *creation* of embryos in the laboratory by IVF.
2. The *removal* of one or more cells from each embryo (a procedure which is believed to not impair the development of the embryos).
3. The *genetic testing* of those cells for the presence of X or Y chromosomes.
4. The *transfer* of embryos of the required sex to the woman.

This technique is highly reliable but an even higher success rate is available via a hybrid method that combines PGD and sperm sorting. Prior to the four-step process of PGD, sperm are sorted by flow cytometry or gradient suspension. Using this approach, a failure to select the desired sex accurately is rare, though, admittedly, this combined approach incurs higher cost. In addition, because sperm sorting minimizes the likelihood that the undesired sex will be created in the first place, a smaller number of embryos need to be created for PGD. As with ordinary PGD, though, ethical concerns for some members of society remain since a number of embryos are created before they can be tested and those of the undesired sex are usually discarded. Moreover, no more than two embryos are generally transferred to the woman concurrently so that some embryos may be left over.[78]

PGD poses comparatively little risk (if any) to the embryo even though determining the gender involves a biopsy whereby one or two cells from the embryo are permanently removed for genetic testing. The embryo then develops without the removed cells. Theoretically, the biopsy may damage the embryo, but the risk is generally considered to be very small.[79]

Postimplantation Sex Selection

A third category of sex selection, and one of the oldest, occurs after an embryo has implanted into the uterine wall of the woman. In this case, a termination of the pregnancy is considered if prenatal testing shows the embryo or foetus to be of the undesired sex though this is generally illegal in most countries.[80] Alternatively, where prenatal examination is unavailable, a foetus may be terminated at birth if it is of the undesired sex. This method, of course, is known as infanticide and is again illegal in most countries.[81] Gender-related abortions still occur in some countries such as the United Kingdom, albeit only in the rare cases where prenatal testing reveals a serious sex-linked disease (which only affects certain sexes) and that may harm the physical or mental health of the woman carrying the foetus or already-existing children.[82]

Arguments in Favour of Sex Selection

With the preceding section outlining the core procedures of sex selection, the focus now shifts to examining the reasons for and against the practice. As will be made clear, medical justification for sex selection constitutes a comparatively small fragment of the arguments, with a majority of claims (on either side of the debate) stemming from social and philosophical considerations. A number of arguments will also be similar to those in favour or in opposition to eugenic selection, in general, which can be found in broader ethical discussion in the following sections of this book.

Medical Reasons

Some medical reasons are sometimes considered for sex selection to avoid giving birth to children affected by severe sex-linked diseases. To date, scientists have identified approximately two hundred such diseases, a majority of which affect only males, though the seriousness of these disorders varies. Whereas colour blindness is relatively minor, others, such as haemophilia or Duchenne muscular dystrophy, may lead to debilitating, life-threatening or terminal physical dysfunction. Prospective parents may then elect to avoid, through prenatal sex selection, the challenges often associated with the more extreme sex-linked diseases.[83]

Nonmedical Reasons

Societal Reasons

In some societies, children of a certain sex may be considered more desirable than those of the opposite sex. For example, some prospective parents may wish to have a son to carry on a family name and/or receive the family inheritance. In other cases, the parents' desire for male children may stem from the more basic desire to survive with the help they may provide. In addition, male children do not cost the family a dowry payment in contrast to girls, who may be the source of a large payment to her husband's relatives. From a financial perspective, a son is generally seen as an asset, whilst a daughter may be considered a liability.

Thus, without sex selection, a family may end up with an undesired daughter who may experience a very low quality of life, not least because she may be abused. The practice of sex selection may then allow couples to choose the desired male child, avoiding the daughter, who would be considered as a burden. Sex selection may also decrease the number of abortions taking place on healthy foetuses of the wrong sex in society where such terminations are already taking place. Indeed, in communities that favour one sex over another, these terminations are sometimes considered following prenatal sex identification procedures such as ultrasound scanning.

Opponents of sex selection may counter this argument by claiming that allowing prenatal testing to be used in this way could be construed as an implicit endorsement of the termination of foetuses of an undesired sex as well as support for the discrimination that gender-directed abortion reflects. Indeed, it can be argued that permitting sex selection in support of such preferences is likely to reinforce discrimination and be contrary to the respect for equality to which all human beings are entitled.

Family Balancing

In some cases, when two parents already have at least one child of a particular sex, they may believe that having a child of the opposite sex will enable them to have a balanced family. This desire for children of both sexes may derive from any number of reasons, including one (or both) parent's perceived ability to relate more intimately with one sex over the other. Parents may also wish to expose their children to regular interactions with the opposite sex to provide them with a fuller life experience. Understandably, sex selection for the sake of family balancing may be seen as a variant of the social reasons discussed above. However, a key difference is that under this scenario the risks of reinforcing discrimination are considerably reduced since the sex of the first child will not have been deliberately chosen. Sex selection is only used to choose a child of the opposite sex for the sake of increasing diversity, not for discriminating against a particular gender. In fact, it is suggested that regular implementation of sex selection may actually benefit children, since more children would be of the preferred and desired sex and far less likely to be rejected by their parents.

According to this line of reasoning, parents should then be able to exercise their autonomy by choosing to have a balanced family with their preference posing few (if any) risks to societal values. It could even be argued that a society would benefit from balanced families because children with regular exposure to both genders may become better participants in this society. Following such a rationale, some couples may actually decide to have more children than they otherwise would through natural procreation solely because they want a child of a particular sex or a child of each sex. The availability of sex selection, on the other hand, would enable these couples to have fewer children, thereby reducing or reversing population growth in some countries and liberating resources for needy members. In light of the familial and societal advantages associated with sex selection, any argument against the practice engenders the following question, 'Why should the state prevent sex selection if the practice clearly pursues the greater good of both family and society?'[84]

Arguments against Sex Selection

Whilst there may be good medical and societal reasons for taking a course of action, there may be better reasons for not doing it. The following section, therefore, outlines key medical and philosophical considerations for rejecting sex selection.

Medical Reasons

As noted above, a key medical reason for considering sex selection concerns the possibility of preventing the occurrence of sex-linked diseases. But current research does not offer conclusive evidence regarding the safety of certain sex-selection procedures. As already mentioned, flow cytometry is not certifiably safe, and guarantees about its long-term consequences will only be known as more data become available. Relatedly, sperm sorting by gradient methods may pose a risk from a psychological perspective. This is because the margin of error is relatively high (see above), and potential parents run the risk, therefore, of suffering psychological distress and upset if they eventually conceive a child (using sex selection) of the undesired sex affected by a genetic disorder.[85]

Nonmedical Reasons

In addition to the medical reasons just given, a number of nonmedical factors advise against sex selection. The United Kingdom's Human Embryology and Fertilisation Authority (HFEA) has compiled a concise yet representative list of these factors in its 2002 report on the subject.[86] The great advantage of the HFEA report is its dependence upon responses from survey participants who are parents with each reason against sex selection being more than theoretical or academic. The arguments reflect the opinion of people who, presumably, could participate in a sex-selection procedure but have considered at least one reason why they might decline to access such a procedure.

Gender Preference and its Consequences

One type of objection to sex selection concerns the equal treatment of the children or future children (embryos and foetuses) involved in the selection procedures.[87] According to this objection, allowing parents to indulge their preferences for children of a certain sex (often boys) may foster environments in which women are treated negatively. This may happen when parents seek to especially value a male offspring because he will preserve the family's presence in society through factors such as the continuation of a name or business. In this kind of environment, the birth of a girl may be seen as a disappointment.

The negative ramifications of these views are not limited to countries such as India, where gender discrimination and sex selection may have been evident for generations.[88] To the contrary, these views are detrimental to any society because they cut into the basic foundation of universal equality upon which the modern, developed world is built.[89] In this regard, the Health Council of the Netherlands has indicated that:

> The possibility cannot be excluded that the actual availability of sex-selective insemination as a family-planning instrument will result in parents finding the sex of their children more important than they claim at present. Because choice involves making distinctions, the possibility of sex selection could result in the undermining of the idea of sexual equality and therefore of the struggle for emancipation. Making sex an object of choice could lead to the reinforcement of stereotypical ideas about sexual roles.[90]

Although the absence of sex selection procedures would not guarantee equal treatment for women, active legislation against the practice may secure better opportunities for future generations of women as differences between the sexes receded as deciding factors for a person's place and role in society.

The Balance of the Sexes

The natural sex ratio at birth is roughly 105 boys born for every 100 girls. But in several countries the ratio has already reached 120 baby boys born for every 100 girls. Since 1990 this discrepancy, at least in Asia, has been widely attributed to a preference of male over female children.[91] In addition, there is evidence that the ratio at birth of boys to girls is even rising among certain ethnic groups in the United States.[92] An accumulation of the different decisions in one direction could eventually lead to large-scale sociological problems. For example, the State Population and Family Planning Commission of China has already predicted that by 2020 roughly 30 million Chinese men will be unable to marry on account of the gender imbalance.[93] The economic and social ramifications of this bride crisis have yet to be fully articulated, but early reports suggest difficult sociological consequences.

Future Possible Consequences and the 'Slippery Slope'

A final objection is a form of the ever-popular 'slippery-slope' argument. With sex selection, a concern exists that the impulse to select for gender will eventually lead to selection for more trivial matters, such as eye colour or complexion. In 2009, an American physician, Jeffrey Steinberg of the Fertility Institutes, ignited controversy by claiming to have nearly perfected the technology for eye and hair colour. After receiving a cautionary enquiry from the Vatican he postponed plans to complete the technology, but even now he says that 'it will be here in the future'.[94] One respondent to the HFEA study recognized an inconsistency between allowing sex selection and prohibiting selection for intelligence, if this was ever possible, 'we wouldn't have a leg to stand on'.[95] Concerns about the slippery slope reflect the ongoing development of fertility treatments. Sex selection may only be the first step down a long stairway to an unknown future that nobody can really predict. Admittedly, there will always be a few hard cases for which a certain option may seem reasonable, but for physicians to conform to the wishes of their patients in these hard cases opens the door to widespread, future practice.

Legislation

Council of Europe (Forty-seven Countries)

Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (CETS – No. 164, Oviedo, 4 April 1997)[96]

> Article 14 – Non-selection of sex
>
> The use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided.

United Kingdom

United Kingdom law already permits sex selection for medical reasons under the amended Human Fertilisation and Embryology Act 1990. This is possible either by elective termination of the embryo or foetus at risk of carrying a disorder or by testing and selection of embryos conceived through in vitro fertilization (IVF) before they are transferred to the woman. Practitioners of these procedures are required to be licensed and to follow strict guidelines.[97] The newer Human Fertilisation and Embryology Act 2008 (Schedule 2, Section 3 – Embryo testing and sex selection), categorically prohibits sex selection of offspring for nonmedical reasons.

Egg and Sperm Selection

So far, this book has engaged broad issues related to the selection of persons, considering medical and nonmedical arguments for and against the practice. This section considers the question of gamete donation and selection, which is becoming ever more widespread in society. These procedures enable preconception selection and, in certain circumstances, are borne out of eugenic considerations.

Sperm Selection

While the sperm-sorting procedures discussed in previous sections allow preconception gender selection, current technology does not generally permit sperm selection on the basis of other genetic traits. At present a sperm cell is only selected for its quality in conjunction with two procedures. The first is when a man is being considered to be a sperm donor in reproductive clinics whereby only donors with healthy sperm, with no known genetic disorders, are used. The second is a procedure called intracytoplasmic sperm injection (ICSI), which is used when the sperm of a man is unable to fertilize an egg naturally. This procedure is typically used when the sperm is unable to move with sufficient vigor to reach the egg, a disorder called 'low motility'. With ICSI, a scientist selects the best sperm cell produced by the man and injects it directly into the egg of the woman in a laboratory. The resulting embryo is then implanted into the woman's uterus.

Science has not yet developed techniques for selecting more definite genetic traits. For example, a sperm cell supposedly containing the genetic makeup for blue eyes cannot be intentionally selected from those coded for brown eyes. In fact, research on the modification of the germline, that is, on genetically altering sperm or egg cells, is fraught with problems, including serious side effects for the cells in question. In this respect, the medical ethicist Marc Lappé warns that genetic modification of gametes should only occur as a secondary effect to the treatment of a person using gene therapy on his or her somatic cells, in other words, on nongerm cells. Even then, Lappé recommends that gene therapy should only be a procedure of last resort given the risk of harm.[98] Thus, at present, sperm may only be selected on the rather nontechnical basis of donor screening. This means that a man, when donating sperm, reveals various details concerning his genetic traits, such as eye colour and disease history, as well as less determining qualities, such as education and career aspirations.

One form of eugenic sperm selection is called eutelegenesis, first proposed in 1935.[99] This is the artificial insemination with sperm from specially selected men. Upon donation, sperm samples are usually classified on the basis of donor characteristics, such as health, hair and eye colour, education level as well as skin tone, and then refrigerated in designated storage at a sperm bank.[100] Prospective parents subsequently select the desired donor sperm from the bank according to biological qualities and other characteristics of the sperm donor.[101] Once these choices have been made, the woman then awaits the time of her menstrual cycle that best facilitates conception through artificial insemination with the selected donor sperm. If the procedure is successful, she will gives birth to a baby, making her both the genetic and gestational mother.

On the assumption that individuals with a supposed desirable characteristic can (to some extent) reproduce this characteristic in their children, eugenicists have identified eutelegenesis as a potential means of improving the human genetic heritage.[102] Various interesting proposals have been suggested, including the offer by the National Research Foundation for Eugenics Alleviation in New York to send superior American sperm to solitary British women during the Second World War.[103] Eutelegenesis, however, has not yet met with any success. As discussed later in this book, the only sperm bank created on the basis of specific eugenic ideology closed in 1999 due to lack of interest.

Egg Selection

Many of the issues related to egg selection are similar to those of sperm selection. As with sperm, prospective parents and fertility clinics seek egg donors whom they choose for various characteristics.[104] However, the donation of eggs is far more demanding than sperm donation, not least because of the potential risks associated to the medical procedure required for extracting the eggs. A woman who experiences a successful inducement for egg production will deliver an average of ten to fifteen eggs, though some treatments may result in more than twenty eggs in a single cycle.[105] Since storing eggs is more difficult than storing sperm, the removal of the donor's eggs usually occurs just before the eggs are fertilized in vitro and the resulting embryos implanted into the woman or stored for later use. Arguably, recent developments in the use of stem cells may address some of the limitations in obtaining large quantities of human eggs. Researchers are optimistic about the possibility of producing, in the laboratory, very large amounts of eggs from the stem cells of a single woman, which could then be used in selection.[106,107]

Another possible procedure, which seeks to make healthy eggs, especially in the context of mitochondrial disorders, is called maternal spindle transfer. However, because it can be recognized as a kind of germline intervention through genetic modification, it will be discussed in a later section (Eugenics by Genetic Modification).

Specific Ethical Issues relating to Eugenics in the Selection of Gametes

Though overlapping in places with the ethical arguments for or against eugenic selection in general (which will be considered later in this book), several specific ethical problems related to gamete selection deserve attention. For example, there is the matter of compensation that gamete donors receive. In 1991, Shelley Smith founded The Egg Donor Program in Los Angeles to combat infertility. To be able to meet this goal, the program solicits egg donations from 'beautiful and accomplished women with special qualities'.[108] Donors receive financial compensation, and recipients pay high fees. In exchange for these fees, the recipients are guaranteed that the donated eggs will come from women who are physically attractive and intellectually superior. However, in 2000, a firestorm arose when a couple in Southern California offered $100,000 for eggs that would match the profile of donors such as those associated with The Egg Donor Program. While Shelley Smith did not broker the deal, she did comment on the matter. As quoted in the *Chicago Tribune,* Smith noted that a price of $100,000 suggested that the eggs in question were commodities to be traded rather than loving contributions towards the life of a future child.[109] Ironically, however, eggs donated through Smith's own organization earn the donors varying levels of compensation, suggesting that even the eggs which she processes may be more than gifts offered out of compassion.[110]

As with all matters of procreation, in spite of the exorbitant costs and emotional challenges involved in these (and other) programs, participants are not promised success. The outcome of every procedure is shrouded by an element of uncertainty. Until science has mastered the human genome, there can be no guarantee that a child will meet parental expectations.[111] The 2010 birth of Nmachi Ihegboro illustrates this to the extreme. Both biological parents of Nmachi are black Nigerians living in London, but Nmachi was born with white skin and a shock of blonde hair. Professor Bryan Sykes, a geneticist at Oxford University, confirmed that the child did not have albinism. To Sykes, the best explanation for this anomalous birth was an admission that the 'rules of genetics are complex and we still don't understand what happens in many cases'.[112] Still, in spite of this uncertainty, some people believe that the advantages of gamete selection counterbalance the possible risks, as the booming business of gamete donation confirms though most parents still prefer to procreate children 'of their own' using their own gametes. Choosing a child's traits, moreover, is not without ethical questions, as exemplified by the case, reported in 2002, of Sharon Duchesneau and Candace

McCullough, a lesbian couple from the United States.[113] Both women are deaf, and they wanted their children to also be deaf. To achieve this, the women sought a sperm donor with an inheritable form of deafness, but fertility clinics refused to supply the desired donor sperm, claiming that inheritable deafness was a trait that disqualified potential donors. There was no available donor sperm that would meet the couple's criteria, and no clinic would even support the quest for such sperm. Undeterred, however, the couple obtained sperm from a family friend whose congenital deafness spanned five generations and thus virtually assured the couple of success in conceiving a deaf child. The procedure succeeded, and Duchesneau and McCullough became mothers to a deaf girl. After their first success, the couple conceived again and now have a deaf son.

The Duchesneau and McCullough story has sparked controversy, not least in the United Kingdom, where other couples have wanted to select for a deaf child.[114] While some have argued against such developments on the basis that gamete selection for any reason is wrong, others have reasoned that such developments were unethical because it is the parents' and health professionals' duty to guard the interests of a prospective child, even in assisted reproduction. A number of analysts have also considered the ethical matters inherent in the Duchesneau and McCullough case as distinct from the more common perpetuation of congenital deafness by means of natural procreation between parents with inheritable genetic conditions. Indeed, Duchesneau and McCullough deliberately selected for a trait that many in society consider to be a genetic disorder.[115] In response, the couple claimed that deafness should not be considered as a disability but a cultural identity. They wanted their children to share in their identity and argued that their decision was no different to choosing the colour or gender of a child.[116]

Another case of controversial gamete donation occurred in 1993 when a black South African woman, unable to produce her own eggs as a result of a tumour, chose to be implanted with an embryo created through the use of her white husband's sperm and the donated egg of a white woman. The woman's primary motivation was a belief that a white child would have a better future than one of mixed race.[117]

These two examples raise questions about the extent to which people should be able to select donor characteristics. Is it ethical to select for race, if it is believed that the selected child will have a better future than a child of the naturally occurring race? And is the practice of selecting a trait widely accepted as a genetic disorder ethical, even if this is undertaken to facilitate bonding between the child and the parents?[118] These questions pose genuine ethical challenges, especially since gamete selection for eugenic purposes has already gone beyond screening for physical characteristics such as deafness or skin colour. Sperm selection has been used in trying to select for other traits such as intelligence. This was based on a proposal by the Nobel Prize winner H.J. Muller. In 1959, Muller suggested that sperm donors with the highest physical, mental and psychological characteristics should be chosen so that parents could create genetically superior children. Such an approach would then avoid using the very ordinary sperm available from a typical male partner in a couple. In addition, Muller proposed to establish deep-frozen sperm banks that comprehensively recorded donor characteristics. He further mandated that sperm donations could only be used twenty years after donation in order to facilitate an adequate evaluation of the donor's genetic heritage. The sperm of the best donors could then be enlisted to produce children down throughout the ages until the general population eventually reached the donors' level of superiority.[119,120]

In 1981, following correspondence with Muller, the American businessman Robert K. Graham eventually established the Repository for Germinal Choice.[121] Graham's goal was to provide sperm for women or couples who desired to have a child with a trait such as superior intelligence. The Repository only accepted sperm donations from Nobel Prize laureates or other comparably accomplished donors, such as leading personalities in the academic and business worlds. In spite of its tantalizing potential, however, the Repository for Germinal Choice produced relatively few children. In 1999, when the repository was finally closed following Graham's death two years earlier, only 215 children had been born with sperm from the Repository.[122]

While the Repository only accepted sperm which was expected to produce highly gifted children, most fertility clinics in the United States, on the other hand, offer a wide range of donors who can be selected for characteristics such as education level, appearance and ethnic origin. Still, the basic question remains, 'What traits (if any) may prospective parents ethically select?' Under United Kingdom legislation, a number of factors may motivate gamete selection. For medical reasons, prospective parents may choose gametes that will enable them to have children without inherited genetic disorders, particularly sex-linked disorders such as Duchenne muscular dystrophy. But nonmedical reasons are also considered acceptable. In both the United Kingdom and the United States, fertility clinics are expected to strive to provide gametes from a donor whose ethnic background and physical characteristics match, as far as possible, those of the affected or infertile partner. The aim is to minimize social stigma that donor-conceived children may experience within their own family on account of noticeable differences. Some couples may even opt to receive gametes from a donor with a particular nongenetic trait, such as a religious background, to facilitate the perceived cohesion between a donor-conceived child and his or her family.

These attempts to bind donor-conceived children with their families suggests that gamete selection raises concerns about the identity of the child conceived with donated gametes. Although the child will certainly be in relationship with the parents that enabled his or her conception, the child will also have an indissoluble link to his or her gametal parents on account of the shared genetic material. Undoubtedly, responsible (nongametal) parents will seek to foster a loving environment in which the child relates to them as parents in a similar manner to an adopted child. Nevertheless, on account of the biological bond that exists through gamete donation, the resulting child may want to have a relationship with his or her gametal parent.

To facilitate this relationship, the child's social parents may concede to reveal the child's biological background. However, in doing this, the parents risk feeling somewhat marginalized unless they can understand that any attachment the child may express towards his or her gametal parents is qualitatively different and does not replace the love the child feels for, and has experienced from, the nongametal social parents. Further, in disclosing the complex circumstances of the child's conception, the nongametal parents should be willing to help the child through what may be an emotionally tumultuous experience. The child may even feel a sense of rejection from the gametal parents or may feel disconnected from, or out of place with, the social parents. Initiating such discussion of conception procedures may also be difficult for the (nongametal) parents.[123]

In spite of the sensitivity of the matter, social parents will prevent significant heartache if they voluntarily raise the subject of the child's biological heritage, rather than waiting until the child discovers this link independently or even hoping that the subject will never arise. The final option – ignoring the issue – is the least advisable, since during childhood as many as 50 per cent of donor insemination children may suspect that their social father is not their gametal father.[124]

A final unrelated question that arises concerning the selection of gametes in a couple is whether each gamete may be considered as a kind of representative of each partner in the procreative process. In this perspective, each sperm cell, though somewhat different genetically from each other, becomes a representative of the whole man, and each egg cell, though somewhat genetically different from each other, becomes a representative of the whole woman. It can then be argued that because the partners in a couple unconditionally accept each other, they should then perhaps also unconditionally accept whichever representative gamete from each other is used in procreation, i.e., without selection. Of course, in normal intercourse, there is a natural form of competition between the very large number of sperm cells seeking to fertilize the woman's egg, but this process is not linked to any deliberate and intentional ethical decision. In a way, the vast quantities of sperm and (to some extent) eggs available for procreation by a couple allows natural selection to occur but also enables the couple just to accept unconditionally whatever is procreated through 'chance' with no selection of the gametes (representing each partner) taking place.

Legislation

International Legislation

At present there is no international consensus on gamete selection. Some countries prohibit such selection while others have more flexible regulations. In the majority of countries where gamete selection is possible, an authority oversees and regulates good practice.

Legislation in the United Kingdom

Egg and sperm donation as well as selection is legal in the United Kingdom provided the centre providing the procedure obtains a licence from the Human Fertilisation and Embryology Authority or any official body with the same remit. However, in the United Kingdom, selecting gamete donors for disability is prohibited. Section 14 (4) of the Human Fertilisation and Embryology Act 2008 states that 'persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop a serious physical or mental disability, a serious illness, or any other serious medical condition, must not be preferred to those that are not known to have such an abnormality'.

Section 3 of the Human Fertilisation and Embryology Act 2008 also indicates that if regulations exist, a maternal spindle transfer can take place to prevent the transmission of serious mitochondrial disease.

Prenatal Genetic Selection

Most women in developed countries will be offered some form of prenatal examination while they are expecting a child. These prenatal screening tests are intended to help identify those who have an increased risk of having a baby with a disorder.[125] Women identified as being at an increased risk, such as those over age thirty-five or those who knowingly carry an heritable disorder, are then offered a diagnostic test. This determines whether the baby has a chromosomal abnormality such as Down syndrome or a genetic mutation disorder such as cystic fibrosis.[126] Generally, the diagnostic tests which are performed are either amniocentesis or chorionic villus sampling (CVS). These tests involve taking a biological sample by inserting a needle into either the amniotic sac or the outer membrane surrounding the foetus (the chorion). The invasiveness of these tests varies and may carry a small risk of miscarriage.

The use of these procedures is increasing and showing no signs of discontinuation. What is more, the capacity for screening both prospective parents and foetuses is certain to rise as the number of sequenced human genomes increases and the testing efficiency improves.[127] Private companies already offer prenatal genetic testing for more than seventy disorders by using microarray technology that has the capacity to test for hundreds of different genes at the same time. Some experts predict that prenatal screening for a large number of disorders may become quite ordinary if the costs of testing continue to decrease, though the usefulness of so much genetic information for parents is still unclear.[128] For scientists, however, the value is remarkable as it will permit a better understanding of the influence of genetic characteristics on future human persons. But no genetic selection of the foetus can go beyond the parameters of parental inheritance.

Some observers suggest that attitudes and opinions obtained in the context of prenatal genetic diagnosis may reflect how society considers the rise of the new eugenics.[129] Society's assessment of prenatal testing may then become a predictor for the ever-increasing choice available for selecting children. If so, then arguments related to prenatal testing could be adapted for engaging the broader question of future eugenic selection.

Arguments in Favour of Prenatal Genetic Diagnosis (PND)

PND for Medical Reasons

As already noted, prenatal diagnosis has enabled couples to be informed about the status of their foetus. If the foetus is eventually diagnosed as having a disorder, the test also enables parents to make an informed decision about terminating the foetus. Parents who do terminate an affected foetus may then avoid the challenges of raising a child with a severe disorder. Without the option of prenatal screening, many couples at high risk may choose not to bear their own children, though some may opt for adoption. Advocates of PND thus emphasize the significant medical advantages of the procedure. By testing for disorders prior to the birth of the foetus, prospective parents may gain peace of mind since their prospective child will be free of the difficult experiences associated with severe disorders. Yet the reverse may also be the case with couples who have already decided not to have an abortion. If they decide to screen to have peace of mind (after inadequate counselling) with regard to a disorder, they may then become distressed by the positive results for the disorder or even the uncertainty of the outcome.

PND for Nonmedical reasons

Prenatal testing for medical reasons is far more common than testing for nonmedical reasons. This is because PND often induces a high risk of emotional trauma on account of the threat of miscarriage as well as the anxiety associated with awaiting the test results. Therefore, it is extremely unlikely that this procedure would be used to select out foetuses other than those who have a serious medical disorder. Moreover, from an ethical perspective, few would consider the use of PND for nonmedical reasons as being appropriate.

Arguments against Prenatal Genetic Diagnosis (PND)

Moral Status of Foetus

Initial arguments opposing PND note that the procedure always assumes the availability of an abortion should the foetus be affected by a medical disorder. But, as is well-known, many members of society are prepared to consider a foetus as morally equal to an adult. From this perspective, PND would be considered as unethical as any other procedure that requires a termination.[130] Similarly, while not according a foetus the same moral status as an adult, others deny the appropriateness of PND and any subsequent abortion on the grounds that a foetus is still morally significant and thus worthy of preservation.

These different views reflect society's divergent opinions about the moral status of the embryo and foetus, and there is no consensus about the extent to which the embryo or foetus should be protected. Nor is there any consensus about when, why and at what stages of embryonic development protections are required. To be clear, the debate does not contest whether human life ought to be protected. Rather, the issue hinges on what counts as a human person, i.e., whether an embryo or foetus has personhood to the same degree as a human being who has been born and whether the embryo or foetus ought to be protected to the same extent as it would were it allowed to develop after birth.[131]

Since PND may result in the elimination of an individual, rather than providing treatment to support an individual's life, another argument against PND concerns its place in medical practice. This is because an abortion only eliminates the individual before he or she is born instead of seeking to provide treatment. In other words, it becomes a form of negative destructive eugenics though voluntarily undertaken by the woman. In this regard, though nondirective counselling enables the parents to make a decision in accordance to their values, the prospect of disability is often seen as negative and is not neutral. Thus, while the counselling may be well-intentioned for the parents' interests, the unborn embryo or foetus is often still affected by a latent bias against preserving a life that may be born with disability. In the absence of therapeutic interventions, even the availability of PND implies an expectation that an abnormal foetus should be aborted and that certain disorders cannot be considered in a positive or neutral light.[132]

The practice of prenatal screening may, therefore, encourage a new, culturally acceptable standard by which certain disabilities invalidate the continued life of an embryo or foetus.[133] Parents confronted with the decision to terminate a future child affected by a disorder face a moral quandary: do they maintain the embryo's or foetus's life in spite of the disability or do they prevent physical suffering and end the life before birth? Recent trends both amongst healthcare professionals and amongst the general public suggest that embryos and foetuses should meet a threshold of quality of life before they are considered to be worthy of postnatal life.[134]

Risks of Discrimination

Prenatal screening may promote discrimination against certain types of human persons by allowing parents to choose the qualities of their children on the basis of genetic knowledge. By advocating the termination of a pregnancy – both implicitly and explicitly – on account of a genetic disorder in the foetus, PND tacitly states that persons with those disorders are generally less desirable than the persons who do not have the disorder. Proponents of PND may protest at this characterization of the practice and may note that couples opting for abortion do so freely, without coercion and often out of sympathy for the prospective child that would have to endure a lifetime of suffering and poor quality of life. However, there is no denying that foetuses which do not have any serious abnormalities do not face the same abortive outcome. Only foetuses considered to carry genetic abnormalities are de-selected, while healthy, not-at-risk foetuses are permitted to survive until birth. As Julian Savulescu explains, this can also be considered discriminatory in the context of permissible regulations for the termination of late pregnancies which exist, for example, in the United Kingdom. He indicates that 'current practice of [late termination of pregnancy] … institutionalises killing of foetuses with abnormalities perceived to be severe, but not of foetuses with perceived minor abnormalities. This is discrimination against foetuses with disability… Allowing [late termination of pregnancy] for serious abnormality but disallowing it for minor or no abnormality is passive eugenics.'[135]

Thus, PND may shift societal attitudes away from the long-entrenched conviction that all human beings are equal and unconditionally worthy of existence. By means of PND, some potential members of society (i.e., the persons who would develop from foetuses consigned to termination) are deliberately discarded on account of their biological makeup. The equal value and worth of all human life is thereby significantly challenged.

The Widening Scope for Terminations

Some commentators are concerned about the widening scope of prenatal genetic testing and what appear to be increasingly trivial reasons for terminating a pregnancy. Disquiet has been expressed that PND may even encourage the eventual objectification of children as prospective parents continue to select children on the basis of any criterion other than unconditional acceptance.[136] In seeking to answer this legitimate concern, the Human Genetics Commission in the United Kingdom proposed in 2006 the *seriousness* of a disorder as an essential criterion for consideration prior to a termination for a disorder. Accordingly, under United Kingdom law, an abortion is only permissible following PND when two physicians jointly recognize a substantial risk that the foetus would be born with a 'serious' handicap.[137] Though, in this context, defining 'serious' has proven to be notoriously difficult.[138]

One option for clarifying the term 'serious' might be a careful delineation of criteria that contribute to a widespread understanding of what constitutes a poor quality of life. Physicians would then be required to limit post-PND abortions to cases meeting these criteria. However, this option may be difficult to implement since judgements regarding the quality of a life are highly subjective and vary widely. Further, genetic disorders occur in gradations of severity, and their consequences are often difficult to predict.

Illustrative of this subjectivity, the United Kingdom Human Genetics Commission emphasizes that individuals with genetic disorders, as well as their families and medical professionals, have different views about which conditions give rise to what may be considered to be a poor quality of life. Generally, individuals who have themselves lived with a genetic disorder or who have lived in close proximity to persons with a disorder often rate the quality of their lives more highly than medical professionals.[139] Defining what counts as a 'serious' disorder, therefore, seems to be highly contextual and dependent upon the perceived potential for assistance. Financial and social resources available to prospective parents also affect a decision to maintain or terminate pregnancy. If parents believe they will be able, with the assistance of society, to support a disabled child, it is more likely that they will not consider a termination.

Legislation

European Legislation

A recent case in the European Court of Human Rights affirmed the lack of protection for the human foetus. In *Vo v. France* (2004), the court refused to prosecute a physician whose negligence led to the death (abortion) of a six-month-old foetus. The court concluded that the foetus was not covered by Article 2 of the European Convention on Human Rights (ECHR).[140] This ruling followed the earlier case of *Paton v. UK* (1980) in which the life of the foetus was declared to be an extension of the mother's life and thus not independently entitled to protection by law.[141]

United Kingdom Legislation

The Abortion Act (1967) (as amended by the Human Fertilisation and Embryology Act (1990)) covering England, Scotland and Wales allows the termination of a pregnancy in a number of circumstances, offering a defence to prosecution under the Offences against the Person Act (1861). However, this latter act does not apply in Scotland, where 'assault' is addressed under common law. The Abortion Act 1967 is invalid in Northern Ireland, where it is not legal to carry out a therapeutic termination of a pregnancy other than to save the life of the mother or to prevent serious damage to her physical or mental health (*R v. Bourne* [1938] 3 All E.R. 615).[142]

As previously noted, the legal termination of a pregnancy requires two licensed medical practitioners to agree that the proposed abortion is legitimate based on the criteria stipulated by the act and that the abortion complies with the Abortion Act (1967) in every respect. Under Section 1 the grounds for an abortion are:

> (a) that the pregnancy has not exceeded its twenty-fourth week and that the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman or any existing children of her family; or
> (b) that the termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman; or
> (c) that the continuance of the pregnancy would involve risk to the life of the pregnant woman, greater than if the pregnancy were terminated; or
> (d) that there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped.

The act goes on to state that 'in determining whether the continuance of pregnancy would involve such risk of injury to health…, account may be taken of the pregnant woman's actual or reasonably foreseeable environment'.[143]

In general, the law permits most forms of terminations that are requested by a woman. This is primarily because legislation does not recognise the foetus as an independent legal person.[144] Consequently, the foetus does not have equal rights with a person who is born and whom the law recognizes as being entitled to full legal protection. Up to twenty-four weeks, the Abortion Act (1967) allows a pregnancy to be terminated if 'the continuation of the pregnancy would involve risk, greater than if the pregnancy were terminated of injury to the physical or mental health of the pregnant woman or any existing children of her family'.

Cases related to terminating abnormal foetuses follow the criteria specified by the United Kingdom Royal College of Obstetricians and Gynaecologists (RCOG). Chapter 3 of the RCOG guidance report entitled *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales (May 2010)* sought to interpret and apply the Abortion Act (1967) to individual pregnancies that have been precisely diagnosed in which the foetus was abnormal or at risk of being abnormal.[145] To do this the college included the following clarifications in its discussion:

What Does 'Substantial Risk' Mean in the Legislation?

The college acknowledged that there was no definition in the act concerning 'substantial risk' and that the notion may be considered as being somewhat subjective. However, the term 'substantial' in the act covered a number of characteristics which could be determined, amongst other aspects, as 'important' or 'having real substance'. In this regard, it recognized that there was some flexibility in the term while emphasizing that it was different from a 'certainty of abnormality'. The college also acknowledged that the concept of 'substantial risk' could only be considered on a case-by-case basis and would depend on the perceived seriousness and consequences of the disorder as well as on the likelihood of the expectations.

This reflects the fact that foetal disorders can only be detected with variable levels of certainty. Thus, when the notion of a substantial risk for a foetus is proposed, this should be the position of someone with experience who has no direct interest in the pregnancy being considered or its outcome. This experience would be informed by data relevant to the case in hand and any published information relating to the short- and long-term future outcome for the foetus.

What Does 'Seriously Handicapped' Mean in the Legislation?

The RCOG recognizes that the concept of 'serious handicap' has not been defined in United Kingdom legislation or interpreted in the courts. However, the RCOG notes that the concept includes the cases where foetal abnormality is so severe that no survival is expected after birth. When this is not the case and the foetus is considered to be able to survive after birth, the RCOG acknowledges that the concept of 'serious handicap' is not determined in any precise manner and leaves some flexibility of scope to medical professionals. In the United Kingdom 2013 report on the Parliamentary Inquiry into Abortion on the Grounds of Disability, the RCOG suggested that 'doctors are guided by the view that a serious handicap is a condition that is not trivial and/or readily correctable. This suggests that the level of disability is based on the assessment of whether the child will suffer significant and long term impairment in such a way that it impacts on their ability to function in society unsupported.'[146]

Preimplantation Embryonic Selection

The focus of the previous section addressed procedures that enable the selection (or deselection) of implanted embryos and foetuses. Naturally, the issues at stake concern the development and the life of the embryo or foetus. In this section, the focus shifts to examine procedures that allow the screening of an embryo before it is implanted into the woman. This is made possible through the combination of two procedures:[147] (1) in vitro fertilization (IVF), whereby a woman's eggs are fertilized with a man's sperm in a laboratory, creating embryos that are then left to develop, usually for three days, during which time they grow to about the eight-cell stage, and (2) genetic testing of one or two of the embryo's cells.[148]

Preimplantation Genetic Screening (PGS)

PGS is a procedure that enables embryos to be screened for any obvious chromosomal abnormalities (as opposed to a particular gene) such as aneuploidy (abnormal chromosome number) prior to the embryo's implantation into the woman. PGS does not always give a diagnosis regarding conditions affecting postnatal developments. Rather, for patients thought to be at a higher than average risk of conceiving abnormal embryos, the procedure is typically aimed at identifying embryos that would generally not develop or implant in a natural manner.[149] Most cases of preimplantation deselection of embryos are based on this course of action.[150]

As the first step in the procedure, a clinician performs a biopsy on an embryo created by IVF, removing one cell that is then examined for chromosomal abnormalities.[151] If any disorders are present, the embryo is deselected for implantation into the woman. The biopsy process is repeated for each embryo, and one or two embryos without the specific disorder being tested are then selected for implantation. If all goes well, a nine-month gestation follows, and the woman then gives birth to a child or children without the disorder.

Preimplantation Genetic Diagnosis (PGD)

Though similar to PGS, preimplantation genetic diagnosis (PGD) involves testing an embryo to diagnose its genetic health from a DNA and not a chromosomal perspective. Most commonly, PGD benefits individuals or couples who suspect or are aware that they may be carriers of a genetic disorder. As with PGS, the procedure begins with the IVF creation of embryos that developed in the laboratory until the embryos usually consist of at least eight cells. At this stage, an embryologist removes one or two of the cells from each embryo and examines them for the faulty gene in question. Embryos without the defective gene can then be implanted in the hope that they will develop normally. Any remaining unaffected embryos are stored for later use while those with a copy of the faulty gene are usually destroyed.

People choose PGD for several reasons, but nearly all are motivated by the desire to allow only the development of embryos without a genetic disorder that have a full potential to implant.[152] Generally, however, only single-gene disorders such as cystic fibrosis are presently considered for PGD. As already discussed, some genetic disorders are also sex-linked, and PGD may permit prospective parents to select an embryo based on its sex to avoid a gender-linked disease. Similarly, clinicians may use PGD to detect chromosomal disorders or rearrangements.[153] Another use of PGD does not have in mind the health of a future child resulting from the embryo. Rather, PGD is used to select an embryo that will, if implanted and brought to term, be a tissue match for an existing person who could benefit from a transplant of cells, such as umbilical cord stem cells.

PGD can also help prospective parents who have already experienced several terminations of pregnancies where the foetus is affected by a serious disorder. The procedure may, indeed, be used to enable parents choose an unaffected embryo prior to implantation. Similarly, by allowing the selection or deselection of embryos prior to implantation, PGD offers an alternative for people who object to terminations on moral grounds but who may accept the destruction of embryos.

The practice of PGD and selective transfer is still relatively new. At the same time, PGD is quickly becoming more common in reproductive clinics, as an ever-increasing number of people receive some form of technological assistance for reproduction. According to one study, in parts of Western Europe, roughly 5 per cent of all births involve these new technologies. In the United States, the figure stands at roughly 1 per cent and rising.[154]

The anticipated development of genetic screening will make many more couples aware of the risks of natural reproduction. These couples may then choose PGD to reduce risks. However, the anticipated development of improved and more precise screening techniques may also enable PGD users to select for what they view as desirable genes. As a result, the possibility of positive eugenics through embryo selection cannot be easily dismissed.[155]

It is difficult to predict how likely or widespread such practices may become. Still, a number of practical issues must be addressed before PGD is used for the selection of what is considered to be desirable traits. In addition, many appealing human traits, such as eye or hair colour, are likely to be controlled by more than one gene. Consequently, the contribution of any single gene identified through PGD is likely to be small, and the probability of finding all the 'desired' genetic variants in a single embryo is exponentially even smaller. In the end, there is little guarantee that PGD could efficiently select embryos on the basis of physical traits even if testing for multiple genetic variants would be marginally successful. The fundamental reasons for this limitation are the limited availability of DNA from the cell(s) being tested by the procedure, the sensitivity of the genetic tests, and the ability to perform multiple tests on the same sample.

What is more, selecting for traits controlled by multiple genes would require screening a large number of embryos to find one with the desirable complement. But most rounds of IVF create only about a dozen embryos, i.e., too few to allow optimal screening for the desired traits. At present, it is even possible that following PGD none of the embryos would be suitable for transfer, let alone capable of maturation.[156] Still, in a matter of years, techniques may be so finely tuned that screening IVF embryos for multiple genetic variants could be feasible, allowing selection for traits controlled by more than one gene.[157] Obtaining large numbers of eggs through the use of stem cells would also facilitate the process, potentially giving couples or individuals access to hundreds of embryos from which to choose.[158]

Preimplantation Genetic Haplotyping (PGH)

Preimplantation genetic haplotyping (PGH) is similar to PGD. However, instead of identifying the specific dysfunctional mutation in the embryo, scientists explore a set of DNA 'markers' or signature near the faulty gene in a chromosome associated with a certain disease. One of the perceived advantages of PGH is that it is available to families carrying rare mutations as well as to those with more common, previously identified mutations. PGH also enables doctors to distinguish affected male embryos from unaffected ones, potentially increasing the number of healthy embryos for implantation. Families concerned about creating a male child with a sex-linked disease, such as Duchenne muscular dystrophy, could especially benefit from PGH.

