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Bad Neuenahr-Ahrweiler GmbH

Direktor:
Professor Dr. Carl Friedrich Gethmann

Societal Decision Making and the New Eugenics

by

Michael J. Selgelid, Ph.D.

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Wilhelmstraße 56, D-53474 Bad Neuenahr-Ahrweiler
Telefon: ++49 - (0)2641 - 973 - 300, Telefax - 320
e-mail: europaeische.akademie@dlr.de
www.europaeische-akademie-aw.de

Director:

Professor Dr. Carl Friedrich Gethmann (V.i.S.d.P.)

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Foreword

The Europäische Akademie Bad Neuenahr-Ahrweiler GmbH is concerned with the scientific study of consequences of scientific and technological advance for individual and social life. Areas of focus include recent developments in biological sciences and medical disciplines. The work of the Europäische Akademie mostly takes place in temporary interdisciplinary project groups, whose members are recognised scientists from European universities and research institutes. In addition to the project groups, special topics are explored in accompanying studies.

At the beginning of the year 2001 the Europäische Akademie set up an interdisciplinary project on *Embryo Experimentation in Europe*. It aims to clarify how a scientifically and socially acceptable regulation of research on human embryos can be achieved in Europe. Issues raised by the topic “Embryo Experimentation” include social and ethical implications of PGD (Preimplantation Genetic Diagnosis), which might be used for different selective purposes in reproductive medicine.

The present study on *Societal Decision Making and the New Eugenics*, by Michael J. Selgelid, questions the ethical acceptability of genetic interventions – such as prenatal diagnosis and selective abortion – aimed at offspring enhancement. It was written while he was hosted by the Research Fellowship Programme at the Europäische Akademie. It also reflects work from his Philosophy Ph.D. Dissertation, titled *Neugenics: Genetically-Informed Reproductive Decision Making*, at the University of California, San Diego.

Dr. Selgelid is currently a Research Fellow and Lecturer in Bioethics at the University of the Witwatersrand in Johannesburg, South Africa.

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Minou Bernadette Friele, M.A.

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SOCIETAL DECISION MAKING AND THE NEW EUGENICS¹

Michael J. Selgelid, Ph.D.
Bioethics; Health Sciences
University of the Witwatersrand
Johannesburg, South Africa
biomich@chiron.wits.ac.za

ABSTRACT

Suppose we accept prenatal diagnosis and the selective abortion of fetuses that test positive for severe genetic disorders to be both morally and socially acceptable. Should we consider prenatal diagnosis and selective abortion (or other genetic interventions such as preimplantation diagnosis, genetic therapy, cloning, etc.) for nontherapeutic purposes to be acceptable as well? On the one hand, the social aim to promote liberty in general, and reproductive liberty in particular, provides reason for thinking that individuals should be free to make their own decisions about whether or not to employ whatever genetic services might be developed and offered by private enterprise. On the other hand, interventions aimed at enhancement would (in many cases) presumably only be available to those who are financially fortunate. A worry is that unequal access to enhancements that provide competitive advantages to offspring will further and more permanently increase existing unjust disparities between the haves and have-nots. The aim to promote liberty might thus conflict with the social aim of equality. An additional worry is that the development and provision of nontherapeutic genetic interventions would drain limited medical resources away from therapeutic purposes which would ultimately be more fruitful. The promotion of liberty might also thus conflict with the aim to promote aggregate utility. Assuming there is no reason to think that the promotion of liberty should be given absolute priority over both equality and aggregate utility, we need to think more about how to make trade-offs between these three legitimate social aims. There is reason to think that equality is especially important in the context of health care. Restrictions might thus be warranted.

I. Introduction

Many people are worried that recent rapid advances in genetic science and technology, exemplified by the completion of Human Genome Project, will lead to a revival of eugenics. Those who fear genetics for this reason probably associate ‘eugenics’ with early 20th century sterilization programs in the United States and Scandinavia or, more dramatically, with the Nazi program of “Racial Hygiene”. ‘Eugenics’ eventually became, and for a long time has remained, primarily a pejorative term largely as a result of its association with such socially abhorrent projects and practices. The disrepute of eugenics was also partly based on the fact that it became clear, in retrospect, that early eugenic practices were based on bad science.

Not everyone nowadays, however, thinks that eugenics is necessarily an altogether bad thing. In their recently co-authored book, for example, four highly respected American bioethicists – i.e. Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Wikler – argue that certain practices involving “eugenics” may nonetheless be morally acceptable (and perhaps in some cases even morally required).² Many other socially concerned writers and thinkers, such as Philip Kitcher, have also argued in a similar vein.³ Rather than automatically rejecting anything that might be considered “eugenics” as inherently evil, it has apparently become intellectually fashionable, in the United States at least, to make a distinction between the bad “old eugenics” of the early 20th century and a potentially acceptable “new eugenics”.⁴

¹ I have benefited greatly from guidance by Philip Kitcher.

² Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Wikler, *From Chance to Choice: Genetics and Justice* (New York: Cambridge University Press, 2000), hereafter referred to as ‘Buchanan et al. CTC’.

³ See Philip Kitcher, *The Lives to Come* (New York: Simon and Schuster, 1996), hereafter referred to as ‘Kitcher LTC’.

⁴ For a more thorough discussion of “old” versus “new” eugenics, see Michael J. Selgelid, “Neugenics?”, in *Monash Bioethics Review*, Vol. 19, No. 4, October 2000, pp. 9-33. I there roughly define eugenics as the “science” which aims to improve human lives by employing an understanding of heredity in the exertion of control over who gets born or who reproduces. I hope it will be clear to the reader that (1) there are good reasons for using such a definition of ‘eugenics’, and that (2) the question of whether or not this is the “correct” definition of ‘eugenics’ is quite irrelevant to the main issues I aim to explore. I will primarily be concerned with questions regarding the ethics of genetically-informed reproductive decision-making – and the ways in which the government should (or should not) be involved.

Perhaps the most commonly cited example of a *morally permissible eugenic practice* involves the selective abortion of fetuses prenatally diagnosed with the severest kinds of genetic disorders, such as Tay-Sachs and Lesch-Nyhan disease. Although the practice of abortion is itself morally controversial, cases like these are often claimed to be among the clearest situations where termination of pregnancy is acceptable. Abortion in such circumstances is commonly considered morally permissible, and perhaps even praiseworthy, precisely because the intention and result would be the prevention of lives doomed to misery and early death. For those who are not absolutely opposed to the practice of abortion for religious reasons, abortion aimed at the prevention of extreme suffering usually seems especially unproblematic.

Advocates of a “new eugenics” regularly argue that parents should be both (1) free to make their own decisions about whether or not to employ genetic tests made available by recent scientific advances and (2) free to make their own decisions about whether or not to continue pregnancy when (severe) genetic disorders are revealed. Whereas the evils of the “old eugenics” are often attributed to the fact that it involved societal decision making in the pursuit of social goals (in particular, the promotion of efficiency and the genetic quality of populations), coercion, and gross violations of reproductive liberty (and other basic human rights); one might think that this “new eugenics” would be different and more benign to the extent that reproductive decisions are autonomously made by individuals (i.e. potential parents) in pursuit of their own goals (i.e. the promotion of the well-being of family members) without coercive governmental intrusion.⁵ The moral lessons to be learned from the “old eugenics”, one might claim, are (1) that reproductive decisions should be made by individuals rather than the government and (2) that reproductive liberties should be strictly maintained without societal coercion.

Elsewhere I argue that the contrasts often thought to distinguish the old eugenics from the new eugenics are flawed in numerous ways.⁶ One of

⁵ Another claim made to distinguish the old from the new eugenics is that: While the old eugenics was based on bad science, the new eugenics will be based on a dramatically improved understanding of genetic inheritance. For a brief discussion of the relevance of this scientific contrast, see my “Neugenics?”, pp. 23-24.

⁶ Ibid..

my conclusions is that it would be a mistake to think that the hope for a morally acceptable new eugenics would best be realized if the government (1) refrains from making policy decisions related to reproduction and (2) places absolute value on the reproductive liberty of individuals. In my opinion, a major problem with the old eugenics was *imbalance* between governmental and individual decision making, rather than the exercise of governmental decision making *per se*. Too much power and control, that is, was placed in the hands of the government, while too little power and control was left in the hands of (victimized) individuals. Another problem was *imbalance* in the governmental pursuit of *social goals*. If it is safe to assume that *legitimate social goals* include the promotion of *liberty, equality, and efficiency* (i.e. aggregate utility), then the old eugenicists were probably guilty of placing too much weight on the promotion of (apparent) efficiency, and too little weight on the promotion of equality and very basic liberties.⁷ The aim to promote efficiency *per se*, however, presumably would not itself seem objectionable – even in the context of reproduction – if it had been pursued via morally acceptable methods (which paid due respect to equality and liberty).