Arguments in favour of Preimplantation Embryonic Selection (PES)

PES for Medical Reasons

For many couples, a significant advantage of PES over PND is the elimination of the trauma that regularly accompanies considering, let alone choosing, to terminate a pregnancy.[159] Indeed, if PND reveals a disorder, the couple faces the predicament of either terminating the pregnancy or accepting the challenges of raising a child with a physical abnormality. With PES, on the other hand, affected embryos may be identified before the pregnancy is established, and only unaffected embryos are then transferred to the uterus while the others are destroyed. Thus, for those couples who do not believe that an embryo has any significant moral status, PES offers the possibility of considering a pregnancy without the anxiety of transferring a disorder. But, more importantly, it allows the couple to have children who are biologically their own without the disease in question since the embryos with the illness are selected out. Many, therefore, believe that the ethical concerns regarding PND do not apply in the same way in the use of PES.[160]

PES for Nonmedical Reasons

Parental Freedom and Responsibility

From a nonmedical perspective, PES offers a number of advantages for the prospective parents. First, the procedure may enable parents to have children 'of their own' while fulfilling a perceived responsibility to future children so that they developed healthily both physically and psychologically. With PES, a greater number of parents may acquire a new, more accessible means of accomplishing this task.[161] There is also the possibility of using the technique for selecting specific characteristics, rather than purely the absence of diseases or disorders. In this context, it is the choice of an individual couple that is being respected, a choice which, it is suggested, should be taken freely without the intervention of a third party.

Familial Solidarity

Another nonmedical argument for PES relates to the values that are found at the core of a family and, by extension, in society at large. It is indeed no secret that similarities and commonalities create social bonds. As advances in medical technology identify a growing number of genetically determined traits, PES will likely allow couples to select for these traits, including such bond-creating factors as intelligence, musicality or athleticism. Families in which parents can have children 'of their own' who share multiple common traits may then develop a greater sense of solidarity between members and become more intimate with one another. Such families would offer children the opportunity to grow up in a better environment and develop social skills that enable them to contribute meaningfully to a stronger society.

Arguments against Preimplantation Embryonic Selection (PES)

Though a number of eugenic issues associated with PES are general in nature and are addressed in the second half of this book, others are more specific. In particular, there are concerns about the range of both present and future conditions for which this technique should be used. Additionally, from a more practical perspective, PES has a number of important limitations.[162] These include:

- the limited and very small number of embryos that are currently available for selection;
- the hyperstimulation of a woman's ovaries to produce multiple eggs at once – which carries its own medical risks;
- the limitation of PGD as a means to eliminate all disabilities from the population;[163]
- the high cost of the treatment, which may limit some prospective patients.

Potentially, if IVF pregnancy rates dramatically improved, the use of PGD and other forms of embryo selection may also increase. At present, however, it seems likely that PND (and, if necessary, termination) will remain the more common approach for couples who are at risk of transmitting a serious disease to their children.[164]

Specific reasons for opposing PES fall into two broad categories of ethical discussion: scientific and sociological. As will be clear, the sociological reasons parallel objections to similar practices that have previously been covered. In noting these objections, the aim is to continue to develop a coherent picture of current selection practices. Admittedly, with new developments, the scientific objections to PES may be neutralized, but the sociological concerns will remain because they derive from deeper matters. To leave the reader with a broad picture of arguments against PES, the scientific issues will precede the sociological.

Destruction of Possible Embryos

Creation and Destruction of Those Embryos that are Not Selected

Some individuals object to PES because the procedure allows the destruction of the human embryos that are not selected for implantation. For those who believe that embryos are human persons with a right to life from the moment of creation, or who are willing to give them the benefit of the doubt, PES is linked to the morally impermissible action of destroying such embryos. Generally, those with this view then see no difference between PES and PND.

Destruction of Totipotent Cells

Some countries are currently home to fierce debates about the nature of the one or two cells that are removed from the embryo and subjected to genetic testing. If such cells are considered totipotent, that is, capable of being considered as complete embryos in their own right, then their use in the testing procedure becomes controversial. This is because the procedure would result in their destruction and could be regarded as the destruction of embryos, which for some people is equivalent to destroying human beings.[165]

In Germany, for example, the Embryo Protection Act (13 December 1990) protects the embryo from the one-cell stage of the fertilized egg until complete nidation (implantation) in the uterus.[166] Moreover, according to this act the legal definition of an embryo is 'the fertilised egg from the moment of the fusion of the cell nuclei of egg and spermium, and every totipotent cell taken from an embryo since these cells have the potential to develop into a human individual'.[167] According to German legislation, this means that every cell of the eight-cell embryo (on the third or fourth day of embryonic development) may be under the strongest possible protection, since it is probable (subject to confirmation) that some of the cells at the eight-cell stage are totipotent and may legally qualify as embryos.[168,169]

The intent of the law is unmistakable, as the Embryo Protection Act states that it is forbidden 'to dispose of an embryo, or to deliver, acquire, or use an embryo for purposes not serving its preservation'.[170] In other words, under German law, a human totipotent cell can be assimilated to a human embryo if it is capable of developing into an early human embryo. As a result, the totipotent cell would also be protected from destruction.[171]

This means that all biopsies of totipotent cells for research or analytical purposes such as in certain forms of PES are similarly forbidden, even if the original embryo, from which the cells were taken, is not harmed. However, if the cells are not totipotent, then the removal of cells for PGD in Germany would be possible.[172,173] This means only using cells taken later than the fourth day after fertilization, i.e., following the complete loss of totipotency of the early cells making up the original embryo.[174]

In this regard, and considering the ethical discussions relating to procedures such as PES taking place in the wider medical ethics community, two further considerations can be made. First, only a limited amount of scientific information is currently available concerning the 'potency' of human cell(s) taken from an eight-cell embryo in a procedure such as PES. Secondly, the scientific community in some countries may do well to engage the opinions of their neighbours, thereby fostering a more global approach to present and future challenges in medical ethics.[175]

Safety of Biopsy

There are also concerns about whether removing one or two cells from an embryo can jeopardize the embryo's further development and the overall health of the future child. This concern becomes more acute when the embryo does not stand to benefit from the process. However, although current evidence suggests that the procedure inflicts neither any immediately visible harm on the early embryos nor any obvious harm on the resulting child, more attention concerning the long-term risks to the child born through PGD is required before the procedure may be employed merely for 'improvement' purposes.[176,177]

No Guarantee that the Child Born Will Have the Desired Traits

Another concern about PES stems from the nature of genetic disorders. Not all genetic variations are similar, and each variation has a different penetrance factor, that is, a measure of effectiveness and power. For example, the disorder that causes Huntington's disease has a 100 per cent penetrance, meaning that if someone has the genetic variation, and assuming the person does not die of something else, the disease will eventually manifest itself in every person who is an affected carrier of the mutation. Other genetically determined conditions have a much lower penetrance, such as only 15 per cent for left-handedness. Understanding penetrance factors is important for making decisions regarding selection procedures since the presence of a genetic disorder does not guarantee that the person will actually suffer from the defective gene. This uncertainty comes home in relation to PES because even if an embryo is identified as carrying a genetic abnormality, there is no guarantee that the abnormality will result in a disorder or disease in the person concerned. Thus, on account of the detection offered by PES many embryos may eventually be destroyed because they have a low penetrance genetic condition even though the condition would never have led to a disease if they had been left to develop.

In addition, though PES permits prospective parents to deselect embryos for undesired traits and to select embryos promising to exhibit more desirable traits, the success of PES remains uncertain. There is no guarantee that the child born after this procedure would actually manifest the chosen traits. The interaction of nature and nurture (biology and environment) in human development is too complex to make such results predictable. At present, because of the intricate manner in which genes function, it is actually difficult for PES to be used for any traits that depend on more than one gene.

Though perhaps obvious, it is worth emphasizing that PES does not fully allow for so-called designer babies, since the procedure can only select genes originating in the genetic parents of the embryo.[178] Thus, on account of the distinct complexities of human genetics, parents who stake their hopes on the power of PES to provide them with the ideal child may be setting themselves up for being disappointed.

Increasing Number of Supernumerary Embryos

It has been noted that recent trends giving ever more choice in the field of reproductive technologies have also increased the number of embryos and foetuses being destroyed. With PES, several embryos are created but only a few selected and implanted (or frozen in storage). The result is a significant number of embryos considered surplus or 'waste'.

Scientists have already determined about six thousand genetic disorders caused by a mutation in a single gene.[179] But if a consignment of embryos, originating from a couple, is tested for a large number of genetic disorders, then it is likely that only a small number, if any, embryos will eventually be shown to be free from all these tested disorders. In practice, this would mean that testing for a number of traits may eventually result in none of the embryos beings considered for implantation into a woman.[180] The fate of these spare embryos, which in certain countries, such as the United Kingdom, are being numbered in the hundreds of thousands, elicits concern. One option for dealing with the excess embryos would be to create fewer embryos. But even then some would still be considered excess, requiring a decision about whether they should be discarded, frozen, adopted by other parents, given to research or have any other fate.

Confusion of Responsibility

To date, the practice of PES has occurred as parents have voluntarily consented to undergo the procedure, and no third parties have intervened to compel the use of the practice. If, however, PES becomes significantly linked to the concept of parental responsibility, the voluntary nature of PES may be jeopardized, as the practice comes under growing expectations from the general public. Society may then pressure couples to screen their reproductive choices, with any failure to comply with societal demands leading to ostracism. It is even conceivable that parents' responsibility to their children (and, in turn, to humanity) would be stretched to undergo PES to prevent the birth of offspring affected by a disorder.[181] Widespread use of PES may then result in an overexpansion of parental duties, so that failure to use PES (and thereby preventing the birth of children with serious disorders) would constitute a failure of parental duty. What is more, societies and their governmental counterparts may end up having to support PES financially to enable parents to fulfil their responsibilities towards their children.

Slippery Slope

A fourth concern with PES is the eugenic slippery slope which was already mentioned in the section addressing sex selection. In other words, that PES may initiate a mindset resulting in an entrenched societal practice of valuing people on the basis of increasingly trivial characteristics. Without significant restraints, commendable reasons for PES may disintegrate as the procedure becomes more widely available. Consequently, the current practice of only screening out what are considered disorders could expand to include the screening out of less-desirable physical traits as well. As the bioscience commentator David King remarks, '[PGD] may exacerbate the eugenic features of prenatal testing and make possible an expanded form of free-market eugenics.'[182] Conceivably, a frequent and unrestrained use of PES could undermine the bedrock of free society: the equality of all its members. In this way, PES raises ethical issues similar to those raised by PND, in particular, discrimination and stigmatization of certain types of people as well as the difficult issue of defining the seriousness of a disorder. In the past, PGD was commonly only used to test for very serious disorders. However, this is now changing as some countries, such as the United Kingdom, are increasingly considering PGD for late-onset diseases which are expressed in the later life of the individual or low-penetrance diseases which only affect a relatively low proportion of individuals with the genetic alteration. The fact that this screening occurs even when some form of treatment may be available indicates that there has already been some movement down a slope, with more disorders now being likely to be considered for PGD.[183]

Creation of Orphan Diseases

On account of the complexity and limited understanding of gene mutations, most genetic disorders will remain untreatable for the foreseeable future. Thus, the only procedures presently available for addressing many genetic disorders are PGD and PND. But an obvious consequence of increasingly deselecting embryos with certain genetic disorders is that fewer individuals with those diseases will eventually exist. In turn, governments and the pharmaceutical industry will view these diseases as rare or orphan diseases and thus unprofitable avenues for further research. Investment in this research will then wither, and people currently living with these diseases will lose hope of an appropriate treatment.

A recent development in medical technology illustrates this point.[184] In January 2011, a hospital in Scotland offered Stephen and Lee Thomas a preimplantation test for cystic fibrosis (CF). The couple's first child was born with CF, and they did not want to risk conceiving another child with the same disease. With the aid of PES the couple was able to avoid a child born with CF. Understandably, they were thrilled at their experience. 'We were really lucky that it worked for us first time', said Lee Thomas. However, the emergence of a new approach to the disease raises the distinct question of whether the beginning of the end for CF research has arrived.

Possibility of Screening-in What is Considered by Many as a Genetic Disorder

A further problem with PES relates to the medical reasons that support the procedure. The concern is that, rather than being used to select out genetic disorders, the procedure may be used to choose embryos which are affected by a certain condition. For example, had the technology been available, the previously mentioned case of Duchesneau and McCullough could have used PES to select embryos that carried a gene for deafness. Even though deafness is widely regarded as a disorder to be avoided, Duchesneau and McCullough desired a deaf child in order to facilitate family solidarity. Not surprisingly, however, such use of PES is controversial. The difference between using PES to select for what can be considered a genetic disorder and refusing to use PES to screen for disorders is important. The former intentionally chooses disorders, whereas the latter simply accepts the imperfections of human existence. Admittedly, there is a fine line between the two, but the active nature of deliberately selecting what could be considered a negative trait makes the action ethically dubious. In fact, in the United Kingdom this use of PES is prohibited in law.

Saviour Siblings

In recent years, scientific advances have enabled a new application for PGD procedures which raises unique ethical questions.[185] Popular parlance refers to the issue as the 'saviour siblings' debate since the purpose of this specific PGD procedure is to determine whether an embryo has the potential to provide a life-saving treatment for an already-born child who has the same biological parents as the embryo.[186] This application of PGD would be useful if the older sibling suffered from a grave illness such as a serious blood disorder.[187] To facilitate treatment for this child, the parents would undergo IVF to create a number of embryos. PGD would then be used to select the appropriate embryo (whose cells are immunologically compatible with the sick, older child) which would be implanted into the mother to give a healthy infant.[188] At birth, stem cells from the umbilical cord (or after birth from the bone marrow) of the child would then be collected and used to treat the older sibling. Since these cells would be immunologically compatible with the sick child, there should be no rejection problems when they are transplanted. In this case, although PGD may ensure the health of the embryo itself, the primary aim is to establish the potential of the embryo (and the future child) as a source of hope for the health of the older sibling.[189]

The first treatment from a saviour sibling was undertaken in the United States in October 2000 for the Nash family, whose daughter Molly had a serious bone marrow disorder called Fanconi anaemia. After four attempts and the creation of about thirty embryos, the couple successfully used PGD to conceive a healthy son. This boy provided his sister with a stem cell transplant from his umbilical cord. The procedure was described as 'a complete success' and Molly's health improved dramatically.[190]

Ethical Discussion about Saviour Siblings

Some commentators argue that using PGD for a 'saviour sibling' procedure is a distortion of the original purpose of PGD, which was to avoid a genetic disorder.[191] By this reasoning, PGD is acceptable when employed for the prevention of a life with a disorder. But as soon as it is employed for the improvement of existing life, PGD becomes unacceptable. When used to create a saviour sibling, PGD permits the creation of an individual that will exist primarily for the benefit of another person, not for his or her own sake. This, it is suggested, is a form of instrumentalization of the child.[192] Parents pursuing the creation of a saviour sibling might respond to this claim by stating that even though they want a saviour sibling for their sick child, they also desire to have an additional healthy child.[193] Such a position was the case for the British couple Amy and Anthony Maguire, who used saviour sibling technology to create a match for their son Connor, who suffered from aplastic anaemia, a disease that prevents bone marrow from producing sufficient new cells to replenish blood cells.[194] The Maguires' efforts were successful, and they became parents of twins, in 2007, who were both matches for Connor. In the light of a situation like the Maguires', some commentators note the importance of the parents' motivation in determining whether PGD in this specific situation would be ethically acceptable.[195]

At the same time, parental motivations are notoriously difficult to establish.[196] It is possible to envision a situation in which PGD might reveal that the only healthy embryos after a round of IVF were those which were immunologically *in*compatible with the existing child. In this case, the maturation of these embryos would not assist the existing child. The parents would then have three options: (1) continue with the procedure regardless of the needs of the older child, (2) conserve the embryos for possible future use or (3) destroy the embryos. In the event that the couple refused to transfer any of these healthy embryos, it could be inferred that their original motivation was not purely based on having a healthy child but to use the embryo for another purpose. As discussed above, this would be a possible case of the instrumentalization of the embryos since, to all appearances, the embryos were only valuable when they could provide a service.

Concerns about instrumentalization also arise if, at birth, an insufficient quantity of umbilical cord blood is obtained. The newborn child could then be considered for bone marrow removal that would be transplanted into the older sibling. But if this also proved unsuccessful the so-called saviour sibling would have effectively failed to save his or her older sibling. The question then arises whether the child's existence is itself a failure. But, on what grounds is it legitimate to judge the success of a person's life, especially when the person was created for a purpose over which he or she has no control? Similarly, is it proper to burden an embryo, let alone an infant or child, with the task of being a 'saviour' to a sibling? Perhaps even more challenging is the question whether a child's very existence should depend on fulfilling the hopes of his or her anxious parents and siblings.[197,198]

That being said, nondirective counselling should be considered before such a procedure is undertaken to ensure that the welfare of any future child is carefully examined. In particular, parents should evaluate how they may react should cells of the 'saviour sibling' fail to produce the desired result. The use of PGD for selecting a donor child mandates an intensely self-reflective approach to the procedure. While it is highly probable that many families would love a child who was ultimately unable to donate tissue, all families opting for saviour sibling PGD must recognize the possibility that they may eventually struggle to view the child as worthy of unconditional acceptance regardless of the success of cell donation.

Finally, it has been noted that sometimes, against all hopes, the creation of a saviour sibling is unsuccessful. In the case of Raj and Shahana Hashmi, in the United Kingdom, six IVF cycles were insufficient to create a viable donor-embryo that could eventually lead to the treatment of their older son.[199] Similarly, in the Nash case, though the procedure led to the birth of a baby boy who was a match for his older sister, thirty embryos were created and four pregnancies attempted for the birth of one child.[200] Therefore, in light of the frequent difficulty of creating saviour siblings, concern arises that PGD may lead parents to a relentless pursuit of the creation and, if the match fails, the subsequent (large-scale) destruction of embryos. This pursuit would, of course, be understandable in the light of the parents' desperation to save a child's life. But this may give rise to a significant amount of psychological distress which could result in a situation which was worse than before the saviour sibling procedure was contemplated.[201] In addition to the physical toll wrought by multiple rounds of IVF, such unchecked use of PGD may also raise the ethical concerns noted in the previous section (arguments against PES).

Legislation

International Legislation

At present there is no international consensus on PES and the different procedures coming under this category. Some countries prohibit PES while others have more flexible regulations.[202] In the majority of countries where PGD is possible, an authority oversees and regulates good practice for PGD in addition to prenatal diagnosis (PND).

United Kingdom Legislation[203]

In the United Kingdom, all decisions about PGD are governed by the Human Fertilisation and Embryology Act 1990 – updated in 2008 – the HFEA Code of Practice and case law. Although the Human Fertilisation and Embryology Act 1990 does not mention PGD specifically, it can be licensed under Schedule 2, Section 1(1)(d) as a practice 'designed to secure that embryos are in a suitable condition to be placed in a woman'.

The more recent Human Fertilisation and Embryology Act 2008 indicated in Schedule 2, Section 3 (embryo testing) that a licence cannot authorize the testing of an embryo, except for some of the following purposes:

> (a) establishing whether the embryo has a gene, chromosome or mitochondrion abnormality that may affect its capacity to result in a live birth,

> (b) in a case where there is a particular risk that the embryo may have any gene, chromosome or mitochondrion abnormality, establishing whether it has that abnormality or any other gene, chromosome or mitochondrion abnormality,
> (c) in a case where there is a particular risk that any resulting child will have or develop a gender-related serious medical condition,
> (d) in a case where a person ('the sibling') who is the child of the persons whose gametes are used to bring about the creation of the embryo (or of either of those persons) suffers from a serious medical condition which could be treated by umbilical cord blood stem cells, bone marrow or other tissue of any resulting child, establishing whether the tissue of any resulting child would be compatible with that of the sibling.

But before a licence can be obtained for a PGD procedure, the HFEA (or a similar official body with the same remit) must establish that it is 'necessary or desirable for the purposes of providing treatment services' in conformity with Schedule 1(3) of the HFE Act 1990 (this part of the act was not updated in 2008).

With this act, the HFEA also registered its judgement that guidelines for PGD should follow those already established for PND. In addition, the HFEA implied that a list of specific conditions was unnecessary and that general principles would suffice to instruct the medical community.[204] The Human Fertilisation and Embryology Act 1990 which amended the Abortion Act 1967 requires two medical personnel to determine that a pregnancy can be terminated at any gestation if 'there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped'. In this regard, it is accepted that it is for the woman to decide whether or not to place a certain kind of embryo in her body. Generally, however, PGD is only made available in the United Kingdom where there is a significant risk of a serious genetic disorder being present in the embryo.

With respect to PGD using tissue typing to help an older sibling, in February 2002 the HFEA eventually granted permission to the Hashmi family to undergo PGD in order to conceive a healthy 'donor sibling' for their son, who was affected by Thalassaemia. After several unsuccessful attempts, however, the treatment was abandoned. In July 2004, the HFEA announced that it would also licence PGD for tissue-typing in cases where searches for an existing matched donor prove unsuccessful. It then agreed, in May 2006, that the use of PGD embryo testing for inherited susceptibility conditions such as inherited breast, ovarian and bowel cancers should be allowed.[205]

In the United Kingdom it is not possible to specifically select embryos for disability. Section 14(4) of the Human Fertilisation and Embryology Act 2008 states, 'Persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop a serious physical or mental disability, a serious illness, or any other serious medical condition, must not be preferred to those that are not known to have such an abnormality.'

Selection through Human Reproductive Cloning

The study of practices available to prospective parents for selecting offspring now turns currently available procedures to the futuristic practice of human selection through cloning. Cloning is usually defined as a procedure that enables one organism to be created as a genetic copy of another organism. Not surprisingly, perhaps, the English 'clone' is etymologically related to the Greek word *klon* meaning 'twig'.

The prospect of cloning for improving the human genetic heritage was first suggested as far back as 1963 when the British biologist J.B.S. Haldane proposed that the most talented human beings should be selected for cloning. In 1966 Joshua Lederberg of Stanford University followed Haldane in arguing that the cloning procedure could be used to reproduce already existing persons who have been demonstrated to be valuable and of quality.[206]

The specific cloning procedure considered in this chapter is called somatic cell nuclear replacement (SCNR). Genetic material from the nucleus of one cell from a donor organism is removed and introduced into an unfertilized egg or one-cell embryo whose own genetic material (nucleus) has been removed.[207] The nuclear genes of the cloned cell are thus identical to those of the donor organism.[208] Although not yet possible in primates, nuclear replacement has the potential to create a clone of an adult human, thus exactly reproducing the adult; this is defined as reproductive cloning. The majority of scientists, however, consider SCNR more valuable (and more likely) for the purposes of research into the behaviour of adult stem cells and the manner in which they could be manipulated in the context of general research.[209] At present, then, reproductive cloning is more a theoretical than a practical possibility. Nevertheless, it raises important ethical questions that relate to the larger discussion of the new eugenics.

More recently, a procedure called pronuclear transfer which is very similar to cloning has been suggested as a possible way of making sure an early embryo is healthy, especially in the context of mitochondrial disorders. Mitochondria are very small entities found in all the cells of the human body which produce the energy that it needs to survive. For a cell to function and replicate properly, the thirty-seven genes in every mitochondria must interact properly with the genes in its chromosomes. With pronuclear transfer, the pronuclei (containing all the nuclear DNA from both parents) from a fertilized egg affected by dysfunctional mitochondria are transferred into a second fertilized egg from a second woman, with healthy mitochondria, which had been emptied of its own nuclear material.[210]

Because the genome of any future descendants may be modified in this way in a manner that is considered to be positive, the procedure may be considered as a form or eugenics.[211] In this regard, it may also be recognized as a kind of germline intervention through genetic modification (see later section entitled Eugenics by Genetic Modification). But since new embryos can be produced in this way through cell nuclear replacement, which can then be selected on the basis of their health, pronucleus transfer can also be considered in this chapter.

Arguments in Favour of Selection through Reproductive Cloning

It may be possible in the distant future for researchers eventually to overcome the scientific difficulties currently involved with human SCNR. Society will then have to address a number of complex ethical issues, including applying the cloning procedure to eugenics. Unlike natural or even most forms of assisted procreation, reproductive cloning would create a child with the genotype (genetic makeup) of the person who donated the cell for the SCNR procedure.[212] In other words, with the help of medical technology, parents may be able to choose the genetic endowment of their children, thus making it possible for one generation to exercise a determinative control over the next.[213] Whether this control is the prerogative of parents, let alone beneficial for the created children, remains a much debated question.

Generally, there are two main arguments which suggest that reproductive cloning might contribute positively to human society. In both cases, as with other selection procedures, it enables prospective parents to procreate children of their choice.

Fertility

An initial, perceived advantage of reproductive cloning coincides with earlier discussions about reproductive technology: couples could employ the procedure to have a child genetically related to at least one of them, a child that could be considered 'their own'.[214] This scenario could arise when, under natural circumstances, a couple was unable to have children because of homosexuality, fertility problems or concerns about giving birth to a child with a genetic disorder.[215] Reproductive cloning would then offer all the seeming advantages of other forms of reproductive assistance but with the added attraction of limiting the genetic material to the prospective parents. In this way parents could avoid the possible psychological concerns that may accompany the use of donor gametes or embryos. Raising children who were very similar to one of the parents may also be an advantage in that the relevant person would already know some of the biological features and appreciate some of the difficulties or capacities in the cloned child.

Societal Progress

The other possible benefit of reproductive cloning is its expected ability to replicate remarkable human beings. In theory, parents or society could reproduce individuals with outstanding traits such as intellectual capacity, talent or beauty, where these traits are presumed to have a genetic contribution. Moreover, not only may these superb individuals be extremely talented, they may also be endowed with gifts of leadership, confidence and enterprise, enabling them to encourage others to explore new horizons of human accomplishment. These enhanced individuals would, of course, also be able to reproduce in a normal fashion, thereby extending their superior genetic endowments to future generations.

In light of these future possibilities, society may agree that cloning is a viable means for advancing the whole of human civilization. As a result and because many more children with clear biological advantages may be created, a competitive setting may appear pushing for ever more enhancement and progress.[216] It should be noted, however, that cloning may not always produce the desired expectations and substantial behavioural or even physical differences may occur between the cell donor and the resulting cloned child. For example, personality differences are not uncommon between identical twins (reared together) who are a form of clones.

Arguments against Selection through Reproductive Cloning

Biomedical and Psychological Risk

At present, scientific objections to reproductive cloning are overwhelming. Producing Dolly the sheep required 277 attempts, and cloning humans will certainly prove even more difficult.[217] Scientists also remain uncertain about the biological consequences of producing cloned animals. Some studies demonstrate a high rate of malformations (including extraordinary size) and premature deaths. Similar dangers would likely beset human cloning.

In addition to the biological problems, there may be several unknown consequences relating to the psychological effects of the procedure on the cloned individuals. These could arise, for example, from unhealthy expectations and control of the parents. As the American ethicist Leon Kass indicates, 'Through cloning, we can work our wants and wills on the very identity of our children, exercising control as never before.'[218]

Admittedly, without actually examining live subjects, there is no way to determine how cloned persons would view their own identity, their genetic parents or the scientists that participated in their creation.[219] Still, in light of the unanimously recognized scientific problems with reproductive cloning, the psychological issues comprise a relevant body of objections that may lend weight to a firm stance against creating human beings in this manner.[220]

Undermining Human Dignity

Though some might argue that reproductive cloning may benefit society, as previously noted, these benefits could also undermine the concept of inherent human dignity. The European Parliament voiced this concern in 1997:

> [T]he cloning … of human beings cannot under any circumstances be justified or tolerated by any society, because it is a serious violation of fundamental human rights and is contrary to the principle of equality of human beings, as it permits a eugenic and racist selection of the human race, it offends against human dignity and it requires experimentation on humans.[221]

Similarly, in 2002, the President's Council on Bioethics of the United States argued that the underlying problem with reproductive cloning is 'that human dignity is at stake'.[222] Admittedly, every human child is dependent on the lives of those who have control and influence over them. But these American ethicists suggested that the cloned life is uniquely bound or indebted to its caregivers.

To the detractors of reproductive cloning, the difference between the cloned and noncloned life lies in a simple difference: one was created to meet precise specifications, while the other has emerged through random human agency. In cloning, however, the processes that give rise to natural procreation have been manipulated to satisfy the demands of the powerful over the weak. Cloned persons would be indebted to their creators in two ways. First, they would owe their very existence, which may be regarded as a universal debt, to their creators. Secondly, they would have a perceived responsibility to live particular and prescribed lives to please those who brought these lives into existence. As with other practices already reviewed in this book, cloning thus threatens to objectify the human person and, in so doing, undermines the respect due to his or her inherent human dignity.[223]

Cloning and Eugenics

Assuming that medical technology continues to develop to yet unimagined heights, it is possible to enquire whether there are any reasons for believing that selecting a cloned child is ethically acceptable. And, if a prospective couple could satisfactorily demonstrate motives that did not instrumentalize or objectify the created child, could they ethically create a child through cloning?

The risk, however, of falling prey to a program of new eugenics remains a major (if not insurmountable) hurdle to reproductive cloning. The eugenics-related concern about reproductive cloning stems from the possibility that cloning would be used to select only children who meet certain criteria, such as beauty, intelligence and physical prowess.[224]

Noting this anxiety clarifies that concerns about reproductive cloning pertain to matters beyond a couple's fertility. Theoretically, a couple in a loving relationship might jointly contribute biological and even genetic material that could be used in a cloning procedure. For example, a man might be the somatic cell donor, while the woman supplies an unfertilized egg. In this respect, cloning may be considered as being similar in some aspects to the commonly accepted practice of IVF.[225]

There is justifiable concern, though, that the legalization of reproductive cloning would lead to the practice of selecting offspring that may satisfy the demands of their prospective parents and would, at the same time, generally correspond to the values and expectations of the broader human society. In short, the real eugenic concern relates to the possibility that a child could be valued for a reason other than his or her mere existence.[226] Any reproductive cloning intent on creating a more perfect human being should, therefore, be deemed questionable. Pursuing such a procedure may set society at large on a collision course with a discriminatory future.

Theoretically, governments could implement safeguards to prevent any possible risks with eugenic cloning. But the eugenic mistakes at the beginning of the twentieth century present a strong counterargument to any reassurance based on faith in the goodwill of human society. It is true that some may construe the suggestion of a new eugenics as fear-mongering. At the same time, mentioning the potentially insidious side of reproductive cloning may enable a frank look at humanity's capacity for self-deceit. Regardless of scientific developments, the practice of reproductive cloning should not proceed without exceptional caution, wisdom and further honest, transparent discussions across society.

Legislation

United Nations Education, Scientific and Cultural Organization

The Universal Declaration of the Human Genome and Human Rights (Adopted on 11 November 1997)

> Article 11
>
> Practices that are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted.

Council of Europe (Forty-seven Countries)

Additional Protocol to the Convention on Human Rights and Biomedicine, on the Prohibition of Cloning Human Beings (Entered into force on 1 March 2001)[227]

> Article 1:
>
> (1) Any intervention seeking to create a human being genetically identical to another human being, whether living or dead, is prohibited.
> (2) For the purpose of this article, the term human being 'genetically identical' to another human being means a human being sharing with another the same nuclear gene set.

European Union (Twenty-eight Countries)

Charter of Fundamental Rights of the European Union (Adopted at the Nice Summit in December 2000)

> Article 3(2):
>
> In the fields of medicine and biology, the following must be respected in particular… the prohibition of the reproductive cloning of human beings.

United Kingdom Legislation

The Human Fertilisation and Embryology Act 2008 effectively prohibits reproductive cloning (and replaces the Human Reproductive Cloning Act 2001) by stating in Section 3 that no person shall place in a woman an embryo unless:

a) it has been created by the fertilization of a permitted egg by permitted sperm,
b) no nuclear or mitochondrial DNA of any cell of the embryo has been altered, and
c) no cell has been added to it other than by division of the embryo's own cells.

However, it also indicates that an exception exists since regulations may provide that a form of Cell Nuclear Replacement can take place to prevent the transmission of serious mitochondrial disease.

Selection through Infanticide

Yet another possible means of selecting offspring concerns deselecting newly born children through the killing of infants. Infanticide is the killing of a born child, through either a direct act or the intentional withholding or withdrawing of ordinary care vital to the child's survival, such as the provision of food and fluids.

To a majority of commentators (not to mention the general public) infanticide is deeply offensive since an infant is considered in law to be a human child and thus protected by all the human rights conventions. To some, however, an infant child has (or should have) no guarantee to life. For example, in 1978, Francis Crick, Nobel Prize winner and co-discoverer of DNA, was quoted as saying, '[N]o newborn infant should be declared human until it has passed certain tests regarding its genetic endowment and that if it fails these tests it forfeits the right to live.'[228] But Crick's bold statement in many ways was not the first. In 1973, James D. Watson, Crick's colleague with whom he shared the Nobel Prize for determining the double helix of DNA suggested that 'If a child were not declared alive until three days after birth, then all parents could be allowed the choice that only a few are given under the present system. The doctor could allow the child to die if the parents so choose and save a lot of misery and suffering'.[229] Although Watson himself decried this future, he observed that it was a logical conclusion to draw based on philosophies and legislation that guarded the life of full-term babies.

Over thirty years later, the same reasoning made a public appearance in the United Kingdom. In 2004, Professor John Harris, a past member of the British Medical Association's ethics committee and a professor of bioethics at the University of Manchester endorsed what could be understood as a limited acceptance for infanticide. This would be in circumstances such as when a genetic disorder is undetected during pregnancy. In this respect he said, 'I don't think infanticide is always unjustifiable. I don't think it is plausible to think that there is any moral change that occurs during the journey down the birth canal.'[230] These examples demonstrate that there is undoubtedly a resurgence of proposals, that are argued as being rational, to reconsider infanticide as a viable option for dealing with a child born with a serious physical disorder.

Arguments in Favour of Selection through Infanticide

Reasons for supporting infanticide fall into two categories. Firstly, proponents argue that a child's death may be justified if he or she is incompatible with the successful lives of family and/or society. In other words, if a child is considered to have a seemingly pointless life or to be socially useless and is a crushing burden on others, a family may then have a legitimate reason to orchestrate the child's death.[231]

Secondly, proponents observe that there is little logical difference between a late-pregnancy foetus and a newborn baby. As already noted, John Harris believes it is unlikely that a foetus undergoes a significant transformation in moral status in its birth. Harris observed further: 'People who think there is a difference between infanticide and late abortion have to ask the question: what has happened to the fetus in the time it takes to pass down the birth canal and into the world which changes its moral status? I don't think anything has happened in that time.'[232]

In light of this imprecise distinction in moral status, ideological supporters of infanticide propose that it should be legalized if third trimester abortion is legal.[233] Following the logic of Harris (and others), the ex utero life of the foetus (a newborn baby) should not receive special protection and infanticide is justified if a disorder is present.[234] Again, Harris's reasoning is worth quoting: 'It is well-known that where a serious abnormality is not picked up – when you get a very seriously handicapped or indeed a very premature newborn which suffers brain damage – that what effectively happens is that steps are taken not to sustain it on life-support.'[235]

Of course, underlying all discussion of abortion and infanticide is the complex matter of the stage at which an entity should be recognized as having full moral status. If the beginning of biological life coincides with the beginning of human personhood, then widespread beliefs about abortion may need to be reexamined if not overturned. On the other hand, if 'to be a person, one must have the capacity for self-consciousness', then not only does abortion find sturdy footings, but infanticide, as well, becomes more intellectually acceptable.[236] As the Princeton bioethicist Peter Singer made clear in 1993:

> Regarding newborn infants as replaceable, as we now regard fetuses, would have considerable advantages over prenatal diagnosis followed by abortion. Prenatal diagnosis still cannot detect major disabilities ... At present, parents can choose to keep or destroy their disabled offspring only if the disability happens to be detected during pregnancy ... If disabled newborn infants were not regarded as having a right to life

> until, say, a week or a month after birth it would allow parents, in consultation with their doctors, to choose on the basis of far greater knowledge of the infant's condition than is possible before birth.[237]

In noting the close logical link between infanticide and third trimester abortion, Harris and others have also suggested that countries in the developing world already widely accept some form of infanticide as a means of selecting children.[238] By implication, legislation against outright infanticide, as in the United Kingdom, is both illogical and inconsistent with the practice of a majority of human civilizations.

Taking Social Darwinism as an example, it is possible also to argue that controlled infanticide, just as controlled third trimester abortions on the grounds of health concerns, could actually aid societal progress by offering yet another means for culling genetically defective human beings. By this reasoning, an accepted practice of infanticide in human society would merely be a further step towards a certain form of eugenics.

Arguments against Selection through Infanticide

In spite of the logical reasoning in favour of infanticide, the ethical codes that underpin today's global society have wholeheartedly rejected infanticide. Indeed, the apparent strength of an argument is by no means an indication of its acceptability, nor is the apparent limitation of an argument indicative of its failure. The twentieth century provides scores of examples of circumstances where acceptable practices were based on improvable assumptions, most obviously, of course, the eugenic programs noted earlier in this book.

As the following section on infanticide legislation illustrates, there is widespread agreement that any act of infanticide is an unacceptable means by which to select human offspring. As numerous legal and ethical codes indicate, the prohibition of infanticide originates in the belief that it constitutes a form of murder, since the being whose life is ended (in an act of infanticide) is a human person. As one ethicist notes, among civilized human society there is virtual unanimity that the slaughter of an animal, such as a calf, is qualitatively different to the slaughter of a human infant, who is considered to have an inherent human dignity.[239]

This is not to say that violence against animals is ethically acceptable but that human beings recognize a distinction between a nonhuman animal and a fellow human being. Though philosophers such as Peter Singer may develop coherent ethical paradigms that cut across species distinctions, it is very unlikely that society at large will accept an ethical theory that accords greater moral value to a mature monkey than to a human infant.[240] There is a consensus that any killing of a born child is contrary to the inviolable right to life enshrined in international human rights documents which underpin civilized society.

Legislation

United Nations

The Universal Declaration of Human Rights (Adopted and proclaimed on 10 December 1948)

> Article 1
>
> All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.
>
> Article 3
>
> Everyone has the right to life, liberty and security of person.

Council of Europe (Forty-seven Countries)

Convention for the Protection of Human Rights and Fundamental Freedoms (Entered into force on 3 September 1953)

> Article 2 – Right to life – indent 1:
>
> Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.

United Kingdom legislation

Any person convicted of killing a child is guilty of murder in England, Scotland and Wales. Murder is a common law offence and is labelled with the legal jargon, *malum in se*, or 'evil in itself'.

In the United Kingdom, the Infanticide Act 1922, which was repealed in 1938 by a new act with the same name, defines 'infanticide' as a specific crime that can only be committed by the mother during the first twelve months of her infant's life. The reasoning behind this specification was to allow some measure of leniency where the death of a child came as a result of a mother's temporary loss of proper mental function on account of postnatal depression. Importantly, this distinction does not diminish the humanity or moral value of the infant but protects the mother from being put on trial for murder and the more serious consequences associated with such a verdict.

Eugenics by Genetic Modification

Recent advances in biotechnology have created numerous procedures for selecting offspring. This book has, so far, explained and ethically evaluated the potential of preembryonic, embryonic, foetal and even postnatal methods available to prospective parents in their search for healthy and desirable children. The final procedure for discussion is genetic modification that would provide enhancement to potential or already existing beings.

Eugenic genetic modifications can take place in two different manners. The first, somatic cell gene modifications, only affects the somatic (nonreproductive) body cells of an individual at whatever stage of development. The second possibility is called germline genetic modifications in which a genetic modification occurs in the reproductive cells (or their precursors), thereby affecting potential future generations. In some cases, however, somatic gene modifications may also modify the germline as an unwanted secondary effect.

Interestingly some commentators, such as John Harris and others, believe that there are strong ethical grounds to engage in human germline modification suggesting that it can even be morally obligatory, at least on the individual level. They are optimistic in believing that no serious ethical reasons remain in terms of developing the procedures[241] and that 'once the issues of safety and efficacy have been overcome, it would be unethical to proscribe [human germline genetic modification], given the potential benefits that it promises'.[242] Other commentators, though, are less optimistic about the future of germline modifications, believing that a number of ethical problems will persist.[243]

Full-blown eugenics by genetic modification, however, is still many years away from becoming reality. But this does not mean that reflection on the basic ethical issues involved is unnecessary at this stage. The eugenic principles remain, even though the characteristics of this procedure are somewhat different from the previous possibilities. The procedure of genetically modifying gametes, embryos, foetuses and postnatal persons is the only procedure in which a selection step is not directly involved. There is no comparison between possible future entities or entities that already exist. Instead, in most cases there is a comparison between two different states of an existing and same entity. Thus, the ethical issues partially differ from those already studied. For that matter, the procedure is probably better characterized as a 'transformation' rather than a 'selection'.

The process requires first identifying the specific variants of genes whose presence (or absence) correlates with certain desired traits, such as athleticism or aptitude for languages. Once these variants have been identified, the genes in question may then be isolated and removed or inserted into the already existing person, embryo or gamete (egg or sperm cell). This removal or insertion of the genes would be undertaken in such a manner that the genes would eventually contribute to the desired observable traits. In principle (though not yet in practice), any genetic modification of gametes or early embryos would also exist in the offspring of the person created by these gametes or embryos.[244]

Interestingly, many of the ethical issues that arise with genetic modification are comparable to those in which a modification would be sought through a means that is not generally considered as genetic. Certain pharmaceutical drugs, radiation therapy or forms of surgery could also be considered as affecting in an irreversible manner gametes, embryos, foetuses and persons that have been born. Consequently, commentators may already have addressed some of the ethical issues related to genetic modification.

Possible Genetic Developments

The vision of the human future anticipated by some experts of germline engineering comprises a number of advances in the capacity of science to change the human body. These include, for example, the prolongation of life, the elimination of addictions and even the redesign of human beings.[245]

But to be clear, the idea of genetically designing a baby is currently only a feature of science fiction, and many factors make it unlikely that this fiction will soon become fact. Perhaps chief among these factors is the lack of understanding about the complex relationship between a person's genes and his or her environment.[246] Thus, the scientific risks and consequences for the subject and his or her eventual offspring remain very much uncertain and may cause more harm than good with current technology.[247] As already noted, many desirable characteristics such as beauty or intelligence derive from the interaction between nature and nurture that still lacks a fully scientific explanation. Until this interaction is clarified, significant genetic modifications of gametes, embryos foetuses or postnatal persons will remain a matter of conjecture for the distant future.

Different Possible Stages of Genetic Modification

When considering a genetic modification on a person or possible future person, three different stages may be examined.

(1) The suggested modification may be considered for an individual who suffers from a disorder or who is seeking to have a genetic treatment. The Council of Europe has already considered and accepted this possibility. In Article 13 of its Convention on Human Rights and Biomedicine, the council stated that such a procedure may be acceptable if it is for 'preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants'. Interestingly, this statement is not an outright prohibition of modifying gametes which may affect future generations, but only if the modification takes place as a secondary and unwanted side effect to the clinical purposes for the individual. This may be similar to what is already happening in radiation therapy where a person is treated even though his or her germline may be affected and thus have consequences for future descendants.[248] In other words, the principle of seeking to use a powerful treatment (even on children) with the aim of saving life with the knowledge that mutations on their germ cells may take place has been received as being ethical. The proportionality between the risks and the benefit is

seen as acceptable. However, any genetic modification of a whole person (including his or her gametes) would still remain prohibited for purely eugenic reasons.

(2) The genes of a developing embryo may be directly modified. As yet, this is not a real possibility except with pronuclear transfer (see section on Selection through Human Reproductive Cloning). Current international legislation, such as the Council of Europe Convention mentioned above, prohibits this type of modification for eugenic purposes since there are no clear, clinical purposes for the individual.