My worry, then, is not that the advancement of genetic science will lead to a revival of eugenics. The old eugenics left a shameful scar on human history, and this provides reason to exercise caution. It does not follow, however, that eugenics *per se* is an inherently, or inevitably, evil practice.⁸ The immorality of prenatal diagnosis and the selective abortion of fetuses diagnosed with the most severe genetic disorders, for example, is by no means clearly evident. Indeed there are numerous reasons for considering this to be a *praiseworthy* practice.⁹ There are, furthermore, perhaps even better reasons for reaching the judgment that it would be unjust for western democratic societies to prohibit such a practice. In light of the fact that the moral controversy surrounding abortion is largely a

⁷ Another problem with the old eugenics, clear in retrospect, was that practitioners of the old eugenics were both (1) mistaken about the effectiveness (towards the promotion of efficiency) of their methods and (2) mistaken in their beliefs regarding heredity. Governments that indulged in the old eugenics should thus also be criticized for making *hasty and inadequately founded* decisions.

⁸ These last two points are made by Kitcher in LTC and Buchanan et al. in CTC.

⁹ See Kitcher LTC.

matter of religious dispute, for example, absolute prohibition of abortion would appear to be a form of religious oppression, where the idiosyncratic views of one group are imposed on the rest of society.¹⁰ In any case, as I said before, selective abortion in the circumstances under discussion is widely agreed to be among the clearest cases where the practice of abortion should be tolerated.

Rather than worrying about eugenics per se, then, I am worried that tolerance of the new eugenics thus far described – i.e. where potential parents freely make their own decisions about whether or not to abort fetuses diagnosed with the severest kinds of genetic disorders – will be associated with the idea that governments should both (1) refrain from making policy decisions related to (genetically informed) reproduction more generally, and (2) thus permit unrestricted liberty regarding the kinds of genetic tests which might be developed and used for the selection of offspring. It seems reasonable to fear that the new eugenics, in the absence of governmental involvement, might once again reflect moral imbalance – this time around, however, at *the other extreme* (with the pendulum swung in the opposite direction, in a strikingly reactionary fashion). Leaving all decision making, about the purposes for which genetic tests may be used, in the hands of individuals – and the free market¹¹ – could be socially dangerous for numerous reasons. In particular, legitimate social goals aimed at the promotion of both equality and efficiency¹² may be unacceptably compromised by such a policy. The imbalance to be feared is that too much power and control will be placed in the hands of individuals, while too little power and control remains in the hands of the government – and that this would reflect the placing of too much weight on the social value of (reproductive) liberty, and too little weight on equality and efficiency. If the new eugenics is imbalanced in this way, it might not be benign after all.

¹⁰ See Ronald Dworkin, *Life's Dominion* (New York: Vintage Books, 1994).

¹¹ Dangers posed by the free market may be particularly relevant to the situation in contemporary Germany which appears to be moving towards a more commercialized health care delivery system. See Friedrich Heubel, "Patients or Customers: Ethical Limits of Market Economy in Health Care", in *Journal of Medicine and Philosophy*, 2000, Vol. 25, No. 2, pp. 240-253.

¹² Here and elsewhere I am using the term 'efficiency' to be synonymous with 'aggregate utility'.

While there are good reasons for *promoting societal tolerance* towards the selective abortion of fetuses that test positive for severe conditions such as Tay-Sachs and Lesch-Nyhan disease, a social scenario which involves genetic testing, and abortion of otherwise normal fetuses, with the aim to select hair color, eye color, or sex – or dispositions towards height, weight, strength, sexual preference, or intelligence – sounds troubling. For one thing, the proposed moral justification for abortion in the former kind of case – i.e. prevention of horrible suffering – does not apply to the latter. Some might thus deny the moral permissibility of abortion in the latter.¹³ For those who resist the paternalistic thought that morality should be legislated, however, the mere immorality of an action does not provide sufficient grounds for prohibiting it.

Taking *societal impact* into account we may find stronger reasons for restricting the uses towards which genetic science might be directed. Genetic interventions aimed at enhancement, for example, would likely only be available to those with the extra financial resources to pay for them. The commercial availability of such interventions might thereby exacerbate existing (unjust) social inequalities. The promotion of unrestricted, free-market reproductive liberty may thus conflict with the aim of equality. The promotion of liberty with respect to the ways in which genetic technologies might be developed and used may also conflict with the social aim to promote aggregate utility. Disproportional birth rates of males and females, resulting from a common practice of prenatal sex determination and abortion of females in India and China, provide telling examples of what I here have in mind. There is also the general worry that a significant portion of limited medical resources will be directed – in the promotion of profits and higher incomes – towards uses that are less fruitful than others which might be pursued instead. The likelihood that, and extent to which, the development and use of the kinds of interventions I am worried about would actually diminish equality and aggregate utility cannot be settled via philosophical speculation alone. I do, however, aim to explore possibilities; and, I will recommend further interdisciplinary

¹³ Perhaps appealing to the presumption that, in the absence of exceptional circumstances, human life should be preserved. (Such a view, of course, would be controversial.)

research in sciences (such as sociology, history, psychology, and economics, etc.) that might shed light on likely scenarios.

II. The Slippery Slope

A failure to restrict – or set limits to – the use of genetic technologies *could* result in a slippery slope to another bad eugenics: An unrestricted new eugenics may start with the selective abortion of severely disabled offspring ... but then turn into a practice which includes routine selective abortion of those who would suffer from a variety of late-onset disorders or only relatively minor disorders or no disorders whatsoever. Fetuses will be aborted when there is a high risk of asthma or color-blindness. Females will be aborted when males were wanted, and vice versa. Genetic tests will be available for all sorts of traits and conditions; and, abortion will be available for whatever reason. The recommendation of the (most) liberal eugenicists is that (rich) parents should be permitted to use whatever genetic interventions become (safe and) available for the shaping of offspring.

The following train of thought will eventually motivate some people: “Abortion of fetuses likely to develop into severely disabled infants is morally acceptable *because abortion itself is morally acceptable*. Abortion itself is morally acceptable because fetuses lack moral status. Abortion of any fetus, whether or not it would be healthy, is therefore morally acceptable. If I want to give my child a better life by aborting a healthy fetus when there are good odds I can conceive another whose prospects are more optimal, then morality doesn’t forbid me to do so. I would, of course, need to undergo surgery (and maybe I’d be a bit sad afterwards); but, sometimes it’s worth making sacrifices for our children. In any case, abortion is only a relatively minor operation. My daughter’s life will be considerably better if she has large breasts. Chances are good that if we abort, and conceive again, then our next fetus will have brighter prospects. Luckily we are able afford the expensive ‘new improved diagnostic tests which accurately detect the presence or absence of genetic sequences commonly associated with mammary glands of greater than average mass.’ Some people have hang-ups about abortion ... but they need to get

over it. They're mostly religious fanatics (or suffering from irrational religious residues) anyhow."

Similar rationale will make the practice of abortion much more common if genetic tests become available for detecting the presence or absence of genetic sequences commonly associated with: above or below average height ... above or below average levels of body fat ... memory capacity ... IQ ... aggressiveness ... shyness ... perfect musical pitch¹⁴ ... and athletic ability. The list of traits discovered to be *associated* – perhaps merely statistically correlated – with genetic sequences could possibly go on and on and on. It likely *will* go on and on if it turns out to be profitable for parties to go out and look for the kinds of associations in question. It is important to realize that the possibility that particular genetic sequences will be found *to be associated* with the kinds of traits mentioned does not mean that it would likely be the case that the discovered sequences *cause* the traits in question nor likely that there is an entirely – or primarily – genetic basis for such traits.¹⁵ The detectable sequences might simply be commonly linked with other sequences that merely (sometimes) contribute to the traits in question in very indirect ways; or in some cases it might just be a coincidence that those with the sequence have the trait more often than not (or more often than those who do not have the sequence). The fact of the matter, however, is that genetic tests, even if they do not explicitly purport to detect genes which *cause* traits, may sometimes provide – or at least *appear* to provide – some predictive information to parents. Potential parents may often end up being seduced (by advertisers) into thinking they can predict more about their children than will actually be the case. The main point, however, is that: If there is a profit to be made, then a wide range of both therapeutic and nontherapeutic genetic interventions would likely ensue in an unrestricted free market.

¹⁴ See John Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton, NJ: Princeton University Press, 1994), hereafter referred to as 'Robertson CC', p. 263.

¹⁵ Strictly speaking, genes do not *cause* traits. Traits result from interactions between genes and environments. What I really mean to say, then, is that it may not be the case that the discovered genes make important causal contributions to the traits in question. See Jonathan Michael Kaplan, *The Limits and Lies of Human Genetic Research: Dangers for Social Policy* (New York: Routledge, 2000).

Some deny that we really need to worry about the slippery slope argument. “The kind of thinking described two paragraphs back,” they say, “is too far removed from most people’s attitudes towards abortion. Parents would not take such drastic measures for such trivial reasons. In addition to being unrealistic, the example is unnecessarily offensive. Who would want to provide their daughters with traits which would promote their sexual objectification?”

The claim that my example is far removed from *most people’s* attitudes towards abortion is quite correct. Fetuses are, however, already terminated for extremely worrisome reasons. Sex selection already occurs – and is quite common in places like India and China where sons are preferred to daughters. My guess is that at least some parents, nowadays, would already employ interventions aimed at breast enhancement if the necessary technology were in fact available. In any case, the objection that this would today be incredibly rare misses a crucial point of the slippery slope argument which cannot be simply ignored. The argument claims that: Over a period of time, we get *warmed up* to the idea. *First* we think it’s okay to abort fetuses diagnosed with the severest handicaps. *Then* we think it’s okay to abort fetuses that would suffer from slightly less severe conditions than that, *then* we think that it is okay to abort fetuses that would suffer from slightly less severe conditions, and so on, and so on. We become more and more comfortable with the taking of fetal life, and more and more comfortable with selecting the traits of our offspring. What seems outrageous now will not seem so outrageous then. (History is full of examples!) If there are profits to be made by biotechnology companies offering genetic tests (and/or other interventions), then they encourage the entire process by continually offering new choices, cunningly explaining why we should (or “need” to) take advantage of services offered.¹⁶ Their power to influence and manipulate our beliefs, desires, and actions should not be overlooked. We eventually become acclimatized to a world where the shaping of offspring is common. We are led down a path we are made to believe we have chosen.

¹⁶ One explanation for the rampant consumerism of contemporary times is that antics of advertisers really are so cunning – often based on the science of psychology.

The history of cosmetic surgery is quite revealing.¹⁷ What starts out as a practice aimed at restoring the appearance of those disfigured turns into a booming industry where doctors make millions performing face-lifts, tummy-tucks, breast implants, and liposuction, time after time, making (wealthy) women more and more “beautiful”. Who would have previously thought that so many women would be willing to undergo surgery – and pay piles of money – to have silicon (and saline) sacks installed in their chests? Who would have thought that so many physicians (i.e. “healers”) would be willing to spend their time and use their precious skills on what should (in many cases) be such (medically) unnecessary services? The sad truth is that society as a whole, and industry in particular, places enormous pressure on women to conform to highly-questionable, unrealistic (hence the resort to *plastic*) standards of appearance. These pressures move them to expend great effort and take drastic actions they otherwise would not want to pursue – and which should ultimately be unnecessary. The (perhaps forgivable) acquiescence, and compliance, of many then has the further result of increasing pressure on others to conform. Suspect standards of appearance are both validated and shifted by the very same actions. Medical practitioners pursuing higher incomes are often quite willing to complicitly encourage the run-away process that results.

It is not hard to imagine the same kinds of factors and pressures impacting the decisions parents might make when choosing the traits of their offspring. The same kinds of political, prejudicial, and economic pressures may *push* us down the slippery slope – and make it look like free choice. It would not be crazy to worry that even the most offensive interventions would be used if they do become available. Slippery slopes are not (always) just the stuff of hysterical fantasy. If a wide range of genetic interventions is in fact developed, there is no reason to think that some of the most worrisome ones would not be employed. (History has already shown that the most abhorrent actions are real possibilities when it comes to eugenics.)

¹⁷ The following draws heavily from Margaret Olivia Little, “Cosmetic Surgery, Suspect Norms, and the Ethics of Complicity”, hereafter referred to as ‘Little CSC’, and Susan Bordo “Braveheart, Babe, and the Contemporary Body”, hereafter referred to as ‘Bordo BB’, both of which can be found in *Enhancing Human Traits: Ethical and Social Implications*, ed. by Erik Parens (Washington, D.C.: Georgetown University Press, 1998), hereafter referred to as ‘Parens EHT’.

There are plenty of examples to consider: Increased height, decreased weight, increased intelligence, sense of humor, hair color, eye color, and longevity are just a few of many traits for which *some* genetic association may be (at least *claimed* to be) discovered. At least some interventions aimed at influencing such traits would presumably be sought by consumers if the necessary technologies do in fact become commercially available.¹⁸ “A recent poll suggested [it is already the case] that 11 percent of Americans might abort a fetus predisposed to obesity.”¹⁹ Thus far we have primarily focused discussion on the issue of selective abortion, but we should keep in mind that genetic tests also make possible preimplantation diagnostic testing of IVF (*in vitro* fertilization) embryos. Parents who undergo IVF treatment will be provided with genetic information about a large number of embryos produced in test tubes – and then get to choose which one(s) to implant in the mother’s uterus.²⁰ A wide range of genetic therapies – and even human cloning – may also someday provide ways to exert selective control over offspring without the resort to abortion.

The fact that genetic therapy and cloning at present remain in the world of science fiction does not imply that these are not already worthy of careful consideration. First, as is commonly acknowledged, it is worth thinking about the difficult ethical questions posed by such powerful technical abilities before we become more concretely faced with them. A danger to avoid is that scientific developments will outpace ethical thinking. We should consider future possibilities ahead of time, so we are ready to deal with them in a reasonable and responsible way when (and if) they arrive. Perhaps more importantly, it is worth giving thought to future possible technologies for another reason as well. We may, upon reflection,

¹⁸ The claim that such interventions would actually be sought if available was also made by Peter Singer, “Shopping at the Genetic Supermarket”, hereafter referred to as ‘Singer SGS’, lecture at the Murdoch Research Institute, Royal Children’s Hospital, Melbourne, Australia, August 2000. Mehlman and Botkin argue that “private industry is bound to invest heavily in enhancement research in view of the potential commercial rewards.” They cite current practices involving human growth hormone as evidence for this claim. See Maxwell J. Mehlman and Jeffrey R. Botkin, *Access to the Genome: The Challenge to Equality* (Washington, D.C.: Georgetown University Press, 1998), hereafter referred to as ‘Mehlman and Botkin ATG’, p. 52.

¹⁹ Deborah Kaplan, “Prenatal Screening and its Impact on Persons with Disabilities”, in *Bioethics: An Anthology*, ed. by Helga Kuhse and Peter Singer, hereafter referred to as ‘Kuhse and Singer BA’ (Oxford, UK: Blackwell, 1999), p. 134.

²⁰ Philip Kitcher, “Creating Perfect People: The Genetic Revolution and Human Possibilities”, The Templeton Lecture at the University of Sydney, July 13, 2000.

decide that there are some kinds of choices we don't want to be faced with, some kinds of interventions we think should not be available, some uses of science and technology which would not be socially acceptable. If this is the case, then it is worth reaching this conclusion ahead of time, thus avoiding a situation where scientists waste a bunch of their time (and, often, taxpayers' money) developing technologies that we – as a society – are unwilling to tolerate, do not want at all, or do not want very much in comparison with other possible alternatives. Reaching such a determination ahead of time would promote the likelihood that developments in science and technology move in more socially fruitful directions.

This last point is that society as a whole needs to become more involved with decisions that influence the directions and uses of scientific research. One justification for this claim is quite obvious. Much research is backed by public funds. Given that various alternative publicly funded research programs would likely have different kinds of impacts on society, the public has a right to become more involved with decisions about research projects pursued. A second point is that some influence over private enterprise might be warranted. Suppose the public has an interest in pursuing the extensive research required to gain a better understanding of information embodied by the map of the human genome. Or suppose the public has an interest in promoting the development of (certain) genetic therapies or cloning techniques. Suppose the public realizes that the information revealed, and the techniques developed, could be put to some uses which are socially beneficial and some uses which are socially dangerous. Suppose the social dangers are extremely serious. Should we think that the choices are either

(1) the benefits will have to be forgone because they are not worth the dangers,

or

(2) we must endure the dangers if we hope to enjoy the benefits?

Why not think that there is an additional option:

(3) the projects will be pursued in order to achieve the benefits, and legislation will be imposed to prevent the dangers from being realized?