(3) Deliberate genetic modification could occur at the gametal level prior to the creation of an embryo. As with the direct modification of an embryo, this is currently prohibited by international law, though some work is already being considered in the creation of eggs free from mitochondrial disorders. This is a procedure, which seeks to make healthy eggs, especially in the context of mitochondrial disorders, and is called maternal spindle transfer.[249] With this procedure, the pronucleus (containing all the nuclear DNA) from an unfertilized egg affected by dysfunctional mitochondria is transferred into a donated second egg, with healthy mitochondria (containing mitochondrial DNA), which was emptied of its own nuclear material beforehand.[250] Because the genetic heritage of any future descendants may be modified in this way, the procedure may be considered as a form of eugenics and as a kind of germline intervention through genetic modification. In this regard, it should again be noted that the modification of gametes may occur under international regulations but only as a secondary effect of the main treatment of a person for clinical reasons.[251]

From an ethical, cultural and philosophical perspective, it is interesting to explore how gametes may often be described. For example, they can be understood as being, in a way, representative bodies or even ambassadors of the person taking part in the creation of the embryo. In this manner, both the sperm and egg, respectively, may represent the man and woman in the act of creating an embryo. Thus, if one gamete did not entirely originate from one of the partners but was subsequently modified to a significant extent after it had been produced by one of the partners, it may no longer be understood to be fully representative of the individual. If this happened, it may give rise to further ethical questions that may be similar, though not identical, to those that arise in discussions about the use of donor gametes in reproduction.[252] On the other hand, if a treatment such as gene therapy modified the gametes in conjunction with all the other cells of the person whom they represent, then the gametes may still be considered as real representatives of the whole person. This would then be similar to what occurs in natural reproduction.

Another reason for questioning the legitimacy of eugenic genetic modification stems from the types of characteristics that parents may desire in their children. Many of these traits, such as athleticism or intelligence, may be polygenic and multifactorial in nature. In other words, they may result from a complex relationship between a number of genes as well as the environment of the person. So far, only a relatively small number of traits have been identified as originating in a small number of genes. Thus, given the uncertainty still reigning in human genetics, there is no certainty of outcome. Moreover, inserting the right genes into the appropriate place on a chromosome without upsetting the biological equilibrium of the cell is a difficult operation. If the genes are misplaced other genes may be deactivated. It should also be noted that many genes influence a number of different traits. This means that even if a new gene were introduced to influence a certain trait, it may unexpectedly influence other traits. The overall result would be a modification that may be less than beneficial.[253] The fear of misplacing genes is not purely academic; there have already been cases of gene therapy in which genes have been transferred into certain patients that have produced very serious side effects.[254]

A suggested future alternative to the risks of inserting genes into the wrong place would be first to incorporate the new gene into an artificial chromosome which would then be placed into the cell alongside the already existing chromosomes.[255] At present, though, this procedure is still very much at the research stage and is not being considered for use in the near future. A related approach called chromosomal transfer could also facilitate gene therapy. In this procedure, desirable chromosomes are taken from an already existing donor (either animal or human) and fused with cells from a patient, thereby transferring the beneficial trait.[256] In the distant future these artificial or transplant chromosomes could also be incorporated into gametes or early embryos. Of course, it would be incumbent upon the scientists involved to ensure that the embryos were able to replicate properly during cell division. A failure to ensure this would very much compromise any advantage additional chromosomes might offer. For instance, an extra chromosome 21 in the cells of an individual gives rise to Down syndrome.

On account of the associated risks, gene therapy has only been considered when an ailment is severe and no other treatment is available. As it currently stands, such a therapy for the mere purpose of enhancement may be viewed as reckless and unethical. This is especially the case if any negative consequences may continue into successive generations.[257]

Identity Modification

Another ethical concern with the modification of a person's genome is whether the change would completely alter the person's identity. In other words, would the genetic modification create a new person different from the original person?[258] With PGD a clinician selects between different embryos; a prospectively healthy baby is chosen over another that may not be healthy. In other words, PGD selects between different embryos and prevents the birth of the person with the disorder. If, on the other hand, a significant genetic modification of an embryo with a disorder took place giving rise to a healthy baby, it may be possible to ask whether a new embryo was created (in which case the original one no longer exists) or whether the original embryo continues to exist and is simply modified.[259] In the case of genetic modification, the answer may not be straightforward and may depend on the amount but also the function of the genes being acted upon.[260,261] If the change is as limited as the insertion or mutation of one or two genes which do not affect the identity of a person, the procedure, no doubt, would be equal to any other therapy in human medicine. The intervention would be seen as a repair exercise similar to radiation treatment that also creates genetic mutations in a person. However, if a future procedure could replace five or six chromosomes in a one-cell embryo, more questions relating to the retention of the original identity of the embryo could be asked. Genetic modification could actually create another person.

The advent of such technology would, understandably, raise various ethical questions. As the ethicist Nicholas Agar recognizes, genetic changes 'will either be sufficiently minor or late-acting for us to say that the resulting individual is the same as the one who would have existed had his parents not used enhancement technologies.... Other ways of modifying a genome will be substantial and early-acting enough to replace one individual for another'.[262]

In summary, the safety and effectiveness of any kind of genetic modification procedure are fraught with challenges. The extraordinary difficulties, both practical and ethical, related to these modifications drastically reduce the likelihood that any treatment or enhancement using such a procedure on human individuals would be considered for large scale applications in the foreseeable future.[263]

Legislation

United Nations Science and Cultural Organization (UNESCO)

UNESCO's Universal Declaration on the Human Genome and Human Rights, which was endorsed by the United Nations General Assembly on 9 December 1998, indicates in Article 24 that germline interventions could be considered as a practice that would be 'contrary to human dignity'.

Council of Europe (Forty-seven Countries)

In Article 13, the Council of Europe Convention on Human Rights and Biomedicine[264] indicates regarding 'interventions on the human genome' that, '[a]n intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants'.

In this regard, the Explanatory Report for Article 13 mentions that:

> 91. Interventions seeking to introduce any modification in the genome of any descendants are prohibited. Consequently, in particular genetic modifications of spermatozoa or ova for fertilisation are not allowed. Medical research aiming to in-

> troduce genetic modifications in spermatozoa or ova which are not for procreation is only permissible if carried out in vitro with the approval of the appropriate ethical or regulatory body.
>
> 92. On the other hand the article does not rule out interventions for a somatic purpose which might have unwanted side-effects on the germ cell line. Such may be the case, for example, for certain treatments of cancer by radiotherapy or chemotherapy, which may affect the reproductive system of the person undergoing the treatment.

European Union (Twenty-eight Countries)

The European Union Directive on clinical trials (2001/20/EC) Article 9(6) states that: 'No gene therapy trials may be carried out which result in modifications to the subject's germ line genetic identity.'

United Kingdom Legislation

As a result of the 1992 report of the Committee on the Ethics of Gene Therapy (Clothier Committee), a number of recommendations on gene therapy (genetic engineering in humans) were proposed which were limited to life threatening diseases or disorders. These regulations are now taken into account by the United Kingdom Gene Therapy Advisory Committee (GTAC), or any similar future body with the same remit, which has a UK-wide responsibility for the ethical oversight of proposals to conduct clinical trials involving gene therapies with respect to their scientific merits as well as the potential benefits and risks. The committee also provides advice to United Kingdom health ministers on developments in gene therapy. Regarding the modification of gametes or embryos, the Human Fertilisation and Embryology Act 2008, Section 3(5) indicates that any gametes or embryos used for human reproduction should not have been modified. The only exception is if the egg or embryo has 'had applied to it in prescribed circumstances a prescribed process designed to prevent the transmission of serious mitochondrial disease'.

Notes

1. President's Council, *Beyond Therapy,* 34.
2. The United Kingdom has not signed or ratified this convention.
3. Black, *War Against the Weak,* 188.
4. J. Glad. 2008. *Future Human Evolution: Eugenics in the Twenty-First Century,* Schuylkill Haven, PA: Hermitage Publisher, 50.
5. E. Porqueres i Gené and J. Wilgaux. 2009. 'Incest, Embodiment, Genes and Kinship', in J. Edwards and C. Salazar (eds), *European Kinship in the Age of Biotechnology,* New York: Berghahn Books, 2009, 116.
6. R. Bixler. 1982. 'Comment on the Incidence and Purpose of Royal Sibling Incest', *American Ethnologist* 9, 580–82.
7. E. Porqueres i Gené and J. Wilgaux, *Incest, Embodiment, Genes and Kinship,* 117.

8. E. Zerubavel. 2012. *Ancestors & Relatives: Genealogy, Identity & Community,* Oxford: Oxford University Press, 60.
9. E. Porqueres i Gené and J. Wilgaux, *Incest, Embodiment, Genes and Kinship,* 118–19.
10. E. Porqueres i Gené and J. Wilgaux, *Incest, Embodiment, Genes and Kinship,* 119.
11. For example, Leviticus 18:6–18, 20:11–21 and Deuteronomy 22:30, 27:2–23.
12. St. Augustine and many other Church Fathers considered incest between siblings as only being acceptable if no alternatives existed in the newly created world. But as soon as this was no longer the case, it was expected that the net of social affection became broader through individuals marrying outside of their family. Social networking was also enhanced in that incest became shameful. St. Augustine, *City of God,* 15.16.1–2.
13. A debate has arisen on the origins of the taboo on incestuous relationships. Some commentators believe that it is not based on concerns of biological closeness. See C. Lévi-Strauss. 1969. *The Elementary Structures of Kinship revised edition,* translated from the French by James Harle Bell and John Richard von Sturmer. Boston: Beacon Press. 13–14. Others, on the other hand, have supported a biological basis for the taboo. See G. Kushnick and Fessler, D. M. T. 2011. Karo Batak Cousin Marriage, Cosocialization, and the Westermarck Hypothesis. *Current Anthropology* 52 (3), 443 and also D. M. T, Fessler. 2007. Neglected Natural Experiments Germane to the Westermarck Hypothesis. *Human Nature* 18 (4), 355–64.
14. P. Parkes. 2005. 'Milk Kinship in Islam. Substance, Structure, History', *Social Anthropology* 13 (3), 307–29.
15. The Code of Canon Law stipulates:
    1091 §1. In the direct line of consanguinity marriage is invalid between all ancestors and descendants, both legitimate and natural.
    §2. In the collateral line marriage is invalid up to and including the fourth degree.
    §3. The impediment of consanguinity is not multiplied.
    §4. A marriage is never permitted if doubt exists whether the partners are related by consanguinity in any degree of the direct line or in the second degree of the collateral line.
    Can. 1092 Affinity in the direct line in any degree invalidates a marriage.
    Can. 1094 Those who are related in the direct line or in the second degree of the collateral line by a legal relationship arising from adoption cannot contract marriage together validly.
    Code of Canon Law, Libreria Editrice Vaticana, 1983, Retrieved 16 March 2011 from http://www.vatican.va/archive/ENG1104/_INDEX.HTM.
16. H. Höhne. 2000. *The Order of the Death's Head: The Story of Hitler's SS,* New York: Penguin Books, 148.
17. J.M. Steiner. 1975. *Power Politics and Social Change in National Socialist Germany: A Process of Escalation into Mass Destruction,* The Hague: Mouton, 78–79. Note that the term 'Aryan' as used in Nazi laws and regulations generally denoted a person of non-Jewish, European origin.
18. M. Mouton. 2007. *From Nurturing the Nation to Purifying the Volk: Weimar and Nazi Family Policy, 1918–1945,* Cambridge: Cambridge University Press, 88.
19. P. Ioannou. 1999. 'Thalassemia Prevention in Cyprus: Past, Present and Future', in R.F. Chadwick et al. (eds), *The Ethics of Genetic Screening,* Dordrecht: Kluwer Academic Publishers, 58.
20. United Kingdom Human Genetics Commission. 2011. *Increasing Options, Informing Choice: A Report on Preconception Genetic Testing and Screening,* London: Human Genetics Commission, 16.
21. Ioannou, 'Thalassemia Prevention', 61–62. Perhaps one factor limiting the success of the program was the significant number of arranged marriages in rural Cyprus that paid little heed to medical advice.
22. M. Henderson, 2010. 'How a Community Stamped Out Tay–Sachs Disease with Genetic Screening', *The Times,* 8 February. Retrieved 20 September 2010 from http://www.timesonline.co.uk/tol/news/science/genetics/article7018441.ece.

23. The PHG Foundation. 2009. *Tay–Sachs Disease Carrier Screening in the Ashkenazi Jewish Population,* Cambridge: The PHG Foundation, 1.
24. J. Ekstein and H. Katzenstein. 2001. 'The Dor Yeshorim Story: Community-Based Carrier Screening for Tay–Sachs Disease', in R.J. Desnick and M.K. Kaback, *Tay–Sachs Disease,* London: Academic Press, 297–310.
25. Rosen, 'Eugenics – Sacred and Profane', 80.
26. A. Dockser Marcus. 2012. 'A Community's Twist on Genetic Tests', *The Wall Street Journal,* 9 July 2012.
27. The other disorders being tested by Dor Yeshorim include (1) Familial dysautonomia, (2) Cystic fibrosis, (3) Canavan disease lycogen storage disease (type 1), (4) Fanconi anemia (type C), (5) Bloom syndrome, (6) Niemann-Pick disease, (7) Mucolipidosis (type IV) and (8) Gaucher's disease (only by request). Rosen, 'Eugenics – Sacred and Profane', 84.
28. Another option is for the couple to undergo preimplantation genetic diagnosis whereby only unaffected embryos are implanted into the mother's womb to guarantee, if the pregnancy is successful, the birth of a healthy child.
29. The PHG Foundation. 2009. *Tay–Sachs Disease carrier screening in the Ashkenazi Jewish Population,* Cambridge: The PHG Foundation, 7.
30. Admittedly, benefitting a nonentity (a potential child that will not exist under any condition) presents tricky logical problems, but the reader can surely recognize the validity of highlighting this interest group (potential children). On this topic see below regarding 'wrongful birth'.
31. D.J. Galton. 2002. *Eugenics: The Future of the Human Life in the 21st Century,* London: Abacus, 223.
32. On this see especially A.E. Raz and Y. Vizner. 2008. 'Carrier Matching and Collective Socialization in Community Genetics: Dor Yeshorim and the Reinforcement of Stigma', *Social Science and Medicine* 67, 1368.
33. M. Levin. 1999. 'Screening Jews and Genes: A Consideration of the Ethics of Genetic Screening within the Jewish Community: Challenges and Responses', *Genetic Testing* 3, 207–13.
34. Rosen, 'Eugenics—Sacred and Profane', 82
35. Rosen, 'Eugenics—Sacred and Profane', 82
36. L.V. Thompson. 1971. '*Lebensborn* and the Eugenics Policy of the *Reichsführer-SS*', *Central European History* 4, 54–77.
37. United Kingdom Human Genetics Commission, *Increasing Options, Informing Choice,* 6.
38. United Kingdom Human Genetics Commission, *Increasing Options, Informing Choice,* 6.
39. United Kingdom Human Genetics Commission, *Increasing Options, Informing Choice,* 11.
40. United Kingdom Human Genetics Commission, *Increasing Options, Informing Choice,* 5.
41. It should be noted that a couple who decides not to reproduce their own genetic material may still become parents by adopting or by using donated gametes.
42. P. Ramsey. 1970. *Fabricated Man: The Ethics of Genetic Control,* New Haven: Yale University Press, 35. L.M. Purdy suggests that people with Huntington's have a similar duty not to have children affected by the disease. 1996. *Reproducing Persons: Issues in Feminist Bioethics,* Ithaca, NY: Cornell University Press, 39–40.
43. Though not related to eugenics, as such, some organizations such as ProjectPrevention (www.projectprevention.org) in the United States are already paying some women, who cannot look after their children because of drug or alcohol addictions, to have long term or permanent birth control.
44. R.M. Green. 2007. *Babies by Design: The Ethics of Genetic Choice,* New Haven: Yale University Press, 213.
45. Pope Pius XI, *Casti connubii,* §§ 53–56, 59. Cf. Pope Paul VI. 1968. *Humane Vitae,* §§ 11,13–16, 24, In these paragraphs it is proposed that every sexual act should have procreative potential which permits birth control by deployment of natural infertility or periods of infertility.
46. Green, *Babies by Design,* 211.

47. M. Spriggs and J. Savulescu. 2002. 'The Perruche Judgment and the "Right Not to Be Born"', *Journal of Medical Ethics* 28, 63–64.
48. L. Fatimathas. 2011. '"Wrongful Life" – the Children who Sue for Being Born', *BioNews,* 631, 31 October 2011, Retrieved 12 July 2012 from http://www.bionews.org.uk/page_110794.asp.
49. D. Heyd. 2009. 'The Intractability of the Nonidentity Problem', in M.A. Roberts and D.T. Wasserman (eds), *Harming Future Persons: Ethics, Genetics and the Nonidentity Problem,* New York: Springer, 2009, 15.
50. Parkinson v St James and Seacroft University NHS Hospital Trust (2001) 3 *All England Reports 97.*
51. United Kingdom Human Genetics Commission. 2006. *Making Babies: Reproductive Decisions and Genetic Technologies,* London: Human Genetics Commission. 22.
52. *McKay v. Essex Health Authority* (1982) 2 *All England Reports* 771.
53. Here the contrast is with nonexistent children such as feature in the nonidentity problem noted above.
54. R.D. Moore. 2009. *Adopted for Life,* Wheaton, IL: Crossway Books, 2009, 148.
55. R. Nixon. 2008. 'De-Emphasis on Race in Adoption Is Criticized', *The New York Times,* 27 May. Retrieved 8 August 2011 from http://www.nytimes.com/2008/05/27/us/27adopt.html.
56. 2011. 'Barnardo's Ex-head Says Race Issues Threaten Adoptions', *BBC News,* 22 January. Retrieved 29 March 2011 from http://www.bbc.co.uk/news/education-12258379.
57. J.S. Modell. 2002. *A Sealed and Secret Kinship: the Culture of Policies and Practices in American Adoption.* Oxford: Berghahn Books, 6–7.
58. A. Smajdor. 2009. 'Genetic Testing of Children Prior to Adoption', *BioNews* 52. Retrieved 8 August 2011 from http://www.bionews.org.uk/page_47035.asp.
59. England and Wales High Court (Family Division): *Y and Z (Children), Re [2013] EWHC 953 (Fam) (25 April 2013).*
60. W. Lesch. 1999. 'What Claims Can Be Based on the Desire for a Healthy Child? Towards an Ethics of "Informed Desires"', in E. Hildt and S. Graumann (eds), *Genetics in Human Reproduction,* Aldershot, UK: Ashgate, 223–33.
61. M. Melhuus and S. Howell. 2009. 'Adoption and Assisted Conception: One Universe of Unnatural Procreation. An Examination of Norwegian Legislation', in J. Edwards and C. Salazar (eds), *European Kinship in the Age of Biotechnology,* New York: Berghahn Books, 2009, 151–52.
62. M. Melhuus and S. Howell, *Adoption and Assisted Conception: One Universe of Unnatural Procreation. An Examination of Norwegian Legislation,* 151.
63. Positive discrimination by the adoption agency, however, may be seen as appropriate, as parents affected by a disorder would be 'specialists' in this disorder and may be able to better cope than someone who is inexperienced.
64. To be clear, the focus in this section is scientific sex selection, not alternative methods of questionable efficacy that are part of a couple's private life. For a selection of these methods see HFEA. 2002. *Sex Selection: Choice and Responsibility in Human Reproduction,* London: Human Fertilization and Embryology Authority, 10n4.
65. S. Wilkinson. 2008. 'Sexism, Sex Selection and "Family Balancing"' *Medical Law Review* 16, 369–70.
66. President's Council, *Beyond Therapy,* 57.
67. There are certain rare chromosomal abnormalities, which vary in severity, when people have more or fewer than two sex chromosomes.
68. HFEA, *Sex Selection: Choice and Responsibility,* 10.
69. HFEA, *Sex Selection: Choice and Responsibility,* 11.
70. HFEA, *Sex Selection: Choice and Responsibility,* 11.
71. Cf. A.C. Kinsella and S.D. Minteer. 2008. 'Microchip Devices for Bioanalysis', in J.M. Walker and R. Rapley (eds), *Molecular Biomethods Handbook,* Totowa, NJ: Humana Press, 855.

72. HFEA, *Sex Selection: Choice and Responsibility,* 11.
73. MicroSort® current results as of 1 January 2008, http://www.microsort.net/results.php. Cf. J.D. Schulman and D.S. Karabinus. 2005. 'Scientific Aspects of Preconception Gender Selection', *Reproductive BioMedicine Online,* 10 (S1), 111–15.
74. T.K. Suh, J.L. Schenk and G.E. Seidel, Jr. 2005. 'High Pressure Flow Cytometric Sorting Damages Sperm', *Theriogenology* 64, 1047.
75. HFEA, *Sex Selection: Choice and Responsibility* 12–13. For further discussion see, e.g., J.A. Robertson, 2001. 'Preconception Gender Selection', *American Journal of Bioethics* 1(1), 2–9.
76. H. D. Guthrie, et al., 2002. 'Flow Cytometric Sperm Sorting: Effects of Varying Laser Power on Embryo Development in Swine', *Molecular Reproduction and Development* 61, 87–92.
77. It should go without saying that the success of PGD, as with any procedure for genetic screening, hinges, in part, on the skill of the clinician.
78. HFEA, *Sex Selection: Choice and Responsibility,* 16.
79. The HFEA notes that United Kingdom law requires PGD clinicians to perform embryo biopsy without harming the embryo, HFEA, *Sex Selection: Choice and Responsibility,* 14, n. 6.
80. For a concise point-counterpoint introduction to ethical issues associated with postimplantation sex selection, see F. Shenfield. 1994. 'Sex Selection: A Matter for "Fancy" or for Ethical Debate', *Human Reproduction* 9, 69; and M. M. Seibel, et al. 1994. 'Gender Distribution, Not Sex Selection', *Human Reproduction* 9, 69–70.
81. In the United Kingdom as of the Infanticide Act 1922, repealed and reenacted in the Infanticide Act 1938. Though illegal in practice, infanticide finds theoretical support on philosophical and logical grounds from the likes of M. Tooley. 1972. 'Abortion and Infanticide', *Philosophy and Public Affairs* 2, 37–65. Worryingly, Tooley's argument allows that not only infants but also some *adult* humans forfeit the right to life that has been universally recognized since the 1948 UN Universal Declaration of Human Rights.
82. HFEA, *Sex Selection: Choice and Responsibility,* 6.
83. HFEA, *Sex Selection: Choice and Responsibility,* 7.
84. HFEA, *Sex Selection: Choice and Responsibility,* 29.
85. HFEA. 2002. *Sex Selection: Options for Regulation,* London: Human Fertilization and Embryology Authority, 28.
86. See HFEA, *Sex Selection: Choice and Responsibility,* 24–29.
87. The HFEA also notes that some people accept the argument from financial equality: since sex selection would not be universally affordable, it should not be permitted at all. As seen in a later chapter of this book, this is similar to an argument sometimes encountered against all practices of the new eugenics.
88. See recently the research from S.M. George, who argues that women continue to 'disappear' from India on account of what she calls 'the genocidal practice of sex selection' that has replaced the previous practice of induced infant mortality. 2006. 'Millions of Missing Girls: From Fetal Sexing to High Technology Sex Selection in India', *Prenatal Diagnosis* 26, 604–09.
89. The first article of the Universal Declaration of Human Rights states unequivocally, 'All human beings are born free and equal in dignity and rights.'
90. Health Council of the Netherlands. 1995. *Sex Selection for Non-medical Reasons,* The Hague: Health Council of the Netherlands, 37.
91. The pioneering study on this subject was published by Nobel laureate A. Sen. 1990. 'More Than 100 Million Women Are Missing', *The New York Review of Books* 37(20). Sen also published his findings in 1992. 'Missing Women', *British Medical Journal* 304, 587–88. See also S. M. George, 'Millions of Missing Girls', noted above.
92. President's Council, *Beyond Therapy,* 58–59.
93. 2007. 'Chinese Facing Shortage of Wives', *BBC News,* 12 January. Retrieved 15 January 2011 from http://news.bbc.co.uk/1/hi/6254763.stm.

94. L. Adams. 2010. 'Top IVF Doctor Defends Offering Help for Parents to Pick Babies' Sex', *Daily Record,* 29 July. Retrieved 11 August 2011 from http://tinyurl.com/DailyRecord-sex-selection.
95. HFEA, *Sex Selection: Options for Regulation,* 28.
96. The United Kingdom has not signed or ratified this convention.
97. HFEA, *Sex Selection: Choice and Responsibility,* 7.
98. M. Lappé. 1991. 'Ethical Issues in Manipulating the Human Germ Line', *Journal of Medicine and Philosophy* 16, 621–39.
99. Richards, 'Artificial Insemination and Eugenics', 211–21.
100. The London Sperm Bank also lists height, hobbies/interests, ethnic origin, occupation, race and religion. Retrieved 15 January 2011 from http://donor.londonspermbank.com/index.php/.
101. For example, the London Sperm Bank instructs its clients to choose 'the donor with the most appealing characteristics'. Retrieved 15 January 2011 from http://www.londonspermbank.com/looking_for_donated_sperm.html.
102. J. McMillan. 2007. 'The Return of the Inseminator: Eutelegenesis in Past and Contemporary Reproductive Ethics', *Studies in History and Philosophy of Biological and Biomedical Sciences* 38(2), 393–410.
103. Richards, Artificial Insemination and Eugenics, 211–21.
104. One egg donation program lists donors' age, ethnic origin, hair and eye colour, height, weight and education. Retrieved 8 August 2011 from http://www.advancedfertility.com/egg-donors-list.htm.
105. The possibility of even fifty eggs is reported in G. Sher, V.M. Davis and J. Stoess. 2005. *In Vitro Fertilization: the A.R.T. of Making Babies,* 3rd ed., New York: Facts on File, 63.
106. M. Henderson. 2008. 'Sperm and Eggs from Stem Cells "in 15 Years"', *The Times,* 15 April. Retrieved 29 September 2010 from http://www.timesonline.co.uk/tol/news/science/article3746760.ece. Cf. 2009. 'Stem Cells Changed Into Precursors For Sperm, Eggs', *ScienceDaily,* 29 October. Retrieved 29 September 2010 from http://www.sciencedaily.com/releases/2009/10/091028142225.htm.
107. K. Hayashi et al. 2012. 'Offspring from Oocytes Derived from in Vitro Primordial Germ Cell–Like Cells in Mice', *Science* DOI: 10.1126/science.1226889, 4 October 2012.
108. Retrieved 18 October 2010 from http://www.eggdonation.com/becoming-an-egg-donor/BecominganEggDonor.php.
109. M. Enge. 2000. 'Ad Seeks Donor Eggs for $100,000, Possible New High', *Chicago Tribune,* 10 February. Retrieved 18 October 2010 from http://articles.chicagotribune.com/2000-02-10/news/0002100320_1_egg-donor-program-infertile-ads.
110. Retrieved 18 October 2010 from http://www.eggdonation.com/becoming-an-egg-donor/r.php.
111. E.N. Glenn. 2009. *Shades of Difference: Why Skin Color Matters,* Stanford, CA: Stanford University Press, 136.
112. C. Murphy. 2010. 'Baby Tale Not Black and White', *BBC News,* 20 July. Retrieved 31 May 2011 from http://www.bbc.co.uk/news/health-10697682.
113. M. Spriggs. 2002. 'Lesbian Couple Create a Child Who is Deaf Like Them', *Journal of Medical Ethics* 28, 283.
114. D. Lawson. 2008. 'Of Course a Deaf Couple Want a Deaf Child', *The Independent,* 11 March. Retrieved 30 September 2010 from http://tinyurl.com/deaf-couple-and-child.
115. United Kingdom Human Genetics Commission. 2004. *Choosing the Future: Genetics and Reproductive Decision Making,* London: UK Department of Health, 24–25.
116. For a balanced approach from the perspective of Duchesneau and McCullough, see, H. Dirksen and L. Bauman. 2005. 'Designing Deaf Babies and the Question of Disability', *Journal of Deaf Studies and Deaf Education* 10(3), 311–15.

117. The Church of Scotland Board of Social Responsibility. 1996. *Pre-Conceived Ideas: A Christian Perspective of IVF and Embryology,* Edinburgh: Saint Andrew Press, 7.
118. Human Genetics Commission, *Choosing the Future,* 24–25.
119. H.J. Muller. 1959. 'The Guidance of Human Evolution', *Perspectives in Biology and Medicine* 3(1), 1–43.
120. Ramsey, *Fabricated Man, 49.*
121. D.M. Tober. 2002. 'Semen as Gift, Semen as Goods: Reproductive Workers and the Market in Altruism', in N. Scheper-Hughes and L.J.D. Wacquant (eds), *Commodifying Bodies,* London: Sage, 149.
122. Green, *Babies by Design,* 165. For the full story of the Repository see, D. Plotz. 2005. *The Genius Factory: The Curious Story of the Nobel Prize Sperm Bank,* New York: Random House.
123. A European study of donor insemination families in the United Kingdom, Italy, the Netherlands and Spain found that only 12 per cent of the mothers had planned to tell the child about his or her conception procedure, while 75 per cent had decided not to do so. By the time the children reached eleven to twelve years of age, less than 9 per cent of parents had informed their children about their conception procedure, S. Golombok et al. 2002. 'The European Study of Assisted Reproduction Families: The Transition to Adolescence', *Human Reproduction* 17(3) 830–40.
124. M. Braid. 2002. 'Your Daddy was a Donor', *The Observer,* 20 January. Retrieved 9 August 2011 from http://observer.guardian.co.uk/review/story/0%2C6903%2C636020%2C00.html.
125. Prenatal screening is a public health program that provides a pregnant woman with a test to determine whether her foetus faces an increased risk of having a genetic disorder. If so, the woman is then offered a prenatal diagnostic test to investigate the reason for the test results and any repercussions for the health of the future baby.
126. Prenatal diagnosis is a procedure undertaken on woman to diagnose a particular genetic condition that her foetus may have.
127. Cf. P.S. Bisen, M. Debnath and G.B.K.S. Prasad. 2010. *Molecular Diagnostics: Promises and Possibilities,* Dordrecht: Springer, 94–95.
128. The President's Council on Bioethics. 2008. *The Changing Moral Focus of Newborn Screening,* Washington DC: President's Council, 80–81.
129. President's Council, *Beyond Therapy,* 35.
130. Representative of this position, see Pope John Paul II. 1995. *Evangelium Vitae.*
131. The literature on this topic is massive. A valuable entry into the debate is D. Evans (ed.). 1996. *Conceiving the Embryo: Ethics, Law, and Practice in Human Embryology,* The Hague: Kluwer Law International.
132. President's Council, *Beyond Therapy,* 36.
133. D.P. Dixon. 2008. 'Informed Consent or Institutionalized Eugenics? How the Medical Profession Encourages Abortion of Fetuses with Down Syndrome', *Issues in Law and Medicine* 24(1), 3–59.
134. Cf. President's Council, *Beyond Therapy,* 36–37.
135. J. Savulescu. 2001. 'Is current practice around late termination of pregnancy eugenic and discriminatory? Maternal interests and abortion', *Journal of Medical Ethics* 27, 167.
136. Ibid.
137. Notably, under these circumstances, the law allows termination at any stage of gestation.
138. Human Genetics Commission, *Making Babies,* 36–37.
139. Ibid.
140. Article 2 of the ECHR begins, 'Everyone's right to life shall be protected by law.'
141. For nuanced discussion opposing *Vo v. France* see A. Plomer. 2005. 'A Foetal Right to Life? The Case of Vo v France', *Human Rights Law Review* 5(2), 311–38.

142. Human Genetics Commission. 2000. *Prenatal Genetic Testing: Report for Consultation,* London: Health Departments of the United Kingdom, 29.
143. *Abortion Act 1967,* §1.2.
144. This is true in both the United Kingdom and in Europe.
145. Royal College of Obstetricians and Gynaecologists. 2010. *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales: Report of a Working Party,* London: RCOG Press, 8–10.
146. United Kingdom Parliament. 2013. *Parliamentary Inquiry into Abortion on the Grounds of Disability,* United Kingdom Parliament, 16.
147. Chung, *Designer Myths,* 9.
148. For a comprehensive review of the ethical issues relating to Preimplantation Embryonic Selection, see: German Ethics Council, Preimplantation. 2012. *Genetic Diagnosis: Opinion,* Berlin: The German Ethics Council.
149. For example, see A. Lashwood and T. El-Toukhy. 2009. 'Preimplantation Genetic Diagnosis: Current Practice and Future Possibilities', in S. Kehoe, L. Chitty and T. Homfray (eds), *Reproductive Genetics,* London: RCOG Press, 35–58.
150. J. Gunning. 2008. 'The Broadening Impact of Preimplantation Genetic Diagnosis: A Slide Down the Slippery Slope or Meeting Market Demand?', *Human Reproduction and Genetic Ethics* 14(1), 34–35.
151. As hinted above, aneuploidy involves missing or extra copies of chromosomes. An example of aneuploidy is Down syndrome, which is caused by a partial or whole twenty-first chromosome.
152. For a list and discussion of these reasons see House of Commons, *Human Reproductive Technologies,* 56–57. Also, HFEA. 2005. *Choices & Boundaries: Should People Be Able to Select Embryos Free from an Inherited Susceptibility to Cancer,* London: Human Fertilization and Embryology Authority 8.
153. To identify or confirm abnormal chromosomal arrangements clinicians use a technique called fluorescence in situ hybridisation (FISH). For the details, consult Y. Verlinsky and A. Kuliev. 2005. *Practical Preimplantation Genetic Diagnosis,* Dordrecht: Springer, 21–25.
154. President's Council, *Beyond Therapy,* 43–44.
155. President's Council, *Beyond Therapy,* 40.
156. J. Harper and D. Wells. 2001. 'Future Developments in PGD', in J.C. Harper, J.D.A. Delhanty, A.H. Handyside (eds), *Preimplantation Genetic Diagnosis,* Chichester: Wiley, 259.
157. Ibid.
158. J. Marchant. 2006. 'Mature Sperm and Eggs Grown from Same Stem Cells', *Nature News,* 23 June. Retrieved 11 February 2011 from http://www.nature.com/news/2006/060623/full/news060619-13.html.
159. In theory PES obviates the need or possibility of termination. However, PES results are currently routinely controlled by a later PND that could lead to a termination if the original PES was insufficient.
160. As, for example, Nuffield Council, *Genetics and Human Behaviour,* 152.
161. For more on the legal foundations of parental duties in the United Kingdom, see K. Boele-Woelki, B. Braat and I. Curry-Sumner (eds). 2005. *European Family Law in Action: Volume III – Parental Responsibilities,* Oxford: Intersentia.
162. As many have recognized, e.g., Human Genetics Commission, *Choosing the Future,* 18–19.
163. Chung, *Designer Myths,* 17. More specifically, roughly 4 per cent of all newborns are affected by at least one disorder, but only one third of these can be detected by PGD.
164. Cf. Lashwood and El-Toukhy, 'Preimplantation Genetic Diagnosis', 50.
165. D. Solter et al. 2003. *Embryo Research in Pluralistic Europe,* Dordrecht: Springer, 145–46.
166. R. Wolfrum and A.C. Zeller. 1999. 'Legal Aspects of Research with Human Pluripotent Stem Cells in Germany', *Biomedical Ethics* 4(3), 102–07.
167. Wolfrum and Zeller, 'Legal Aspects of Research', 102.

168. Wolfrum and Zeller, 'Legal Aspects of Research', 102–07.
169. By the eight-cell stage, only a very few number of blastomeres are totipotent. In experiments in various mammals, only one or two blastomeres remain totipotent at this stage. See: Deutsche Akademie der Naturforscher Leopoldina – Nationale Akademie der Wissenschaften . 2011. *Ad-hoc Statement Preimplantation Genetic Diagnosis (PGD), The Effects of Limited Approval in Germany,* Deutsche Akademie der Naturforscher Leopoldina – Nationale Akademie der Wissenschaften, January 2011, 8. Retrieved 12 July 2012 from http://www.leopoldina.org/uploads/tx_leopublication/stellungnahme_PID_2011_final_a4ansicht_EN_02.pdf.
170. Embryo Protection Act (12.13.1990), translated and quoted in Wolfrum and Zeller, 'Legal Aspects of Research', 103.
171. E. Hildt. 1996. 'Preimplantation Diagnosis in Germany', *Biomedical Ethics* 1(2), 28–29.
172. The position on PES in Germany has developed since 2010, when Germany's Federal Supreme Court decided to acquit a gynaecologist of an illegal abortion after he chose to carry out PGS on several human embryos and discard those with a genetic disorder. A. Tuffs. 2010. 'Court Allows Preimplantation Genetic Diagnosis in Germany', *British Medical Journal* 341(3747), 120–21.
173. In July 2011, the German parliament also voted to allow PGD in certain circumstances. These are if the parents are at high risk of passing on a genetic disorder to their children or if there is a high risk of miscarriage or stillbirth because of a genetic dysfunction. A. Tuffs. 2011. 'Germany Relaxes Law on Preimplantation Genetic Diagnosis', *British Medical Journal* 343, 119.
174. The German Ethics Council. 2012. *Preimplantation Genetic Diagnosis: Opinion,* Berlin: The German Ethics Council, 14.
175. This may be particularly necessary in the United Kingdom, where, since the early 1990s, both scientists and the general public have nearly unanimously assumed the nonprotected status of totipotent cells.
176. Editorial. 2001. 'Preimplantation Donor Selection', *The Lancet* 358(9289), 1195.
177. House of Commons, *Human Reproductive Technologies,* 60. Also, J.L. Simpson. 2010. 'Children Born after Preimplantation Genetic Diagnosis Show No Increase in Congenital Abnormalities', *Human Reproduction* 25(1), 6–8.
178. President's Council on Bioethics. 2004. *Reproduction & Responsibility: The Regulation of New Biotechnologies,* Washington DC: President's Council, 94–95.
179. A. Taylor. 2008. *A Guide to Pre-implantation Genetic Diagnosis,* London: Galton Institute, 35.
180. Chung, *Designer Myths,* 19.
181. President's Council, *Reproduction & Responsibility,* 96–97.
182. D. King 1999. 'Preimplantation Genetic Diagnosis and the "New" Eugenics', *Journal of Medical Ethics* 25, 176.
183. Gunning, 'The Broadening Impact', 29–37.
184. C. Lavelle. 2011. 'Parents' Joy at Success of Gene Testing', *The Herald,* 17 January. Retrieved 17 January 2011 from http://tinyurl.com/herald-cf.
185. The best-selling novel *My Sister's Keeper* by Jodi Picoult (2004) explores some of these questions on a popular level, as does the film of the same title (2009).
186. At present, it is generally a sibling that is considered for the treatment, but it could also be a close relative such as a cousin. In this regard, a child could even, theoretically, be conceived to save his or her parent (saviour offspring).
187. There are a number of genetic conditions that result in blood disorders. Techniques for treating these include transplants of haemopoietic stem cells (precursors of blood cells) from a tissue-matched donor. Sources of such stem cells are the bone marrow and the umbilical cord blood.
188. House of Commons, *Human Reproductive Technologies,* 58.
189. In some cases, however, umbilical cord blood may be able to treat a wide range of diseases, including some that are not genetically based. This raises the possibility of using PGD purely

for the purposes of establishing immunological compatibility and, consequently, PGD would offer no benefits to the embryo.

190. For the whole story, see B. Whitehouse. 2010. *The Match: 'Savior Siblings' and One Family's Battle to Heal Their Daughter,* Boston: Beacon Press.
191. Human Genetics Commission, *Choosing the Future,* 13.
192. See M. Häyry, 2010. *Rationality and the Genetic Challenge: Making People Better,* Cambridge: Cambridge University Press, 99–123.
193. There are, of course, other arguments and ample literature on this topic. For an introduction see Wilkinson, *Choosing Tomorrow's Children,* 107–29.
194. R. Smith. 2009. 'Britain's Only Saviour Sibling Twins', *The Telegraph,* 9 August. Retrieved 20 April 2010 from http://www.telegraph.co.uk/health/children_shealth/5998991/Britains-only-saviour-sibling-twins.html.
195. For concise arguments against consideration of motives, see J. Robertson. 2004. 'Embryo Screening for Tissue Matching', *Fertility and Sterility* 82, 290–91.
196. In light of this difficulty, it is ironic that traditional Kantian ethics has privileged the role of motives for determining moral actions, N. Warburton. 2004. *Philosophy: The Basics,* 4th ed., Oxford: Routledge, 42–45.
197. President's Council, *Reproduction & Responsibility,* 96.
198. Comité consultatif national d'éthique pour les sciences de la vie et de la santé (CCNE). 2002, *Reflections Concerning an Extension of Preimplantation Genetic Diagnosis, Opinion No. 72,* Paris: CCNE.
199. The Hashmi case was the first to receive permission from the HFEA for using PGD for tissue-matching. For an excellent survey of the case see B.A. Hocking and E. Ryrstedt. 2009. 'The Perils of Terminology and the "Saviour Sibling" Dilemma', in B.A. Hocking (ed.), *The Nexus of Law and Biology: New Ethical Challenges,* Surrey, England: Ashgate, 1–8.
200. R. Rowland. 2001. 'Genetic Testing of Embryos Raises Ethical Issues', *CNN.com,* 27 June. Retrieved 9 August 2011 from http://archives.cnn.com/2001/HEALTH/06/27/embryo.testing/.
201. J. Aznar. 2010. *Designer Babies: A Question of Ethics, Medicina y Ética* 21(4), 347–68.
202. D. Solter et al., Embryo Research in Pluralistic Europe, 270–395.
203. For a full digest of relevant United Kingdom legislation see HFEA, *Choices & Boundaries,* 9.
204. See, HFEA. 1999. *Consultation Document on Preimplantation Genetic Diagnosis,* London: Human Fertilisation and Embryology Authority, 10.
205. 2006. 'Watchdog Backs More Embryo Checks', *BBC News,* 10 May. Retrieved 1 February 2011 from http://news.bbc.co.uk/1/hi/health/4756697.stm.
206. J. Lederberg. 1966. 'Experimental Genetics and Human Evolution', *Bulletin of the Atomic Scientists* 22, 4–11.
207. An introduction to the practice is K.E. Latham, S. Gao and Z. Han. 2007. 'Somatic Cell Nuclei in Cloning: Strangers Travelling in a Foreign Land', in P. Sutovsky (ed.), *Somatic Cell Nuclear Transfer,* New York: Springer Science, 14–29.
208. Nuclear genes are the genes found in the nucleus, the control centre of the cell. Mitochiondrial genes are found in the mitodchondria, the so-called powerhouses of the cell.
209. House of Lords. 2002. *Stem Cell Research, Report from the Select Committee,* London: The Stationery Office, 47.
210. Nuffield Council on Bioethics. 2012. *Novel Techniques for the Prevention of Mitochondrial DNA Disorders: an Ethical Review,* London: Nuffield Council on Bioethics, London, 32–41.
211. S.A. Newman. 2013. 'The British Embryo Authority and the Chamber of Eugenics', *The Huffington Post,* Retrieved 15 April 2013 from http://www.huffingtonpost.com/stuart-a-newman/mitochondrial-replacement-ethics_b_2837818.html.
212. The donor is termed the 'somatic cell donor' since he or she has given a somatic cell, the type of cell that makes up the majority of human cells.