In a way we might worry that the relevant legislation would infringe upon the liberty of individuals and private companies. But this isn't necessarily quite right: Society wouldn't be preventing private individuals and private companies from doing anything they would have been able to do if we as a community had not pursued the project in the first place.²¹

Why would it be unjust for society to implement a policy that says, "We are going to uncover the following information and develop the following techniques, but we shall impose limits on the ways in which this information and these techniques may be used"? Why should society as a whole be deprived of a right so often respected in private industry? If private corporations should be granted intellectual property rights, and be allowed to maintain control over the ways in which their discoveries may be put to use, then why shouldn't society as a whole reserve this same kind of protection over the uses of what might analogously be considered public (intellectual) property? Why should private individuals and corporations be free to use public (intellectual) property in whatever ways they wish – regardless of the impact on legitimate social interests?

Perhaps I'm getting a bit ahead of myself. For now the main point is that the dangers posed by the slippery slope argument should not be ignored. The Human Genome Project has uncovered information that may facilitate the development of genetic interventions most members of society might not approve of. If there are adequate financial incentives – and a lack of restrictions – there is every reason to think that private companies will develop (through their own research which takes advantage of much research which the public has already financed) disturbing genetic technologies and interventions.

Some might say that I have an over-anxious, distorted, cynical view about the degree to which medical science is a profit-driven, commercialized enterprise. Those who have worked in the medical industry, however, should admit that this kind of response to my worry is a bit naive.²² The situation with cosmetic surgery may already prove my point.

²¹ Assuming that all the required research would not be possible through private funding.

²² My worries are partly the product of personal first-hand experience in the business world of the high-tech medical industry.

In any case, a quick glance through the recent issue of *Nature* where the map of the Human Genome Project is published reveals a veritable frenzy of commercialized scientific activity.²³ It is a thick volume filled with page after page after page of advertisements. Anyone who thought that science embodies the innocent pursuit of knowledge aimed at satisfying curiosity and improving the lot of humankind – remote from the profit-driven world of commercial private enterprise – should be surprised and disturbed by the images there revealed.²⁴ “With so many potential targets, where do you direct your discovery effort? ... Zero in on *commercially promising* drug targets with DeltaBase(TM) ... Register for our online demo and receive a **FREE** t-shirt ... DeltaBase(TM) ... *Take the lead.*”²⁵

It is easy to imagine motivations behind Amgen, Inc.’s payment of \$20 million (USA) to Rockefeller University for the rights to products resulting from the discovery of the *ob* gene.²⁶ It is no secret in Washington, D.C. that choices to fund the Human Genome Project were heavily influenced by the aim to retain an economic U.S. competitive advantage over Japan in the biotechnology industry.²⁷ It is well known that much academic research is funded by private enterprise, that many academic scientists are major shareholders in biotechnology companies, and that universities themselves have taken an increasingly commercialized approach to biological research in recent decades.²⁸ It is no mystery why so many genomic sequences have been patented by Celera Genomics and others. It is not so surprising to hear that pharmaceutical companies are more than

²³ See *Nature*, 15 February 2001.

²⁴ Ironically, the version of the map of the human genome simultaneously published in the corresponding issue of *Science* (16 February 2001) – which is a “not-for-profit publication” (but nonetheless contains its fair share of advertisements) – is itself patented by Celera Genomics. See *The Economist*, 17 February 2001.

²⁵ This add appears in both *Nature* and *Science*, their emphasis on ‘free’, other emphasis is mine. I must admit that the add does specifically refer to “disease-relevant mammalian genes” and “therapeutic value”.

²⁶ See Mehlman and Botkin ATG, pp. 35-36. The *ob* gene has been associated with obesity in mice.

²⁷ See Robert Cook-Deegan, *The Gene Wars: Science, Politics, and the Human Genome* (New York: Norton, 1995), esp. Chapter 15. Here and elsewhere, I hope that European readers will recognize the relevance of my criticisms of the U.S. to the European context. Commercialization of medicine is not just an American phenomenon; and, in any case, there is often much to learn from the faults of others.

²⁸ See Diana B. Dutton, *Worse Than Disease: Pitfalls of Medical Progress*, hereafter referred to as ‘Dutton WTD’ (New York: Cambridge University Press, 1988).

willing to employ massive marketing campaigns and make *billions* of dollars pushing pills which are known (by the FDA as well as the companies themselves) to be just barely more effective than placebos.²⁹ It is not hard to explain the “10/90 divide” whereby “less than 10% of [health] research funds are spent on the diseases that account for 90% of the global burden of disease.”³⁰ Until recently put under (public and ultimately economic) pressure, manufacturers of AIDS medications did not seem terribly concerned that their treatments were (and still are) unavailable in sub-Saharan Africa where they are by far needed most. Even when faced with humanitarian emergencies where *millions* will die, pharmaceutical companies seem most concerned about getting pills to those who can pay – a lot – for them. *It’s just business as usual.* (Haven’t we already slipped down a slope?) The monetary motive behind (much) biological and medical science is all too apparent. It would be extremely naive to deny that the pursuit of profits plays a major role in the direction of medical research and development.

The vast majority of medical science is, of course, aimed at the alleviation of suffering. This is a good thing. Luckily, in a free market it is often extremely profitable for private industry to develop important therapeutic technologies. Unfortunately, however, it is sometimes more profitable to develop and market technologies which are less necessary than others, or not (perceived to be) necessary at all (until illusions are created through advertising). The reality is that, in an unrestricted market, profits will be pursued in whatever ways are permitted. The *bottom line* is that many “medical” decisions are made with money in mind. In the absence of governmental restrictions, a wide range of both therapeutic and nontherapeutic genetic interventions would likely be offered and employed if it becomes both technically feasible and profitable for biotechnology companies to develop them. “The sex of children is already up for sale” in the

²⁹ See Stephan S. Hall, “Claritin and Schering-Plough: A Prescription for Profit”, *The New York Times on the Web*, 11 March 2001, <http://www.nytimes.com/2001/03/11/magazine/11/CLARITIN.html?pagewanted=print>. Also see “Pill Pushers”, *The Economist*, 21 April 2001, p. 66: “When it comes to brand recognition, few would have bet on Claratin against Coke. But over the past couple of years Schering-Plough’s little white anti-allergy pill has had more advertising dollars lavished on it in America than the famous red can.”

³⁰ Kelley Lee and Anne Mills, “Strengthening Governance for Global Health Research”, *British Medical Journal*, 321, 775.

United States. In Fairfax, Virginia, for example, the Genetics and IVF Institute offers a sperm sorting process called “Microsort” to IVF parents who want to choose the sex of their children “for \$3000 a go; it plans to double production soon ... Looking at surveys showing that around one in four American couples might use sex-selection, *Fortune* recently calculated that the market could be worth \$200m a year.”³¹

“So what?” one might ask. “Why shouldn’t private corporations be free to develop any interventions that consumers will want? Why shouldn’t private individuals be free to make their own decisions about what kinds of genetic services to seek? The commercialization of medicine is a good thing because this promotes competition, efficiency, and innovation. Our advanced understanding of biology and medicine is itself largely the result of the pioneering spirit and excellence encouraged by incentives offered through commercialism and the free market. Why is this something to complain about? Biotechnology companies will only make profits by offering services consumers actually want? Why shouldn’t consumers be able to get what they want? Why should the government intrude to determine what ‘should’ be available and what is ‘really needed’? This would only stifle innovation, frustrate consumer desires, and infringe upon the freedom of private parties. Who cares if there’s a ‘slippery slope’ towards interventions aimed at enhancement. Enhancement, by definition, is a good thing. Why shouldn’t parents be free to enhance their children in whatever ways they see fit? We generally already allow parents to pursue the enhancement of their children through (private) education and a wide variety of other means. Why should genetic enhancement be considered any different? Why should the government be given the authority to judge and coerce the reproductive decisions of private individuals?”

III. Social Concerns

I have repeatedly suggested that there are some kinds of genetic interventions that we should be socially concerned about. I have raised worries, for example, about genetic testing and the selective abortion of normal, healthy fetuses by parents who aim to enhance the traits of their offspring

³¹ *The Economist*, 14 April 2001, p. 20.

by making them taller, thinner, or more intelligent, etc.. I have also raised worries that other kinds of genetic interventions (such as genetic therapy and reproductive cloning) may eventually be developed and employed for the same kinds of purposes. I have perhaps even suggested that we should be worried about genetic testing and the selective abortion of fetuses diagnosed with relatively minor *disorders*. Why are these things to be worried about? Why think that governmental restrictions might be warranted?