213. President's Council on Bioethics. 2002. *Human Cloning and Human Dignity: An Ethical Inquiry,* Washington DC: President's Council, 104–05.
214. Jackson, *Regulating Reproduction,* 257. Jackson considers this issue to be the most compelling reason for allowing reproductive cloning. Unfortunately, she comes dangerously close to advocating a view of reproduction that objectifies children. She rightly notes that people desiring to reproduce feel the desire with exceptional depth and complexity, but then she states that the 'misfortune' of involuntary infertility 'can now be alleviated' (259). The implication here is that the production of children is simply the outcome of a biological process and that the children exist as a means to enable parental happiness.
215. House of Commons, *Human Reproductive Technologies,* 33.
216. A corollary to these benefits resulting from cloning concerns the legality of the practice. According to some commentators, legislative bodies may only hope to pursue responsible laws if reproductive cloning is permitted. In short, it is argued that anti-cloning legislation may not only be built on shaky objections, but may ultimately, enshrine a prejudiced and indefensible perspective towards any cloned human being. K.L. Macintosh. 2005. *Illegal Beings: Human Clones and the Law,* Cambridge: Cambridge University Press, 154–75. J.C. Kunich presents a similar argument, 2003. *The Naked Clone,* Westport, CT: Praeger.
217. I. Wilmut, K. Campbell and C. Tudge. 2001. *The Second Creation: Dolly and the Age of Biological Control,* Cambridge, MA: Harvard University Press, 216.
218. L.R. Kass. 1998. 'The Wisdom of Repugnance: Why We Should Ban the Cloning of Humans', *Valparaiso University Law Review* 32, 682.
219. A.E. Shamoo and D.B. Resnik. 2009. *Responsible Conduct of Research,* 2nd ed., Oxford: Oxford University Press, 311.
220. Any number of sources will advocate the position sketched in this section. For official opinion from the United Kingdom government see, House of Lords, *Stem Cell Research,* 59.
221. European Parliament, 'Resolution on Cloning', March 1997, quoted in House of Lords, *Stem Cell Research,* 59.
222. President's Council, *Human Cloning,* 105–06.
223. Admittedly, as already noted, instrumentalization largely hinges on motives. Thus, the threat to human dignity may be largely side-stepped if pursued with proper motives.
224. President's Council, *Human Cloning,* 105–06.
225. Cf. J. Harris. 2002. '"Goodbye Dolly?": the Ethics of Human Cloning', in H. LaFollete (ed.), *Ethics in Practice: An Anthology,* 2nd ed., Oxford: Blackwell, 208, n. 19.
226. J.F. Kilner. 2000. 'Human Cloning', in J.F. Kilner, P. C. Cunningham and W. D. Hager (eds), *The Reproduction Revolution,* Grand Rapids, MI: William B. Eerdmans Publishing Co., 124–43.
227. The United Kingdom has not signed or ratified this convention.
228. Quoted in Schaeffer and Koop, *Whatever Happened to the Human Race?,* 38.
229. Quoted in 1973. 'Medicine: Endorsing Infanticide', *Time,* 28 May. Retrieved 10 August 2011 from http://www.time.com/time/magazine/article/0,9171,910661,00.html.
230. E. Day. 2005. 'Infanticide is Justifiable in Some Cases, Says Ethics Professor', *The Telegraph,* 25 January. Retrieved 10 August 2011 from http://tinyurl.com/telegraph-harris-interview.
231. A.G.M. Campbell and R.S. Duff. 1979. 'Debate: Author's Response to Richard Sherlock's Commentary', *Journal of Medical Ethics* 5, 141–42.
232. Day, 'Infanticide is Justifiable in Some Cases'.
233. Third trimester is any time after twenty-four weeks of gestation. In the United Kingdom, third-trimester abortions are permitted when there is 'substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped' or if the health of the mother is gravely endangered, Human Fertilisation and Embryology Act 1990, chapter 37. In 2009, roughly 1 per cent of abortions in the United Kingdom

took place as a means of deselecting a child that would face this substantial risk of long-term health challenges. For statistics in Scotland see http://www.isdscotland.org/isd/6207.html (accessed 21 July 2010) and for England and Wales see, *Statistical Bulletin—Abortion Statistics England and Wales: 2009,* 4. Retrieved 21 July 2010 from http://tinyurl.com/39y2ad2.

234. A recent reflection on the convergence of infanticide and abortion practice is J. McMahan. 2007. 'Infanticide' *Utilitas* 19, 131–59.
235. Day, 'Infanticide is Justifiable in Some Cases'.
236. J. McMahan. 2002. *The Ethics of Killing,* Oxford: Oxford University Press, 6.
237. P. Singer. 1993. *Practical Ethics,* 2nd ed., Cambridge: Cambridge University Press, 190.
238. For discussion of the ongoing battle against sex-selection by infanticide in the developing world, see, e.g., R.D. Bhatnaga and R. Dube. 2005. *Female Infanticide in India: A Feminist Cultural History,* Albany, NY: SUNY Press.
239. O. O'Donovan. 1984. *Begotten or Made,* Oxford: Oxford University Press, 51. While, to the distaste of some, O'Donovan's Christian faith may shape his conclusions regarding the treatment of human persons, his observation regarding the common societal assumptions is essentially value neutral.
240. The legitimacy of this societal consensus cannot be addressed here, except to note that, since the first publication of Singer's *Practical Ethics* in 1979, ethicists have recognized both the force and the flaws of finding a basis for moral equality between species.
241. K.R. Smith, S. Chan and J. Harris. 2012. 'Human Germline Genetic Modification: Scientific and Bioethical Perspectives', *Archives of Medical Research* 43, 491–513.
242. K.R. Smith, et al. Human Germline Genetic Modification: Scientific and Bioethical Perspectives, 493.
243. A. Sutton. 2013. 'A Case Against Germ-Line Gene Therapy', *Ethics & Medicine* 29(1), 17–22.
244. For the basics of germline engineering, see M.R. Capecchi. 2000. 'Human Germline Gene Therapy: How and Why', in G. Stock and J. Campbell (eds), *Engineering the Human Germline: An Exploration of the Science and Ethics of Altering the Genes We Pass to Our Children,* New York: Oxford University Press, 31–42.
245. For the developments discussed below, see L.M. Silver. 1997. *Remaking Eden: Cloning and Beyond in a Brave New World,* New York: Avon Books, 204–11 and 227–39. Also throughout G. Stock and J. Campbell (eds), *Engineering the Human Germline.*
246. Human Genetics Commission, *Choosing the Future,* 19–20.
247. S.D. Pattinson. 2002. *Influencing Traits Before Birth,* Surrey, UK: Ashgate, 132–33.
248. R.M. Blaese. 2003. 'Germ-Line Modification in Clinical Medicine', in Chapman and Frankel, *Designing Our Descendants,* 68–76.
249. Mitochondria are very small entities found in all the cells of the human body which produce the energy that they need to survive. Depending on its function, a cell may contain a few hundred to a few thousand mitochondria. For a cell to function and replicate properly, the thirty-seven genes in every mitochondria must interact properly with the genes in its chromosomes (which contain approximately twenty thousand to thirty thousand genes).
250. Nuffield Council on Bioethics. 2012. *Novel Techniques for the Prevention of Mitochondrial DNA Disorders: an Ethical Review,* London: Nuffield Council on Bioethics, 32–41.
251. Interestingly, some faith committees have already considered the deliberate genetic modifications of gametes. In its paper 'Communion and Stewardship', the International Theological Commission of the Catholic Church indicated that germline genetic engineering, in itself, would be acceptable with a therapeutic goal in a person, i.e., not just as a secondary effect in the treatment of an individual. It stated that the use of gene therapy in the stem cells that produce a man's sperm, whereby he can bring into existence healthy offspring through a conjugal act could be considered.

The International Theological Commission, however, is only an advisory body, and its opinions do not form part of the Magisterium of the Catholic Church, that is, its official teaching. A number of Catholic experts disagree with this conclusion.
See International Theological Commission. 2009. 'Communion and Stewardship: Human Persons Created in the Image of God', in M. Sharkey and T. Weinandy (eds), *International Theological Commission: Texts and Documents Volume 2.* San Francisco: Ignatius Press, 349. See also: A. Moraczewski. 2003. 'Germ-Line Interventions and the Moral Tradition of the Catholic Church', in Chapman and Frankel, *Designing Our Descendants,* 199–211.

252. Naturally occurring spontaneous genetic disorders affecting the germ line, such as those that give rise to Down syndrome, would also have to be studied in this regard.
253. President's Council, *Beyond Therapy,* 38–39.
254. M. Cavazzana-Calvo, A. Thrasher and F. Mavilio. 2004. 'The Future of Gene Therapy', *Nature* 427, 779–81 .
255. J. Gordon. 2003. *The Science and Ethics of Engineering the Human Germ Line: Mendel's Maze,* New York: Wiley-Liss, 195. More technically, F. Recillas-Targas et al. 2011. 'Gene Expression in Mammalian Cells', in M. Starkey and R. Elaswarapu (eds), *Genomics: Essential Methods,* Hoboken: Wiley, 157.
256. Recillas-Targas, 'Gene Expression', 163.
257. President's Council, *Beyond Therapy,* 38–39.
258. I. Persson, 'Does Gene Therapy Have Ethically Problematic Effects on Identity?', in E. Hildt and S. Graumann (eds), *Genetics in Human Reproduction,* Aldershot, UK: Ashgate, 1999, 127–32.
259. P.N. Ossorio. 2003. 'Inheritable Genetic Modifications' in Chapman and Frankel, *Designing Our Descendants,* 259–62.
260. N. Holtug. 2009. 'Who Cares About Identity?' in M.A. Roberts and D.T.Wasserman (eds), *Harming Future Persons: Ethics, Genetics and the Nonidentity Problem,* New York: Springer, 2009, 85.
261. Nuffield Council on Bioethics. 2012. *Novel Techniques for the Prevention of Mitochondrial DNA Disorders: an Ethical Review,* London Nuffield Council on Bioethics, 62.
262. Agar, *Liberal Eugenics,* 103.
263. President's Council, *Beyond Therapy,* 39–40.
264. Council of Europe. 1997. *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine,* ETS – No. 164, Oviedo.

GENERAL ETHICAL DISCUSSION

The different eugenic procedures presented above range from the already established to the highly speculative, and some may never become a reality.[1] But regardless of practicability, the various procedures are similar inasmuch as they each offer the option of selecting traits. The option of selecting is the central tenet of the new eugenics.[2] Currently, the primary (though not only) motivation driving many of these procedures is the desire to deselect entities (gametes, foetuses, embryos and even infants) that may mature into children with severe medical problems, the exception being the genetic modification of entities such as gametes, embryos, foetuses or postnatal persons.

However, motivation is a fragile guide to ethical correctness, not least because it may easily be falsified or manipulated. Defining ethical appropriateness as synonymous with good motives all but guarantees improper practices. This risk is very real with the selection procedures described in this book. While many in society have concluded that selection procedures may be appropriate when the goal is to avoid haramful disorders, there is still a broad agreement that the same procedures should not be used for enhancement. But this demarcation becomes convoluted by the difficulty of discerning therapy from enhancement even though the child's best interests are often the reason behind both concepts.

Employing these selection procedures may also lead to unforeseen consequences, for the relationship between parents and their children or how society views children (e.g., as objects or subjects), among other issues. Entrenched practice of eugenic procedures may alter society's view on procreation. Current widespread acceptance of some disorders may weaken so that there is eventually no tolerance for disorders. Similarly, the current trepidation accompanying assisted reproduction may dissipate so that assisted reproduction becomes the norm rather than the exception. In the light of these possibilities, scrupulous analysis is imperative to move forward both ethically and responsibly.

A brief example illustrates the importance of carefully assessing these procedures from a social, economic, biomedical and worldview perspective. In the

United Kingdom one governmental advisory body recognized the ethical uncertainty of using PGD to deselect embryos that are only unaffected carriers of a recessive genetic disorder. The concern was that these embryos are actually healthy in themselves, since they carry but do not express a genetic disorder, and would have no effect on the health of the resulting child.[3]

Rigorous analysis of many of these selection procedures will, therefore, need to contend with a perceived nonnegotiable axiom in bioethics: that society should respect the reproductive autonomy of individuals and that they should have the right to use selective procedures even if others disagree. As the argument goes, restricting selection procedures is inappropriate because all members of society, not simply those with a demonstrable risk, should be permitted to employ these medical technologies. But taken to its logical end, reproductive autonomy risks legitimizing widespread societal eugenics. As the sociologist Marque-Luisa Miringoff remarked:

> In eliminating individuals with unwanted diseases, we also create a mind-set that justifies the process of human selection. We thus move the questionable arena of human worth, and to some degree eugenic thought. We forgo the idea of therapeutic change ... and opt instead for elimination. Individuals are seen as flawed. It is easier and more desirable to prevent their existence than to work for their survival.[4]

In assessing the new procedures from an ethical perspective, it is also important to learn from the history of eugenic movements. This book began with an account of the origins and consequences of the eugenic regimes in the twentieth century. But of course, mere knowledge of history is inadequate for making wise judgements about twenty-first-century ethics conundrums. Buchanan et al. are correct to emphasize the importance of understanding precisely what was ethically unacceptable with past eugenic programs:

> For the history of eugenics to be instructive in ensuring social justice with greater knowledge about genes, and perhaps some ability to alter them, the key question is whether ... eugenics was wrong in its very inception. If so, any eugenics program will be wrong. On the other hand, if the abuses done in the name of eugenics do not necessarily reflect badly on eugenic ideas themselves, then our task will be to ensure that any eugenic interventions of the future avoids these abuses.[5]

Eugenics has always been considered to be controversial because of its association with extremely sensitive issues such as race, disability and the relative worth or value of different individuals and the manner in which they are considered by society.[6] The eugenic movements of the past did not hide the foundational belief that some individuals posed a genetic threat to society and that procedures, such as sterilizations and euthanasia, may become necessary. Of course, these procedures are now seen as reprehensible, and any reminiscence of past programs is rightly accompanied with a deep sense of outrage and dismay.

But today, concerns about eugenics relate almost exclusively to the past discriminatory measures that marked the twentieth century, and anxieties regarding existing practices are rare. This sense of security, however, is fragile and the selection procedures taking place at present, and addressed in this book, may appear uncomfortably similar to procedures of an older era. In addition, a creeping sense of unease about current eugenic procedures derives from more than a concern with the science that undergirds the various practices. As the US President's Council on Human Bioethics observed in 2002, the unease comes from a candid acknowledgement that when society crosses the line between therapy and enhancement it is in 'uncharted waters, without a map, without a compass, and without a clear destination'.[7] Once in this eugenic frontier, society will find it very difficult to return to the safety of its present ethical values. It is, therefore, imperative to examine the general arguments both in favour and opposed to the new eugenics in order to proportionally evaluate whether the novel procedures being proposed should be welcomed or shunned.

Notes

1. For a recent fictional portrayal of genetic engineering employed for producing superior children, see the novel by K. Joseph. 2005. *The Champion Maker,* Bloomington, IN: Unlimited Publishing.
2. As already seen, the exception to this criterion of choice is genetic modification that results as a secondary effect of therapy for a disorder.
3. In fact, in some circumstances, being an unaffected carrier of a genetic disorder may even be associated with a certain amount of resistance to certain diseases. Human Genetics Commission, *Choosing the Future,* 22, 25.
4. M.-L. Miringoff. 1991. *The Social Costs of Genetic Welfare,* Piscataway, NJ: Rutgers University Press, 159–60.
5. A. Buchanan et al. 2000. *From Chance to Choice: Genetics and Justice,* Cambridge: Cambridge University Press, 42–43.
6. Kevles, *In the Name of Eugenics,* 300–301.
7. President's Council, *Human Cloning and Human Dignity,* 109–10.

ARGUMENTS SUPPORTING THE NEW EUGENICS

This section looks at some of the perceived positive returns of eugenic practices and why a real interest in selection is developing in certain sections of the general public. In the appeal such procedures may present, two points deserve attention. First, eugenic procedures may indeed facilitate the wellbeing of individuals and their families. Secondly, that access to eugenics may assist in the functioning of a balanced and durable society.

Healthier Children

Some commentators support eugenic practices by arguing that selection procedures improve the wellbeing of society by ensuring the birth of healthier children.[1] For example, since 1978, procedures such as IVF and other assisted reproductive technologies have been recognized as contributing positively to the interests of numerous infertile couples by enabling them to have children of their own. But with the advent of new reproductive procedures, such as those surveyed earlier, couples now have the option not only to procreate children by overcoming nature's limitations but to ensure that the children will be healthy.

For the vast majority, however, the goal is not positive eugenics but a form of negative eugenics. The goal is to ensure that children with certain disabilities are not born. Under this scheme, families are able to ensure that they are not affected by defective and detrimental specimens. For example, prenatal screening can detect disorders and afford parents the option of terminating the pregnancy to prevent the ailment from being perpetuated.

While justice and economic efficiency certainly drive the pursuit of a healthier genetic future, it is empathy towards suffering that powers the eugenic engine with unparalleled force.[2] By enabling the deselection of embryos or foetuses that have debilitating conditions, such as Tay–Sachs disease, the new eugenics is principally based on the reduction of suffering. Similarly, if empathy may be considered to be central to good medical practice,[3] then certain eugenic procedures may be perceived to have an essential role in what supporters of the new eugenics consider to be the ethical practice of medicine.[4]

This reflects the principle of the Golden Rule – doing to others what one would like others to do in return – which suggests that a person should prevent others from experiencing what he or she would want to avoid (if at all possible). For example, it is difficult to see how anyone could wish the sufferings of Tay–Sachs upon another person. Basic empathy, then, suggests the ethical appropriateness of negative eugenic procedures that prevent the birth of children with Tay–Sachs. It should be emphasized, however, that the Golden Rule is not a system of ethics in itself but it does shed some light on the reasons some give for supporting the quest of the new eugenics.[5] Moreover, the rule does not actually mandate taking decisions for others who are or will be directly affected, as in most eugenic practices. Proper application of the Golden Rule implies that personal autonomy is respected and that a person should not take away this autonomy from others.

Armed with compassion, supporters of the new eugenics may also promote more than the mere alleviation of suffering. Going a step further, it is possible to advocate a eugenic step that promotes desirable characteristics and not just the elimination of the undesirable. Just as parents may seek the best for their future child by selecting only embryos without genetic disorders, so other parents may believe that it is their duty to select only embryos that will have superior traits. In other words, the parents are simply pursuing the best possible life for their possible future child.

Justifying selection for improvement is not difficult in the light of the uncontroversial improvements that parents regularly pursue for their children. Countless parents already enable the improvement of their children's capabilities by providing athletic training or high-calibre education. Given this, supporters of the new eugenics note the difficulty in identifying a legitimate difference between undertaking such activities and genetically improving a child with the aim of developing higher capabilities. After all, most parents not only desire to have healthy children but also highly talented offspring capable of living successful and fulfilling lives in a competitive world.[6]

In this context, however, questions remain concerning the final outcome of these 'enhancements' and whether parents actually have a moral obligation or responsibility to seek 'procreative perfectionism' for their children.[7] For example, commentators, such as the philosopher Jonathan Glover, suggest that parents do not believe that they may have such a responsibility.[8] The medical ethicist Julian Savulescu, on the other hand, uses a principle which he calls Procreative Beneficence to argue that 'couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information'.[9,10] Of course, Savulescu recognizes that this child may not be perfect, but the goal is not perfection. Rather, to Savulescu and others, the goal is optimization. As the reasoning goes, the selection procedures now available in many developed countries enable parents to select possible future children with optimal lives, and parents who do not select these children are somehow derelict in their duty. The argument is thus analogous to the arguments for education. Parents have a responsibility to educate their children, and parents who overlook education are negligent and morally culpable.

But the problem with this argument is the very subjective notion of what constitutes a good or successful life. Does this mean achieving success and recognition amongst one's peers, being able to experience a lot of physical and emotional pleasures? Or could it also mean helping and supporting others even when this means a life of difficulty and suffering? The concept of a 'good life' would vary according to each person's worldview and understanding of what matters in life.[11] Equally, many parents may not share the same worldviews as their prospective children, a reality that may ignite a certain amount of conflict.

Preserving Reproductive Freedoms

A second reason for supporting eugenic practices relates to the concept of parental procreative freedom and autonomy. This may be characterized as a person's entitlement to control his or her own body and to be respected in deciding to have (or not to have) a child.[12] In this regard, the new eugenics contrasts with the earlier practice of eugenics as in Nazi Germany and the United States which, as noted earlier, disregarded parental reproductive freedom and overrode autonomy with the authoritative rule of the state.[13] Nonetheless, even at present, some eugenically driven laws continue to infringe the autonomy of the individual. For example, parents in the United Kingdom cannot select for what is considered to be a disability in a child.[14]

On the whole, though, twenty-first-century global society demonstrates a keen preference for polices that permit an individual to decide how his or her body is used in procreation. This means that it is unlikely that an old regime of coercive eugenics would reemerge in many contemporary societies.

Past eugenic programs also promoted a very specific understanding of the ideal human being, running roughshod over all other values. As the horrors of the beginning of the twentieth century illustrate all too vividly, considerations of what may be perceived as the ideal human being often derived from distorted perspectives with limited views.[15] Individuals with higher intelligence were thought to be more useful and valuable to society simply because of their intelligence.[16] Early eugenicists (and perhaps some today) also believed that antisocial behaviour, such as that associated with crime, could be directly linked to intellectual incompetence.[17]

In contrast, the new eugenics would allow a wider concept of humanity to exist which recognizes that individuals will differ about the kind of children they would want. Rather than restricting the varying opinions and risking the narrow-mindedness of an earlier era, the new eugenics aims to promote diversity, permitting and not coercing individuals to pursue eugenic practices according to their own choices and aspirations. Thus, in preserving reproductive freedoms, a libertarian society would argue that it respects a thoroughgoing commitment to a pluralism of values. This would not, it is suggested, result in a rugged individualism since a libertarian society presumes that an individual is free to act in any manner that he or she wishes as long as this does not impinge upon the freedom of others to act with equal freedom. In fact, the more personal an action becomes, the greater the presumption and justification in favour of autonomy. For example, the freedom to marry whoever one wishes is more secure, as a personal right, than an individual's freedom to protest against military action. This position is often described as 'liberal' because the focus is on liberty[18] and the 'right to procreative autonomy'.[19] This means that the procreative liberty of persons, including choosing whether to have a child at all, is seen as a fundamental right which relates to the most basic meaning and identity that people may give to their lives.[20]

A logical extension of this liberal position is that an individual is entitled to pursue the procedures of the new eugenics without undue interference.[21] From this perspective, only prospective parents, and not the state, should make decisions concerning future children, provided those decisions cause no harm to society or its living members.[22] Julian Savulescu recently illustrated a thorough-going commitment to this perception on reproductive liberty, when he accused the UK's Human Embryology and Fertilisation Authority (HFEA) of too rigorously restricting procreative freedoms. According to Savulescu, in prohibiting sex selection for family balancing, the HFEA 'imposed dominant conservative morality to limit reproduction'.[23] For Savulescu, sex selection for family balancing should be permitted because it causes no harm, not even to the future child, since the child would not exist without the procedure. This is a stereotypical example of the argumentation that underlies the new eugenics.[24]

More controversially, some argue that unless the new eugenics is actually allowed to flourish, a form of compulsion may return. That without access to beneficial eugenic procedures, many future individuals, such as disabled children but also their parents, may experience suffering which they would be obliged to endure. As the argument goes, if libertarian freedom is not protected, some persons may risk a form of oppression similar to the past compulsory and irresponsible eugenic activities.[25] But this association is difficult to substantiate in light of the widely acknowledged ethical difference between acts and omissions where the intention of a perpetrator must be taken into account. A society that voluntarily imposes suffering on its members is inherently different from one that acknowledges that unintended and unwanted suffering can result from a natural procedure.

The theological ethicist Michael Northcott also questions the sense of control that is reflected in the autonomy of eugenic decisions. He emphasizes that those who know that they are not in control may have a greater sense of humility about the very nature of life. On the other hand, an embrace of a genetically controlled future may give rise to a more divided and violent outcome. Northcott then suggests that eugenic autonomous decisions may result in a disregard or even an abandonment of those who were unfortunate enough to have missed out on the opportunities to become biologically acceptable.[26]

In response, proponents of liberal eugenics may contend that an individual's personal reproductive choices cannot possibly harm other individuals or society if they are taken responsibly. But this cannot always be guaranteed, particularly at this early stage of appropriating the new selection procedures.

Thorough analysis is currently difficult since the body of data is comparatively small and immediate evidence of serious risks is also lacking. In such a situation where there is an absence of evidence either way relating to the predicted possible risks arising from procreative freedom in the context of eugenics, the so-called precautionary principle is often evoked as a responsible way forward. In short, this means that any further step should only occur if the freedom to procreate children with selected positive characteristics is demonstrated to have no undesirable latent consequences. This includes on the children themselves, the scientists facilitating the procedure, and children who lack the selected traits. Equally, any developments must not threaten society's decision to regard every individual as bearing equal value.[27] Prospective parents should also be made aware that any selection cannot guarantee any desired outcome since the eugenic procedures deal in the realm of increased or decreased probabilities and not in certainties.[28]

The Effects of Dysgenics on Society

The quest for health and good characteristics can be viewed both positively and negatively. As already mentioned, selection procedures permit prospective parents to have children who are generally free from major health concerns. This is the positive approach. The negative approach, however, is concerned with eliminating bad health or bad traits. To be sure, distinguishing these two approaches to health and biological characteristics is somewhat contrived since the ultimate result is similar. But both approaches find traction in eugenic literature and both may resonate emotionally with the wide variety of parties involved in selection procedures. Everyone from prospective parents to medical practitioners and philosophers developing the theoretical paradigms for the procedures may be compelled to do their part in reducing disease and suffering as well as promoting good characteristics for the sake of the survival of a society.

Since the enforced eugenic practices in antiquity, collective responsibility has ranked as a primary argument in favour of eugenic ideology. All members of society have to participate in the collective goal of creating the ideal society, free of weak and degenerate members who would suppress the overarching quest for progress. This argument also resonated strongly with European and North American societies in the late nineteenth and early twentieth centuries when, as already indicated, men like Galton and Darwin expressed concerns about the manner in which society was developing.

Darwin's son, Leonard, also secretary of the British Eugenics Education Society, shared his father's concern about the future of his country. In 1928, he expressed his worries about the societal detriment brought about by feeble-minded individuals that 'have large families and many descendants because they have little power of looking into the future, or of foreseeing the consequence of their own acts'.[29]

Similarly, in her book entitled *The Pivot of Civilization,* originally published in 1922, Margaret Sanger consecrates a whole chapter on birth control and her complaint that state governments are not doing enough to restrain by force or persuasion the reproduction of what she considers the undesirable. She indicated that:

> There is but one practical and feasible program in handling the great problem of the feeble-minded. That is, as the best authorities are agreed, to prevent the birth of those who would transmit imbecility to their descendants. Feeble-mindedness as investigations and statistics from every country indicate, is invariably associated with an abnormally high rate of fertility. Modern conditions of civilization, as we are continually being reminded, furnish the most favorable breeding-ground for the mental defective, the moron, the imbecile.[30]

In this regard, she specifically criticizes charity work for supporting such a situation:

> The most serious charge that can be brought against modern "benevolence" is that it encourages the perpetuation of defectives, delinquents and dependents. These are the most dangerous elements in the world community, the most devastating curse on human progress and expression.[31]

In the mid-twentieth century the Nobel laureate H.J. Muller also predicted the twilight of humanity unless practical eugenic steps were initiated to regulate society's genetic heritage.[32] More recently, David Galton defended the idea of a restoration of eugenics as defined by Francis Galton, indicating in 2002 that '[t]he new eugenic technology may become a vital weapon to prevent a future genetic deterioration of our species'.[33] And in 2004, the ethicist Nicholas Agar argued that the risks arising from selective enhancement may be considered as small if it is the only way in which the human species would survive.[34]

The fear of dysgenics is, therefore, still present for a number of commentators though, as will be shown in the next section, the cost of care of a person with a genetic disorder is also beginning to resurface in a number of conversations. This also means that national governments, who can often only use consequentialist theories for providing healthcare, will not be impervious to the possibility of limiting in some way the ever increasing healthcare costs.

Cost of Care

An important argument in favour of the new eugenics is related to the scarcity of resources that confronts humanity. People with disability often consume more resources than those without disability, and some disabilities prevent affected persons from participating in society without assistance. These are issues that are not ignored by governments. As the scientist and ethicist David King observes, 'Politicians are looking for ways to cut healthcare budgets, and it is clear that preventing the birth of disabled children, with lifelong healthcare costs, is very cost effective.'[35] Of course, the level of assistance a person needs depends on the severity of the disability. But making sure certain persons with disorders are not born may be regarded by some healthcare providers as less expensive than the care of children with a disorder.[36] A comprehensive study performed in the United States in 2010 noted that if a national program of preimplantation embryonic selection was undertaken for a serious disorder, such as cystic fibrosis, it would be highly cost-effective. In fact billions of dollars would be saved from lifetime treatment costs since persons with the disorder would no longer be brought into existence.[37] Another study in the United Kingdom investigated the costs of sustaining patients older than fifty-nine years of age who lived with an intellectual disability. On average, each patient required over US $60,000 worth of care per year.[38] For affluent patients, this extra expense may be little more than an annoyance, but most patients will surely find the cost prohibitive. Without outside financial assistance, the patient will not survive. One option for this aid is public funds such as provided by the National Health Service (NHS) in the United Kingdom. But the high cost of care for disabled persons has many detractors. Lady Warnock, one of the main architects of human reproduction legislation in the United Kingdom, has actually objected to these high costs of care for high-needs patients. In 2008, during an interview on euthanasia she claimed, 'If you're demented, you're wasting people's lives, your family's lives, and you're wasting the resources of the NHS.'[39] In the United States, not all people with disability benefit from a national care scheme. And at least one study has shown that having a disability is often a financial setback for people without access to third-party assistance.[40] But the challenge is often not limited to the disabled people themselves because, without state aid, their families may assume responsibility for the necessary care. While commendable, this familial generosity may itself be a burden, as a high financial outlay to care for the disabled jeopardizes the economic stability of the family.[41] On a larger scale, exorbitant expenses affect not just families but whole sections of society.[42]

The cost of caring for disabled persons, as an argument for eugenic practices, is not often mentioned since it makes uncomfortable reading being an important argument employed by Nazi Germany. Nevertheless, the burdensome cost of healthcare is a reality. As sociologist Megan Allyse puts it concisely, '[O]ver the course of their lives, children affected with many of the conditions avoidable through PGD need intense and expensive medical care.'[43] US philosopher Arthur Caplan adds, 'When the state of California offers [a test] to all pregnant women it does so in the hope that some of those who are found to have children with neural tube defects will choose not to bring them to term thereby, preventing the state from having to bear the burden of their care.'[44]

As the argument goes, the extra needs of people with disabilities strain the already limited resources of society, and in order to distribute these resources wisely, some selection procedures may be advantageous, if not essential. In the United Kingdom, as in many Western countries, the current population of people with disability approaches 20 per cent of the whole.[45] A decision to deselect embryos thus falls not merely in the domain of personal choice, something that prospective parents can undergo, but the decision is also brought into the public arena because disabled individuals may be considered as a financial burden. From this perspective, whether an embryo with a disability matures is a matter that affects the whole of society, though individuals (or couples) are responsible for the final verdict. But, because their decision bears on the collective experience of society, reference to the larger good is crucial.[46]

This perspective about selection procedures is worth noting because it may be initially attractive. Its logic is simple, and its consequences appear beneficial to the whole of society. At the same time, even the noted supporter of some selection procedures, ethicist Jonathan Glover, states, 'I find repugnant the idea that decisions about the kind of children to be born should be made on grounds of general social utility.'[47] In his most recent treatment of the subject, Glover also treads gently on the topic of disability.[48] He supports selection procedures but for the far more mainstream reasons of reproductive freedom and justice, and he still cautions that future children should not be viewed as a means to parental or societal ends.

Still, while many philosophers and theorists may largely reject an economic perspective on disability and eugenics, some support for this approach remains. Another sociologist, Anne Kerr, notes that research and development of new technology is intimately related to the procedures already discussed in this book. Her observation merits extended quotation because of its descriptiveness.

> There are many layers of investment in the proliferation of these technologies, not in terms of a conspiracy to "search and destroy" disabled fetuses but in terms of networks of relationships between researches, clinicians, funding bodies, manufacturers and academic and medical institutions. These groups are all interested in developing new technologies with bigger return, be it financial or political. The technological imperative is not devoid of humanity, but a product of actors' interests in building careers and laboratories, franchises and footholds in policy work.[49]

In short, the financial side of disability and disease affects a broad sector of society while it is recognized that eliminating nonhealthy conditions could save expenses. But disability and disease also raise financial issues on the profit side of the ledger. Some might object that Kerr has unfairly characterized the technology industry, and, admittedly, the thought of benefitting from others' distress seems insensitive if not perverse. Nevertheless, the inner-workings of society are often far from polite, and this issue is no exception. The procedures of the new eugenics find support in economic terms. By promoting and regulating these procedures, society generates income and furthers the wellbeing of the many involved in research and development.

Finally, in addition to financial advantages, it is recognized that eugenic programs may also address a social cost of care that should not be overlooked. The French physician Farhan Yazdani notes:

> It is true that a severely handicapped child can be an unbearable strain to parents and endanger the development of other children in the family. Social institutions can compensate through a helping hand, but they lack necessary funds for doing so. Again, even though it is morally wrong to eliminate the handicapped before birth, it could be in some cases the least inappropriate solution in our present situation.[50]

However, it can also be suggested that more social research with people who have certain congenital conditions is required before the limitations and suffering, which are assumed in the prenatal literature concerning these conditions, are accepted.[51]

The New Evolution

Many eugenicists view the pursuit of health as being double-edged, requiring both positive steps to achieve good health and negative practices that eliminate poor health. As a result, a certain kind of intentional evolution may arise. This was recognized by the 1921 poster for the International Eugenics Congress which declared, 'Eugenics is the self-direction of human evolution.'[52] In this regard, John Harris builds on this idea an interesting, descriptive twist to his account of ethics and eugenic technology. Countering objections that such technology violates the sacredness of humanity, Harris delves briefly into discussion of evolutionary biology.[53] In short, he argues that the human genome as it currently stands is merely the product of millions of years of evolution and is constantly changing, thus making it incoherent even to speak of 'the' human genome.[54] The logical outworking of this evolutionary view is simple: the mere introduction of changes to the human genome cannot render the technology unacceptable since human genetics is in constant flux. With this clarification, Harris cements the suitability of the title of his book *Enhancing Evolution.* According to Harris, the procedures of what this present book calls the 'new eugenics' are simply the latest in a long line of forces that further and maybe also accelerate evolutionary development. In so doing, he builds on the thinking of Galton who suggested that what nature does blindly and slowly, humankind could do providently and quickly through the development of eugenics.[55]

However, while Harris describes the outcome of the new eugenics as a continuation of human evolution, he notably does not justify selection and enhancement procedures merely because they continue this progress. Rather, he simply characterizes the procedures as tools or means for continuing human evolution. Julian Huxley, however, goes one step further by suggesting that evolution should actually be accelerated by humankind, stating that:

> The challenge is man's obvious imperfection as a psychosocial being; both individually and collectively, he is sadly in need of improvement, yet clearly improvable. The encouragement derives from the fact of past improvement. If blind, opportunistic, and automatic natural selection could conjure man out of a viroid in a couple of thousand million years, what could not man's conscious and purposeful efforts achieve even in a couple of million years, let alone in the thousands of millions to which he can reasonably look forward?[56]

Similarly the legendary scientist James Watson seems to sanction the new eugenic procedures on the grounds of furthering evolution. He stated this plainly in an interview with a German newspaper: 'I think we should improve evolution whenever this is possible, as long as we thereby create healthier and more intelligent human beings.'[57] On the one hand, Watson simply recognizes the fact that humans participate, to some extent, in the evolution of their species. For example, a diet of fried food and a sedentary lifestyle influences the fitness of the human species.[58] Yet, on the other hand, Watson has offered a provocative challenge to detractors of the new eugenics. Since humanity will evolve, Watson reasons that savvy members of the species will intentionally direct evolution, rather than simply accepting the guidance of others and less deliberate factors, such as diet or exercise. As he put elsewhere, 'If more intelligent human beings might someday be created, would we not think less well about ourselves as we exist today? Yet anyone who proclaims that we are now perfect as humans has to be a silly crank.'[59]

The human species will change. Indeed, it is changing and, according to Harris and Watson (and many others), recent advancements of medical technology permit humans to chart a deliberate course into the future rather than merely accepting what the future brings. As the geneticist and bio-businessman Brandon Colby explains, 'Our next major leap of evolution as a species will be one that we control.'[60]

It should be noted that evolutionary theory accounts for both a single organism's fitness but also the fitness of a population (or species).[61] This means that changes across a significant section of a population affected by a disorder could improve the overall health of the population/species.[62] Indeed, one of the consequences of today's eugenic procedures is the prospect of a general enhancement of humanity through reproductive technologies.[63] For some, the desire to improve society is linked to the conviction that evolutionary biology is driving humanity to ever-greater levels of perfection and that technology is merely the most recent, most advanced means in human evolution.

Not unknowingly, then, the University of Oxford has established the Future of Humanity Institute to reflect and advise on the interface between emergent technologies, ethics, and how the human species should and will experience change in coming years.[64] Whatever solutions this institute proposes, the practices of the new eugenics are likely to be included, and the arguments sketched above will form the ideological foundation of this future. Whether the new eugenics will actually become the future of humanity depends in part on how society responds to the arguments against the new eugenics. It is to these that the book now turns.

Notes

1. Savulescu. 'Procreative Beneficence', 413–26.
2. So, G. Meilander. 2002. 'Designing our Descendants', in W. Kristol and E. Cohen (eds), *The Future is Now: America Confronts the New Eugenics,* New York: Rowman and Littlefield, 83.
3. Compassion in the medical profession has featured recently in public discussion, J. Dreaper. 2008. 'Compassion "Key to Good Health Care"', *BBC News,* 30 December. Retrieved 22 June 2010 from http://news.bbc.co.uk/1/hi/health/7797548.stm.
4. A stronger version of this argument states that practicing negative eugenics is actually a matter of justice. Cf. Buchanan et al., *From Chance to Choice,* 61–103. Note, however, the cogent reminder of philosopher Thomas Sewell, 'Justice gives us something, not everything.' 2005. *Elements of Justice,* Cambridge: Cambridge University Press, 10. As elaborated below, there is more at stake in the eugenics debate than justice.
5. J. Wattles. 1997. *The Golden Rule,* New York: Oxford University Press, 165
6. For examples see, President's Council, *Beyond Therapy,* 46.
7. J. Glover. 2006. *Choosing Children: The Ethical Dilemmas of Genetic Intervention,* Oxford: Oxford University Press, 53. This book was also published as J. Glover *Choosing Children: Genes, Disability, and Design,* Oxford: Clarendon.
8. Glover, *Choosing Children,* 50.
9. Savulescu, 'Procreative Beneficence', 415
10. See also J. Savulescu and G. Kahane. 2009. 'The Moral Obligation to Create Children with the Best Chance of the Best Life', *Bioethics* 23(5), 274–90.
11. British Medical Association, *Boosting Your Brainpower,* 31.
12. Cf. Human Genetics Commission, Making Babies, 18.
13. E.g., the compulsory sterilization and segregation programs in the United States and Europe, as well as, of course, those in Nazi Germany. Notably, Francis Galton and, from the 1930s, the British Eugenics Society decried coercive eugenics, Paul, *Controlling Human Heredity,* 133.
14. Also, China's Law on Maternal and Infant Health Care. Adopted in 1994, this law is concerned with negative eugenics. Though beyond the present focus, engaging the eugenic assumptions common among Chinese geneticists would be fruitful for further research. Cf. X. Mao. 1998. 'Geneticists' Views of Ethical Issues in Genetic Testing and Screening: Evidence for Eugenics in China', *American Journal of Human Genetics* 63(3), 688–95.
15. Nuffield Council on Bioethics, *Genetics and Human Behaviour,* 17.

16. Buchanan et al., *From Chance to Choice,* 49.
17. A.C. Carey. 2003. 'Beyond the Medical Model: A Reconsideration of "Feeblemindedness", Citizenship, and Eugenic Restrictions', *Disability & Society* 18, 411–30.
18. In case the connection is not quite obvious, 'liberal' and 'liberty' derive from the Latin word *liber* meaning 'free'; a liberal position is thus one that allows many freedoms.
19. R. Dworkin. 1993. *Life's Dominion: An Argument about Abortion and Euthanasia,* London: Harper Collins, 148.
20. J.A. Robertson. 1994. *Children of Choice: Freedom and the New Reproductive Technologies,* Princeton: Princeton University Press, 24.
21. In this vein, the enforcement of the UK Human Rights Act 1998 has given a renewed force to arguments asserting the rights of the individual against interference from the state. Cf. Dworkin, *Life's Dominion,* 32–35.
22. Glover, *Choosing Children,* 44.
23. J. Savulescu, 2011. 'The HFEA Has Restricted Liberty without Good Cause', *The Guardian,* 7 February. Retrieved 11 August 2011 from http://tinyurl.com/Guardian-Savulescu.
24. Savulescu's article in *The Guardian* (see previous note) gave short shrift to opposing arguments, further illustrating that the debate about the new eugenics is grounded in deep-seated assumptions that often preclude societal consensus.
25. For example, J. Glover. 1984. *What Sort of People Should There Be?,* Harmondsworth: Penguin, 84–89.
26. M.S. Northcott. 2009. 'The Church and the Genomic Project to Secure the Human Future', in M. Bratton (ed.), *God, Ethics and the Human Genome: Theological, Legal and Scientific Perspectives,* London: Church House Publishing, 102–16.
27. British Medical Association, *Boosting Your Brainpower,* 29.
28. D.B. Resnik and D.B. Vorhaus. 2006. 'Genetic Modification and Genetic Determinism', *Philosophy, Ethics, and Humanities in Medicine,* 1(1), 9–11.
29. L. Darwin. 1928. *What is Eugenics?,* London: Watts, 46–47.
30. Sanger, *The Pivot of Civilization,* 107–08.
31. Sanger, *The Pivot of Civilization,* 138.
32. Ramsey, *Fabricated Man,* 29.
33. D.J. Galton. 2002. *Eugenics: The Future of the Human Life in the 21st Century,* London: Abacus, 255.
34. Agar, *Liberal Eugenics,* 163.
35. D. King. 1998.'Eugenic Tendencies in Modern Genetics', *Ethics and Medicine* 14:3, 87.
36. President's Council, *Reproduction & Responsibility,* 96.
37. I. Tur-Kaspa, et al. 2010. 'PGD for All Cystic Fibrosis Carrier Couples: Novel Strategy for Preventive Medicine and Cost Analysis', *Reproductive Biomedicine Online* 21(2), 186–95.
38. A. Strydom et al. 2010. 'Service Use and Cost of Mental Disorder in Older Adults with Intellectual Disability', *British Journal of Psychology* 196, 133–38.
39. M. Wade. 2008. 'You'll Kill Patient Trust if You Let Doctors Help Suicides', *The Times,* 10 October. Retrieved 31 May 2011 from http://www.timesonline.co.uk/tol/news/uk/scotland/article4923128.ece.
40. S. Mitra, P. Findley and U. Sambamoorthi. 2009. 'Health Care Expenditures of Living With a Disability: Total Expenditures, Out-of-Pocket Expenses, and Burden, 1996 to 2004', *Archives of Physical Medicine and Rehabilitation* 90, 1532–40.
41. B.M. Altman, P.F. Cooper and P.J. Cunningham. 1999. 'The Case of Disability in the Family: Impact on Health Care Utilization and Expenditures for Nondisabled Members', *Milbank Quarterly* 77, 39–75.
42. M. Palmer et al. 2011. 'Health Care Utilization, Cost Burden and Coping Strategies by Disability Status: An Analysis of the Viet Nam National Health Survey', *International Journal of Health Planning and Management* 26(3), 31–48.

43. M. Allyse. 2009. 'Commissioning and Providing Pre-implantation Genetic Diagnosis Services', *BioNews* 506. Retrieved 16 May 2011 from http://www.bionews.org.uk/page_38067.asp.
44. A.L. Caplan. 1993. 'Neutrality is Not Morality: The Ethics of Genetic Counselling', in D. Bartels, B. LeRoy and A. Caplan (eds), *Prescribing Our Future: Ethical Challenges in Genetic Counselling,* Hawthorne, New York: Aldine de Gruyter, 159.
45. Eleven million out of roughly 61 million equals 18 per cent of the population, British Medical Association. *Disability Quality within Healthcare: The Role of Healthcare Professionals,* London: British Medical Association, 2007. Contrast with J.L. Scully, suggesting a figure closer to 10 per cent, 2009. 'A Bioethics of Disability and Impairment', in P. Atkinson, P. Glasner and M. Lock (eds), *Handbook of Genetics and Society: Mapping the New Genomic Era,* London: Routledge, 370.
46. W.A. Anderson. 2011. 'Estimates of National Health Care Expenditures Associated With Disability', *Journal of Disability Policy Studies* 21, 230–40.
47. J. Glover. 2001. 'Eugenics: Some Lessons from the Nazi Experience', in J. Harris and S. Holm (eds), *The Future of Human Reproduction,* Oxford: Oxford University Press, 2001, 65. Glover rejects a strong correlation with Nazi eugenics.
48. Glover, *Choosing Children.*
49. A. Kerr. 2004. *Genetics and Society: A Sociology of Disease,* London: Routledge, 73.
50. F. Yazdani. 1998. 'Ethical Decision-making for In Vitro Fertilisation in a Multicultural Setting', in E. Hildt and D. Mieth (eds), *In Vitro Fertilisation in the 1990s,* Aldershot, UK: Ashgate, 125.
51. P. Alderson. 2001. 'Down's Syndrome: Cost, Quality and Value of Life', *Social Science and Medicine* 53, 627–38.
52. N. Comfort. 2012. 'The Eugenic Impulse', *The Chronicle of Higher Education* 12 November 2012.
53. Harris, *Enhancing Evolution,* 15–17.
54. Among many others, cf., E.T. Juengst. 2009. 'What's Taxonomy Got to Do with It? Species Integrity, Human Rights and Science Policy', in Savulescu and Bostrom, *Human Enhancement,* 43–58.
55. F. Galton. 1904. 'Eugenics: Its Definition, Scope, and Aims', *American Journal of Sociology,* 10(1): 1–25.
56. J. Huxley. 1963. 'The Future of Man', in G.E.W. Wolstenholme (ed.), *Man and His Future,* Boston: Little, Brown & Co, 4.
57. J. Müller-Jung. 2000. 'Sollen wir den Piloten ins Gehirn blicken? Ein Gespräch mit James D. Watson, dem Pionier der Erbgutanalyse', *Frankfurter Allgemeine Zeitung* 52, 28 June.
58. A recent report from the UK National Health Service suggests this may be a genuine concern, as just over 23 per cent of children in England are overweight. NHS, *National Child Measurement Program: England, 2009/10 School Year,* 2010. Retrieved 28 April 2011 from http://tinyurl.com/3wtzlas.
59. J.D. Watson. 1997. 'Genes and Politics', *Journal of Molecular Medicine* 75, 636.
60. Quoted in C. Abraham. 2012. 'Unnatural Selection: Is Evolving Reproductive Technology Ushering in a New Age of Eugenics?', *The Globe and Mail,* 7 January 2012.
61. E. Sober. 2006. 'The Two Faces of Fitness', in E. Sober (ed.), *Conceptual Issues in Evolutionary Biology,* 3rd ed., Cambridge, MA: MIT Press, 25–38.
62. For the scope of change see, N. Daniels. 2009. 'Can Anyone Really be Talking About Ethically Modifying Human Nature?', in J. Savulescu and N. Bostrom, *Human Enhancement,* 33–36.
63. See, for example, Agar, *Liberal Eugenics,* 5. Buchanan et al. laud early-twentieth-century eugenicists for their efforts in this regard, *From Chance to Choice,* 46–47.
64. See http://www.fhi.ox.ac.uk/ (accessed 4 August 2011).

ARGUMENTS OPPOSING THE NEW EUGENICS

Having sketched some of the most important arguments supporting the new eugenics, attention now turns to arguments against the proposals. As will be clear, this section attempts to show that, in spite of the challenging arguments above, many of the procedures involved in the new eugenics should perhaps be excluded from biomedical programs. The arguments in this chapter consider eugenics from the perspective of (1) selected human individuals (including embryos and foetuses), (2) prospective parents and (3) society at large. As in the previous section, the arguments are not fully comprehensive but represent, instead, an attempt to marshal common and compelling reasons.

Destruction of Embryos and Foetuses

Opposition towards many forms of eugenic practices, such as PGD and PND, often stems from the belief that all living human beings have full, inherent dignity and thus deserve protection from the moment of their creation. As a consequence, the argument can be made that any increased access to embryonic and foetal selection would also amplify the number of human beings destroyed.

As mentioned in the earlier discussion on infanticide, the question of the inherent value of human life is deeply philosophical in nature; thus, science alone is unable to provide adequate answers. From a scientific perspective, all life, including all human life, can just be reduced to biochemistry which does not have any inherent value or reason to survive. Further, any position on the value of human life is usually grounded in essentially improvable assumptions which may all have validity in their own right. Consequently, society in general is unable to reach a consensus about the moral status of the human embryo or foetus.[1]

Equally intractable is the associated debate about human dignity. The bioethicist Ruth Macklin famously argued in 2003 that the concept of human dignity is not useful, since in her mind, the concept is both imprecise and worn-out.[2] In contrast, the legal ethicist Roberto Andorno has contended that a robust conception of human dignity is the only solid foundation for future bioethical legislation.[3] Space constraints prevent an adequate development of the debate, not to mention a substantive, fresh contribution. However, referencing inherent human dignity serves at least to highlight a common argument against abortion and, in the same way, against eugenic practices that destroy any form of living human being.[4]

In addition, since international legislation does employ the concept of human dignity, it may be that supporters of the notion far outweigh its detractors. This international support suggests that the academic critics of human dignity would do well to consider that any universal respect for the human person is also likely to require a universally binding ethical principle which can be considered as an alternative to human dignity. For this reason, if inherent human dignity is to be rejected as an ethical foundation, the onus falls on its detractors to conjure an equally effective and meaningful overriding principle if a civilized society is to survive. Until this happens, inherent human dignity remains an essential safeguard against any theory or practice that would construct a hierarchical or unequal value between human beings. This is because the concept of universal human dignity equalizes the worth and rights of all persons as being shared by every member of the human family. In this way, it may also impede those who would suggest that certain human beings are to be considered less worthy of ethical treatment.

Reduction in Scope of Reproductive Choice

A second objection to eugenic procedures concerns the possible limitation of genetic variety in a society or community.[5] As an increasing number of parents opt for eugenic practices, they would eventually limit their selection to a restricted set of characteristics for future children which conforms to more 'acceptable' norms or deselect embryos or foetuses that do not conform to these norms. But in so doing, they would also contribute to the homogenization of genetic traits in society. In other words, there are concerns that a widespread acceptance of eugenic practices could reduce the scope of reproductive choices so that eventually only people deemed physically superior would reproduce. Society would eventually only be populated by people with this high calibre of characteristics.

In the distant future, as selected children mature and seek their own reproductive partners, they may also face a limited choice since today's genetic diversity will decrease as more children are created out of eugenic motivation and thus have similar biological characteristics. From another angle, reproductive eugenic selection might even be construed as coercing choice for future generations since, in a very real way, individuals will not have as large a choice of reproductive partners as their forbearers. Ironically, then, eugenic selection may limit the freedoms of future members of society while today it is proposed as the exercise of reproductive freedom. To be clear, however, it is impossible to demonstrate that genetic variety is in any way morally superior to genetic similarity. The core to this objection is then ultimately based on a limitation of choice of reproductive partners in future generations.

Interfering with Nature or 'Playing God'

One objection to eugenic selection deals with concerns about interrupting the natural manner in which human life comes into existence. These objections encompass both religious and secular unease. From a religious perspective, some people believe that selections, such as artificially choosing the sex of a child, violate the divine prerogative to determine a person's gender. Under this argument, tinkering with genetic selection in this way is tantamount to 'playing God', something which a number of people of religious faith find inappropriate. The 2002 UK HFEA report entitled *Sex Selection: Choice and Responsibility*[6] quotes the opposition of one Muslim man: 'It's saying you know better than what Allah wanted for you.'[7]

The secular form of this concern has a similar emphasis but without invoking a deity.[8] It recognizes that humanity may be affected by a sense of hubris, i.e., a certain amount of pride, arrogance and false belief in its own capacities while insisting on its right to use these abilities without properly understanding their possible consequences. The argument about not playing God accepts that parents have not, until now, controlled the biological characteristics of their children but humbly accepted, instead, the result of the natural lottery. By this argument, resisting the desire to interfere with this natural way of bringing forth children would reflect a surrendering of any control over the child and would encourage parents to accept their children unconditionally from birth. Further, this reasoning supposes that the balanced equilibriums of nature should be respected, not least because any deviation from this may have unforeseen and potentially irreversible consequences.

Widened Definitions of what Counts as a Disorder

Grave concerns relating to eugenic procedures also arise because selection procedures may contribute to a widening of the definition of what counts as a serious physical disorder. This is important since, in the United Kingdom, disability provisions already permit abortions to be carried out until birth.[9] The ambiguity of what counts as a 'serious' condition worthy of termination has already affected a notable interest group of society: those with Down syndrome. In 2006, the UK newspaper *The Telegraph* reported that the number of abortions for this condition had already reached record levels, with 92 per cent of all foetuses diagnosed in utero being terminated.[10] Since 62 per cent of all Down syndrome cases are detected in utero, this figure means that 57 per cent of all foetuses ever conceived with Down syndrome were aborted, though some variation in this rate has recently been observed.[11,12] One of the reasons for the high rate of termination for foetuses with this disorder is that consenting adults and medical professionals have considered Down syndrome sufficiently serious as to warrant an abortion. In contrast, a 2011 study has shown that when the parents do keep their child with Down syndrome, 79 per cent believed that their outlook on life was more positive because of their child.[13]

Another UK newspaper, the *Sunday Times*, reported that between 1996 and 2004, more than twenty babies in the United Kingdom had been terminated after twenty weeks because scans indicated they had club feet. A further four were aborted because they had webbed fingers or extra digits. This created a certain amount of controversy when the figures were published since these conditions can all be appropriately corrected through surgery or physiotherapy.[14] This same *Sunday Times* article interviewed David Wildgrove, the father of a boy born with club feet. Prior to the boy's birth, he was asked to consider an abortion for the foetus when the club feet were detected. Reflecting on the incident for the interview, Mr Wildgrove was quoted as being 'appalled'.[15] These examples demonstrate that the seriousness of disorders needs to be carefully defined and explained if the concept is not to be abused; something that will now be attempted.

Disability

In seeking to clarify the relevant terms, it may be appropriate to begin with the concept of 'disability' itself, though this is no easy task since the literature on disability actually offers several definitions.[16] An adequate understanding of disability, moreover, does not only include a physiological or clinical condition but also contains a marker of social relationship between an individual and society. Among other current proposals, the recent welfare-based definition of Savulescu and Kahane describes disability as something that (1) considerably reduces the wellbeing of an individual when compared to other persons or (2) makes it impossible or very difficult for an individual to carry out a natural human ability.[17]

While the welfare-based definition is an attempt to formulate a nuanced approach, it may not be entirely satisfactory since it overlooks the individual's own opinion. It also overstresses the comparative element in the measure of relative disability. That said, objective standards of disability are often absent in many official guidelines, as is any awareness of the so-called disabled person's perspective on his or her condition.[18] Still, to be practicably helpful, a definition of disability should have some concrete attributes. In this regard, the work of the World Health Organization (WHO) is helpful for providing concrete measures for disability. In 1980, the WHO published the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH). This influential document filled a void in the world of healthcare, not least because it provided definitions of key terms. For example, the ICIDH stated that disability could be characterized as 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'.[19] Another feature of the 1980 ICIDH document was the sustained reflection on the severity of disabilities. To address the challenging process of distinguishing between varying degrees of severity, the ICIDH offered seven concrete levels of disability, ranging from '0 – not disabled' to '6 – complete inability'.

When the ICIDH definition was published, it was welcomed for addressing a growing global awareness of disability, but it also attracted a healthy measure of criticism for framing the concept in a manner that was independent of context.[20] As a result, the WHO revisited the ICIDH in 2001 and provided a substantially revised guidance on the health and function of the human body which was more acceptable to disabled people because less dependent on the medical model: 'Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).'[21]

Ultimately, it is difficult to frame a definition of disability based on either purely social or biological considerations. For this reason the discussion of disability is characterized by its fluidity because what counts as a disability may vary from one individual to the next. For example, in 1999, the UK Human Fertilisation and Embryology Authority (HFEA) presumed to speak for the British population in noting that 'most people' would consider the lower levels of the 1980 ICIDH as representing a minor disability, while levels three and higher would count as a significant disability.[22] But in couching its opinion as representing a majority of the population, the HFEA inadvertently highlighted the continued lack of objectivity in discussing disability.

Another concern with the HFEA report was its reliance upon the 1996 guidance produced by the Royal College of Obstetricians and Gynaecologists (RCOG).[23] In response to criticism and developments in disability studies, the RCOG updated its guidance entitled *Termination of Pregnancy for Fetal Abnormality* in 2010 with an emphasis that discussion of disability should take into account the likelihood that a person with disability may experience difficulties exacerbated by the disability. Thus, according to the RCOG in its report on the termination of pregnancy for foetal abnormality, medical professionals should consider the following factors in making their assessment:

- the potential for effective treatment, either in utero or after birth;
- on the part of the child, the probable degree of self-awareness and of ability to communicate with others;
- the suffering that would be experienced;

- the probability of being able to live alone and to be self-supportive as an adult;
- on the part of society, the extent to which actions performed by individuals without disability that are essential for health would have to be provided by others.[24]

However, these characterizations of a serious disability have been criticized for setting an impossible, overly objective standard. Reflecting on the RCOG abortion guidance, legal ethicist Rosamund Scott has called for a less clinical and more social perspective on disability, arguing that the role played by a person's community should be taken into account in any decision about the presence of a disability.[25] By Scott's approach, a person's medical condition may be considered as a disability, in part, based on the support he or she receives but the opinion of the individual remains crucial. By this reasoning, a person whom society considers disabled may not see himself or herself as such. Deafness, for example, may not appear on everyone's list of disabilities, particularly for those who are themselves deaf.[26]

In summary, both in the present consideration of eugenics and in disability studies more generally, fruitful discussion of the term 'disability' is inextricable from the related matter of seriousness. Consequently, before any concluding considerations are made a look at the 'seriousness' of a disorder is necessary.

Seriousness of a Disorder

As with 'disability', what constitutes the 'seriousness' of a disorder is seldom clear. As the UK House of Lords remarked in 2002, '[I]t is uncertain whether it means serious for the individual or serious for society.'[27] Similarly, in 2003, the US President's Council on Bioethics noted that, with advances in selective technology, '[I]t is likely to prove impossible to draw a clear line between identifiable serious disorders and those disorders that parents might (or should) be able to find acceptable.' Perhaps giving further reason for concern is the ambiguity that shrouds 'what resources society will be able to draw upon to assist parents in making such important decisions'.[28] This means that if a eugenic selection is made that is considered to be acceptable based on the seriousness of a disorder, the question then arises, on what basis do healthcare professionals distinguish the serious from the nonserious?[29] Is it not likely that an exhaustive list of serious disorders would be difficult to frame satisfactorily? There are at least four reasons for this difficulty.[30]

Disorders May Vary

First, many disorders occur in different degrees of seriousness. Just as the common cold may affect one person more aggressively than another, so disorders differ in their expression between individuals. The same disorder can also be expressed in different ways. In one individual, for example, cystic fibrosis may lead to death in childhood, while others affected by the disease may live into their thirties or later.[31] Similarly, some individuals with cystic fibrosis respond well to medical treatment, enjoying relief from symptoms and even longer life, while others do not. To account for gradations of seriousness, the following four characteristics have been suggested which can be used to determine whether a genetic disorder is serious[32]:

(1) The effectiveness of treatment
(2) The manner in which it affects the child and family
(3) The age at which the disorder is expressed
(4) The probability that an individual, who is a carrier of a genetic disorder, will eventually develop the associated illness.

As the knowledge of the genetic basis of disorders increases, such characteristics may, however, need to be reassessed if they are to remain appropriate and relevant taking into account the possibility of new treatments arising.

Perceptions May Vary

A second challenge for defining seriousness is that individuals and families may perceive disorders, pain and suffering differently. For instance, one person may find the noise of sixty decibels (as in normal conversation) to be tolerable, while another may wince with pain. If a similarly objective scale were applied to biological disorders, comparable results could be obtained. In this way, a person whose condition measured a 5 out of 10 might tolerate the associated discomforts, while another may find the same condition entirely debilitating.

Two related issues are the mechanism for determining the seriousness of a child's disorder and who should decide. Should it be the prospective parents, the physicians or the indefinite organism called 'society' or maybe a combination of these parties? Individuals, who have experience of a disorder within their family, including parents who already have a disabled child, will undoubtedly have specific but also variable views. First-hand knowledge of a disorder will account for factors that a purely clinical approach cannot foresee. Indeed, the latter may largely, if not entirely, preclude individual perceptions. The disparity between professional and personal perceptions may then result in an inconsistent approach to defining the severity of a disorder. As a result, a eugenic procedure may be permissible in one setting but not in another.

If these considerations were not complex enough, defining disability becomes even more difficult in light of reproductive technology. This is because as soon as a couple asks a third party, such as the state, for assistance with reproduction, this third party has a responsibility and therefore also a say in the procreative process. Hence, if a third party, such as a government that represents the views of the general public, objects to a procedure, it does not have a duty to comply with the wishes of the would be parents. In other words, even though it is generally recognized that the views of those directly affected by a medical condition should be given substantial weight, they may not always be best placed to judge a condition, including its seriousness. For example, it is likely (and understandable) that people confronted with decisions about disability will primarily consider their own interests rather than the wider implications for society of their actions. This means that, for the good of society, decisions relating to eugenic practices should account for all relevant ethical considerations, including those of society. Consequently, the parties requesting treatment should not be exclusively responsible for deciding the seriousness of a condition.

Still, stipulating the level of input from people seeking treatment is difficult. On one proposal, a committee comprising persons directly affected by the condition, medical practitioners experienced in working with affected people, and impartial professionals drawn from *inter alia* medicine and ethics could adjudicate decisions. Ethical issues involved with each condition for which prospective parents seek a selection procedure would then be the primary focus of the committee. But regardless of specific mechanisms for determining seriousness, the voice of people with disabilities is of vital importance. In this regard, it should be noted that some of the most passionate objectors to the use of selection procedures, such as embryo selection, are disabled persons. As examined later in this study, this is because disabled persons often take offense that society should judge their lives as not being worth living. Admittedly, proponents of selection procedures may protest that screening embryos (i.e., future individuals) for disorders does not actually constitute a judgement against people already living with disability. But, regardless of intention, disabled persons may feel concerned.

Definitions May Discriminate

A third hurdle for a unanimous understanding of severity is that precise definitions might be perceived as discriminatory by some interest groups who have their own specific perspective of values or concerns. The World Health Organization definition of disability strongly suggests that this concern is not merely theoretical. Developments in genetic research have already alarmed disability rights groups, when certain procedures are used to deselect an embryo or foetus that is considered to have a serious disorder.[33] As the Council of Europe recognizes, screening against disability may 'undermine the equal value of human beings' and may be prone to occur under the pretence of objectivity rather than recognising 'that notions like "severe genetic diseases" are social constructions reflecting the misperceptions of those "temporarily able"'.[34] As an alternative to selective procedures, disability groups propose increased societal and familial support which, they suggest, will eventually erode what they consider to be artificial and dangerous definitions.[35]

If, under a restrictive definition of 'disability', selection eventually gives rise to stigmatization of and/or discrimination against certain sections of society, a broader definition will likely bring even further frustration for people with disability. At the same time, refusing to define 'disability' poses its own problems, even threatening the autonomy of the prospective parents by restricting consideration of matters that may preclude an informed decision.

Risk of Inflexibility

Finally, a fourth obstacle to objective identification of serious disorders is that, once made, definitions tend to be inflexible even if new treatments appear. This is because whether in law or medicine, altering an established principle often requires extraordinary effort on the part of interested parties. There is a fear that equally robust challenges to the definitions will prevent a smooth updating of legal descriptions about severity, and consequently, it is unlikely that satisfactory definitions could be developed.[36] Moreover, an inflexibility relating to the seriousness of a disorder may not reflect the reality of the dysfunction. The seriousness of an illness may also vary for many reasons and cannot just be reduced, in most cases, to the existence of a specific definition.

How Should the Seriousness of a Disorder be Considered?

In summary, these four considerations highlight the distinct challenge of adequately defining the 'seriousness' of a disorder and, in turn, of constructing an appropriate list of severe disabilities. Even from a nonbiological perspective, Kay Chung from the UK Progress Educational Trust observes, 'The burden of a condition varies in degree according to any number of social reasons of which the most obvious are financial, cultural and psychological.'[37] Nonetheless, the fact that such a list of severe disorders does not exist generates the additional problem of highly subjective decisions and disparate practices. With no formal direction, practices will vary wildly, leading to confusion and even abuse. Although difficult and very likely to frustrate certain parties, some effort to define 'severe' is important.

As the World Health Organization's disability definition suggests, a nuanced account of what counts as disability or severity requires awareness of social norms.[38] Indeed, disorders that society now considers nonserious were deemed severe in previous generations.[39] Thus, these criteria must be employed cautiously, and any disorder now labelled 'severe' should be reviewed regularly since medical progress will continue to eliminate concerns about the restrictive power of disorders.[40]

In summary, eugenic selections may complicate ethical matters by expanding the definition of 'disabled' and 'serious' to include conditions for which medical treatment may already be available or conditions that do not necessarily meet accepted standards for seriousness, such as a foetus with club feet. This is because criteria for defining the terms 'serious' and 'disability' are highly debatable and nebulous. Until universal definitions emerge, therefore, a decision about whether an eventual eugenic selection may be ethically acceptable to some people will likely be as elusive as the definitions.

Pressures from Society

To this point in the book, societal pressure has featured more than once as a potential concern with eugenic selection procedures. Accordingly, there is a risk that prospective parents may begin to feel indirectly coerced by society to pursue selection procedures in order to meet cultural expectations. The widespread availability and practice of these procedures may eventually change standards for what is considered 'normal'. Furthermore, the more options become available to a person does not necessarily mean that he or she is provided with a greater freedom to act because of a number of pressures which may restrict certain choices.

These pressures may have several consequences for the whole of society. The first – that societal pressure leads to stigmatization – is the subject of the next section. The second possible consequence is that society may (directly or indirectly) pass judgement on parents if their children do not meet certain health criteria. This concern stems from an analogy with the common and current practice of often praising parents for their children's appearance or innate skill, suggesting that parents may also be held responsible for failing to produce healthy children.[41]

At least one preliminary study has already attempted to trace a relationship between physical disorders and perceived parental responsibility for the disorders. In the study's first scenario, a pregnant woman was offered but declined a test for Down syndrome, while in the second, no testing was available. In both scenarios, the woman subsequently gave birth to a child with Down syndrome. The study's results indicated that many of the participants, randomly selected from the medical field and the general public, believed that the woman in the first scenario was more responsible for the genetic disorder of her child than the woman in the second scenario.[42]

While the researchers recognize the limitations of their study, their tentative conclusion reflects the case made here regarding the possible negative consequences of selection procedures. This concern arises when parents opt to pursue a perceived solution with which they may be uncomfortable, rather than maintaining their own ethical compass. To put it more simply, the problem surfaces because they would be influenced by peer pressure and the right to exercise their conscience would erode.[43] As the legal ethicist Shaun Pattinson observes, 'The empirical evidence does indeed suggest that gradually increasing social pressure is a realistic consequence of widespread trait selection. This social pressure is also likely to be directed towards children with the undesired genes, rather than being restricted to the parents of such children.'[44] In this scenario, the freedom to choose, so prized by proponents of selection procedures, would paradoxically be limited to those who choose to select while the choice *not* to select would be undermined.[45] In a survey, published in 1995, already more than 10 per cent of obstetricians in England and Wales believed that society should not be expected to cover the costs of specialized care for children with severe disability when parents refused prenatal diagnosis.[46]

As David King argues, 'It will be seen as irresponsible and cruel to even consider bringing a disabled child into the world. We may soon start to hear that every child has the "right" to a healthy genetic endowment.'[47] In short, once different eugenic procedures become commonly acceptable in a society, parents may eventually have no choice but to use them if they want the best for their children as they compete against other improved children.[48] In other words, if a certain amount of choice is given to parents, as is suggested with liberal eugenics, then there may still be a certain direction in which eugenics is driven which, if not controlled by the state, will still be restrained by public opinion and market forces.[49]

To be fair, the possibility of misapplying blame does not, in itself, constitute a substantial ethical objection to eugenic procedures. However, as noted in the previous section, society has a responsibility to protect all its members, even those who are perceived to make the wrong decision. This means that to maintain the ethical highroad, society should consider the serious dangers that may exist if and when selection procedures become the societal norm and expectation.[50]

Fairness

Another objection to the selection procedures of the new eugenics concerns the issue of fairness. The heart of the problem, here, is whether these procedures support the principles of impartiality, equality and lack of prejudice. From the outset, this objection may meet resistance since, after all, fairness is a controversial topic open to numerous critiques in its own right. Thus, while recognizing potential problems with the notion of fairness, this section will offer little outright rebuttal, focusing instead on a development of the two strongest strands of the argument.

Fairness and the Open Future Argument

Making a decision for another person is often a complex and difficult undertaking, especially when it concerns a prospective child. Of course, parents regularly make such decisions for their offspring once they are born and until they reach the age of consent or even later. This usually happens with the best of intentions for the child and is generally accepted by society. But because both the children and the parents are part of society, legislation enacted by this society can also direct what may be in the best interest of a child. This means that societal interventions may take place to protect a child from something that society believes should not occur. One of the factors that is taken into account when considering such decisions is the manner in which an intervention may affect a child's future capacity to choose. This suggests that, though it may sometimes be necessary to curtail a child's freedom in certain circumstances, it may also be seen as appropriate to seek to facilitate a child's future freedom to make his or her own choices.[51]

In light of this, the first strand of the fairness argument concerns the future of the potential child. In short, it suggests that selection procedures for the presence or absence of particular qualities may determine a child's future in an unacceptable manner, preventing the child from defining his or her own freedom to choose when he or she grows up. The core of the problem rests on the opinion that selection has a narrowing effect and thus hinders a child from 'maximizing his chances for self-fulfilment'.[52]

According to this argument, when parents impose their own preferences on their children, they become the architects or bio-designers of their children's future. In so doing, the parents refuse an 'open future' because they prevent their children from choosing their own lives. Instead the children are restricted to the bio-design of a third party and to a form of unacceptable genetic control of one generation over the next.[53] As the argument goes, in this situation the child may have grounds for complaint. For example, if parents select for a son with brilliant musical aptitude, the child may protest that his gifts, and thus his likely future, were predetermined by his parents. Yet not all complaints may come from the children who were actually selected since some unselected children may resent the fact that they do not have the genetic capacities that their peers received. Within this context, there is then a risk that a selected or unselected child may be brought into the position of being a judge over the biological tastes and values of his or her parents.[54]

The German ethicist Jürgen Habermas offers an apt summary of the key issue:

> Exercising the power to dispose over the genetic predisposition of a future person means that from that point on, each person, whether she has been genetically programmed or not, can regard her own genome as the consequence of a criticizable action or omission. The young person can call his designer to account, and demand a justification for why, in deciding on this or that genetic inheritance, the designer failed to choose athletic ability or musical talent, which would have been vastly more useful for the career that she had actually chosen to pursue.[55]

Children, like young animals of other species, instinctively interact with their parents in a spirit of trust, appreciating and accepting parental direction. By Habermas' reasoning, however, the existence of selection procedures violates the natural order of parent-child relationships by giving children a legitimate reason to question their parents' choices. The sense of safety that naturally flows out of children's trust for their parents is weakened.[56] This opens children to a relational wasteland in which the innocence and security of early years has dissolved, leaving them bereft of allies and forced to contend for their own rights. But a healthy human development depends on a healthy relationship between child and parent. Thus, any action that prevents this relational health may be morally dubious. In the same vein, Leon Kass is critical of the control parents may have over their offspring in the context of selecting (when possible) for a certain kind of clone indicating that:

> The child is given a genotype that has already lived, with full expectation that this blueprint of a past life ought to be controlling of the life that is to come. Cloning is inherently despotic, for it seeks to make one's children (or someone else's children) after one's own image (or an image of one's choosing) and their future according to one's will. In some cases, the despotism may be mild and benevolent. In other cases, it will be mischievous and downright tyrannical. But despotism – the control of another through one's will – it inevitably will be.[57]

But the 'open future' argument gives rise to a number of questions. One objection to the argument is that it trades on an ambiguity about what actually constitutes an 'open future'. Further, it is unclear at what age a child may no longer be entitled to this openness but may be held responsible for the path his or her life will take.[58] Another argument questioning the 'open future' concept is the fact that no child enters this world with a completely open future. In the earliest stages of embryonic creation and prenatal development, every child receives a limited number of specific biological traits with the genetic lottery constraining every member of the human species. As John Harris put it in his 2006 book *Enhancing Evolution,* '[W]e are all in the position of having had "the way we are" determined by a combination of the acts and omissions of our parents and others with whom we have interacted since conception.'[59] At the same time, environmental influences play a very important role in who an individual becomes, especially if many selected genes only have a limited impact on the physical makeup of the person. Children may even deliberately seek to counter or neutralize, in their wilful behaviours, any genetic design their parents may have given them with the corresponding expectations.[60] In addition, it could be argued that children would have a far greater potential for self-fulfilment if they were free from a debilitating disorder which would put severe restrictions on their lives.

As noted in the earlier discussion of wrongful life, protests of this kind relate to what is known as the 'non-identity problem'. In short, this philosophical dilemma emphasizes the difficulty of drawing ethical conclusions about a person who does not yet exist if those conclusions will result in the person not actually existing. For example, a girl cannot legitimately complain that her parents selected her for her gender because, had they not, she would not have existed. Here the nonidentity problem aims to show that the 'open future' argument is an inappropriate argument against the new eugenics. This is because the set of biological characteristics with which each person is created is part of who they are in their identity and very existence. Children cannot then complain about not having an open future since, had they not been born with their own set of biological characteristics (whether determined by their parents or by chance), they would not exist to bring a complaint.

Finally, one may suggest that orchestrating a child's development in the prenatal stages of life is no different from controlling a child's development after birth. For instance, moral instruction generally encourages a child to embrace certain principles and reject others, and this type of control meets with little opposition.[61]

Opponents of the open future argument thus question why what may be similar to instruction before birth should be opposed in any way.

In reply, it is possible to note that there is, to some extent, a qualitative difference between biological predetermination and social determination. This is because the former rigidly directs a person's very existence, as such, whereas the latter only conditions his or her existence.

To conclude, the 'open future' fairness argument has been challenged by a number of serious concerns and arguments. However, it may still be useful, in some measure, when slightly reformulated; seen differently, the 'open future' argument may propose a compelling critique of selection procedures by returning to the parent-child relationship. From this perspective, the problem with selection is not that it inordinately directs a child's future but that, from the outset, it introduces detrimental qualities of control and conditions to the parent-child relationship that fundamentally alters the child's life. In this way, the 'open future' argument anticipates an upcoming section of this book that examines unconditional acceptance by the parents as an argument that may be used against the procedures of the new eugenics.

Equal Access to Eugenics

The second part of the fairness argument focuses on the future of society. This part of the discussion recognizes that, for good or for ill, financial resources are not usually spread evenly across the general public. Consequently, some individuals may be unable to afford selection procedures that are too expensive. As with all technological developments, the cost would certainly exceed what some people could afford. Thus, unless limited to those who had the appropriate means, the procedures could become a serious financial drain on the resources of an already fragile economy.[62] The financial intervention of healthcare providers introduces another interested party into the already complex web of bodies with a stake in selection. In itself, this factor may already be a significant objection to selection because a matter which is as personal and private as the creation of life should normally only be limited by the couple concerned.

More seriously, however, the cost of selection may also lead to a genetic inequality amongst future individuals though in some respects, it should be noted that this unfairness already exists in many other arenas of public life. Any individual who accepts the right of parents to put their children into an expensive private school or hospital cannot use the fairness argument as a reason for rejecting the use of biological selection. But the central point of this fairness argument emphasizes that these inequalities should not be strengthened or encouraged in any way. A society should not attempt to further divide itself into what the legal ethicist Maxwell Mehlman called the 'genobility' and the rest.[63] In this regard, the possibility for a society to be divided between a biological elite with increased intelligence and other physical characteristics who would have power over a biological underclass was already suggested by Plato in his book entitled *Republic.* In this case an elite class of 'Guardians' would be formed through selection which would be restricted from any reproduction with ordinary individuals.[64] This would, in a way, be a society similar to what already exists in countries such as the United Kingdom with its aristocratic upper classes which still have considerable political power in the House of Lords. Until very recently in the United Kingdom, marriages generally only took place between individuals of the same upper class in order to preserve the 'blue' or noble blood. In other words, this powerful biological aristocratic upper class was considered as being superior in some way, and it was, therefore, seen as reasonable for them to reproduce amongst themselves. They also enjoyed the financial wealth and advantages that their positions provided.

In this regard, the US President's Council on Human Bioethics has noted that in a genetically stratified society, it may only be the rich who enjoy the privilege of genetic health if eugenic procedures are accepted, given the extraordinary cost of procedures.[65] Consequently, the sufferings of the poor may be multiplied by the same eugenic developments since they would have to contend with discrimination for genetic heritage in addition to the discriminations they already experience because of their economic situation.[66]

In response to this form of the fairness argument, the ethicist Ronald Green has suggested that inequality is not necessarily always detrimental to society. Instead, he argues that a measure of inequality may actually give rise to some advantages. For instance, Green suggests that just as philanthropic organizations help and assist the economically poor, so Mehlman's 'genobility' may act beneficently towards the genetically poor in a way that is currently not possible. In short, according to Green, a certain measure of genetic inequality should not be the basis for alarm.[67] But in pleading for an acceptable inequality, Green's proposal may mean limiting selection procedures which should be freely available for all, to only a few privileged individuals making the whole practice seem less than beneficent.

Philosopher Michael Sandel also emphasizes the principle of equality and solidarity in society, arguing that any positive genetic trait in a person should be availability to all. To Sandel, society should be a place in which inequality is resisted by independent equals who work together to use their different gifts to the benefit of the community. He writes:

> If our genetic endowments are gifts, rather than achievements for which we can claim credit, it is a mistake and a conceit to assume that we are entitled to the full measure of the bounty they reap in a market economy. We therefore have an obligation to share this bounty with those who, through no fault of their own, lack comparable gifts. Here, then, is the connection between solidarity and giftedness: A lively sense of the contingency of our gifts – an awareness that none of us is wholly responsible for his or her success – saves a meritocratic society from sliding into the smug assumption that success is the crown of virtue, that the rich are rich because they are more deserving than the poor.[68]

Another response to this form of fairness argument recognizes that humanity is already divided. For example, people are already categorized on the basis of whether they are infected with HIV/AIDS or whether they have clean drinking water. But it is difficult to imagine a compassionate and rational person objecting to providing help for the sick unless a treatment became economically available to absolutely all those who needed it. For instance, if a cure for HIV/AIDS became available, with enough doses for only 10 per cent of the over 30 million people with the disease, only very few (if any) would object to distributing this treatment to only 10 per cent of the patients even though the other 90 per cent would get nothing. In other words, even though an action may seem unfair, it may still be appropriate to help some individuals.[69] By this reasoning, the fairness argument is weakened because aiding individuals through selection procedures is preferable to aiding no one. As Nicholas Agar recognizes with respect to the costs of eugenic procedures, 'To insist on universal access would be, in effect, to ban all but the most rudimentary enhancement technologies.'[70]

The Challenges of Reducing Unfairness

The increasing costs of producing new eugenic procedures may exacerbate the differences between individuals who can afford to acquire a biological advantage in a competitive environment and those who are too poor to afford the treatment. But, as already indicated, this situation is not a new one since the wealthy already have advantages such as private healthcare and superior education, though a lot depends on the rest of the assumed social and political contexts. This means that the introduction of eugenic procedures into a society may only be of concern if it did not already have procedures in place seeking to redress any nonegalitarian tendencies. For example, if selection procedures eventually gave rise to a small elite group of privileged persons who flaunted and enjoyed their superiority, while disregarding the rest of society, then it is very unlikely that the majority (those not in the elite) would assess the situation positively.[71] This form of unfairness may even be compounded if the resources devoted to the enhancement of the elite are diverted from aiding the poor. To address this unbalance society may then decide to restrict selective enhancement though creating and justifying a feasible mechanism for such restrictions may pose immense challenges.

Discrimination Against Disability and Suffering

Another argument against the procedures of the new eugenics concerns the likelihood of discrimination against people with disabilities. Discrimination on the basis of disability according to the 2006 UN Convention on the Rights of Persons with Disabilities means:

> any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.[72]

To understand the discrimination argument in the context, for instance, of reproductive eugenics, a distinction between two types of reproductive rights should be emphasized. The first are fundamental reproductive rights which concern the question of whether to create a child in the first place; these rights are generally acknowledged and respected in international legislation. In contrast, substantive rights concern the question whether specific characteristics may be intentionally selected in a child.

It is generally agreed that regulations may legitimately limit substantive reproductive decisions without undermining the more basic and legally protected fundamental reproductive rights which are negative rights, i.e., there is a freedom of the person not to be interfered with by the state.[73] Thus, the decision to procreate a person is a qualitatively different decision than the one of selecting between persons.

In this regard, the ethicist Stephen Wilkinson defines selective reproduction as 'the attempt to create one possible future child rather than a different possible future child'.[74] Admittedly, this definition is broad, emphasizing the fact that no characteristic of a person or child would be modified; only a choosing between different possible future persons would be taking place. But any selective action in reproduction is not just a selection against a disorder or for a positive trait in a future person; rather, it is a choice between different persons, as such, even if they are sometimes only theoretical or imaginary and do not in fact exist when the decision is being made.

Of course, there are no ethical consequences for a prospective parent to imagine or desire different possible future children who, as already mentioned, are imaginary persons. Nearly all future parents long to have healthy as opposed to disabled children. However, when prospective parents initiate specific and concrete decisions to select between real or even imaginary children they make a public, factual and very definite discriminatory appraisal. While they may not discriminate against existing persons, as such, if they remain imaginary, the actual decision still remains a discriminatory decision which is very real.[75]

This type of critical evaluation is similar to what prospective adoptive parents may experience if an irresponsible adoption agency is not careful to put the needs of a child as a priority. Indeed, if the interests of the child to be adopted are not paramount, then adoptive parents may establish criteria for their possible future child, such as good physical and mental health, sex, age or ethnicity. Of course, when prospective adoptive parents make these decisions, the possible future child that they want to adopt may only exist in their imagination and not in reality.

They are not, therefore, discriminating against any existing person in particular. However, their decision to initiate an adoption process by selecting between persons with specified biological characteristics can be considered as a discriminatory decision if no justifiable reasons are present.[76] In other words, it is the possibility of 'choosing' that is at the core of the problem in any kind of selection process of real or imaginary persons since most choices reflect, to some extent, a preference. Moreover, any decision in this area may already reflect the set of values of a person. This means that an act of discrimination would betray a person's willingness to weigh the significance of one child's life and existence over another on the grounds of the child's biological characteristics.

Obviously, the possibility of choosing reflects an individual's right to autonomy, but it also reflects this individual's moral values or ethical principles. Furthermore, the act of selecting a child is a decision that inevitably becomes public and may even become publically acceptable which could then entail dangerous consequences for the whole of society. In turn, both the disabled and nondisabled communities may assume that a certain amount of discrimination against the very existence of some disabled persons is acceptable, though it is not always easy to interpret the unintentional messages that may be received by individuals.

But not all discriminatory decisions involve reproductive procedures. For instance, a couple may forgo procreating children of their own because they are both carriers of a serious genetic disorder. Exercising this right not to have children, however, may still send a message that certain existing persons should not have existed which may be negatively perceived by those who are affected by a similar disorder. Admittedly, a decision by parents not to have a child is fundamentally different to the one that arises in selection, but it may still reflect a similar kind of thinking. If the previous couple who decided not to have a child because of the risks of disability, agreed, instead, to adopt a child, what would happen if the adoption agency enabled them to choose between a healthy child and another one who is affected by the very same disorder that the couple decided to avoid in foregoing procreation? Would not their decision to select between the two children again become very real? This decision would also reflect their set of values that influenced their decision not to have a child in the first place.

In these circumstances, if the couple eventually decided to relinquish the decision to choose between the two children to the adoption agency, then the parental decision to select between persons, as such, would not be involved. On the other hand, if the couple did select between the two children being put up for adoption, then this will publically reflect their values. In other words, it would be a decision (if it became public) that would certainly be of interest, and of consequence, to people who already live with the disorder in question. Thus, an important objection to eugenic selection relates to how people with disabilities may be indirectly affected by a societal acceptance of widespread selection. In other words, the fundamental concern of this objection is that eugenic selection may lead society towards a direction that may, arguably, devalue and discriminate against disabled persons.