A. The Morality of Killing

Many will think that the abortion of healthy fetuses, or those expected to suffer from only relatively minor disorders, would be (highly) immoral. Abortion involves the taking of human life, and it is not entirely clear that fetuses lack substantial value and significant moral rights. It is plausible, perhaps even common sense, to suppose that fetuses are *partial* persons with at least *some* moral status.³² For those who subscribe to a quality of life ethic, healthy fetuses expected to develop into persons with relatively high quality lives should be valued highly – especially when a child is wanted. In any case, abortion involves a nontrivial, invasive medical procedure and the employment of limited medical resources that should be reserved for the (restoration of functioning and the) prevention and alleviation of suffering.³³

A natural and common attitude presumes that fetal life should be preserved in the absence of exceptional circumstances.³⁴ It is right for

³² Perhaps depending on their stage of development.

³³ Given the fact that escalated costs make medical care unavailable to many, this last point should not be taken lightly.

³⁴ I should here make more explicit my view on abortion put forth in Michael J. Selgelid, “Eugenic Abortion, Moral Uncertainty, and Social Consequences”, in *Monash Bioethics Review*, Vol. 20, No. 2, April 2001, pp. 26-42. There I argue that the moral status of the fetus is ultimately uncertain and that this uncertainty itself makes abortion morally *problematic*. Secular philosophy does not conclusively demonstrate that fetuses lack rights and value altogether; and, secular philosophy cannot tell us exactly what rights or how much value, if any, are embodied by fetuses. A wide range of views (about the moral status of the fetus) are compatible with both reason and the available evidence. There is at least a chance or risk that fetuses do embody significant moral status. Given this possibility, abortion should not be procured for trivial reasons (such as the aim to select for eye color). Given that it is not clear that the fetus does in fact possess much moral status, on the other hand, abortion can be considered acceptable in exceptional circumstances. This view is appropriate for a religiously neutral state and compatible with widely shared ideas about the circumstances in which abortion should be considered morally permissible – i.e. cases where pregnancy is due to rape or threatens the life of the mother or would lead to a life full of suffering (and cases where no child is wanted or likely to be properly cared for).

parents to aim to promote the well-being of their children; but, it is distasteful to think that abortion should be viewed as just one more means towards this end. Abortion is a morally problematic intervention that should be resorted to only when *necessary*. In any case, the proposed justification for the eugenic abortion of fetuses diagnosed with conditions such as Tay-Sachs and Lesch-Nyhan disease – i.e. prevention of horrible suffering – does not apply to cases where parents aim to enhance (or select relatively unimportant) traits of their children.

Perhaps there are good reasons for thinking that it would be immoral for parents to abort a fetus for relatively trivial reasons – when they hope to have a child that is male rather than female; or when they prefer blondes to brunettes, or blue eyes to brown. We do not, however, always think that morality should be enforced by law. There are good reasons for resisting the temptation to legislate morality. The fact that *most* people consider certain practices to be *immoral* does not itself imply that the practices in question should be *forbidden*. Perhaps there are many societies where most people consider homosexual practices to be immoral; but, it would surely be wrong for them to therefore forbid homosexuality.³⁵ This would involve what John Stuart Mill calls the “tyranny of the majority”. Consenting adults should be free to do as they please, according to Mill, so long as their practice does not cause direct harm to others. The proper authority of the law should be restricted to the prevention of direct harm.³⁶ There will often be reasonable disagreement about what is moral or immoral. Imposing one particular moral view on the rest of society – just because it is the most common view – entails political oppression. A just society – rather than stifling the individuality and autonomy of its members – is tolerant in the acceptance of individual differences.

³⁵ Devlin would disagree. See P. Devlin, “The Enforcement of Morals”, in *Crime and Punishment*, ed. by Michael J. Gorr and Sterling Howard (Jones and Bartlett).

³⁶ See John Stuart Mill, “On Liberty”, hereafter referred to as ‘Mill OL’, in UOLRG. Ultimately I will disagree with Mill’s position by claiming that legislation is sometimes justified in order to promote equality and/or aggregate utility even when it isn’t clearly required in order to prevent “direct” harm. Mill seems to think that the maximal promotion of liberty will inevitably lead to the maximization of aggregate utility. This to me sounds dubious; and, in any case, I believe that equality should also be taken into account. (Paternalism is not the only motive for prohibiting practices that do not entail “direct” harm.) For the purpose of my current discussion, however, this disagreement with Mill is beside the point.

Some might object that even the Millian perspective may justify the imposition of legislative restrictions on abortion. Abortion (of a healthy fetus) *might* involve *direct harm* to a being with (significant) moral status. One could coherently claim that in exceptional circumstances abortion should be permitted but nevertheless argue that the (apparent) immorality of abortion in more trivial cases is the sort that justifies legislative coercion.³⁷ Elsewhere I argue that the moral status of the fetus is ultimately *uncertain* – that there is a *chance* or *risk* that the being involved possesses the (natural) rights and value of prototypical persons – or at least significant moral status.³⁸ If this is correct, then there is a risk or chance that abortion of a (healthy) fetus involves the kind of direct harm that Mill advocates prevention of.³⁹ Surely the state is justified in prohibiting actions – like firing bullets out of windows at night – that have a decent chance of harming someone.⁴⁰

This kind of argument takes the idea that the fetus might embody significant moral status perhaps *too* seriously. There is much reasonable dispute about whether or not there is any (significant) chance that the fetus is worthy of protection by the law. Proponents of procreative liberty would argue that the burden of proof that there is a significantly good chance that the fetus embodies much moral status falls on those who advocate imposition of legislative restrictions. My argument that the status of the fetus is ultimately uncertain – and my claim that common sense might suggest that fetuses are partial persons with partial moral status – does not provide *evidence* that it is *in fact likely* that a being with much moral status is involved. My moral recommendation to parents is to (reflect upon the matter themselves and) give the (relatively healthy) fetus the benefit of the doubt. My political recommendation to the state – with regard to the worry that the fetus might be worthy of a right to protection – on the other hand, is to give parents the benefit of the doubt and allow

³⁷ The idea here is that in some cases a risk of harm is warranted but in others it is not.

³⁸ See footnote #34 and my “Eugenic Abortion, Moral Uncertainty, and Social Consequences”.

³⁹ The objection might include the claim that a religiously neutral state *must* take the idea that the moral status of the fetus is uncertain – and the idea that there is a *decent chance* that the fetus does in fact embody significant moral status – quite seriously.

⁴⁰ In exceptional circumstances, on the other hand, we would deny that this kind of action should be punished – i.e. suppose that it is necessary to scare away a deadly beast and there are not too many people in the vicinity who might get wounded.

them to make their own moral judgments.⁴¹ This position is not as paradoxical as it may at first appear. I might similarly encourage others to refrain from killing and eating animals without suggesting that the reasons for abstinence are clear enough to be enforced by law. Mill would ultimately approve of this kind of approach.

I will soon, however, discuss reasons why restrictions might be warranted in order to protect legitimate social interests. If we find compelling communal reasons why restrictions might be warranted, the apparent immorality of aborting healthy fetuses might then become more relevant. In the aim to promote legitimate social goals, that is, we might feel more justified in restricting actions which we have good reasons to consider immoral than we would in restricting actions which are more innocuous. Ronald Dworkin, for example, argues that if actions are immoral, “then the freedom to pursue them counts for less. We do not need so strong a justification, in terms of the social importance of the institutions being protected, if we are confident that no one has a moral right to do what we want to prohibit.”⁴² The apparent immorality of aborting healthy fetuses (when children are wanted) may not itself provide sufficient justification for imposing restrictions, but the apparent immorality of this kind of practice may tip the balance in favor of restrictions once we take social impact – regarding equality and aggregate utility – into consideration. It might not be entirely clear that healthy fetuses are worthy of protection; but it is likewise not entirely clear that anyone has a moral right to employ limited medical resources to kill them without having compelling reasons for doing so.⁴³ It is not entirely clear that anyone has a *moral right* to employ limited medical resources to find out whether or not their fetus would turn into a blue-eyed boy, for example, and kill it otherwise.

B. Child Safety

Let’s focus our attention on *genetic therapy* for the moment. There may be good reasons for thinking that further experimentation with, and

⁴¹ Ultimately, then, I recommend a moral risk-taking strategy (under conditions of uncertainty) to parents without claiming that this particular risk-taking strategy should be enforced by law.

⁴² See Ronald Dworkin, *Taking Rights Seriously* (London: Duckworth, 1977), pp. 246-247.

⁴³ It is important to explicitly inform the reader that this view is compatible with what is ultimately a permissive policy towards abortion. On my view, the fact that no child is wanted counts as a (relatively) compelling reason for terminating pregnancy.

perhaps the eventual standard use of, this kind of intervention (if it is shown to be safe and effective) might be warranted as a means for treating (embryos, fetuses, or infants with) very serious disorders. We might nonetheless object – on grounds of concern for the child – to *experimentation* with and/or the *use* of this kind of technique for nontherapeutic purposes. A hope of medical geneticists is that techniques can be developed which allow the insertion of properly functioning, desirable genes into the genomes of (at least some cells of) those who lack them and/or that it will become possible to delete malfunctioning genes or deleterious genetic sequences from the patient's (perhaps, for example, the fetus's) genome (or at least from the genomes of some of her cells). One method of genetic therapy currently in clinical trials (roughly) involves the injection of previously extracted and cultured cells – into which desired genetic sequences have been inserted (in vitro) – back into the patient's tissues.