Advocates of the new eugenics demur, however, pointing out that it is important to distinguish between a particular genetic disorder and the person having that disorder. They suggest that an ailment may be valued negatively, but the person with the disorder may be valued positively. By this reasoning, there is no conflict of interest between attempts to eradicate a disorder and the help afforded to those who are affected by the same disorder. As Stephen Wilkinson puts it, 'There is nothing wrong with assigning a negative value to the functional impairment aspects of disability and this negative valuation of impairment does not entail and need not be accompanied by any negative valuation of the *person* [italics original] with the impairment.'[77] David Galton makes a similar point in arguing that prohibiting such eugenic selection on the basis of a risk of discrimination towards individuals with a disability who already exist would be similar to stopping children at risk of polio from being vaccinated to prevent paralysis. This is because existing adults, who have already a dysfunctional leg from a previous infection, may feel discriminated against and undervalued.[78]

The German Ethics Council's report on preimplantation genetic diagnosis, published in 2012, also argues that:

> [P]arents with a genetic risk who already have a child with a disability … cannot be accused, if they express a wish that their second child may not have a disability, that they wish to reject or humiliate the first child. It is argued that prenatal practice and postnatal reality must be distinguished in principle.[79]

However, though well-intentioned, these arguments are not convincing since making sure that certain disorders are not brought into existence through eugenic selection means making sure certain persons with these disorders are not brought into existence. And such a statement is clearly discriminatory.[80]

Thus despite reassurances,[81] it is difficult to understand how, on the one hand, it is possible to affirm that a certain disorder should not exist while, at the same time, insisting that such a position would not have any negative consequences on how persons born with the same disorder are perceived. Persons born with a disability may recognize that their disorder is part of who they are as persons and is associated to their very existence including the origins of this existence. In other words, the argument does not account for the intimate connection between a person's identity, the origins of his or her existence and his or her disability.[82,83] The Chief Executive of the UK Cystic Fibrosis Trust explained, in 2003, that data relating to preimplantation diagnosis or prenatal tests amongst families at risk of having children with this very serious disorder was difficult to obtain. This was because 'Families obviously feel that a child already born affected by Cystic Fibrosis may feel unwanted if they know their parents have made a decision of this nature in relation to a subsequent pregnancy.'[84] Thus making sure certain disorders are not brought into existence will certainly give a worrying message to persons, who exist with such a disorder, that they should not have been brought into existence. As the Disabled Peoples International statement on 'the new eugenics' explains on the issue of prenatal selection, "The underlying reason for prenatal screening and testing is the elimination of the impaired fetus. This sends a discriminatory message to say that disabled people's lives are not worth living or worthy of support.'[85] Didier Sicard, past president of the French National Consultative Ethics Council, also indicates that "Concern for the other may first mean recognising his or her right to exist".[86]

A similar point related to the necessity of existence of a child in whom a disorder is present is made by the moral theologian and ethicist Oliver O'Donovan in commentating on abortion, remarking:

> But that the interests of a fetus which might achieve life outside the womb, though under a disadvantage, could be served by destruction, is a most obscure claim. And the obscurity is deepened when the argument from compassion is combined with the insistence that the fetus is not a person, and so, presumably, not a suitable object for compassion. It is a strange conclusion indeed, that one may render a service of kindness to a Nobody which it would be immoral to render to a Somebody![87]

Of course, though it is recognized that the important concept of identity is difficult to define, it may be argued that some aspects of the identity of persons may change when they become sick or healthy. But this does not affect them as existing persons in time and space. A person's temporary or permanent state of health cannot be inherently associated with his or her right to exist. This also means that the decision to change an existing person through treatment while preserving their personal identity is completely different from deciding which person should exist in the first place. In this regard, it is also essential not to equate an afflicted person with a disorder instead of only being affected by a disorder. For example, it is important to emphasize that a person has haemophilia or diabetes instead of just reducing this person to being a haemophiliac or diabetic.[88] Disorders cannot exist on their own without persons nor can persons be considered as disorders. And a person is never just a disorder that should not exist.

More importantly, and somewhat related to the previous response, is the fact that persons who are actually born with a certain positive or negative characteristic may regard themselves (as whole persons) as being associated with this specific trait or ability. People are sometimes very proud of attributes with which they are born since, for whatever reason, they see them as a full part of their identity even though they have not earned them in any way. For example, persons are usually proud of their intelligence, eloquence or good looks and see this as part of who they really are as persons. Similarly, individuals with a disability may see their disability as a full part of who they are in spite of the challenges the disability may create.

Observing the connection between disability and identity is, therefore, essential, since many disabled people intuitively understand that children without disabilities are generally more desirable than children with disabilities.[89] This is an awareness that may lead disabled individuals to perceive themselves as different from those who are nondisabled not merely in their capabilities but also on the basis of who they are as persons.[90] In one sense, this should come as no surprise since, as already indicated, nondisabled people are certainly shaped by their abilities. For instance, world-class athletes who train to perfection may think of themselves in terms of the ability to succeed. Their value as persons often hinges on their success, and a failure to succeed may communicate to them that they are failures.

Similarly, people with disabilities may sometimes consider themselves as less capable or even less valued than the so-called 'able-bodied' because they may be unable to achieve an expected or desired performance or successful accomplishment in various fields.[91] Still, as disability rights advocates recognize, considerations such as these are inappropriate because they may reflect an unstated assumption that disability is unacceptable or that disabled people may be seen as unwanted in some way.[92,93]

The Perception of Disability

If some members of the disability community are correct, modern society has not fully succeeded in respecting the needs and rights of disabled people. Selection procedures may then only exacerbate the perceived discrimination and/or the feeling of inferiority that persons with disability may experience.[94] As the ethicist and neonatal paediatrician John Wyatt explains:

> In fact many in the disabled rights movement regard antenatal testing for fetal abnormalities as a form of social discrimination against disabled people. They argue that it is disingenuous for scientists and clinicians to claim that the development of antenatal screening is neutral and value free. The option of abortion for a range of genetic and other disorders places a negative value on people with the condition, and implies that it is socially desirable to prevent the birth of certain fetuses.[95]

Thus, although it is sometimes difficult to interpret the unintentional messages that may be received by individuals, the rationale behind the intentional selection of 'normal' characteristics, or even the availability of such selective tests, may easily translate into an unintentional negative response towards people with a disorder.[96] Moreover, those witnessing an action or a decision may make mistaken inferences about these actions or decisions that cannot be controlled by the person(s) making the action or decision.[97] This means that what other people actually think is important. As the bioethicist Søren Holm indicates: 'If having a particular disability is an essential part of my personal identity, part of what I am, the mere fact that I know or have reasonable reasons to believe … that others evaluate that disability negatively may affect my sense of identity and social standing negatively. And I may justifiably feel that way even if the negative evaluation does not lead to any actual discrimination.'[98]

For example, the United Kingdom's prohibition in the use of PGD to select for deafness can send the message that the disorder is a serious disability that should be avoided – a position that many in the deaf community reject. This may be one of the reasons why the disabled community is sometimes so vocal in stating that they are, in fact, similar to any other community with specific needs. They suggest that society has not sufficiently adapted or made an effort to accept or integrate them.[99] That society works with nondisabled people far more readily than with persons who may have a disorder.[100]

The lack of success to fully integrate persons with a disorder thus poses a major question about the appropriateness of sanctioning selection procedures as a common approach to reproduction. Since society already struggles to affirm the equal value of people with disabilities, how much more difficult will it be when society grows accustomed to making sure persons with a disorder do not exist?

Ironically, then, selection procedures may actually be self-defeating. Societal pressure towards the new eugenics may inadvertently reduce the impact of inherent and equal rights. Over time, as disability becomes less common, economic factors may also undermine the equality that disabled people experience.[101] For instance, the cost of caring for disabilities may increase as the demand for services decreases. More specifically, the cost of assisted living facilities will rise if fewer people eventually need them. As selection procedures reduce the number of persons born with special needs, the voices of those with disability may become increasingly difficult to hear amidst the numerous other interest groups in society.

Thus, in light of the threat posed by selection procedures, and despite some reassurances[102], individuals living with disability are unlikely to view these procedures as beneficial, either for them or for society at large, since they will increasingly be seen as an unfortunate minority.[103] In reality, selection may make matters worse since the procedures will likely reinforce the view that disability is undesirable and to be avoided. This, in turn, will have inevitable implications for disabled people and the manner in which they see their value of life and their right to exist.[104] As Ian Macrae, the editor of the magazine *Disability Now* and who is himself affected by a congenital condition, pointed out that the screening of embryos 're-enforces the stereotypical notion that … disabled lives are intrinsically less valuable'. Macrae would prefer a society that can address the different needs that these people have, rather than making sure that they do not exist.[105]

Finally, the very fact that many disabled individuals may already feel deeply distressed because of the risks to their self-perception arising from the possibility of deselection can be considered as yet another important reason for rejecting the procedure.

Discriminating Against Disability and Suffering

Selecting not to have people with disability may also be in conflict with contemporary values, including the most basic ethical principle of modern society: the equality of all humanity. It would contradict Article I of the UN Universal Declaration on Human Rights which states that 'All human beings are born free and equal in dignity and rights.' In short, regardless of the severity of a disorder, a person with disability is of equal worth and value to humanity as a person without a disorder. It also means that no matter how much suffering a person experiences in his or her life, this suffering has no implications, whatsoever, on his or her inherent worth and value as a person.[106] Any deviance from these axioms would be the demise of the principles enacted in the UN Declaration and, in turn, of contemporary civilized societies. In other words, the value and worth of a human person (whether disabled or not) cannot be associated, in any way, to their perceived suffering or contentment. It also means that their inherent dignity is in an altogether different ethical dimension or category to how they feel or their experience of life.

Most parents who have welcomed a seriously disabled child, who may be affected by a considerable amount of suffering or even a very short life, do not regret the existence of the child as such.[107] Instead it is the possible suffering, not the child, that the parents wish to remove. Though devastated by any suffering their child endures (and their own suffering in this regard), most parents remain grateful for the existence of their child, who is extremely important to them. They would never choose to exchange this child for another, healthier child.[108]

Though perhaps obvious, the parents' desire to eliminate suffering is grounded in an assumption that the life of a child is inherently valuable.[109] This is not to say that the parents welcome the child's suffering. As already emphasized, in philosophy and medicine it is important to differentiate between disorders and the very existence of persons with those disorders.

Support for Disability

The seriousness of a disorder may be substantially mitigated by a caring society. Every individual is embedded within a community, and that community wields tremendous influence over the wellbeing of its members. This means that a more communal approach to disability may actually decrease an individual's perceived need to pursue selection and that it is a community that is at fault for a person's difficulty to integrate.[110] As disability advocates tirelessly explain, physical conditions may, in many cases, be bearable if supportive relationships undergird the disability. Of course, the disadvantages related to disability are not always the result of social discrimination; the disorder itself may cause a limited function that a community cannot fully overturn.[111] As Jonathan Glover explains, 'To many disabilities, there is a contribution from a variety of sources, including functional limitation and social context.'[112]

Generally, however, by attending to the needs of all human interest groups, both the disabled and the nondisabled, selection procedures may not be seen as the solution. Again, as already noted, this conclusion does not support the proliferation of suffering. Rather, it recognizes that suffering and the value of existence are categorically different concepts that are bound by the need for supporting relationships.

Support for selection procedures often derives from a desire to act beneficently for possible future children, and without a doubt this motivation is laudable. But at the same time, the pursuit of beneficence for future children may simultaneously offend, if not harm, the disability community. This is a paradox because eugenic selection may be seen as privileging the nonexistent children (without disability who might be selected) over the existent (the disabled community). Clearly, then, attending to the needs of the disability community suggests the inappropriateness of the procedures currently under consideration.

Concerns about discrimination are also associated with the risk of a slippery slope that may develop in the future if society adopts selection procedures as a regular part of human reproduction. If some procedures for deselecting disability were accepted, as already demonstrated, it may be very difficult to draw a line between treatment and enhancement. With this difficulty comes the risk that the people viewed as less significant and worthy – those with traits that society has deemed undesirable – will be trampled in the rush to an eminent eugenic future.

Positive Eugenics and Discrimination

A further development to the objection against selection based on possible discrimination focuses on the practice of choosing possible future children for positive traits, not just for the absence of disability. As technology improves, parents may eventually have the option of selecting the kind of children they want on the basis of superior characteristics, such as athletic ability or musical prodigy. If this practice became widespread it would likely polarize the societal perspectives on disability as well as ability. A person with a so-called normal ability could then be considered mediocre, and a greater number of individuals may, as a result, be subject to discrimination simply for lacking superior abilities. Admittedly, selecting for positive qualities is very different from actively discriminating against people with disabilities. After all, nearly every person alive has some degree of ability and disability. Allowing positive selection for capabilities does not, in itself, constitute an unacceptable level of discrimination, though there is a risk that allowing enhancements to take place may eventually lead to preferring these enhancements and finally to requiring them.[113]

Compassionate Society

In embarking on a program of eugenic improvement society may, unfortunately, enter a vicious circle with respect to the way it considers disabled persons. This is because the manner in which society views the disabled community directly influences the way society views itself. Encouraged by a eugenic ideal, society may see people with disabilities as pitiful and worthy of stigmatization or discrimination, rather than as valuable and full participants. Society may then become more rigorous, rugged and rigid, rather than compassionate and caring. The widespread use of eugenic procedures may diminish tolerance and compassion for the 'imperfect', especially for those born with disorders that could have been selected out. With a diminished tolerance, both those born with a disorder as well as those who supported their existence may gradually be seen in a negative light. For example, parents who have a child with Down syndrome may be asked why they did not have a termination or whether they had received sufficient antenatal counselling concerning the challenges of raising a disabled child. The overarching message in such a scenario would be that a disabled child is an undesired one in society. Questions may then be asked about the manner in which such a society will be considered in the future when it seeks to select out its weakest members instead of caring for them in a spirit of compassion.

Conditional and Unconditional Acceptance

In this book, a final objection to the new eugenics builds on the previous section. As already noted, society's acceptance of selection procedures may bode poorly for the future of persons with disability. Behind this concern about discrimination lies a principle that may be formulated like this: 'Human persons should always treat every other human person without prejudice.' Or, to focus the principle for the present topic of eugenic selection: 'A parent should always accept his or her child unconditionally.' These concepts find strong support in international law. As already mentioned, the UN Universal Declaration of Human Rights establishes an obligation for human beings to exercise mutual unconditional acceptance in dignity and in a spirit of brotherhood. In other words, the inherent significance of every human life is to be seen as equal without any exceptions.

There are no contingencies for accepting the inherent value or worth of a child (any more than for an adult).[114] However, the willingness with which society has embraced eugenic selection procedures seems to communicate a strong disagreement with, or even a dismissal of, this principle. Though paying lip service to the UN's principle that 'all human beings are born free and equal in dignity and rights', supporters of reproductive selection appear to add the caveat 'but some lives are preferred over others', or as George Orwell put it in his book *Animal Farm,* that all are equal but some are 'more equal than others'.[115]

Recent decades have seen a substantial critique of the idea that human life has inherent worth and significance.[116] As an alternative, some suggest that what makes a human life valuable is its quality, not its mere existence, and that only human life meeting certain physical or mental characteristics is morally valuable and deserving of protection or acceptance.[117] By this reasoning, any human being (especially a foetus or infant) that fails to meet such conditions forfeits a claim to unconditional acceptance.[118] As a result, many scientists, journalists, social workers and healthcare professionals, as well as vocal ethicists seem to support eugenic procedures in which one being is preferred over another and in which selection is actually possible. As already noted, in the United Kingdom, about 92 per cent of foetuses diagnosed with Down syndrome are terminated because of their genetic disorder.[119] More radical still are those cases in which prospective parents eliminate a foetus on account of a correctable disorder such as cleft palate. Admittedly, all cases of these so-called eugenic abortions account for only 1 per cent of abortions in the United Kingdom, but the figures do not give licence to overlook the principle of unconditional acceptance.[120] As Nicholas Agar indicates, such liberal views relating to selection may result in genocide by stealth in that entire communities of persons with certain genetic characteristics are taken out of existence.[121]

Parents' Perspective

In order to clarify all the different perspectives relating to the concept of unconditional acceptance it is important to try to dissociate those that may be related to the parents and those that may have consequences on the children born from selection. In this regard, the following study will begin by examining the parents' perspective and the reasons why they may want to have and/or select a child.

Parents' Perspective and Unconditional Acceptance

In discussing the ethics of eugenic procedures, the manner of acting without prejudice towards others is exceptionally relevant. For parents to select one embryo over another is unmistakably an act of making a value judgement concerning one being over and above another on the basis of predetermined opinions and perceptions. In the eyes of parents or the healthcare professionals who perform the selection, a future child *with* a disability is seen as less desirable or valuable than a child *without* a disability. This also means that deselecting an embryo on account of a disability is not merely deselecting this disability; rather it is deselecting a kind of person. Thus, rejecting offspring who fail to meet certain standards may be a violation of the principle of unconditional acceptance and the universal equality of all human beings. Moreover, accepting a child because he or she is healthy is as problematic as rejecting a child because he or she is disabled.

Complete openness towards the prospective child and not making any choices between possible future children may represent, in this way, one of the most important signs of unconditional acceptance of this child.

In this regard, there is an additional concern since all selection procedures risk the holistic wellbeing of children created through the procedures by attaching contingencies to their existence.[122] In short, there is concern that selected children may experience a conditional acceptance from their parents if they learn that their initial existence depended on meeting certain conditions and not upon the simple value of existence in itself. Since their parents are already predisposed to imposing conditions on acceptance there is an equal danger that conditions for acceptance will continue to mark the parent-child relationship.[123]

For example, if a child were selected to be healthy but then sustained an injury after a foolish accident which he or she could have prevented, the parents may be understandably angry about the child's foolishness. This is because the parents had invested both financially and emotionally in the child's health. But to continue to accept the child for who he or she is, the parents will have to endure their anger (and sorrow) without communicating any disappointment to their son or daughter. They must also find fresh reasons for accepting the child or else risk rejecting him or her on account of the injury. But the frailty of human nature makes it unlikely that the parents will be able to conceal these feelings from the child. In turn, the child may internalize the parents' discontent and come to believe that their disappointment reflects a certain amount of rejection for who he or she is. As in many other situations involving the absence of parental acceptance, the child may then experience difficulty in self-acceptance and, ultimately, in providing unconditional acceptance to others, thereby perpetuating the dysfunction.

Admittedly, there is no necessary reason to believe that parents would withhold their approval or unconditional acceptance even though the child no longer experiences what they selected him or her to be.[124] Similarly, parents may still unconditionally accept a child who does not eventually manifest the characteristics that they had originally chosen.[125,126] Still, parents who endure the challenges of selection procedures already evidence an inclination towards conditionality by the very fact that they have selected their child for his or her (expected) health. A willingness to select on the basis of health may indicate an equal willingness to practice conditional acceptance.[127]

In order to act without injustice, parents would have to accept children in an unconditional manner. To put it another way, parents should not predicate the acceptance of a child on the basis of any of the child's positive or negative characteristics. A child is a human person and thus inherently valuable and worthy of acceptance in any social community. Historically, of course, parents have generally accepted their children regardless of their biological traits, but selection technologies now allow parents to accept a child only if he or she meets their expectations.[128]

Having said this, the mere prospect of parental disappointment does not in itself constitute an ethical objection to the selection procedures under discussion. An action such as selection cannot be ethically suspect simply because it may create disappointment in the parents. However, in the case of eugenic selection, the parents' disappointment may eventually translate into a disapproval of the child resulting in an eventual nonacceptance of the child for who he or she is. Again, the possibility of a slippery slope is itself insufficient to invalidate selection procedures. But, in conjunction with the other arguments already noted, as well as what follows in the next section, the prospect of slipping down the rails to widespread conditional acceptance is a challenging plank in the larger argument against the new eugenic procedures.

Parents' Perspective and Conditional Existence

As the previous section indicated, the availability of specific preconditions for reproduction raises the possibility that these could come between the procreators (parents) and their child. Of course, definitive possible outcomes on the long-term effects of selection procedures are still unavailable. But possible risks relating to the selection procedures on the parent-child relationship deserve further exploration in order to create a judicious analysis of the new eugenics.

Throughout the course of human history parents have generally accepted their children unconditionally no matter when or how they came into existence. In a way, the unconditional acceptance of the parents for each other 'expanded' towards the resulting child who was also unconditionally accepted. Whether or not this acceptance of the child required a conscious effort is immaterial. What is relevant to the present discussion is that humanity has prospered while parents have viewed their children as inherently significant and worthy. This perspective matters because it illustrates the eugenic situation as an anomaly. With the new reproductive technologies now available, parents risk seeing their children as objects or possessions that must be constructed to certain standards to merit acceptance. Yet, when parents procreate children, they bring forth people who, like themselves, are worthy of equal acceptance by all members of society. The recognition of this inherent significance is a right that does not need to be earned and is independent of any natural limitations or abilities.[129]

Generally, prior to the advent of reproductive technologies a couple could not deliberately influence any of their children's genetic traits. As a result, if they were disappointed about the features of their child, the couple clearly had no rational reason for regret. They had no alternative, since nothing could have been done to alter their child's genetic makeup. A form of 'natural humility' was present in which parents unconditionally accepted their children in the manner in which they were born in an attitude of openness to the unchosen and uncontrolled.[130,131]

With eugenic procedures, on the other hand, parents now have the opportunity to choose children with various characteristics. It also means that what counts as an acceptable birth is an open question, and the various possible answers have subtle but profound ramifications for the parent-child relationship. The attitude of parents towards their children may slowly be shifting from 'unconditional acceptance to critical scrutiny'.[132] As never before, parents may greet their child's arrival into the world with the critical eye of a consumer, questioning whether their heavily invested expectations have been met, rather than the tender eye of eager caretakers. If a selection procedure proves to be inaccurate and fails to select the desired traits, a couple faces the dilemma of aborting, giving up for adoption or parenting a child whom they originally did not want. Unless selection becomes 100 per cent reliable, children without the traits may still be born and face potentially serious ramifications.[133] In fact, if the child does not fulfil expectations, a degree of disappointment and rejection may be expressed by the parents which is commensurable to the unfulfilled preconditions. This may be even more strongly expressed than if natural conception had taken place since the more reliable the selection process, the greater the parents' surprise and distress if they obtain a child with the 'wrong' trait. Thus, to prevent these dangerous possibilities, opponents of selection, such as sex selection, believe it is best simply to disallow such selective procedures in the first place.[134]

Today's context of choice, investment and conditions for existence prompts probing questions about how parents will relate to children they create through selection procedures. As the legal ethicist Roberto Andorno explains with respect to a pregnancy, 'The ethical problem arises when, in order to obtain the birth of a healthy child, certain necessary "quality" criteria are determined which the foetus must fulfil in order to have the right to be born, indeed this presupposes that children are no longer desired *for their own sake* [emphasis original].'[135]

To some extent, then, some parents may reject the offspring they laboured to create, though others may learn to accept their child unconditionally, even if the child fails to satisfy their hopes. In this regard, it is important to note that accepting a child unconditionally may also mean that there is no desire to control or determine the manner in which he or she exists. This means that parents who conceive without selection procedures may already be stating that they will accept their child unconditionally.

In summary, a prenatal choice through a selection procedure may open the door to parents feeling a sense of regret concerning their choice at a later stage in the child's life. Rather than being content with the mere existence of their child, they may eventually wish that they had chosen differently before his or her birth. While this regret would be lamentable in its own right, it is particularly concerning because of the consequences it may have on the child who knows that his or her parents regret his or her very existence. Without selection procedures, on the other hand, the opportunity for regret about the child's existence is minimal since he or she would simply be considered the consequence of fate. In turn, these children may find it easier to accept that they have a general right to exist.[136]

Deciding Whether or Not to Have a Child

Parents usually have very different of reasons for having, or not having, a child. A number of these may be considered as entirely legitimate, including the companionship a child may provide in a family. Others may be less acceptable, for instance, if parents are planning to exploit their child in some way or consider him or her as an object. Similarly, parents may have many reasons for not wanting to have a child including both ethical and unethical motives.

Broadly speaking, there are two stages in the parental decision process. First, whether or not parents want to have a child, and if they do, then secondly, whether or not they want to select the child's characteristics. In each of these stages complex eugenic considerations may be playing a part, but it is important that they are considered consecutively in order to clarify the decision-making process.

Deciding to Have a Child

Parents need to decide, first of all, whether or not to have a child. Some commentators have denied that the decision to have a child can result solely out of interest for the child, since, when the decision is made, no child yet exists. To put it positively, these thinkers argue that the only reason why a decision to have a child is made is because the child is seen as a means to the ends of the parents' interests, whatever these may be.[137] However, this perspective may represent only one angle of the situation. Indeed, in a purely human context the term 'procreation' reflects the Latin word *pro*, meaning, 'on behalf of' or 'for'. This means that children are not only procreated 'for' the parents but also 'for' the child's sake, whoever he or she will be. Personal existence is then seen as something that is positive, in itself, and to be welcomed even though it cannot, of course, be compared to nonexistence. This implies that one cannot assert that a child should or should not exist because of who he or she is. It is impossible to compare existing harm to nonexisting harm since such statements do not mean anything that can be understood in any reasonable way.

As the philosopher Joel Feinberg puts it, '[T]o be harmed is to be put in a worse condition than one would otherwise be in (to be made "worse off"), but if the negligent act had not occurred … [the child] would not have existed at all.'[138] Given this, a parent cannot harm a child merely by bringing him or her into existence.[139] This would be the case, even if the parent foreknew that the child would have a serious genetic disorder. Similarly, it is often difficult to judge whether the creation of a child (whoever he or she may be) is a good or bad action or whether it is right or wrong. This is because these are comparative terms which seek to evaluate existence with nonexistence which does not have any rational meaning. Any definitions of such terms are equally hard to provide since they are inevitably tied to improvable, subjectivities. For example, what some may consider 'good', others will consider 'neutral' or to be expected.

In contrast, the initial reasons for creating a child and the method of its creation may be considered as ethical or unethical. For example, it may be seen as irresponsible and unethical for parents to envisage bringing into existence a child if they have no prior intention of looking after and caring for him or her. Once the child exists, his or her future prospects may also be considered as positive or negative, depending on whether he or she may experience a lot of suffering or exploitation. But the sheer fact of bringing a child into existence cannot be criticized or condemned. This means that one should never argue that a person should not have been brought into existence. As soon as a life is procreated, regardless of his or her state of health and the amount of pleasure or suffering he or she may experience, this life should immediately be welcomed into existence with all the inherent, immeasurable, equal and inviolable dignity that the life of every person merits. Furthermore, if all lives are always considered to be worth living in an equal manner and for the sheer sake of existence, all life should be accepted in the same way. The public anger following the Perruche wrongful life case in France vividly reflected this conviction (see section on Selection to Have Many, Few or No Children).

An important implication of this perspective on life concerns the future of civilized society. If society intends to remain with the values it sought to protect in the second half of the twentieth century, every child's existence, whatever it may be, should be seen as inherently valuable as an end in itself. Every child is endowed with the same moral status, nature and essence as his or her procreators and deserves treatment that reflects these deepest realities.[140] Some may try to support the legitimacy of wrongful lives by suggesting that society has an obligation to produce the children that are least likely to be disadvantaged, such as those without physical or mental impairments. But from this perspective, one focuses on enabling the best overall result, rather than focusing on the interests of a particular child. In other words, this position is open to challenge since it appears to reject all but the best possible children.[141]

Similarly, some commentators have argued that parents may have a responsibility, in some circumstances, to avoid bringing children into existence who would be affected by a significant amount of suffering or a severely diminished quality of life to themselves or others.[142] But as soon as a person exists, any suggestion that this life is wronged because of its existence can be challenged since the wrong could only have been avoided by also preventing the very existence of the person.[143] Moreover, the child cannot be said to have been wronged since a child without the disorder would be a different child. As Jonathan Glover observes:

> The claim under consideration is that to be brought into existence with an extremely severe disability may not be in the best interest of a child. This entails a general problem of comparing existence with nonexistence. When medical techniques determine that some people rather than others come into existence, can those people be said to be better or worse off for the intervention?[144]

The philosopher Derek Parfit clarifies this argument with the example of a woman who decides to postpone coming off the contraceptive pill. She is told that if she stops taking the pill and conceived immediately, her child would have a disorder. On the other hand, if she waited another three months to conceive, the causes for the disorder in the child would have subsided and she could have a healthy child.[145] Parfit then concludes, 'It seems clear that it would be wrong for this . . . woman, by not waiting, to deliberately have a handicapped rather than a normal child.' However, he then begins to question his statement, since waiting three months would create a totally different child, not the same child without the disorder. It is a choice between different possible children. The first child would have been born with a disability and the second one, who would be completely different from the first, would have been born without a disability. But in both cases, the disabled and nondisabled children come into existence as they are.[146,147] As argued earlier, the state of the children relating to disability is intrinsically part of their creation, their identity and who they are as persons. For instance, bringing a child into existence with a disorder means that this child's very existence is associated to the disorder. Since this is the case, the question arises whether the woman should even make a choice between the two persons if she has already made the first decision to have a child.

In this scenario, it should be noted that the woman's dilemma is different from deciding whether to treat a disorder in an existing person. Indeed, if a healthcare professional did not initiate the appropriate treatment for a patient, he or she would be acting unethically. An existing person is valued by society in just the same way as any other person whether or not he or she is disabled. Thus, in a similar way to the person who is treated, the inherent value, worth and dignity of the two possible future children who could be born three months apart is exactly the same and is not affected by their potential state of ability or disability and how much pleasure or suffering they may experience. There are no grounds, therefore, based on inherent dignity and value considerations to select between them since they are completely equal from these perspectives.

Stephen Wilkinson, among others, resists this conclusion, suggesting that the message 'It would be better if you did not exist' '[i]s defensible because selecting higher over lower probable future welfare is permissible and rational (other things being equal)'.[148] Similarly, the philosopher and bioethicist Dan Brock argues:

> Individuals are morally required not to let any possible child … for whose welfare they are responsible experience serious suffering or limited opportunity if they can act so that, without imposing substantial burdens or costs on themselves or others, any alternative possible child … for whose welfare they would be responsible will not experience serious suffering or limited opportunity.[149]

Both streams of argument imply that it is ethically better for a child to be created healthy and happy than creating one who is not. In doing so, however, these arguments concentrate their attention on consequentialist considerations, i.e., the quality of life of children or on their biological characteristics. But if all persons are equal in their inherent dignity, there is no basis to select between possible future children or state that any life is unworthy of life.

Deciding Not to Have a Child

In some circumstances, the decision by a couple not to have a child has no ethical consequence for the new eugenics, for example, if they believe they would be inadequate parents, for reasons such as age, finances or societal support. In this case, the decision is not based on selection *between* children or possible future children. Indeed, had the parents decided to have a child, they would have been prepared to have *any* child. In other words, the emphasis here is on the parents and their situational background and not on the child's characteristics or quality of life, as such.[150]

In contrast, if prospective parents do decide to have a child but subsequently change their minds out of concern for the likely biological quality of the child (and they have the means to look after him or her), then a significantly different situation arises that may be considered as eugenic. This kind of about-turn could happen in several ways, and the following examples may clarify the similarities between the different decision stages.

(1) Prospective parents may decide to bring their own child into existence but then relinquish the child into adoption because of the child's disability.[151]
(2) Prospective adoptive parents could decide to adopt a child but then reject the one being proposed by the adoption agency because he or she has a disability.
(3) Prospective parents can decide to have their own child but then change their minds because they were informed of the perceived risk that he or she would have a disorder.

In each of these three cases there are different ethical repercussions, but the ethical components are similar. In every case an initial decision to have a child was taken each time by the parents, which eventually resulted in them changing their mind because of considerations related to the biological quality of their prospective child. Thus, each decision not eventually to have a child could be considered as having a eugenic perspective.

Admittedly, in the third situation, it may be impossible for someone other than the parents to distinguish between their decision not to have a child because of his or her disability and the already mentioned general decision not to have a child. But the parents themselves, of course, would know whether the basis of their decision was related to eugenic considerations, i.e., on the biological quality of the child.

A similar case would exist if parents first decide to create a child and then decide (in a subsequent decision) to take specific drugs (or undertake any other measures) to influence the biological quality of their child (before it is created) which are unrelated to the specific health considerations of the parents.[152] Indeed, this second decision would also be considered as having a selective component. It would be about making a choice between what kind of child the parents prefer since the children who would be born with or without the use of drugs (or any other specific actions) would be different (this is because of the already mentioned nonidentity problem). In other words, a decision on the value of the possible future children would be made and whether one should exist preferably to another.

Parents, of course, have a responsibility to be healthy for their own sake, and this may mean behaving in a certain way, such as taking certain dietary or other supplements. Because of this, parents who seek to live in a healthy manner may have a positive influence on the prospective child in a direct and undissociable manner. A woman who stops smoking before becoming pregnant is doing so as much for herself as for the possible future child. It is a kind of 'double-effect'. Similarly, a woman planning to become pregnant may take some folic acid supplements to reduce the risk of spina bifida in her future child. But she is doing this primarily because she wants to be healthy for the pregnancy and knows that she is deficient, herself (i.e., her own body is deficient), of folic acid. This health treatment of the woman, of course, has a beneficial though secondary effect on the future child. However, if a woman behaves in a specific manner before conception with the sole purpose of having a certain kind of child (she may want one with a particular trait or even a disorder) then the situation would be similar to the one just mentioned above where a drug was taken for selective purposes. [153]

To summarize, in all the above parental cases, individuals have made an initial noneugenic decision to have a child but have subsequently made a second decision which certainly has a eugenic element since it is based on the biological quality or characteristics of the prospective child. Of course these decisions are perfectly understandable and defensible if the basis of all ethical evaluation in society is reduced to the avoidance or diminution of suffering. But where there is a deeper meaning to life even in the face of suffering then such decisions become questionable. This happens when all human life is recognized as having an inherent and equal dignity or worth no matter how much happiness or suffering is experienced.

To be sure, in certain cases it may be difficult for the couple, once they have decided to have a child, to subsequently find ways of having a child without having to make a choice based on biological quality. Should a woman who has decided to have a child with her partner and who knows that she would conceive a child with a disorder because she is momentarily affected by a sickness, wait until the illness disappears? In a way, if she wants to bypass any eugenic considerations relating to the kinds of individuals who should exist and the messages this may represent concerning her own ethical values as well as how this decision may be received by others, she should not seek to make a decision, in other words, to prefer the possible future disabled child over the possible future nondisabled child or the reverse. This means that parents may need seriously to examine the basis of their value systems before even deciding to have a child if they do not want to be confronted, afterwards, with a decision which may be seen as eugenic.

Deciding to Have a Certain Kind of Child

Finally, if parents believe they would be suitable parents, decide to have a child and then take specific actions to determine their future child's characteristics in order to provide what they believe will be a high quality of life, then they would have clearly acted with eugenic motivation, based on the definition presented in this book. As already mentioned, this course of action would be liable to accusations of discrimination between certain kinds of persons.

Parental Expectations and the Instrumentalization and Objectification of the Child

Through various legislation and declarations, contemporary civilized society has affirmed that a child is neither an asset, an instrument towards another person's ends, a commodity with a certain monetary value or an object that may be judged for success. Nevertheless, the eugenic procedures described in this book, may be slowly undermining this widespread view. In certain circumstances, screening and selection may raise the possibility that parents will view and treat their children as products or instruments which will fulfil their own desires. Selection procedures risk creating an unfortunate society in which parents would create only a particular kind of child in accordance to the parents' preferences. Of course, even without selection procedures this is already a possibility, but parents who spend considerable financial and social capital to create a child may be more prone to the risk of considering him or her as a product or an instrument to their own ends. They may even consider the child as a reward for their sacrifice and determination in procreating a healthy child.

In 2010, a case in Canada illustrated concerns about the correlation between selection procedures and the instrumentalization and objectification of children. A couple asked a surrogate to gestate their embryo since the commissioning woman could not carry the embryo herself. But when the couple discovered that the foetus was likely to be affected with Down syndrome they asked the surrogate to have an abortion. This proposed action, however, gave rise to serious misgivings in the gestating woman who was extremely upset by what was being asked. Reflecting on the case, bioethicist Françoise Baylis noted, 'The child is seen by the commissioning parents as a product, and in this case a substandard product because of a genetic condition.'[154] But, as already argued, a child cannot be seen as an object. For that matter, even in an irresponsible society, a child should never be regarded in such as way. Instead, a child is always and unequivocally a person in his or her own right.

In this regard, it is possible to ask whether the widespread use of selection procedures may actually encourage an objectification or instrumentalist view of the prenatal child.[155] The question remains whether such procedures may signal a conviction that children are really only valuable for the enjoyment they bring to their parents.[156] For example, when parents choose one embryo over another in order to ensure that they have a girl instead of a boy, a charge of instrumentalization or objectification seems possible. A glance through the website of the Fertility Institutes, an international reproductive medicine organization, confirms suspicions of instrumentalization. Advertising their PGD treatments, the Fertility

Institutes claim that their services allow a person 'to be *certain* your next child will be the gender you're hoping for'.[157]

The risk of instrumentalizing a child is also reflected in that parents who select have strong reasons to believe that they could have had a child with other traits who would have been very different from the one they created. It also means that selection is liable to involve the imposition of stereotypical expectations on a child even though he or she turns out to be very different. This may only make it more difficult for parents to accept any child unconditionally.[158] In this regard, it is possible to argue that the instrumentalization of a child may reflect a conditional acceptance.

In the end, any intentional selection of the prospective child's biological characteristics becomes important because the parents recognize that *they* would prefer some traits over and above others. The root issue is the parents' desire and how they will consider the child as a key to fulfilling their desires rather than as a human being inherently worthy of appreciation regardless of the possible future child's identity and characteristics.[159] The idea of *conditional parenthood,* whereby individuals only accept to be parents if their child attains certain biological criteria, may constitute in this way, an unacceptable transgression of what is understood in traditional parenthood. This is because the attempt to directly influence predetermined fundamental characteristics in the child may transform the parent-child relationship into a unilateral and instrumentalized relationship.[160]

The bioethicist and philosopher David Resnik has also argued that valuing an embryo for its genetic makeup, such as with preimplantation embryonic selection, rather than for its mere existence, may lead to valuing the future child on the same grounds. Resnik contends further that this may eventually lead to a society-wide shift in considering persons as property.[161] While Resnik's slippery slope may seem far-fetched to its detractors, his argument is more than a mere warning since he provides a rational basis for advocating unconditional acceptance. Resnik is thus concerned with grounding the long-term wellbeing of every member of society. In short, he argues that it is important that even embryos are valued for more than their biological traits because the complexity of the human person requires that truly ethical actions account for more than physical characteristics such as health. In this respect children are no different from adults.

Child's Perspective

The risks associated with setting conditions on the birth of a child can also be examined from the perspective of the child created through selection procedures. All children want to know that they are unconditionally accepted by their parents. They want to have assurance that their parents regard them as significant and inherently worthy, regardless of disability or health. This is true whether they are seen by society as genetically superior or weak or whether they attain a certain standard of performance. Yet a child who knows he or she was accepted for a reason other than mere existence may very likely face existential questions that a child should not have to consider.[162] Of course, in longing for unconditional acceptance children are no different from most adults. All human persons, regardless of age, want to know that their existence matters. Children, like adults, want to know that they have an unconditional right to a place in this world and that their lives are inherently worthy and not merely a matter of fulfilling arbitrary criteria. Having a right to exist and a place in society is crucial to a person's wellbeing and identity. A sense of belonging to a community (including a family) is integral to human identity because every human being seeks meaningful connections with fellow members of humanity. This feature unifies the entire human species and enables the development of a healthy emotional and psychological balance.

Unfortunately, however, this sense of belonging often goes unfulfilled. Consequently, a constant striving for this acceptance characterizes humanity. In a myriad of ways, human beings strive to make their mark on society or impress their peers to attain approval. For example, schoolchildren show off before their playmates and duel each other for the title of 'coolest kid' or 'best athlete'. Adults also play this social game, as professionals seek to be recognized through their success in the workplace or through charitable efforts in society. But what would happen if a child eventually came to realize that he or she only came to exist because certain conditional characteristics were fulfilled? Would not this child begin to doubt whether he or she had a real place in society? As the legal ethicist Roberto Andorno notes:

> This individual will live with the awareness that he only deserved to be born because he possessed the characteristics that others wanted, and not because his life had any intrinsic value. This clearly contradicts the very idea of human dignity, which implies that every individual has an inherent worth as part of humankind and that, as a result, all *human beings have the same worth* [emphasis original].'[163]

When persons are at the weakest and most vulnerable stages of their lives, such as in infancy, this demonstration of unconditional acceptance is mandatory for their survival since they could scarcely be expected to meet the conditions that would arise. For example, newborns could not meet any condition since they lack the ability to act voluntarily, and fortunately, most very small children are cared for with unconditional acceptance.

Of course, children come into existence for all sorts of reasons. Some of them were planned and others were surprises, some were wanted and others not. But, in this regard, the unwanted are sometimes faced with the most piercing questions about their identity.[164] Some commentators recognize the sense of rejection and loss that often exists throughout the adoption experience. In their study of the reasons many adopted persons search for their birth parents, the social care researchers David Howe and Julia Feast write, 'The experience of adopted people who search for birth relatives follows … a story which throws light on not only adopted people's search for identity but on the universal themes of who we are and where we belong.'[165] Howe and Feast also indicated that the desire to feel 'whole' and 'connected' is independent of the adoption's success. But the authors admit that the question of why identity is meaningful to adopted persons is still unclear. They write, 'Issues around identity and the desire to establish a full personal history appear to crop up in most findings, but beyond that the picture remains blurred.'[166] The desire for individuals to understand their identity and their reason for existing is universal and timeless. Nearly two hundred years ago, Mary Shelley explored the search for identity and the longing to understand existence in the classic novel *Frankenstein* (first published 1818), which is often considered as an allegory of what the future may hold.

The title of the book refers to a scientist, named Dr. Frankenstein, who creates a new living being from the body parts of human corpses. He first intended his creature to be beautiful, but the result was more a monster than a man. Because of this, Dr. Frankenstein eventually regrets his experiment and runs away in terror. But the monster, who has no name, tracks him down in a search for meaning and identity. The monster is gripped with a very deep sense of rejection and isolation. He does not understand why he was created or why his creator has abandoned him. The cry of the monster expresses his distress: 'My person was hideous and my stature gigantic. What did this mean? Who was I? What was I? Whence did I come? What was my destination? These questions continually recurred, but I was unable to solve them.'[167] Of course, this tale is only a parable, but the mere fact that readers understand the plight of the monster is noteworthy. It also begs the questions whether similar existential questions will ever arise in persons who know that they only exist because they fulfilled certain conditions. The uniqueness, identity and individuality of children may inextricably be linked to their understanding of the reasons for their existence.

Child's Perspective and Unconditional Acceptance

Until now, a parent has never had any choice in the kind of child he or she brings into existence. In the future this may change with parents choosing what kind of children they want. In contrast, however, both now and in the future, it will remain the case that the child will never be able to choose what kind of parents he or she will have. A certain unbalance in the parent-child relationship may result which may have consequences for the child.

Attaining holistic wellbeing requires that a child recognizes that he or she is unconditionally accepted and does not have to earn parental approval. Though perhaps largely foreign to modern human bioethics, the importance of a sense of unconditional acceptance by children has long been acknowledged in other fields such as in psychology which emphasized this concept for over fifty years. Drawing on years of research on human behaviour, the American psychologist Carl Rogers popularized a notion of unconditional acceptance by the parents of their children with what he termed 'unconditional positive regard'.[168] In his own words, this means 'an outgoing positive feeling, without reservations, without evaluations'.[169]

Today this description of unconditional acceptance has become a key tenet of various strands of psychology, including the examination of parent-child relationships.[170] Counsellors and therapists understand that the absence of unconditional positive regard from the parent to the child detracts from the child's overall self-acceptance. To support a healthy child's holistic wellbeing, parents must affirm the child 'down to the very essence of [his or her] being' so that the child is confirmed in his or her 'uniqueness, individuality and humanity'.[171] If parents affirm a child for anything other than the simple fact of his or her existence, then the child may miss what is an essential component to experiencing a full and balanced life in which he or she recognizes that he or she has an accepted place.[172]

In addition, if children realize that their existence is predicated on the fulfilment of certain conditions, it is likely that some children may question whether they have an unconditional place in society. They will always know that their lives are associated with this selection and the related conditions, rather than appreciating their lives for their own value. Worse, they will know that had they not fulfilled the conditions, they would not even have been born. Consequently, they may struggle with self-acceptance, even as they grapple with the ordinary challenges accompanying childhood and the transition to maturity. Some children may then report a negative experience of life if they perceive that they have to earn their parents' approval or acceptance.