A discussion of the technical complexities posed by various possible forms of genetic therapy, and the hurdles which must be overcome before they provide viable treatment options, would take us much too far afield. Suffice it to say for now, however, that:

- (1) we are here still largely addressing the realm of science fiction,
and
- (2) given important technical difficulties and our poor understanding of many relevant genetic mechanisms, experimentation with such techniques potentially involves great risks,
but
- (3) many scientists nonetheless hope and believe that genetic therapy will become an important viable (perhaps preventative) treatment option in years or decades to come, and
- (4) clinical trials are already under way.

Human experimentation first began in 1990 and, after somewhat encouraging initial results, five years later there were already “100 protocols that [had] either been approved by the NIH Recombinant DNA Advi-

sory Committee or that [were] under review at the U.S. Food and Drug Administration.”⁴⁴ By the year 2000, over 300 trials had already been run so far. The death of an eighteen-year-old human subject (named Jesse Gelsinger) involved in clinical trials of genetic therapy, at the University of Pennsylvania in the Fall of 1999, has recently brought this kind of experimentation under increased scrutiny.⁴⁵

Genetic therapy trials have thus far focused on finding treatments or cures for serious disorders. Given the potentially enormous unknown risks involved with this kind of procedure (the details of which I won't go into), a concern for the well-being of children who could potentially be seriously harmed by such interventions warrants a limitation on experimentation to those who would suffer tremendously anyway without them. For those who are (or will be) terribly sick, the risks involved might sometimes be warranted. But the risk of disaster in the aim to make what would have been a healthy child's life “even better” is surely not justified.

Discussions about the morality of genetic interventions aimed at enhancement often start with the assumption (or fantasy) that we *already* have safe and effective techniques on hand.⁴⁶ What we need to keep in mind, however, is that we presumably will not have safe and effective means of influencing particular traits in specific ways until we conduct dangerous experiments aimed at influencing those particular traits in those specific ways. If there is no urgent need to alter those traits in those ways, then the risks involved in (experimentally) developing techniques to alter them in those ways might never be justified to begin with. A discussion of the ethics of enhancement (via genetic therapy) that begins with the assumption that we *already* have safe and effective means of enhancing traits might ultimately begin with an assumption that unjustifiable risks have already been taken (in the presumably necessary and dangerous experimental development of the specific interventions in

⁴⁴ LeRoy Walters and Julie Gage Palmer, “The Ethics of Human Gene Therapy”, in *Contemporary Issues in Bioethics*, ed. by Tom L. Beauchamp and LeRoy Walters, hereafter referred to as ‘Beauchamp and Walters CIB’ (Belmont, CA: Wadsworth, Fifth Edition, 1999), p. 575.

⁴⁵ Satya Shreenivas, “Who Killed Jesse Gelsinger? Ethical Issues in Human Gene Therapy”, in *Monash Bioethics Review*, Vol. 19, No. 3, July 2000, pp. 35-43.

⁴⁶ See, for example, John Harris, *Wonderwoman and Superman: The Ethics of Biotechnology*, hereafter referred to as ‘Harris WS’ (Oxford, UK: Oxford University Press, 1992).

question).⁴⁷ Our situation is one where we need to decide which risks should be permitted (to be imposed on children) in the first place. Safety concerns for children presumably provide reasons for restrictions against the experimental development of genetic therapies aimed at offspring enhancement right from the start.⁴⁸ Similar concerns provide reason to worry about the experimental development of human reproductive cloning.⁴⁹

C. Open Future Worries

Additional worries about (at least some kinds of) nontherapeutic genetic interventions focus on the threat to what Joel Feinberg describes as a child's "right to an open future."⁵⁰ Suppose that parents want to have a son who will turn out to be a basketball superstar, "just like Daddy was"; and so they employ whatever genetic technologies are (we imagine) available in order to increase chances that Junior will be extra-tall. The worry is that parents, in the process, would plan too much of their child's life out for him ahead of time – before he even comes into being. They aim to impose a particular kind of life on the child rather than letting him discover his own personal passions and aspirations. Rather than saying: "Let's have a kid – and let's love, accept, and encourage him whatever he turns out to be like"; they say: "Let's have a kid who will be a basketball superstar!"⁵¹ Their plan gets foisted onto the youngster. The result will likely be stifled autonomy for the child and/or frustration for all parties involved.

⁴⁷ Such discussions, and again I accuse Harris, also often fail to adequately address the (in)justice (regarding the distribution of limited, often public, medical resources) of the research which might make such interventions possible.

⁴⁸ For further discussions of genetic therapy see, W. French Anderson, "Human Gene Therapy", in Beauchamp and Walters CIB, pp. 581-586; W. French Anderson, "Human Gene Therapy: Why Draw a Line?" *Journal of Medicine and Philosophy*, 1985, 14(I), pp. 681-93; W. French Anderson and J. C. Fletcher, "Gene Therapy in Human Beings: When is it Ethical to Begin?", *New England Journal of Medicine*, 1980, 303: 22, pp. 1293-97.

⁴⁹ See Gina Kolata, "Researchers Find Big Risk of Defect in Cloning Animals", *The New York Times on the Web*, 25 March 2001, <http://www.nytimes.com/2001/03/25/science/25CLON.html?page-wanted=print>.

⁵⁰ See Joel Feinberg, "The Child's Right to an Open Future", in *Whose Child? Children's Rights, Parental Authority, and State Power*, ed. by W. Aiken and H. LaFollette (Totowa, NJ: Rowman and Littlefield, 1980). This kind of issue is discussed by Kitcher LTC, Buchanan et. al. in CTC, and Glenn McGee in *The Perfect Baby* (Lanham, MD: Rowman and Littlefield, 1997).

⁵¹ They could, of course, say, "Let's try to have a kid that will turn out to be a basketball star; but, lets love, accept, and encourage him whatever he turns out to be like." A real worry, however, is that the former aim would ultimately corrupt and compromise the latter.

When the baby is born everyone is already standing around waiting for him to hurry up and grow. When birth is announced to friends and family, the parents cite the baby's length rather than weight. Junior is sitting in diapers, crying, and everyone starts telling him right from the start, "*Don't cry Junior. You will be big and tall. You will be a good basketball player. You will be just like Daddy.*" Finally, as he gets older, he gradually starts to understand what they've been saying: That his purpose in life is to become a tall basketball superstar just like Daddy ... Mommy and Daddy paid for it. He is repeatedly reminded about this.

And then the training begins. Lots of practice and special diets. When Junior lacks enthusiasm, no one understands why. They say, "Come on sonny, you might not like it now ... but that's natural ... Daddy didn't like it at first either ... but he turned into a basketball superstar ... and so will you. We didn't spend all that money for nothing you know. *We've worked so hard for you. Don't let us down kiddo.*"

Given the inevitable unpredictabilities in life, Junior might not turn out to be very tall after all; or, he may never come to enjoy basketball or never become very good at it. Perhaps he would have preferred surfing – in which case being shorter might very well have been an advantage to him. The expectations of parents, Junior's (failed) efforts to live up to them, and the pressures preventing him from pursuing other activities he would have found more satisfying might very well, in the end, be sources of tremendous frustration for the child as well as the parents.

Suppose that Junior does in fact turn out to be an extra-tall basketball superstar. I'm not so sure that this would be cause for much celebration if the child's autonomy was part of the price. The scenario described looks like child abuse. A worry about some kinds of genetic interventions is that they would often be part of – and, perhaps more importantly, encourage – a more general practice where parents aim to exert too much calculated control over – and contrivance of – children. Rather than accepting that their children's futures will be uncertain, and should largely be left *open* for children to choose, parents attempt to determine things ahead of time. Rather than cultivating the child's autonomy, they impose their own plans upon him.

Does this provide reason for imposing legislative constraints on the kinds of genetic interventions that should be permitted? I'm not so sure. We generally allow a wide range of freedom for parents to raise their children as they see fit. Major governmental intervention in child rearing could be much too intrusive. We don't want a brigade of bureaucrats patrolling households, monitoring our every action, telling us *what is* and *what is not* appropriate when it comes to raising children. We think that child upbringing (within limits) is largely a private matter that should be left to the discretion of parents. In any case, the (social) costs of widespread governmental intrusion would likely outweigh the benefits.