Conversely, it may also be possible that some children may feel especially valued for having been chosen. For example, they may feel valued for having out-competed all their possible embryonic siblings in PGD for the right to be borne by their parents because of their biological quality.

Other children may feel that, in a society where the biologically enhanced is the norm, an injustice has been done to them if they were not brought into existence to an expected standard (but again the nonidentity problem arises in this case).[173]

Selection procedures are still too new to allow a proper study of these possible outcomes or even risks. Accordingly, the argument made in this chapter may appear overly precautionary, though it does seem clear that any interruption in the unconditional acceptance by parents of children may emotionally affect the child. Some thirty years ago, child psychologist Alice Miller stated this unequivocally: 'As soon as the child is regarded as a possession for which one has a particular goal, as soon as one exerts control over him, his vital growth will be violently interrupted.'[174] Miller's point is that the process of emotional maturation from child to adult requires parents to approach their children with openness rather than determination. The concern is not that of the philosopher Jürgen Habermas and the 'open future' argument explored earlier. Rather, the point is that children only develop into free-thinking, healthy adults if they begin life with a settled awareness of their parents' unconditional positive regard. As already noted several times, children created for the sole purpose of meeting their parents' specific desires will almost certainly face existential questions. Habermas is also concerned about this sense of identity and possible feelings of misplacement when he states that 'the person whose genetic composition has been prenatally altered may, upon learning of the design for her genetic makeup, experience difficulties in understanding herself as an autonomous and equal member of an association of free and equal persons'.[175]

Children may also question or even resent the values of their parents in both (1) the selection process itself and (2) the specific conditions which were set. When they grow up these children may, for example, disapprove of any selection process, as such, since they may consider them as undermining the relationship of unconditional acceptance with their parents. It may even be tremendously awesome for a disabled child to learn eventually that his or her parents could have had a completely healthy child through selection but chose not to make a decision because they wanted him or her *just as much.*

Moreover if children were actually chosen, they may end up disliking the characteristics with which they were born preferring other traits instead, though, of course, they would again run into the nonidentity problem since they would be different persons. But some, ostensibly, may also agree with the selected characteristics given to them by their parents recognizing in these traits a sense of value.

It is interesting to note, here, that many proponents of selection for positive traits have often only proposed certain kinds of physical characteristics for enhancement, such as athletic prowess, aesthetic physique, intelligence or memory. There was seldom any mention of enhancing a person's humility, compassion or sense of justice which are more important though maybe far less biological in nature.

In this regard, the philosopher Alasdair MacIntyre published a short article in 1979 entitled 'Seven Traits for the Future' in which he questioned the choices that many parents may make concerning their future children. He suggested that qualities such as an ability to live with uncertainties, an acceptance of one's mortality and a spirit of hope may be far more important and useful than the physical traits commonly desired. In addition, Julian Savulescu and Ingmar Persson have proposed, in their 2012 book entitled *Unfit for the Future,* that biomedical moral enhancement should seriously be considered through the use of genetics and neurobiology.[176] MacIntyre, however, predicted that if worthy moral attributes were ever selected in future children then '[w]hat we would have done is to design descendants whose virtues would be such that they would be quite unwilling in turn to design *their* descendants [emphasis in the original]'.[177] As a result he concludes that such a project should not be initiated in the first place, '[o]therwise we shall risk producing descendants who will be deeply ungrateful and aghast at the people – ourselves – who brought them into existence'.[178]

In conclusion, the aim of most selection procedures at present is often to ensure that a healthy child is born. Parents seek to obtain a guarantee that their child will not suffer the pains he or she might otherwise experience. And although it is impossible to predict with any certainty how future children may value their selection, they may eventually end up with a diminished sense of self-acceptance and value of their lives, even though they may enjoy superior characteristics such as good physical health. This is because an understanding of 'who one is' involves more than physical characteristics. While the absence of disease is important, the manner in which people accept themselves is also essential for their holistic wellbeing. Thus, selection procedures may raise obstacles to the child's experience of a healthy and necessary degree of self-acceptance.

Conditional Acceptance and Evolutionary Biology

As already indicated, not everyone concurs that selection procedures jeopardize the parents' ability to accept their children unconditionally. Within a framework of evolutionary psychology, some commentators contend that human beings withhold affection naturally because conditional acceptance is a survival strategy enabling the fittest human beings to extend the survival of their genetic lineage. In other words, human beings are actually hardwired for conditional acceptance. The argument suggests further that, in light of limited resources, parents invest in children from whom they are likely to reap reproductive rewards, that is, children who will reproduce and maintain the parents' genes.[179] Thus, not only does the continued existence of the human race depend on some form of selection or contingency in relationships, but the practice of this conditionality is unavoidable.[180] By this reasoning it is suggested that *un*conditional acceptance may be both antithetical to the health of humanity and contrary to human nature.

Accordingly, this objection to unconditional acceptance claims that human beings are programmed and driven to exclude certain members of humanity. At first glance, this objection to unconditional acceptance may seem persuasive, but at least four points suggest its weakness: (1) While conditional acceptance may enable the survival of some humans, there is a considerable absence of any argument for the reasons why survival in itself is valuable or why humanity or a family should seek to want to survive. (2) While evolutionary psychology and conditional acceptance may explain why *some* human beings survive, it does not explain why *all* humans survive. Indeed, some people survive while experiencing and giving unconditional acceptance. (3) The ethicist Ted Peters recognizes that the issue of evolutionary determinism in itself is open to question since there is no agreement about the origins of freedom and free will in a person with respect to decision making.[181] According to Peters, placing conditions on acceptance in order to promote survival is something that may happen, but it is not a human necessity. (4) As noted earlier in this section, child psychologists have identified *un*conditional acceptance as an integral component to a balanced human emotional and psychological development which seems to contradict the argument in favour of conditional acceptance for survival.

In short, serious arguments are necessary to demonstrate that mere survival trumps the prospering of human life. This is because it is likely that a life that prospers will eventually be more likely to procreate.

Each Human Life Should Be Accepted for its Own Sake

This section has argued that the new eugenic procedures are ethically suspect because they may undermine the parents' ability to interact with their children based on the principle of unconditional acceptance. By using selection procedures parents tacitly suggest that they value their children for reasons other than the children's mere existence. In this regard, the philosopher Michael Sandel expresses deep concern at the increasingly common trend to develop selection procedures in his book *The Case against Perfection.* At the core of Sandel's argument lies the contention that human life is a gift, not a commodity, and, as such, each human life should be accepted for its own sake. The following quotation from Sandel summarizes the risks of selection when children are not created from unconditional acceptance which he characterizes as unconditional love: 'Parents bent on enhancing their children are more likely to overreach, to express and entrench attitudes at odds with the norm of unconditional love … We would do better to cultivate a more expansive appreciation of life as a gift that commands our reverence and restricts our use.'[182]

In view of the above, there is a real possibility with selection procedures that prospective parents wanting a healthy child will prioritize their own interests. In this way, selection would not only reflect what the prospective parents consider to be healthy but encourage a transformation of parents' approach towards childbearing. It may even increase their expectations to regulate the nonmedical characteristics of their future child. As a result, the children born from such expectations may feel under considerable pressure to meet their parents' aspirations in order to feel accepted.[183] This means that it is only when parents unconditionally value their children for who they are, as equal fellow human beings, that the children will enjoy a sense of healthy emotional development and acceptance.

Notes

1. T. Banchoff. 2011. *Embryo Politics,* Ithaca, New York: Cornell University Press.
2. R. Macklin. 2003. 'Dignity is a Useless Concept', *British Medical Journal* 327, 1419–20.
3. R. Andorno. 2009. 'Human Dignity and Human Rights as a Common Ground for a Global Bioethics', *Journal of Medicine and Philosophy* 34, 223–40.
4. R.P. Kraynak and G. Tinder (eds). 2003. *In Defense of Human Dignity: Essays for Our Times,* Notre Dame, Indiana: University of Notre Dame Press.
5. Eloquently highlighting this concern is President's Council, *Reproduction and Responsibility,* 96–97.

6. See HFEA, *Sex Selection: Choice and Responsibility,* 24–29.
7. Cf. similar findings reported by E. Dahl et al., 2004. 'Attitudes towards Preconception Sex Selection: A Representative Survey from Germany', *Reproductive BioMedicine* 9, 600–03.
8. As J. Savulescu, 1999. 'Sex Selection: The Case For', *Medical Journal of Australia* 171, 373–75.
9. For example, as allowed by the *Human Embryology and Fertilization Act 1990,* §37
10. 2006. 'Harrison's Parents Chose His Name when He Was 35-Week Foetus – Then They Were Offered a Termination', *The Telegraph,* 21 May. Retrieved 10 August 2011 from http://tinyurl.com/telegraph-harrison.
11. 2008. 'Many Keeping Babies with Down's', *BBC News,* 24 November, Retrieved 20 September 2010 from http://news.bbc.co.uk/1/hi/health/7741411.stm.
12. J.K. Morris and E. Alberman, 'Trends in Down's Syndrome Live Births and Antenatal Diagnoses in England and Wales from 1989 to 2008: Analysis of Data from the National Down Syndrome Cytogenetic Register', *British Medical Journal* 2009; 339:b3794
13. B.G. Skotko, S.P. Levine and R. Goldstein. 2011. 'Having a Son or Daughter with Down Syndrome: Perspectives from Mothers and Fathers'. *Am J Med Genet Part A* 155, 2335–47.
14. L. Rogers. 2006. 'Babies with Club Feet Aborted', *The Sunday Times* 28 May. Retrieved 10 August 2011 from http://www.timesonline.co.uk/tol/news/uk/article669212.ece
15. In July 2011, the UK Department of Health published the 2010 abortion data for England and Wales, including numbers for late-term abortions (after twenty-four weeks gestation). Only ten late-term abortions occurred for Down syndrome, but four hundred and two occurred prior to twenty-four weeks. See C. Dyer. 2011. 'Late Abortion Statistics are Published after Pro-life Group Wins Court Ruling' *BMJ* 343, 67 See also Department of Health, 'Table 11 Legal Abortions: Principal Medical Condition for Abortions Performed under Ground E, 2010'. Retrieved 4 August 2011 from http://tinyurl.com/legal-abortions.
16. One of these definitions is found in the UK Equality Act 2010, which defines a disability as a physical or mental impairment that has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities, Equality Act 2010, Part 2, Chapter 1, 6(1).
17. Savulescu and Kahane, "The Moral Obligation to Create Children', 286.
18. Savulescu and Kahane, "The Moral Obligation to Create Children', 286.
19. World Health Organization. 1980. *International Classification of Impairments, Disabilities and Handicaps: A Manual of Classification Relating to the Consequences of Disease,* Geneva: WHO, 28.
20. On the criticism garnered by the ICIDH, see L. Nordenfelt. 1997. 'The Importance of a Disability/Handicap Distinction', *Journal of Medicine and Philosophy* 22, 607–08.
21. World Health Organization. 2001. *International Classification of Functioning, Disability and Health,* Geneva: WHO, 213.
22. HFEA, *Consultation Document on Preimplantation Genetic Diagnosis,* Annex C: 3.3.3.
23. Royal College of Obstetricians and Gynaecologists. 1996. *Termination of Pregnancy for Fetal Abnormality in England, Wales and Scotland,* London: RCOG Press.
24. Royal College of Obstetricians and Gynaecologists, *Termination of Pregnancy for Fetal Abnormality* (2010), 9.
25. R. Scott. 2002. 'Interpreting the Disability Ground of the Abortion Act', *Cambridge Law Journal* 64, 391.
26. From an academic perspective, see B.J. Brueggemann. 1999. *Lend Me Your Ear: Rhetorical Constructions of Deafness,* Washington DC: Galludet University Press. On a popular level, R. Atkinson. 2008. 'Is Deafness a Disability?', *BBC News,* 2 April. Retrieved 9 August 2011 from http://tinyurl.com/deafness-disability.
27. House of Lords, *Stem Cell Research,* 39.
28. President's Council, *Beyond Therapy,* 56–57.
29. The HFEA noted this in regard to PGD (*Consultation Document,* 9), but the matter extends to other 'eugenic' practices as well.

30. In addition to the four reasons listed below, a further problem with defining 'serious' derives from the inevitable circularity of the enterprise. This, of course, is an ancient problem in ethics and fully satisfactory answers still elude those who apply themselves to the question. For a brief account see A.M. Mardiros. 1952. 'A Circular Procedure in Ethics', *Philosophical Review* 61, 223–25.
31. There is even evidence to suggest that the CF gene expresses itself differently in Asians than in other communities. For example, C.J. Lin et al. note that infection from the pseudomonas bacteria occurs earlier in Asians with CF than in Caucasians, 2008. 'Phenotype and Genotype of Two Taiwanese Cystic Fibrosis Siblings and a Survey of Delta F508 in East Asians', *Pediatrics and Neonatology* 49, 243.
32. J. Botkin. 1995. 'Fetal Privacy and Confidentiality', *Hastings Center Report* 25, 32.
33. For discussion, see e.g., E. Parens and A. Asch. 1999. 'The Disability Rights Critique of Prenatal Testing: Reflections and Recommendations', *Hastings Center Report* 29, S1–S22.
34. Council of Europe Steering Committee on Bioethics. 2003. *The Protection of the Human Embryo In Vitro,* Strasbourg: Council of Europe, 32. Retrieved 15 June 2010 from http://www.coe.int/t/dg3/healthbioethic/texts_and_documents/CDBI-CO-GT3(2003)13E.pdf.
35. M. Saxton helpfully states the goal of disability rights groups in this regard as lobbying for 'the right *not to have to have* an abortion' when informed that a foetus might have a 'serious' condition (italics original), 1997. 'Disability Rights and Selective Abortion' in R. Solinger (ed.), *Abortion Wars: A Half-Century of Struggle, 1950–2000,* Berkeley, CA: University of California Press, 375.
36. D.C. Wertz and B.M. Knoppers. 2002. 'Serious Genetic Disorders: Can or Should They Be Defined?', *American Journal of Medical Genetics* 108, 29–35.
37. Chung, *Designer Myths,* 20.
38. For an attempt to reconsider the ICIDH disability scale with regard to a class of condition known as 'walking disabilities', see, S. van Buuren and M. Hopman-Rock. 2001. 'Revision of the ICIDH Severity of Disabilities Scale by Data Linking and Item Response Theory', *Statistics in Medicine* 20, 1061–76. Page 1072 offers a revised scale.
39. E.g. phenylketunuria (PKU). Without treatment PKU may lead to a number of mental problems and surely did before its discovery in 1933 and subsequent research. Today, however, PKU is so highly treatable that a cookbook has been developed to help PKU sufferers enjoy tasty food without exacerbating their condition: V.S. Schuett. 1997. *Low Protein Cookery for PKU,* 3rd ed., Madison: University of Wisconsin Press.
40. Wertz and Knoppers, 'Serious Genetic Disorders', 29–35.
41. V. English and A. Sommerville. 2002. 'Drawing the Line: The Need for Balance', in *Designer Babies: Where Should We Draw the Line?,* London: Hodder & Stoughton, 9.
42. T. Marteau and H. Drake. 1995. 'Attributions for Disability: The Influence of Genetic Screening', *Social Science and Medicine* 40, 1127–32.
43. On this point, the classic observation of J. S. Mill is apropos: 'The worth of a state, in the long run, is the worth of individuals composing it.' J. Gray (ed.). 1991. *On Liberty and Other Essays,* Oxford: Oxford University Press, 128.
44. Pattinson, *Influencing Traits Before Birth,* 149.
45. Cf. the foreboding opinion of C. Rosen, 'Those who oppose discarding unfit embryos or aborting unfit fetuses will soon become, perhaps already are, a dissident group, tolerated at best, but more likely heavily regulated by a society that increasingly expects only healthy children to be born.' 'Eugenics – Sacred and Profane', 87.
46. J.M. Green. 1995. 'Obstetricians' views on prenatal diagnosis and termination of pregnancy: 1980 compared with 1993'. *British Journal Obstetrics and Gynaecology* 102, 228–32.
47. King, Eugenic Tendencies in Modern Genetics', 87.
48. R. Sparrow. 2011. 'A Not-so-new Eugenics: Harris and Savulescu on Human Enhancement', *Hastings Center Report* 41(1), 32–42.
49. R. Sparrow. 2010. 'Liberalism and Eugenics', *Australasian Journal of Philosophy,* 89(3), 499–517.

50. Contrary to what some might think, this argument does not trade in fear-mongering, nor does it conjure images of a sci-fi reality. In 2004, the Human Genetics Commission reported a case of a woman who, having declined screening, was pressured by Social Services, and because 'she felt she had little choice', eventually aborted the foetus. *Choosing the Future,* 23. See also, B.K. Rothman. 2000. *Recreating Motherhood,* New Brunswick, NJ: Rutgers University Press, 44.
51. British Medical Association. 'Boosting Your Brainpower', 29–30.
52. J. Feinberg. 1980. 'The Child's Right to an Open Future', in W. Aiken (ed.), *Whose Child? Children's Rights, Parental Authority, and State Power,* Totowa, NJ: Rowman & Littlefield, 135.
53. L.R. Kass. 2002. *Life, Liberty and the Defense of Dignity: The Challenge for Bioethics,* San Francisco: Encounter Books, 162.
54. M. Fuchs, et al. 2002. *Die ethische Diskussion über biomedizinische Verbesserungen des Menschen,* Bonn: Deutsche Referenzzentrum für Ethik in den Biowissenschaften, 42–43.
55. Habermas, *The Future of Human Nature,* 82–83.
56. Neatly summarizing this is D. Archard. 2004. *Children: Rights and Childhood,* London: Routledge, 207–19.
57. Kass, 'The Wisdom of Repugnance: Why We Should Ban the Cloning of Humans', 698.
58. C. Mills. 2003. 'The Child's Right to an Open Future', *Journal of Social Philosophy* 34, 499–509.
59. Harris, *Enhancing Evolution,* 140.
60. Resnik and Vorhaus. 2006. 'Genetic Modification and Genetic Determinism', *Philosophy, Ethics, and Humanities in Medicine* 1, 9–11.
61. Though, of course, various humanist groups have opposed religious education. For example, the British Humanist Association funded a billboard campaign with the slogan 'Please don't label me. Let me grow up and choose for myself'. Retrieved 10 August 2011 from http://www.humanism.org.uk/billboards.
62. Of course, prices for PGD will depend on location, but one UK website suggests between £1,000 and £2,000 in addition to the cost of IVF. Retrieved 9 August 2011 from http://www.womenrepublic.co.uk/family_pregnancy/pgd_uk.htm. Compare to the findings of J. Randerson. 2006. 'Studies Cast Doubt on Selection Method for IVF Births', *The Guardian,* 31 January. Retrieved 13 April 2010 from http://tinyurl.com/selection-methods.
63. M. Mehlman. 2003. *Wondergenes: Genetic Enhancement and the Future of Society,* Bloomington: Indiana University Press, 116–17.
64. D.J. Galton. 1998. 'Greek Theories on Eugenics', *Journal of Medical Ethics,* 25, 263–67.
65. President's Council, *Beyond Therapy,* 49.
66. A fuller examination of societal inequality should include substantial discussion on poverty, including what it is, how it happens and how it may be overcome. Practitioners agree that poverty is a complex phenomenon, encompassing financial, relational and emotional shortfalls. Thus, a more equal distribution of financial resources would be insufficient to counteract poverty. And, relevant to the current discussion, lower cost for procedures would be insufficient to counteract genetic inequality. See, e.g., R. Lister. 2004. *Poverty,* Cambridge: Polity Press, 36.
67. R. Green, *Babies by Design,* 147–53.
68. M.J. Sandel. 2007. *The Case against Perfection: Ethics in the Age of Genetic Engineering,* Cambridge, MA: Harvard University Press, 91.
69. K.R. Smith, S. Chan and J. Harris. 2012. 'Human Germline Genetic Modification: Scientific and Bioethical Perspectives', *Archives of Medical Research* 43, 491–513.
70. Agar, *Liberal Eugenics,* 141.
71. Nuffield Council, *Genetics and Human Behaviour,* 153–54.
72. United Nations. 2006. *Convention on the Rights of Persons with Disabilities,* Article 2. Retrieved 20 December 2011 from http://www.un.org/disabilities/default.asp?id=150.
73. K.R. Shah. 2010. 'Selecting Barrenness: The Use of Preimplantation Genetic Diagnosis by Congenitally Infertile Women to Select for Infertility', *Human Reproduction and Genetic Ethics* 16(1), 18.

74. Wilkinson, *Choosing Tomorrow's Children,* 2.
75. Note: Whether a choice is made between foetal, embryonic, imaginary or born individuals, this choice is still very real and may be considered as having discriminatory consequences.
76. Obviously, prospective parents may sometimes have legitimate reasons for wanting to make some restrictions to the kind of child they wish to adopt. For example, as already indicated in the chapter on adoption, they may only decide to have a healthy child because they are not wealthy and are not getting social support so that they can look after the child in an appropriate fashion.
77. Wilkinson, *Choosing Tomorrow's Children,* 166.
78. D.J. Galton, *Eugenics: The Future of the Human Life in the 21st Century,* 46.
79. German Ethics Council. 2012. *Preimplantation Genetic Diagnosis: Opinion,* Berlin: German Ethics Council, 60.
80. The ethicist and neonatal paediatrician John Wyatt makes the point that 'There is widespread condemnation of the abortion of female fetuses for "social" reasons in some Asian countries. This practice is seen as enshrining widespread social discrimination against women in these countries. In the same way social approval of abortion of fetuses with Down's syndrome could even be seen as "chromosomalism", enshrining social discrimination against certain forms of DNA.' In J. Wyatt. 2001. 'Medical Paternalism and the Fetus'. *Journal of Medical Ethics* 27(5): ii15–ii20.
81. See for example, C.A.J. Coady. 2009. 'Playing God', In J. Savulescu and N. Bostrom (eds). 2009. *Human Enhancement,* Oxford: Oxford University Press, 171.
82. Stephen Wilkinson also notes (unpublished paper) that though it is possible to harm someone who already exists by afflicting him or her with a disorder, it is impossible to harm someone who is brought into existence with a disorder since without the disorder he or she would not have existed. Someone else would have existed instead.
83. S.D. Edwards. 2004. 'Disability, identity and the "expressivist objection"', *Journal of Medical Ethics* 30, 418–20.
84. R. Barnes (Chief Executive: Cystic Fibrosis Trust), *Letter to the Scottish Council on Human Bioethics,* 22 July 2003.
85. Disabled Peoples International. 2000. *Disabled people speak on the new genetics,* London: Disabled Peoples International Europe, 8.
86. Sicard, *La science médicale, la naissance et le risque d'eugénisme.*
87. O. O'Donovan. 1980. *The Christian and the Unborn Child,* Bramcote, Notts.: Grove Books, 19.
88. L.R. Kass. 1985. *Toward a More Natural Science: Biology and Human Affairs,* New York: Free Press, 89.
89. A. Fletcher. 2002. 'Making it Better: Disability and Genetic Choice', in *Designer Babies,* 21.
90. Over a generation ago P. Hunt edited a collection of essays that explored this very issue, 1966. *Stigma: The Experience of Disability,* London: G. Chapman. Although society is now far more accommodating towards disabled individuals, the basic insights of this book remain relevant today.
91. This is by no means a universal, and much of the literature in disability studies, as well as disability legislation, aims to counteract this. However, a strong case may be made that on a personal level and uninformed by more academic perspectives, people with disability do indeed wrestle with feelings of inferiority and marginalization.
92. This concern can be seen as arising from the eugenic programs discussed above, in which people without desirable traits were degraded. Whether or not intentionally, an article in *The Telegraph* recently fell prey to this issue by referring to a foetus *without* Down syndrome as 'healthy', thus implying that a foetus with Down syndrome would be unhealthy, R. Smith. 2010. 'Blood Test for Down's Syndrome', *The Telegraph,* 30 June. Retrieved 10 August 2011 from http://tinyurl.com/telegraph-Downs-test. Many foetuses and people living with Down syndrome are healthy, even if they carry an extra chromosome twenty-one.

93. This objection is often defined as 'the expressivist objection'. For more discussion, see S.D. Edwards. 2004. 'Disability, identity and the "expressivist objection"', *Journal of Medical Ethics* 30, 418–20. See also T. Shakespeare. 2006. *Disability Rights and Wrongs,* London: Routledge.
94. H. Houghton. 1994. 'Does Prenatal Diagnosis Discriminate against the Disabled?' In J. McKie (ed.), *Ethical Issues in Prenatal Diagnosis and Termination of Pregnancy,* Melbourne: Centre for Human Bioethics, 97–102: 98.
95. Wyatt, 'Medical Paternalism and the Fetus', ii15–ii20.
96. A similar concern was noted in the 2003 Council of Europe's report entitled 'The Protection of the Human Embryo In Vitro', Strasbourg, Council of Europe, 32.
97. S Holm. 2008. 'The expressivist objection to prenatal diagnosis: can it be laid to rest?', *Journal of Medical Ethics* 34, 24–25.
98. S. Holm. 2008. 'The expressivist objection to prenatal diagnosis: can it be laid to rest?', *Journal of Medical Ethics* 34, 24.
99. T. Shakespeare. 1998. 'Choices and Right: Eugenics, Genetics and Disability Equality', *Disability & Society* 13, 665–81.
100. The first-person account of M.J. Deegan illustrates this well, 2010. '"Feeling Normal" and "Feeling Disabled"', in S. Barnartt (ed.), *Disability as a Fluid State,* Bingley, UK: Emerald.
101. President's Council, *Beyond Therapy,* 56.
102. L. Gillam. 1999. 'Prenatal Diagnosis and Discrimination against the Disabled', *Journal of Medical Ethics* 25, 163.
103. D. King 1999. 'Preimplantation Genetic Diagnosis and the "New" Eugenics', *Journal of Medical Ethics* 25, 176–82.
104. German National Ethics Council . 2003. 'Position in Favour of the Retention and More Precise Specification of the Ban on PGD', in *Opinion: Genetic Diagnosis before and during Pregnancy,* Berlin: Nationaler Ethikrat, 86.
105. Quoted in V. Barford. 2011. 'Should My Hereditary Disability Stop Me Having a Baby?', *BBC News,* 18 April. Retrieved 28 April 2011 from http://www.bbc.co.uk/news/magazine-12987504.
106. It is interesting to note here that the aim of many a utilitarian commentator is the demise of the capacity to suffer in individuals. However, this would also imply the demise of any meaningful free will since all human beings would then be reduced to 'happy' automatons.
107. I. Knight. 2008. 'You Forgot about Love When It Comes to Down's Syndrome, Minette Marrin', *The Sunday Times,* 7 December. Retrieved 11 August 2011 from http://tinyurl.com/SundayTimes-Downs-parents.
108. C. MacKellar. 2011. 'Is Preconception Genetic Testing and Screening Eugenic?' *BioNews,* 18 April. Retrieved 2 June 2011, from http://www.bionews.org.uk/page_93163.asp.
109. Cases of euthanasia with children, however, do exist. A recent case involved an Australian couple suspected of euthanizing their daughter because they were reportedly unable to handle the condition. A. Dale. 2011. 'Rett Syndrome Girl's Dad "Asked about Euthanasia" before She Drowned', *Herald Sun,* 10 January. Retrieved 11 August 2011 from http://tinyurl.com/MelbourneHearldSun.
110. Human Genetics Commission, *Choosing the Future,* 23.
111. L. Gillam. 1999. 'Prenatal Diagnosis and Discrimination against the Disabled', *Journal of Medical Ethics* 25, 163.
112. Glover, Choosing Children, 9.
113. Nuffield Council, *Genetics and Human Behaviour,* 153.
114. One might object that imprisonment constitutes a refusal to accept some humans. Viewed another way, though, prison is simply a unique sector of society, and, as a recent article underscores, even prisoners must receive humane treatment, A. Fraser, A. Gatherer and L. Moller. 2009. 'Social Justice, Public Health and the Vulnerable: Health in Prisons Raises Key Public Health Issues', *Public Health* 123, 407–09.

115. G. Orwell. 1951. *Animal Farm,* New York, Penguin Books, 114.
116. For example, J. Glover. 1977. *Causing Death and Saving Lives,* Harmondsworth: Penguin Books, 39–59.
117. E.g., P. Singer. 1995. 'Presidential Address: Is the Sanctity of Life Ethic Terminally Ill?', *Bioethics* 9, 327–43. H. Kuhse. 1987. *The Sanctity-of-Life Doctrine in Medicine: A Critique,* Oxford: Clarendon.
118. H. Kuhse and P. Singer. 2002. 'Individuals, Humans and Persons: The Issue of Moral Status', in H. Kuhse (ed.), *Unsanctifying Human Life: Essays on Ethics,* Oxford: Blackwell, 188–98.
119. 2006. 'Harrison's Parents Chose His Name when He Was 35-Week Foetus – Then They Were Offered a Termination', *The Telegraph,* 21 May. Retrieved 10 August 2011 from http://tinyurl.com/telegraph-harrison.
120. For the figures see again, Department of Health, 'Table 11 Legal Abortions'.
121. Agar, *Liberal Eugenics,* 149.
122. For more, see section under Arguments Against Eugenics.
123. B. Waters. 2009. *This Mortal Flesh: Incarnation and Bioethics,* Grand Rapids: Brazos Press, 74.
124. Nuffield Council, *Genetics and Human Behaviour,* 154–55.
125. Wilkinson, *Choosing Tomorrow's Children,* 30.
126. D. Brock. 2009. Is Selection of Children Wrong? In J. Savulescu and N. Bostrom (eds). 2009. *Human Enhancement,* Oxford: Oxford University Press, 269.
127. Agar, *Liberal Eugenics,* 115.
128. In child psychology, this principle is so pervasive that a recent therapy manual simply assumes parental approval, S.C. Bratton et al. 2005. *Child-Parent Relationship Therapy (CRPT) Training Manual,* New York: Routledge, 114. To this point in the book the term 'love' has not appeared because of the complications attending a definition of love. However, as L. Thomas clarifies 'parental love' does not constitute 'parental approval', 1989. *Living Morally: A Psychology of Moral Character,* Philadelphia: Temple University Press, 63. In other words, for clarity's sake, in the immediate context 'love' and 'unconditional acceptance' may be considered as expressing similar concepts.
129. As many have recognized, e.g., Nuffield Council, *Genetics and Human Behaviour,* 155.
130. Cf. J. Malek. 2011. 'Use or Refuse Reproductive Genetic Technologies: Which Would a "Good Parent" Do?', *Bioethics* (pre-publication).
131. Nuffield Council, *Genetics and human Behaviour,* 155.
132. President's Council, *Beyond Therapy,* 54–55
133. Indicative of the imprecise results, the Fertility Institutes of North America claim to have 'virtually 100% accuracy'. If 100 per cent accuracy were common, this claim would be banal and unnecessary. Retrieved 11 August 2011 from http://www.fertility-docs.com/fertility_gender.phtml.
134. For a form of this argument see, R. McDougall. 2005. 'Acting Parentally: An Argument Against Sex Selection', *Journal of Medical Ethics* 31, 601–05.
135. 'Le problème éthique apparaît quand, pour obtenir la naissance d'un enfant sain, on fixe certaines exigences de « qualité » que le fœtus doit remplir pour avoir le droit de naître ; cela suppose en effet que les enfants ne sont pas désirés *pour eux-mêmes.*" R. Andorno. 2010. 'Fondements philosophiques et culturels de l'eugénisme sélectif', 130 (trans. C. MacKellar).
136. A right to exist in this world is also what humanity may experience as a group since no choice, as such, was ever made in the past history of the world as to humanity's very existence. This may be particularly recognized by some individuals with certain religious perspectives since some faiths indicate that this choice was made before history began.
137. D.S. Davids. 1997. 'Genetic Dilemmas and the Child's Right to an Open Future', *Hastings Center Report* 27:2, 7–15.
138. J. Feinberg. 1984. *The Moral Limits of the Criminal Law. Volume 1: Harm to Others,* Oxford, Oxford University Press, 102.

139. This is, of course, a contested assertion that has formed a central part of philosophical ethics for several decades under the title of 'the nonidentity problem'. For recent discussion see the essays from several perspectives in Roberts and Wasserman, *Harming Future Persons: Ethics, Genetics and the Nonidentity Problem.*
140. Similarly, if some persons claim that they would prefer to die rather than experience miserable suffering, this does not mean that they prefer nonexistence; rather, they are stating that they want their present lives of pain to end (without any comparison taking place).
141. Human Genetics Commission, *Making Babies,* 23.
142. The literature from this perspective is increasingly voluminous. Representatively, see Savulescu and Kahane, 'The Moral Obligation to Create Children'.
143. D. Parfit. 1986. *Reasons and Persons,* Oxford: Oxford University Press, 351–80.
144. J. Glover. 2001. 'Future People: Disability, and Screening', in J. Harris (ed.), *Bioethics,* Oxford: Oxford University Press, 439.
145. It should be noted that in this example the genetic heritage of the child is not affected. However, the dilemma of the woman may be similar to cases where a genetic disorder may affect a possible future child.
146. D. Parfit. 1976. 'Rights, Interests and Possible People', in S. Gorovitz et al. (eds), *Moral Problems in Medicine,* Englewood Cliffs, NJ: Prentice Hall, 369–75.
147. See also B. Steinbock. 2009. 'Wrongful Life and Procreative Decisions', in M.A. Roberts and D. T. Wasserman (eds), *Harming Future Persons: Ethics, Genetics and the Nonidentity Problem,* New York: Springer, 2009, 169–70.
148. Wilkinson. *Choosing Tomorrow's Children,* 175.
149. D. Brock. 1995. 'The Non-Identity Problem and Genetic Harms', *Bioethics* 9 (3/4), 272–73.
150. S. Wilkinson and E. Garrard. 2013. *Eugenics and the Ethics of Selective Reproduction,* Keele: Keele University, 14–15.
151. In this case, the decision may be considered as being particularly difficult since parents are usually seen as being especially responsible for the children they have procreated.
152. Of course, if conception has already taken place and the mother takes certain drugs to protect the health of the embryo or foetus, this would also be seen as a noneugenic decision. It would be a similar situation to parents giving medication to a child who is sick.
153. A similar example is given by the philosopher Elizabeth Harman in which a government is deciding whether or not to enact a lax nuclear waste disposal policy. If permissive policies are implemented then, over future centuries, many individuals will become sick from the nuclear waste which is not appropriately contained and their children will have genetic mutations. Thus the identity of the persons who exist in the future will be different to those who would have existed if the waste disposal policy had been stringent and responsible. Harman indicates that these sick people would not have existed had there not been a permissive nuclear storage policy. See: E. Harman. 2009. 'Harming as Causing Harm', in M.A. Roberts and D.T. Wasserman (eds), *Harming Future Persons: Ethics, Genetics and the Nonidentity Problem,* New York: Springer, 2009, 138.

    But then should a decision be made between the two permissive and restrictive policies since two sets of people would in both cases exist in the future with an equal value and worth? Here again it should be emphasized that the right and responsible decision by the government should be made, as such, concerning waste disposal irrespective of the kinds of people that will exist in the future. As a result if a safe decision is taken (for its own environmental sake, without looking at the consequences on possible future populations) then healthy populations will arise in the future but they will only exist as a kind of double or secondary effect to the decision.
154. T. Blackwell. 2010. 'Couple Urged Surrogate to Abort Fetus Due to Defect', *National Post.* 6 October. Retrieved 11 August 2011 from http://tinyurl.com/NationalPost-Surrogate.
155. President's Council, *Beyond Therapy,* 54–56.

156. For example, this seems to be the concern of B.K. Rothman. 1988. 'Reproductive Technology and the Commodification of Life', *Women & Health* 13, 95–100. To be fully accurate, selection does not commodify an embryo, since the embryo is not actually sold, but, as explained above, commodification is possible. For expression of these concerns see also, Human Genetics Commission, *Choosing the Future,* 25.
157. Retrieved 5 October 2010 from http://www.fertility-docs.com/fertility_gender.phtml. Emphasis original.
158. Davis, 'Genetic Dilemmas', 7–15.
159. On the distinction between instrumentalization and commodification, see S. Wilkinson. 2007. 'Commodification', in R. Ashcroft et al. (eds), *Principles of Health Care Ethics,* 2nd ed., Chichester: Wiley, 285–87.
160. E. Schockenhoff. 2003. 'Fortpflanzungsfreiheit und verantwortliche Elternschaft. Zur ethischen Problematik des Präimplantationsdiagnostik', *Zeitschrift für Medizinische Ethik* 49, 382.
161. D.B. Resnik. 1998. 'The Commodification of Human Reproductive Materials', *Journal of Medical Ethics* 24, 388–93.
162. President's Council, *Beyond Therapy,* 54–55.
163. 'Cet individu vivra avec la conscience qu'il a mérité de naître uniquement parce qu'il possédait les caractéristiques voulues *par d'autres et non parce que sa vie a une valeur intrinsèque.* Ceci, c'est évident, est contraire à l'idée même de dignité humaine qui suppose que tout individu a une valeur inhérente à sa condition humaine même et que donc, par conséquent, tous les êtres humains *ont la même valeur*'. R. Andorno, 'Fondements philosophiques et culturels de l'eugénisme sélectif', 131–32 (trans. C. MacKellar).
164. Moreover, it is recognized that a person is at a greater risk of suicide when he or she comes to believe that he or she does not have a place in society.
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166. Howe and Feast, *Adoption, Search & Reunion,* 157.
167. M. Shelley. 1994. *Frankenstein,* Penguin Popular Classics: London, 124.
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169. Rogers, *On Becoming a Person,* 62.
170. For example, R. Freeth. 2007. *Humanising Psychiatry and Mental Health Care: the Challenge of the Person,* Oxford: Radcliffe, 135.
171. D. Mearns and M. Cooper. 2005. *Working at Relational Depth in Counselling and Psychotherapy,* London: Sage, 43.
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173. R. Song. 2006. 'Knowing There is No God, Still We Should Not Play God? Habermas on the Future of Human Nature', *Ecotheology* 11(2), 202.
174. A. Miller. 1980. *Prisoners of Childhood,* New York: Basic Books, 75.
175. Habermas, *The Future of Human Nature,* 77–78.
176. J. Savulescu and I. Persson. 2012. *Unfit for the Future: The Urgent Need for Moral Enhancement,* Oxford: Oxford University Press.
177. MacIntyre, 'Seven Traits for the Future', 7
178. MacIntyre, 'Seven Traits for the Future', 7
179. J. Mann. 1992. 'Nurturance or Negligence: Maternal Psychology and Behavioral Preference Among Preterm Twins', in J. H. Barkow, L. Cosmides, and J. Tooby (eds), *The Adapted Mind: Evolutionary Psychology and the Generation of Culture,* Oxford: Oxford University Press, 367–72.
180. For this reason, some cultures practice infanticide, as M. Daly and M. Wilson's report, 1984. 'A Sociobiological Analysis of Human Infanticide', in G. Hausfater and S.B. Hrdy (eds), *Infanticide: Comparative and Evolutionary Perspectives,* New York: Aldine de Gruyter, 487–502.

181. Ted Peters claims: 'The concept of freedom applies to the whole of a person, not to one of his or her parts, even a genetic part. Freedom is exercised at the level of the person, the self, and it takes the form of deliberation, decision, and responsible action', 1997. *Playing God?: Genetic Determinism and Human Freedom,* New York: Routledge, 176.
182. Sandel, *The Case against Perfection,* 49 and 127.
183. President's Council, *Reproduction & Responsibility,* 95–96.

CONCLUSION

The spectre of eugenics programs in the late nineteenth and twentieth centuries, especially during Nazi-era Germany, cast a sinister shadow over the term 'eugenic' and its related practices. In the intervening years, many societies have assiduously distanced themselves from any semblance of eugenics. Sociologist Anne Kerr even quotes an unnamed senior geneticist in the United Kingdom as denying the existence of a new eugenics: 'I think eugenics for me implies a population, a government, a scientifically led race towards something. I base my practice … around patient choice. And I think if we aim it at the individual without bias then hopefully we avoid that [eugenics]'.[1] On the other hand, ethicist Stephen Wilkinson allows that talk of eugenics today may be appropriate if the point is to engage people who otherwise would ignore the issues to hand. But Wilkinson rejects eugenics talk when it is used to manipulate emotions, as when used as a scare tactic.[2]

In this book, as explained earlier, the selection procedures that increasingly feature in assisted reproduction have been described as constituting a new eugenics. The view expressed by the senior geneticist, above, is thus challenged in spite of the subtlety with which the new eugenics is emerging. And, while Wilkinson is right to denounce eugenics talk as a tool of fear-mongering, this book has shown that selection procedures deserve the label 'eugenic', in spite of their commonness. The Danish ethicist Lene Koch puts it well:

> Today eugenics is something few would want to see realised, but we should appreciate that it was originally a focus of a widely held hope for a better and healthier population. The definition of 'better and healthier' may no longer embrace the elimination of socially, morally, and genetically undesirable elements as defined by the early eugenicists, but the hope for better health still underpins the rationale for genetic applications.[3]

At present, there seems to be a kind of growing general consent, a collective approval, a consensus of opinion, an established order for the decision that children with disorders are not born. This has now reached a point where couples considering the termination of a pregnancy because their foetus is affected by a disorder, such as Down syndrome, do not even address the difficult question of the relevance of their individual choice. In a way, society and public opinion has already answered the question of these expectant mothers for them even without any external constraints being present.[4]

This book has sought to address the perceived resurgence of eugenics in the increasingly common procedures available in assisted reproductive technology. Although promising in their potential to address genetic disorders, there is now optimism that new procedures will actually be able to fulfil desires. But as Leon Kass indicated, '[O]nce one blurs the distinction between health promotion and genetic enhancement, between so-called negative and positive eugenics, one opens the door to all future eugenic designs.'[5]

Moreover, and as already argued, these new eugenic procedures derive from an ideology similar to what motivated past eugenics programs. Of course, coercive measures are (largely) absent, but the aim is still to improve and control the genetic heritage of humanity, communities or individuals. To the question whether eugenics has returned in the compassionate guise of medical genetics, the political scientist Diane Paul answers, 'From a historical standpoint, the answer would seem to be yes.'[6] Other commentators, however, are even more categorical. The physician Laurent Alexandre, for example, indicated in 2012, 'The return of eugenics is an ethical and political bomb that has been completely unnoticed', adding, '[W]ithout realising it, we are already on a eugenic toboggan.'[7]

This means that, in light of their historical antecedents, the new procedures presented in this book may be described accurately as constituting a new eugenics.

Of course, accusations of a return to a new eugenics is often criticized or refuted by arguing that there is a right to procreative liberty or that some of the new reproductive procedures cannot be considered as eugenic because they are not imposed by the state. As supporters of selection emphasize, procedures such as preimplantation embryonic selection are purely matters of parental choice. In this context, if the eugenic term is reluctantly accepted by many individuals supporting selection, they emphasize that the voluntary form of selection must be seen as acceptable. As Nicholas Agar suggests, '[T]he addition of the word "liberal" to "eugenics" transforms an evil doctrine into a morally acceptable one.'[8] This is also emphasized by the French physician and politician Bernard Debré, who argued that only the scientific, dictatorial and societal eugenic programs of the nineteenth and twentieth centuries deserve condemnation.[9] In contrast, he suggests that the widespread use of selection procedures, particularly for the deselection of genetic disorders, should be considered as a form of humanitarian assistance that society deserves and should be welcomed.

Until the advent of new reproductive technologies, one of the few ways to influence the traits of a future child was to deselect certain kinds of foetuses through abortion or through the choice, in certain circumstances, of a reproductive partner.