On the other hand, the issue of whether or not to restrict the kinds of *genetic interventions* that should be permitted may be different (from the issue of whether or not the government should interfere with *child upbringing* more generally) in important relevant ways. Suppose that we come to determine that there are some kinds of genetic interventions that there are no sufficiently justifiable good reasons to want, or suppose that there are some kinds of genetic interventions which – if available – would do more harm than good when a plurality of legitimate social interests⁵² are taken into account. Preventing or discouraging these kinds of interventions would not require governmental intrusion into the household. We could simply impose laws that prohibit genetic service providers from offering the interventions in question. Or we could impose laws that make the (most) worrisome interventions more difficult to come by, perhaps with the implementation of procedural requirements, or via the imposition of heavy taxation which might both discourage the development of worrisome interventions in the first place and make them less likely to be used if they are in fact developed. We might also make the existence of such interventions less likely by preventing research and development most likely to lead to them from occurring at public institutions and/or with taxpayers' money. The social dangers could thus be averted without compromising the integrity of the household (and perhaps without violating any important freedom which should be left in the hands of parents). This is the first relevant difference between (1) the genetic interventions

⁵² These would include: liberty, child well-being, equality, and aggregate utility. We will be discussing equality and aggregate utility quite shortly.

in question and (2) many other child rearing practices we may have good reasons to worry about but do not think the government should interfere with.

A second difference recalls something I suggested above – i.e. that some kinds of genetic interventions would not merely compromise child autonomy,⁵³ but might likely also *promote and encourage* autonomy-compromising child rearing practices more generally.⁵⁴ There may also be a third relevant difference between the kinds of genetic interventions we have in mind and child rearing practices that are already tolerated. The influence over the child's autonomy might sometimes strike at a deeper level. Suppose that parents decide to raise their child as a Catholic. When the child grows up she may be able to free herself from the worldview into which she was indoctrinated as a child. She may autonomously decide or discover as an adult, for example, that other pictures of reality make more sense to her. She can disavow her faith in Catholicism and sign up for Islam, New Age Mysticism, The Contemporary Scientific Story, Agnosticism, or whatever suits her fancy. (I do not mean to deny that childhood indoctrination will often make this difficult to do, or influence future choices.) Suppose, on the other hand, that genetic technologies make it possible for parents to influence their children's height in the future. A child who ends up eight feet tall would be stuck in that state for life. Does the liberal eugenicist think that parents should be free to have a child who would be *ten* feet tall if it becomes technically feasible to arrange this? I hope not. In any case, whether or not open future worries themselves provide adequate reasons for restrictions, they (like worries about the morality of killing) should be kept in mind, and might tip the balance in favor of restrictions (or alternative forms of governmental discouragement) once we take other legitimate social aims – such as the promotion of equality and aggregate utility – into account. We shall soon turn our attention to these other legitimate community interests.

One might object to the preceding discussion, complaining that I have once again provided an exaggerated example. “Most parents,” the

⁵³ i.e. limiting the child's options by making him outrageously tall, for example.

⁵⁴ i.e. the rearing of the child in question becomes focused on realizing what the genetic intervention was supposed to bring about.

objection claims, “would not be as bad as those described in the example above. The kinds of parents described would be the rare exception rather than the rule.” My focus on an extreme case, however, was again completely intentional. We need to keep in mind that these most disturbing scenarios may very well occur, sometimes at least, if *no limits* are placed on the ways in which future genetic science and technology might be used. As a society we need to ask if there are sufficiently good reasons for leaving the door wide-open to such possibilities.

We can also easily imagine cases which would not be *as* troublesome as the example discussed above. The vast majority of parents, even those who *do* have (very) particular aspirations in mind for their children, would presumably not be as despotic as those described in our example. This may be true, but the use of genetic technology for the general kind of purpose described above would often (even in less extreme cases) nevertheless be worrisome (though perhaps to a lesser degree) for the very same reasons. We thus need to ask if there is adequate rationale for leaving the door open to what would presumably be more common, but less severe, parental abuses.

D. Equality and Aggregate Utility

1. Positional Advantages

Suppose that genetic intervention aimed at enhancement would *sometimes* be part of – and contributive to – practices which are (to varying degrees) in conflict with the autonomy of, and therefore basically abusive to, children. This does not imply that genetic intervention aimed at enhancement would *always* be bad for the children involved. Genetic intervention aimed at enhancement, for example, need not always have a negative impact on child autonomy. Parents may simply find reason to believe that some traits would likely confer a *general* competitive advantage to their children or, perhaps in some cases, make a more direct contribution to their children’s quality of life. Parents could aim to enhance their children’s general prospects in life, that is, without aiming to impose any particular kind(s) of life upon them.

Parents might rightly believe that being taller than average would provide a general competitive advantage to their child. Perhaps they have seen data suggesting that taller persons are more likely to obtain higher paying jobs, be good at a wide variety of sports, or attract members of the opposite sex. Parents may find good reasons to believe that, in our social context at least, being taller would improve their child's prospects in life even if they do not have any particular kind of life in mind for the child. They may simply be motivated by the desire to *increase the child's options* in life. They might thus aim to enhance her height without wanting to impose any particular kind of life upon her.

Does this mean that there are at least some cases when genetic enhancement of height should be considered socially acceptable? Even if it would in fact be advantageous for a child to be especially tall, there are reasons to worry that genetic enhancement of height would be either unfair or "self-defeating"⁵⁵. Increased height, for example, is presumably a "positional advantage" if it is truly an advantage at all.⁵⁶ Being tall is presumably not itself inherently advantageous. It is being *taller than others* – i.e. having a *competitive advantage* – which might sometimes improve a child's prospects in life. The advantages which one could confer on a child by increasing chances she would be tall, that is, would only be attainable if the necessary technology is not equally available to all.

Suppose that parents aim to increase the height of their child not because (1) they have a particular kind of life in mind for the child for which increased height is an advantage, but because (2) being extra-tall is a competitive advantage more generally speaking. The competitive advantage hoped for would depend upon there being *limited access* to height-enhancing technology. If the technology were available to all, then its use by some would presumably pressure others to use it as well in order to avoid leaving their children at too great a disadvantage. A motivation for allowing the technology might be the aim to promote liberty.⁵⁷ A policy which would *appear* to promote liberty, however, might not

⁵⁵ See Buchanan et. al. CTC.

⁵⁶ See Kitcher LTC and Buchanan et. al. CTC. This point was also made by Peter Singer in SGS.

⁵⁷ See Robert Nozick, *Anarchy, State, and Utopia* (New York: Basic Books, 1974), hereafter referred to as 'Nozick ASU'.

actually do so if the resulting pressures become strong enough over time.⁵⁸ Once enough people start enhancing the height of their children, others may not be left with an effective freedom to refrain if their children would suffer as a result. Once enough people enhance there might not be much choice except to conform. Granting the freedom to choose X or not-X now may lead to a situation where there is not much freedom to choose not-X at some time in the future.⁵⁹ A run-away process leads to a (much) taller population whose members are not any better-off than they would have been if the technology were not available in the first place. To the contrary, most would be worse-off because clothes, cars, and homes would all need to be redesigned in order to accommodate taller people – and there would presumably be a need for increased food production.⁶⁰ Other fruitful purposes for which limited medical resources might have been used are forgone in the process. If the technology in question is made generally available to everyone – or to enough people – then its widespread use would likely thus be self-defeating.⁶¹ Effective liberty will not have increased, and (much) aggregate utility will have been sacrificed. It would be a shame if a publicly funded enterprise such as the Human Genome Project eventually leads to this kind of outcome given that it was justified to the public in virtue of its potential to promote social interests via the treatment and prevention of disease.

It is more likely the case, however, that enhancement-oriented interventions would not be equally available to all. In 1999, 42.5 million Americans (approximately equivalent in number to the entire South African population) – 14.2 percent of the U.S. population – did not have health insurance; and, the number of uninsured is expected to increase in the

⁵⁸ Recall our previous discussion of cosmetics, and see Little CSC and Bordo BB.

⁵⁹ This point was made by Singer in SGS. See also Van De Veer and Pierce, *The Environmental Ethics and Policy Book* (Belmont, CA: Wadsworth, 1994), part V. Recall that one of the selling points of the liberal vision of a new eugenics will have been misleading. The liberal new eugenics was supposed to be different from the old eugenics because the former is supposed to be based on individual free choice, while the latter was based on coercion. If pressures to conform become strong enough, however, then the “freedom” of the new eugenics will (ultimately) be a hoax.

⁶⁰ Singer SGS.