But this has now progressed to procedures, such as preimplantation embryo selection, which enable the selection to take place at a very early stage. In the future, parents may expand selective practices even further not only by selecting for a healthy child but deciding what kind of positive characteristics he or she could have. But whatever benefits this eugenic selection may offer, it also raises numerous questions. Perhaps one of the most challenging, in this regard, is trying to distinguish treatment from enhancement or, for that matter, whether a distinction is even feasible. Such a challenge of creating rigid categories is notoriously difficult.[10]

For example, most people would agree that genetic modifications to treat cystic fibrosis or muscular dystrophy are medical treatments. On the other hand, genetic modifications to provide musical talent, superior strength or increased intelligence are clear examples of enhancement. But some controversial procedures are far more ambiguous. In this category, it is unclear whether a genetically engineered resistance to disease would be considered as a medical treatment or an enhancement. Confronted with the difficulty of deciding where to draw the lines, some may assert that no lines can or should be drawn and that society should resign itself to accepting that the ethics of selection practices (the new eugenics) is fluid. This is especially the case in the field of fertility treatment, where ethical regulation often seems redundant since, in the words of Yury Verlinsky, a PGD pioneer in the United States, 'PGD is just an extension of prenatal diagnosis, and that is self-regulated.'[11] Because of this fluidity, where no clear delimitations are possible, only self-regulatory nonenforceable guidelines from professional bodies have been prepared. As a result, a number of eugenic procedures are already accessible in some countries.[12]

According to this line of reasoning, and although this new eugenic age is still young with many restrictions to liberal practices, there is a real risk that society may be returning towards a quiet tolerance of eugenic policies as in the pre–Second World War years. Indeed, barring an extraordinary reversal in momentum, these selective eugenic practices have arrived as societal fixtures. Perhaps this is because eugenic procedures promise so much more control and autonomy to (1) parents who are used to a consumer culture but also to (2) society that may see them as a source of order. As David King indicates, 'Eugenicists argue for "improvement" of the overall human gene pool, but what really appals them is that the whole business of human reproduction is out of rational control, and is left to chance.'[13] This lack of control of humankind in determining its destiny is also something that Nobel Prize winner James Watson would want to overcome, arguing that:

> Our growing ability to unscramble human genetic destinies will increasingly have an impact on how humans view themselves and justify their behaviour toward others. Our children will more be seen not as expressions of God's will, but as the results of the uncontrollable throw of genetic dice that do not always give us the results we want. At the same time, we will increasingly have the power, through prenatal diagnosis to spot the good throws and to consider discarding through abortion the

> bad ones. But to so proceed flies in the face of the long-cherished idea that all human life is sacred and intrinsically worthwhile. So there is bound to be deep conflict between those persons who want to maintain revered values of the past and those individuals who wish to have their moral values reflect the world as now revealed by observations and experiments of modern science. In particular, we are increasingly going to be accused of unwisely 'playing God' when we use genetics to improve the quality of either current of future human life.[14]

The question is no longer whether society will practice eugenic procedures but which forms of procedures will it allow and in what form will it permit these eugenic practices to develop.[15] Of course, not all forms of procedures involving a eugenic element may raise similar concerns. For example, when a woman is unconsciously attracted to a man for reasons that may include, amongst other things, the rearing of certain kinds of children, this cannot be considered as being unethical. However, when any selection is deliberately proposed on the basis of the biological characteristics or the 'quality control' of a possible future child, the inherent and equal dignity and value of all human beings is challenged.

To encourage a discussion on the moral implications of a noncoercive form of eugenics, Robert Nozick[16] considers the futuristic possibility of a reproductive supermarket where the choices of future parents are not limited by the state. But would such an example of a market or catalogue in which the pictures and expected characteristics of possible future children are presented be seen in any way as threatening to society?

In response, society first needs to be honest with itself in acknowledging that these practices are already beginning to occur and that its responsibilities are being challenged. Secondly, it needs to consider the ethical uncertainties which the new eugenics raises with courage and realism while trying to understand the possible consequences of these questions.

The preceding chapters have marshalled several arguments for and against strategies or decisions aimed at affecting for the better the genetic heritage of a child, a community or humanity in general. Obviously, genetic heritage or quality of life evaluations do not say, by themselves, anything about the moral worth or value of a person and are not discriminatory.[17] But as soon as these evaluations are used for selective decisions or as the basis for the manner in which persons should be treated or considered, discriminatory risks appear. In this regard, one of the main risks of eugenic selection when it seeks to avoid a future child who may be disabled or who may fail to attain expectations is the message that it is giving to society. This is because it is impossible not to conclude that the message inferred, even if unspoken and indirect, is that people with the specific trait who already exist should not have been brought into existence. Following this argument, the point remains that some eugenic selection practices undermine the fundamental ethical principle that all human beings are equal in value and inherent dignity. Of course, a massive literary corpus has addressed the importance of distinguishing between the disorder itself, which is seen as a negative and those who are affected by the disorder, who should be considered as having an equal value and worth to any other existing person. As Julian Savulescu argues:

> Testing [to deselect] for cystic fibrosis or Down syndrome is said to send the message that such lives are less valuable, that those people are of lower status. This is deeply mistaken. To say that a disease is bad is not to say that a person with that disease is less equal or bad in some way. The problem is some people identify with their disease, disorder or some other characteristic about themselves, like sex.[18]

However, as already indicated, these responses remain unconvincing for the very reason that Savulescu mentions, i.e., that people see their disability as part of who they are. When the choice between bringing into existence a disabled or nondisabled person is being considered, it is impossible to separate these persons and who they are from their physical characteristics. This means that if disabled persons realize that individuals with their disabilities are being deselected, they may feel that their very existence is being questioned.[19] Even once they are born, the very identity of persons and the manner in which they understand themselves as individuals cannot be dissociated from their physical features. In summary, any selective choice which becomes public will surely be seen as very significant by the disabled community. For example, Wilkinson and Garrard explain,

> [S]ometimes people make that decision – to have no child rather than have a disabled one… just because they think it would be better in general to bring no child into the world rather than to create one with a disability. In that case, they really are sending out the message that the world would be better if it contained no disabled people (or at least no one with the particular disability in question). Their choice is based on their views about disability and its negative contribution to general welfare, and these views do indeed imply that the world would be better without children with disabilities in it. Such views are perhaps not very common, and acting on them in this way is relatively unusual. Nonetheless it can happen, and in those particular circumstances, the practice of selective reproduction does send out that troubling message.[20]

What is more, there is a real danger of discrimination to suggest that disabilities, which cannot be separated from persons, should not be brought into existence. This is because the disorder's existence cannot be dissociated from a person's existence. Instead, it is all persons with or without a disability who should be able to be brought into existence without favouritism or bias. In other words, saying that a disorder should not exist should never mean that a person with such a disorder should not be brought into existence.

Another argument in favour of certain forms of eugenics is the repeated and increasingly vocal emphasis that parents should never be forced to accept a disabled and suffering child whose birth could have been avoided. A lot of resentment and anger is expressed at such a possibility. It is seen as unacceptably cruel and as something that should never be countenanced. Disabled children are sometimes also presented as the cause of deep suffering in a family and as persons who may even undermine its unity. But these responses cannot repudiate the fact that absolutely all life, in a civilized society, has an equal as well as inherent value and worth. This means that if any human life is ever considered as a life unworthy of life then serious questions could be asked about the value a society places on all human life.

Within this context, a more meaningful and compassionate way forward would be for society to appropriately help and assist parents look after severely disabled children. It would then counter the measures already being undertaken at present making sure that children with, for example, Tay–Sachs are not born to the detriment of valuing these children for who they are. As Emily Rapp, the mother of a child dying from Tay–Sachs, movingly writes:

> I would walk through a tunnel of fire if it would save my son. I would take my chances on a stripped battlefield with a sling and a rock à la David and Goliath if it would make a difference. But it won't. I can roar all I want about the unfairness of this ridiculous disease, but the facts remain. What I can do is protect my son from as much pain as possible, and then finally do the hardest thing of all, a thing most parents will thankfully never have to do: I will love him to the end of his life, and then I will let him go.[21]

Of course, this experience is not always shared, and some parents may deeply regret the existence of their disabled child. In this case, the resulting suffering for them and for their child is not seen as being compensated by the inherent value of the child as such. Had they had the possibility, the parents would have chosen a nondisabled child. In this regard, David King warns that society will need to be wary of the danger of developing what he defines as a 'eugenic common sense', whereby it would be seen as irresponsible to decline the possibility of genetically testing either the future parents or the resulting embryo or foetus. This is because it will be accepted that every child has a 'right' to be genetically healthy.[22]

From this perspective the main arguments in favour of eugenics are based on the ethical theory of consequentialism. As discussed in the introduction, consequentialism weighs the overall amount of pleasure versus suffering a specific action may produce. The new eugenics, just as earlier programs, promises to reduce the amount of suffering that will be experienced either in whole population groups, in families or in individuals. Derek Parfit, for example, proposed the following consequentialist principle for eugenic selection: 'If in either of two possible outcomes the same number of people would ever live, it would be worse if those who live are worse off, or have a lower quality of life, than those who would have lived.'[23] But in suggesting this analysis, Parfit prioritizes a person's quality of life over the equality in inherent dignity, worth and value of every human person which is a fundamental principle of civilized societies. To quote Andorno again: 'In reality, eugenic ideology presupposes stepping from a "worthiness of life" culture to a "quality of life" culture, in other words, to the idea that not every life is worthy of being lived, or to put it more bluntly, that there are some lives that do not have any worth.'[24] This, in short, is the frontline of the fundamental disagreement concerning the new eugenics. On one side, quality of life and the reduction of suffering rank as the top priority; on the other, the focus is on the equal and inherent dignity and worth of all human life while simultaneously pursuing the alleviation of suffering.

This difference is not new. In 1922 H.G. Wells summarized the clear tension that existed between different worldviews when he discussed eugenic birth control, in the context of creating fewer and better children, when it was being discussed in the United Kingdom:

> When we realize clearly this possibility of civilizations being based on very different sets of moral ideas and upon different intellectual methods, we are better able to appreciate the profound significance of the schism in our modern community, which gives us side by side, honest and intelligent people who regard Birth Control as something essentially sweet, sane, clean desirable and necessary, and others equally honest and with as good a claim to intelligence who regard it as not merely unreasonable and unwholesome, but as intolerable and abominable. We are living not in a simple and complete civilization, but in a conflict of at least two civilizations, based on entirely different fundamental ideas, pursuing different methods and with different aims and ends.[25]

Unfortunately, Wells's observations of a divided society are still just as valid. Today, as in 1922, there is a schism, a division between two sides that may have its origins in the new understanding of evolutionary biology. By presenting a purely naturalistic explanation of humanity, there is a risk that one side reduces humanity to biological science and diminishes ethical principles to consequentionalism as well as those that advance the evolutionary process. The French anthropologist Georges Vacher de Lapouge went even further by suggesting that it is science that will give society its new morality as well as its new politics.[26] But this also means that there is no longer any inherent equality between human beings since science, on its own, cannot give any basis for this principle. From this perspective, ridding society of those who are deemed inferior to improve human flourishing would not contradict this new morality.

It is because of the scientific force of the above arguments that eugenic ideology found such a fertile ground, at the beginning of the twentieth century, amongst reputable and eminent academics around the word including the medical and scientific elites.[27]

This book, however, self-consciously lands on the other side and rejects the reduction of human worth and ethics to scientific principles. It is on the side that advocates, instead, the equal dignity and worth of all persons as a more fundamental ethical principle than quality of life comparisons. As the framers of the UN Universal Declaration on Human Rights were aware, without this principle, there is no rational opposition to grave abuses of the human person.

Of course, it is recognized that in contemporary philosophy there is no sustained or logical justification for basic equality. Instead, this equality is usually assumed without an appropriate explanation or defence.[28] A society may believe (and it is only a belief) that all persons are equal in dignity and in worth or it may believe (and it is only a belief) that they are not. But whatever it believes is extremely important. For example, a society which believes that a life is only worthy of life if it has a certain amount of quality is a society built on very fragile grounds. It would beg the question whether society's condemnation of the murder of a person would be dependent on this person's worth based on his or her quality of life. Questions would also be asked as to how society should decide on the quality of life of a person.

With many eugenic procedures, the ominous slogan 'life unworthy of life' creeps back to replace the UN's Universal Declaration of Human Rights' 'inherent dignity' and equality of all human persons which is the basis of civilized society and which was drafted expressly to counter such expressions. It follows that since every possible future child and every existing child are equal in inherent dignity it is possible to question why selection should be considered in the first place. Indeed, any such selection may pose an intrinsic challenge about the manner in which moral reasoning is taking place. Either persons are valued for their inherent worth or they are valued for their quality of life. If they are valued for their inherent worth, then the very act of selection becomes meaningless since everyone is equal and choosing no longer becomes necessary. As Roberto Andorno rhetorically asks, 'Does human selection not contradict the principle according to which all human beings have the same worth, regardless of their state of health?'[29] On the other hand, if a person's quality of life becomes the primordial basis for whether a life is valuable or meaningful, then, of course, eugenic programs become relevant. But is there not, as a result, a risk that the value of a life will only be reduced to an individual's sense of happiness and/or physical characteristics? In this regard, Leon Kass warns that if human life is seen as being devoid of any nonphysical attributes such as inherent dignity, in other words, '[I]f we come to see ourselves as meat, then meat we shall become.'[30]

This battle of values comes to the fore in the current debate about the new eugenics, especially if a society begins to feel weakened or under pressure by a number of constraints such as financial limitations in the health sectors.[31] Again Diane Paul offers an incisive observation: 'One clear lesson from the history of eugenics is this: what may be unthinkable when times are flush may come to seem only good common sense when they are not. In the 1920s, most geneticists found the idea of compulsory sterilization repugnant. In the midst of the Depression, they no longer did'.[32]

Similarly, the biologist and historian Garland Allen has demonstrated that eugenic proposals were increasingly taken seriously in the United States when economic fears and uncertainty were present in society.[33]

Since many of the new selection procedures will eventually affect all of humanity, it is also for society as a whole to consider, discuss and decide the matters related to the developments of eugenics in a democratic manner. This means that the possible benefits but also the risks related to eugenic decisions should not just be made by a few individuals or a small community. The Harvard biologist Ruth Hubbard, put it well:

> [T]he women and men who must live in the world that the scientific/medical/industrial complex constructs must be able to take part in the process by which such decisions are made. Until mechanisms exist that give people a decisive voice in setting the relevant scientific and technical agendas and until scientists and physicians are made accountable to the people whose lives they change, technical innovations do not constitute new choices. They merely replace previous social constraints with new ones.[34]

The consequences cannot be underemphasized, and society needs to remain vigilant. In this regard, the UK Human Genetics Commission warns, 'In a democracy, public understanding of human genetics should serve to create awareness of the dangers of eugenics, and the possible stigmatisation of those carrying or suffering from genetics disorders.'[35] In the Kingdom of Norway, for example, there was an explicit recognition by legislators that many of the new reproductive procedures were associated to certain choices and possible eugenic practices. The law, as a result, emphasizes the crucial importance of the principle of equality in value and worth implicitly rejecting the risks associate to what has been termed a 'sorting society'. As Norwegian social anthropologists Marit Melhuus and Signe Howell indicate:

> A 'sorting society' is understood to be a society that allows, even potentially, for any form of sorting of its members. And applied to [new reproductive technologies] it refers directly to what may be termed a hierarchy of desirability with regards to the potential characteristics of the future child. Because of this present position in Norway it is recognised that 'prospective parents – adoptive or other – may not specify the desired qualities of their future child, such as sex, colour, abilities, etc.[36]

As part of this democratic approach to the new eugenics, readers must grapple with the issues for themselves, assessing the validity of the different ethical arguments. In doing so, wisdom demands that the lessons of history should not be overlooked. The physician, Leo Alexander, one of the leading medical examiners at the Nuremberg Medical Trials, underscored the importance of appreciating historical context, as he reflected on the events of early twentieth century Germany:

> Whatever proportions these crimes finally assumed, it became evident to all who investigated them that they had started from small beginnings. The beginnings at first were merely a subtle shift in emphasis in the basic attitudes of the physicians. It started with the acceptance of the attitude, basic to the euthanasia movement, that there is such a thing as a life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Germans.[37]

Looking at the state of the 1949 culture of American medicine, Alexander then warned:

> In an increasingly utilitarian society these patients are being looked down upon with increasing definiteness as unwanted ballast. A certain amount of rather open contempt for the people who cannot be rehabilitated with present knowledge has developed. This is probably due to a good deal of unconscious hostility, because these people for whom there seem to be no effective remedies, have become a threat to newly acquired delusions of omnipotence.[38]

In his conclusion, Alexander warned that there was a certain logical sequence to the disappearance of civilized behaviour. This begins by recognizing the pragmatic use of scientific developments; it then continues by discarding traditional values in disdainful arrogance of what can be achieved but always ends in a moral and ethical wasteland.[39]

To protect humanity from such a prospect, a compassionate civilized society should learn to accept all possible future children in an environment that reflects its unconditional and equal acceptance of the suffering as well as the happy child. It will then continue to uphold and protect the important inherent equal dignity and value of all human beings – accepting them for who they are and suffering or rejoicing with them in compassion and care.

Wisdom also demands a sense of genuine humility and a refusal to accept the notions that 'It cannot happen here', 'It cannot happen again' or 'It cannot happen to us'. Society cannot rest in the deceptive safety of the present while believing that it is free from the abuses of the past.

Notes

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24. 'En réalité, l'idéologie eugénique suppose le passage d'une culture de la « valeur de la vie » à une culture de « la qualité de vie », c'est-à-dire, à l'idée que toute vie ne vaut pas la peine d'être vécue ou pour le dire plus crûment, *qu'il y a des vies qui n'ont aucune valeur,* Andorno, 'Fondements philosophiques et culturels de l'eugénisme sélectif', 140 (trans. C. MacKellar).
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APPENDIX I

Past and Present Personalities Supporting Eugenic Policies

The following catalogue of quotes supporting eugenic ideologies from eminent personalities helps demonstrate the widespread endorsement and acceptability of the concepts in the late nineteenth and early twentieth centuries. Particularly noteworthy are the nonscientists who viewed eugenic policies as advantageous or even necessary for the well-being or survival of society. When available, direct quotations allow these famous people to express their opinion of eugenics unequivocally. It goes without saying that the names below are representative (not comprehensive) of the many who have advocated varying levels of eugenics over the years.

Alexander Graham Bell (1847–1922, Scotland, United States): best known as one of the inventors of the telephone. Bell was Honorary President of the Second International Congress on Eugenics. Both his mother and wife were deaf and, in 1881, he investigated the rate of deafness in certain communities in Massachusetts. From this he concluded that deafness was hereditary in nature and recommended a marriage prohibition against the deaf. Like many other early eugenicists, he proposed controlling immigration for the purpose of eugenics and warned that boarding schools for the deaf could possibly be considered as breeding places for a deaf human race.[1]

Sir Winston Churchill (1874–1965, England): wartime prime minister of the United Kingdom. Churchill was openly disappointed when Britain resisted positive eugenic action on the grounds of civil liberties. In 1910, Churchill wrote to the then Prime Minister Herbert Asquith to express his support for a bill that proposed the introduction of a compulsory sterilization program in Britain. He indicated that: 'The unnatural and increasingly rapid growth of the feeble-minded and insane classes, coupled as it is with a steady restriction among the thrifty, energetic and superior stocks, constitutes a national and race danger which it is impossible to exaggerate … I feel that the source from which the stream of madness is fed should be cut off and sealed up before another year has passed.'[2] Two years later, Churchill attended the First International Eugenics Congress in London and even agreed to become its vice chairman.

Francis Crick (1916–2004, England): Nobel Prize Laureate, co-discoverer of the structure of the DNA molecule in 1953. In the book *Man and the Future* (1963), Crick suggested that it was time to challenge the belief that everyone had a right to have children. As a result, he proposed that a system for the licensing of procreation should be established since some people were not fit to be parents. In 1978, he went even further, saying, '[N]o newborn infant should be declared human until it has passed certain tests regarding its genetic endowment and that if it fails these tests it forfeits the right to live.'[3]

Charles Darwin (1809–1882, England): British naturalist who achieved lasting fame by devising the theory of evolution through natural selection and sexual selection. Though Darwin himself opposed discrimination against the weak and helpless, in 1871 he wrote:

> With savages, the weak in body or mind are soon eliminated; and those that survive commonly exhibit a vigorous state of health. We civilised men, on the other hand, do our utmost to check the process of elimination, we build asylums for the imbecile, the maimed and sick, we institute poor-laws; and our medical men exert their utmost skill to save the life of everyone to the last moment … No-one who has attended to the breeding of domestic animals will doubt that this must be highly injurious to the race of man. It is surprising how soon a want of care, or care wrongly directed, leads to the degeneration of a domestic race; but excepting in the case of man himself, hardly anyone is so ignorant as to allow his worst animals to breed.[4]

Charles Davenport (1866–1944, United States): prominent American biologist. In 1904 Davenport received funds from the Carnegie Institution to found the Station for Experimental Evolution. In 1910, he opened the Eugenics Records Office to study family pedigrees. From his research, Davenport concluded that societal misfits came from economically and socially poor backgrounds[5] and that society needed protecting from the 'unfit' through immigration restriction and sterilization.[6,7] He predicted that without a solution to the immigration of southeastern Europeans, America would 'rapidly become darker in pigmentation, smaller in stature, more mercurial, more attached to music and art, more given to crimes of larceny, kidnapping, assault, murder, rape and sex-immorality'. He added, '[I]mmigrants are desirable who are of "good blood", undesirable who are of "bad blood"'.[8]

Robert Edwards (1925–2013, England): Nobel Prize winner in 2010 for Physiology or Medicine. He took part in the creation of the first child through IVF. At the 1999 Annual Meeting of the European Society of Human Reproduction he remarked, 'Soon it will be a sin for parents to have a child that carries the heavy burden of genetic disease. We are entering a world where we have to consider the quality of our children.'[9]

Joseph Fletcher (1905–1991, USA): a professor of medical ethics, he was the founder of Situational Ethics, and a member of the American Eugenics Society. He did not believe that persons with certain mental health disorders could be considered as having human dignity and thus formed a kind of underclass. In 1975 he wrote: 'Idiots are not, never were, and never will be in any degree responsible (because they cannot understand consequences of action). Idiots, that is to say, are not human. The problem they pose is not lack of sufficient mind, but of any mind at all. No matter how euphoric their behavior might be, they are outside the pale of human integrity.'[10]

Sir Francis Galton (1822–1911, England): British scientist and early proponent of the eugenics movement. In 1865, he stated that: 'If a twentieth part of the cost and pains were spent in measures for the improvement of the human race that is spent on the improvement of the breed of horses and cattle, what a galaxy of genius might we not create! We might introduce prophets and high priests of civilization into the world, as surely as we can propagate idiots by mating cretins.'[11]

William Rathbone Greg (1809–1881, Scotland): Scottish essayist, whose writings had a strong influence on Darwin. In 1868 he proposed to create a republic in which paternity should be the exclusive remit of those considered to be the elite. [13]

John Burdon Sanderson Haldane (1892–1964, England, Scotland): professor of Genetics and Biometry at University College London. In 1963 he indicated that:

> The recognition of human physiological diversity may have enormous consequences. As soon as its genetical basis is understood large-scale negative eugenics will become possible. There may be no need to forbid marriage; few people will wish to marry a spouse with whom they share a recessive gene …[14]
> … we may expect a drastic reduction in the frequency of undesired abnormalities with simple genetical determination by the end of this [twentieth] century. But we have little notion of how to produce more superior people. Our descendants could of course use men judged superior as stud bulls. …[15]
> … There is, however, another possibility which I at least take seriously … The production of a clone from cells of persons of attested ability would be a very different matter, and might raise the possibilities of human achievement dramatically.[16]

Adolf Hitler (1889–1945, Germany): wartime chancellor of Germany, He wrote in his autobiography *Mein Kampf:* 'The demand that defective people be prevented from propagating equally defective offspring is a demand of the clearest reason and, if systematically executed, represents the most humane act of mankind. It will spare millions of unfortunates undeserved sufferings, and consequently will lead to a rising improvement of health as a whole.'[17]

Sir Julian Huxley (1887–1975, England): professor of physiology at Kings College London and the first director of UNESCO. Huxley was president of the British Eugenics Society from 1959 to 1962 and wrote that: 'Once the full implications of evolutionary biology are grasped, eugenics will inevitably become part of religion of the future, or whatever complex of sentiments may in future take the place of organized religion.'[18]

Reflecting his belief that the lowest classes in a society should not reproduce too quickly, he wrote:

> The lowest strata, allegedly less well-endowed genetically, are reproducing relatively too fast. Therefore … they must not have too easy access to relief or hospital treatment lest the removal of the last check on natural selection should make it too easy for children to be produced or to survive; long unemployment should be a ground for sterilization, or at least relief should be contingent upon no further children being brought into the world.[19]

Hermann Joseph Muller (1890–1967, United States): geneticist and Nobel Prize winner in 1946 for Physiology or Medicine. In his book written in 1925 but first published in 1935 entitled *Out of the Night: A Biologist's View of the Future,* he suggested the mass inseminations of women should take place with the sperm of superior men. In the same book Muller wrote:

> And so we foresee the history of life divided into three main phases. In the long preparatory phase it was the helpless creature of its environment, and natural selection gradually ground it into human shape. In the second – our own short transitional phase – it reaches out at the immediate environment, shaking, shaping and grinding to suit the form, the requirements, the wishes, and the whims of man. And in the long third phase, it will reach down into the secret places of the universe of its own nature, and by aid of its ever growing intelligence and co-operation, shape itself into an increasingly sublime creation – a being beside which the mythical divinities of the past will seem more and more ridiculous, and which setting its own marvellous inner powers against the brute Goliath of the suns and the planets, challenges them to contest.[20]

Muller also argued in 1963 that: '[M]odern civilization has instituted a negative feedback from cultural progress to genetic progress … The social devices and the individual persuasion regarding family size advocated by old-style eugenics are inadequate to meet the situation, except in extreme cases of specific defects. For the major problems concerned with qualitative characters, the more effective method and the one that is ultimately more acceptable psychologically, is germinal choice.'[21]

Friedrich Nietzsche (1844–1900, Germany): a professor of philosophy. Nietzsche promoted many eugenic ideas in his writings and especially in his book *The Will to Power.* In this, he indicated that:

> Society, as the great trustee of life, is responsible to life itself for every miscarried life – it also has to pay for such lives: consequently it ought to prevent them. In numerous cases, society ought to prevent procreation: to this end, it may hold in readiness, without regard to descent, rank, or spirit, the most rigorous means of constraint, deprivation of freedom, in certain circumstances castration … Life itself recognizes no solidarity, no 'equal rights', between the healthy and the degenerate parts of an organism … Sympathy for the decadents, equal rights for the ill-constituted – that would be the profoundest immorality, that would be antinature itself as morality![12]

John Rawls (1921–2002, United States): professor at Harvard University and a leading figure in moral and political philosophy. He did not take any clear position on eugenic policies though did mention that it was in the interest of each individual to have greater natural assets including the best genetic endowment, adding that:

> The pursuit of reasonable policies in this regard is something that earlier generations owe to later ones, this being a question that arises between generations. Thus over time a society is to take steps at least to preserve the general level of natural abilities and to prevent the diffusion of serious defects. These measures are to be guided by principles that the parties would be willing to consent to for the sake of their successors.[22]

Theodore Roosevelt (1858–1919, United States): twenty-sixth president of the United States of America (1901–09). In 1913 Roosevelt wrote: 'I wish very much that the wrong people could be prevented entirely from breeding; and when the evil nature of these people is sufficiently flagrant, this should be done. Criminals should be sterilized and feeble-minded persons forbidden to leave offspring behind them … The emphasis should be laid on getting desirable people to breed.'[23]

Margaret Sanger (1879–1966, United States): birth control activist and founder of the American Birth Control League (which eventually became Planned Parenthood). In 1922, she said, 'Birth control must lead ultimately to a cleaner race.'[24] She had offered a fuller version of this sentiment a year earlier: 'Today eugenics is suggested by the most diverse minds as the most adequate and thorough avenue to the solution of racial, political and social problems. The campaign for birth control is not merely of eugenic value, but is practically identical with the final aims of eugenics.'[25] And, in 1922, she indicated that: '[A]s long as civilized communities encourage unrestrained fecundity in the "normal" members of the population – always of course under the cloak of decency and morality – and penalize every attempt to introduce the principle of discrimination and responsibility in parenthood, they will be faced with the ever-increasing problem of feeble-mindedness, that fertile parent of degeneracy, crime, and pauperism.'[26]

George Bernard Shaw (1856–1950, Ireland): playwright and winner of the Nobel Prize for Literature in 1925. In 1933 he stated: 'If we desire a certain type of civilization, we must exterminate the sort of people who do not fit into it … Extermination must be put on a scientific basis if it is ever to be carried out humanely and apologetically as well as thoroughly.'[27]

William Shockley (1910–1989, England, United States): winner of the 1956 Nobel Prize for Physics for his work on the development of transistors and semiconductor physics. Among Shockley's eugenic ideas was a plan for the government to pay individuals to be voluntarily sterilized at a rate of $1,000 per point scored under on a certain level in an IQ test.[28]

Marie Stopes (1880–1958, Scotland): opened the United Kingdom's first family planning clinic in 1921. Dr. Stopes supported the fight for contraception and was driven by a eugenic philosophy in her concern for the plight of women and their children.[29] Stopes said she 'would like to see the sterilization of those totally unfit for parenthood made an immediate possibility, indeed made compulsory … sterilization under proper conditions … has no deleterious and far-reaching effects on the whole system'.[30] She also wrote that when a responsible government passed legislation for mandatory sterilizations, 'Then at last we will begin to see the elimination of the horror and degradation of humanity, which, at present, is apparently so hopeless and permanent a blot upon the world … The evolution of humanity will take a leap forward when we have around us only fine and beautiful young people.'[31]

Nikola Tesla (1856–1943, Serbian-American): physicist and futurist who was recognized for his contributions to the design of alternating current. In 1960, the unit measure for magnetic field strength was named in his honour. Writing in 1935, he expressed his support for eugenics, stating that: 'The year 2100 will see eugenics universally established … The only method compatible with our notions of civilization and the race is to prevent the breeding of the unfit by sterilization and the deliberate guidance of the mating instinct … A century from now it will no more occur to a normal person to mate with a person eugenically unfit than to marry a habitual criminal.'[32]

James Watson (b. 1928, United States): Nobel Prize Laureate, co-discoverer of the structure of the DNA molecule in 1953. In 1995 he argued that modern society should be liberated from the chains of past atrocities in genetically improving itself, indicating:

> But diabolical as Hitler was, and I don't want to minimize the evil he perpetuated using false genetic arguments, we should not be held hostage to his awful past. For the genetic dice will continue to inflict cruel fates on all too many individuals and their families who do not deserve this damnation. Decency demands that someone must rescue them from genetic hells. If we don't play God, who will?[33]

In 2003, he also wrote in *The Guardian* newspaper:

> If you really are stupid, I would call that a disease ... So I'd like to get rid of that ... It seems unfair that some people don't get the same opportunity. Once you have a way in which you can improve our children, no-one can stop it. It would be stupid not to use it because someone else will. Those parents who enhance their children, then their children are going to be the ones who dominate the world.[34]

Herbert George Wells (1866–1945, England): acclaimed author of science fiction novels such as *The War of the Worlds.* He was concerned that people with a poor genetic heritage would overwhelm society.

> A portion of infant and child mortality represents, no doubt, the lingering and wasteful removal from this world of beings with inherent defects, beings who for the most part ought never to have been born and need not have been born under conditions of greater foresight ... The plain and simple truth is that they are born needlessly. There are still far too many births for our civilization to look after adequately; we are still unfit to be trusted with a rising birth rate ... our civilization at present has neither the courage to kill them outright quickly, cleanly and painlessly, nor the heart and courage and ability to give them what they need.[35]

In 1922 he wrote, 'We want fewer and better children ... and we cannot make the social life and the world-peace we are determined to make, with the ill-bred, ill-trained swarms of inferior citizens that you inflict upon us.'[36] Wells was also convinced that negative eugenics was far more effective than its positive counterpart: 'The way of nature has always been to slay the hindmost, and there is still no other way, unless we can prevent those who would become the hindmost being born. It is in the sterilization of failures, and not in the selections of successes for breeding, that the possibility of an improvement of the human stock lies.'[37]

Notes

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11. Galton, 'Hereditary Talent and Character', 165–66.
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Appendix II

Scottish Council on Human Bioethics
Recommendations on Eugenics

The following recommendations were agreed by the Scottish Council on Human Bioethics and represent the first example of guidelines from a European ethics council on the topic of the new eugenics.

Because different council members had different views concerning the strengths and weaknesses of the arguments in this book, it is not possible to describe the manner in which the recommendations were decided. The recommendations do, however, represent a general consensus of council members.

Recommendations on Eugenics:

1. The freedom of individuals to choose a partner in order to establish a family and have children should be protected.
2. The freedom of parents to decide on the size of their family should be protected.
3. The freedom of parents to choose whether or not to attempt to have a child should be protected.
4. Suing for wrongful life should not take place since it is impossible to compare the advantages or disadvantages of nonexistence over existence.
5. The paramount consideration in adopting a child should be his or her best interests.
6. Medically assisted procreation should not be used for preferring a future child's sex.
7. Eugenic selection using prenatal genetic selection should not be permitted.
8. Eugenic selection using preimplantation embryonic selection should not be permitted.

9. Eugenic selection through human reproductive cloning should be not be permitted.
10. Infanticide should not be permitted.
11. An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.
12. Human embryos and foetuses should not be destroyed through eugenic procedures.
13. Measures should be put into place which counter any societal pressures towards eugenics.
14. Any eugenic action that may reflect or even encourage the discrimination of persons should not be permitted.
15. When the procreation of a child is being considered, this should take place in the context of unconditional acceptance.
16. The creation of genetic social classes should not be permitted.

GLOSSARY

aneuploidy: A condition in which the number of chromosomes in the cell differs from the normal number.

assisted reproductive technologies (ARTs): The collective name for all techniques used artificially to assist women to carry children.

autosomal dominant disorders: Disorders where inheritance of a single mutation from one parent only (or a mutation arising anew during egg or sperm formation) can be sufficient for the person to be affected. Important dominant disorders include Huntington's disease, adult polycystic kidney disease and familial adenomatous polyposis coli (colon cancer).

autosomal recessive disorders: Disorders where a mutation has to be inherited from both parents. Such parents are usually unaffected carriers because they only have a single copy of the mutant gene. Recessive disorders commonly have onset in childhood and include cystic fibrosis, sickle cell disease and thalassaemia.

blastomeres: Cells from an embryo during the early stages of development called 'cleavage stage'.

blastocyst: The stage at which implantation process in the uterus begins, normally reached five to seven days after fertilization.

cell nuclear transfer: Cloning technique where the nucleus of a cell from an organism, such as an animal, is transferred into an egg (oocyte) whose own nucleus has been removed.

cell differentiation: The process by which cells achieve specialised function in an organism.

chromosome: A feature of all plant and animal cells composed of DNA and protein. Chromosomes carry the information necessary for the development and functioning of the body. Humans normally have forty-six chromosomes in the nucleus of their body's cells (twenty-two pairs plus two sex chromosomes, denoted X and Y).

commodification: Term used to describe the treatment of a human being or an entity as an interchangeable marketable commodity which can give rise to commerce. In this regard, a commodity has a price and only an instrumental value.

congenital: Refers to a characteristic present at birth, though not necessarily evident at birth. Often used in the context of negative traits, i.e., 'congenital malformations', deformities, diseases etc. but positive conditions are also congenital.

donor: Donors are people who consent to allow their gametes or embryos to be used in the treatment of others. If the treatment is provided in a licenced centre in the United Kingdom they are not the legal parents of the resulting children. The legal parents are the woman giving birth and usually her partner if she has one.

egg: The gamete produced by a woman during her monthly cycle. The nucleus of an egg always contains an X chromosome, having twenty-three chromosomes in all.

embryo: An embryo is produced by the joining of egg and sperm (fertilization).

embryo biopsy: Removal and examination of one or more cells from a developing embryo for diagnostic purposes.

embryonic stem cells (ES cells): Embryonic cells that can proliferate indefinitely and differentiate into many different tissues. These are pluripotent cells.

endometriosis: Presence of tissue from the inner membrane of the uterus (the endometrium) in abnormal locations such as fallopian tubes, ovaries or the peritoneal cavity. May cause abnormal bleeding and physical pain.

eutelegenesis: a form of positive eugenics in which sperm from specially selected men is used in donor insemination.

fertilization: Fertilization is the joining of a sperm and an egg to produce an embryo. Naturally, fertilization occurs in the woman's body (in vivo), but it can also occur in the laboratory (in vitro).

foetus: The developed embryo at eight to nine weeks of gestation (and until birth). By this time, tissues have begun to differentiate.

flow cytometry (sperm sorting): A method of sperm sorting that involves staining the X- and Y-chromosome-bearing sperm with fluorescent dyes and then sorting them according to the florescence.

gametes: The common name for eggs and sperm cells. A gamete usually has half the number of chromosomes of any other cell.

genetic testing: A procedure geared towards detecting the presence or absence of, or change in, a particular gene or chromosome.

genetic counselling: Guidance regarding genetic disorders. Genetic counsellors can provide information about a range of issues, from risks to treatments.

gradient: A dense liquid used to sort sperm.

gradient methods (sperm sorting): A method of sorting sperm based on the different constitution of X and Y sperm. The sperm are typically put with a gradient and subjected to centrifugation to separate them (this may be combined with a swim-up procedure).

implantation: Process which lasts about one week, beginning when the blastocyst attaches to the wall of the uterus of the woman and ending when the embryo is fully embedded in the wall of the uterus, or exceptionally in an extrauterine place.

inner cell mass: Group of cells in the blastocyst which would eventually develop into the foetus and some of the surrounding membranes.

insemination: The introduction of sperm into a woman's body to create a pregnancy. Artificial insemination can be done using either freshly ejaculated sperm or sperm that has been frozen. Where the sperm of a donor is used (donor insemination, or DI) this will have been frozen to allow time for the donor to be screened for transmissible diseases before insemination takes place.

instrumentalization: Term used to denote the transformation of a person or an entity into a mere means to an end. The person or entity then becomes only the instrument of another person.

in vitro fertilization (IVF): A common technique for overcoming infertility whereby eggs are collected from the woman and fertilised with sperm in the laboratory. Up to two resulting embryos are then transferred to the woman's uterus to begin a pregnancy.

karyotype: Analysis of the number, size and shape of an individual's chromosomes.

late-onset disorder: Disorders that normally become symptomatic in adult life.

lamarckianism: Theory which held that acquired characteristics can be passed on to offspring.

meiosis: The process by which germ cells (i.e., reproductive cells from the ovary or the testes) divide to produce haploid gametes (i.e., which contain only one set of chromosomes which results from the recombination between the maternal and paternal chromosome set of an organism).

monogenic disorders: Disorders arising from defects in a single gene.

monozygotic: Derived from one zygote.

multifactorial condition: A condition caused by the joint effect of several genes and environmental factors (dissimilar to polygenic condition).

multiple birth: Birth of more than one baby from a pregnancy.

mutation: The change in a gene or chromosome that causes a disorder or the inherited susceptibility to a disorder.

neo-malthusianism: Theory advocating for population control programs in order to ensure that sufficient resources are provided for current and future world populations.

objectification: Term used to describe the treatment of a human being as a thing or an object, disregarding his or her personality and inherent dignity.

oocyte: The mature oocyte, also called ovum or egg, is the female gamete, possessing a genome reduced by half (haploid genome), i.e., normally twenty-three chromosomes in humans.

oocyte in the process of fertilization: The result of the penetration of a male gamete into an oocyte; it contains two nuclei (pronuclei), a male pronucleus containing the set of chromosomes of the male sperm cell, and a female pronucleus, containing the set of chromosomes of the female egg.

ovarian hyperstimulation syndrome: An overstimulation of the ovary by hormonal treatment. In its moderate form, it is characterized in particular by enlarged ovaries due to big ovarian cysts. In its more severe form it can be life threatening.

penetrance factor: The frequency with which persons carrying a genetic characteristic responsible for a disease show signs of the disease.

pluripotent: A cell possessing the potential to become any tissue in the final organism.

polygenic condition: A condition caused by the effects of several genes (dissimilar to multifactorial condition).

polyploid: A cell which contains three or more sets of chromosomes rather than the normal two sets (more than forty-six chromosomes in human beings).

posthumanism: Possible future beings that originated from humans or humanity but whose basic capacities so radically exceed those of present humans as to no longer be considered as human in any significant degree or form.[1]

preimplantation genetic diagnosis (PGD): Use of genetic testing on a live embryo to determine the presence, absence or change in a particular gene or chromosome prior to implantation of the embryo in the uterus of a woman.

prenatal diagnosis (PND): A procedure that aims to provide a diagnosis of a particular condition that the foetus might have. There are two primary types:

(a) Amniocentesis – This method involves examining foetal cells taken between fifteen and sixteen weeks of pregnancy from the amniotic fluid which surrounds the foetus. The foetal cells are cultured and the genetic makeup of the foetus determined. This allows testing for chromosomal abnormalities such as Down syndrome and other birth defects.

(b) Chorionic villus sampling (CVS) – This method involves the removal of a small sample of placental tissue between nine and eleven weeks of pregnancy which is tested for genetic abnormalities.

prenatal screening: A public health service that offers pregnant women a test to examine if the baby is at an increased risk of having a particular disorder such as Down syndrome. If a screening test reveals an increased risk, it is followed by the offer of a diagnostic test to clarify the cause of the screening test results and any implications for the health of the baby.

pronuclei: The haploid nuclei of the egg and the sperm cell after fertilization but before the dissolution of their membranes and the first division of the fertilized egg.

social Darwinism: Theory that suggests that natural selection in a society will eventually enable superior groups to outcompete inferior ones.

somatic cells: All body cells that are not part of the germ line.

sperm: The gamete produced by the male, usually through ejaculation. Millions of sperm are present in each ejaculate and roughly half of these will carry X chromosomes, the other half carrying Y chromosomes.

spermatid: Haploid (one set of chromosomes) germ cell resulting from the second meiotic division of spermatogenesis which will then differentiate into spermatozoa.

spermatocyte: Diploid (two sets of chromosomes) germ cell which will undergo meiotic divisions to give haploid spermatids.

sperm sorting: The separation of sperm carrying X chromosomes from those carrying Y chromosomes prior to fertilization in order to determine the sex of offspring.

swim up: A technique for separating sperm, based on their ability to swim through a liquid.

totipotent: Cell from which an entire organism can be formed.

transhumanism: The idea that humanity can transcend or overcome the limitations of human nature.[2] Transhumanism is different from the concept of enhancement in that it seeks to create beings that have never previously existed in the history of humankind. These beings would retain some human characteristics such as with human-nonhuman interspecies beings or cyborgs which combine the human to the robot. Transhumans should, however, be distinguished from posthumans.

uterus: The woman's womb, in which the embryo develops into a baby.

X-linked disorders: Disorders due to a mutation on the X chromosome. X-linked disorders usually only affect males, but the disorders can be transmitted through healthy female carriers.

zygote: The final stage of fertilization, the single cell formed when the two sets of chromosomes, one from the male sperm cell, the other from the female egg, have joined.

Notes

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