⁶¹ From a Kantian perspective, the right to use genetic technologies in order to attain positional advantages for one’s child would thus be denied in virtue of the fact that the maxim of one’s action would not be universalizable. See Immanuel Kant, *Grounding for the Metaphysics of Morals* (Indianapolis: Hackett, reprint, 1993).

immediate future.⁶² To a country that takes pride in its wealth and “high standard of living,” these figures should cause tremendous embarrassment. The United States is the only major industrialized nation that lacks a public health care system. This is surely a distinction in which very little pride should be taken. The *theoretical* claim that a laissez-faire, free market will fail to provide important public goods turns out to be true *in practice* – with regard to health care at least⁶³ – in the United States.⁶⁴ The proportion of GDP spent on health care there is second to none at 14%. In a recent survey of health care systems conducted by the World Health Organisation, however, the world’s only superpower was ranked in 37th place.⁶⁵

Existing disparities in access to *medically necessary* health care services reveal that enhancement technologies would not be generally available to everyone. Given that many people currently cannot even afford basic health care coverage for the treatment and prevention of suffering and disease, it would be very odd to expect that everyone will automatically – or magically – have access to enhancement technologies when and if they come into existence. Even if the United States does finally adopt a universal health care system, surely we should not generally expect enhancement technologies aimed at positional advantages, such as increased height for example, to be included among the services offered.⁶⁶

⁶² Adam Clymer and Robert Pear, “Congress Begins Planning for Increased Number of Uninsured as Economy Slows”, *The New York Times on the Web*, 27 March 2001, <http://www.nytimes.com/2001/03/27/politics/27HEAL.html?pagewanted=print>.

⁶³ The same might be said about public transportation in many, or perhaps most, American cities. The lack of (much) viable public transportation in a city such as Los Angeles (home to a population approximately equivalent in size to that of Australia), for example, surely reveals a fatal flaw somewhere in the system. It is surprising that Americans are not more troubled by the lack of these particular public goods. (Basic science might be considered a strength of the United States in terms of public goods. The *fruits* of such science, however, are too often not available to everyone. See Dutton WTD. Another *strength* of the United States, with respect to public goods, is defense ... plenty of bombs for everyone.)

⁶⁴ The U.S. system, of course, is not entirely laissez-faire; and the health care industry does not there meet all of the (theoretical) conditions of a free market. Will some say that the problem is that the market is not free enough? My best guess is that the opposite is true.

⁶⁵ “Misprescribing for Health Care”, *The Economist*, 14 April 2001, p. 27. Note that Germany did not fare much better: 11% of GDP (“second only to the United States”) spent on health care, and ranked 25th overall by WHO.

⁶⁶ “Enhancement” technology aimed at improving immunity from disease (depending on its expense) might turn out to be a different story. My point for now is that there are at least some interventions aimed at enhancement which we should not expect to see offered. I have attempted to avoid making sweeping claims which draw sharp moral distinctions between “enhancements” and “treatments” of disease; hence my focus on particular kinds of enhancements – i.e. such as those aimed at increased height.

Other nations that provide universal health care coverage clearly would not – or at least should not – generally speaking provide such services either. Why would public health care systems offer services which (1) would (likely) ultimately be self-defeating, and (2) are, in any case, far less urgently needed than other services which could be offered instead? No public health care system will be able to offer *every* kind of genetic intervention that is technically attainable.

Mehlman and Botkin argue that it would likely be prohibitively expensive to always offer even medically important genetic services to everyone. Consider genetic testing for example. Given

(1) the large number of disorders which are likely to have some genetic component,

(2) the fact that hundreds of different mutations often exist for particular genes associated with particular disorders,⁶⁷ and

(3) the large number of people (or fetuses) who are likely to be at risk for some genetic disorder or other,

the total cost of providing (all) medically important diagnostic genetic tests to everyone who needs, or might want, them would likely exceed financial constraints of public health care systems.⁶⁸ The fact that public health care systems (and ordinary private health insurance packages) would not be able to offer some genetic tests to everyone, however, does not imply that it would not be profitable for private industry to develop and offer them if there are enough people willing and able to pay for them. Similar things can presumably be said about other kinds of genetic interventions that may become technically feasible in the future.

The reality is that unless there are restrictions limiting the commercial availability of genetic services, there will likely be some genetic services which are only available to those who are rich enough to afford them (or the expensive private insurance packages which might offer them). Given the expense that would be involved with at least some genetic inter-

⁶⁷ 300 mutations exist for a gene associated with Cystic Fibrosis, but only a few of them account for most cases of the disease. There are similarly hundreds of mutations found in genes associated with breast cancer. The numbers involved will sometimes make genetic testing quite complicated. Mehlman and Botkin ATG, 22-24.

⁶⁸ *Ibid.*, p. 77.

ventions, there is no reason to expect that those which are developed will be made available to everyone unless this is required by law.⁶⁹ If it becomes possible to test and/or influence traits that confer positional advantages, then these would presumably often only be available to those who are relatively wealthy.

Parents who *are* relatively wealthy would presumably sometimes thus be motivated to genetically enhance their children in order to provide them with positional, or competitive, advantages over others. The practice wouldn't be self-defeating so long as these advantages were not available to everyone (or at least not available to enough people). Parents who can afford such interventions could thus provide true benefits to their children. But this seems unfair! The analogy is that there is a race for many of the good things in life, and some people are allowed to purchase head starts for their children. The head starts are not themselves inherently or directly valuable; *they are only valuable because they are denied to others*. Why should wealthy parents be permitted to provide their children with traits that are beneficial *only in virtue of being unfair* (i.e. only in virtue of the fact that they are denied to other presumably equally deserving children)? Would it be illegitimate to impose restrictions on a practice that seems *inherently unfair*? If we can expect impacts on aggregate utility and equality to be substantially adverse in the absence of restrictions, then the fact that the liberty we might want to restrict (in order to protect equality and aggregate utility) is ultimately *the liberty to do something unfair* should surely be taken into consideration and given significant weight. We should also keep in mind that it seems especially perverse for parents to employ *medical* resources, in particular, for the kind of purpose in question.

Argument from Precedent

Some might object that *we already allow* wealthy parents to provide positional advantages to their children insofar as we allow them to send their children to special private schools, training camps, music lessons,

⁶⁹ *Ibid.*, p. 77, p. 109.

and so on. Presumably children who are fortunate enough to attend such schools, etc. often end up with competitive advantages over others, and presumably this is often at least part of the parent's motivation for paying the price to send them there. Given that we allow these other practices, the argument runs, genetic interventions should not be considered any different. Erik Parens calls this "the argument from precedent"⁷⁰. "We already do (or allow) something just like this, so doing (or allowing) this must be okay too." This style of argument is widespread in the bioethics literature concerned with modern reproductive technologies. We are likely to read somewhere, for example, that "since we already allow enhancement via cosmetic surgery, genetic enhancement should be generally permitted too."

There are numerous reasons, however, why this general kind of argument should be treated with suspicion. The obvious first response to this style of argument points out that the fact that we already allow certain practices or consider them to be acceptable does not demonstrate that we *should* allow them or that we *should* consider them to be acceptable. Pointing to a similar practice and saying that we already allow it and consider it to be acceptable is argumentatively inadequate. Something needs to be said about why the already permitted practice should be considered acceptable in the first place (unless this is clearly and completely beyond dispute).

Additional responses to the argument from precedent point to the need to show that, despite the similarities, there are no significant relevant differences between (1) the already accepted practice and (2) the practice in question. There seems to be an important difference between education, on the one hand, and the enhancement of traits such as height, on the other. The benefits gained from increased height are presumably *merely* positional advantages. Education may confer positional advantages, but it provides more direct benefits as well. There is reason to consider the process of education itself to be a worthwhile activity,⁷¹ and reason to consider the fruits of education to be valuable in ways which go beyond the

⁷⁰ See Parens EHT. (The following sentence is not a quote from Parens.)

⁷¹ Ibid..

competitive advantages conferred by higher education. Excellent education would likely promote the quality of an individual's life (according to common conceptions of well-being) even if – or perhaps especially if – it were available to everyone. To say that “enhancing height is just like – and therefore should be considered just as acceptable as – sending our children to the best schools *because* they both confer positional advantages to children” misses a significant moral difference between the two sorts of enhancements. Sending children to the best schools provides things which would be worth having even if they were available to everyone. The same presumably cannot be said for enhancement of height.

A third response to the argument from precedence points out that two kinds of practices which appear to be similar when we examine *isolated incidents* of each may have quite different *consequences* when considered as *practices*. Considered in isolation cosmetic surgery and genetic enhancement might have much in common. We might find no relevant difference between cosmetic surgery *per se* and genetic enhancement *per se*. Let's assume that this is the case. One might nonetheless worry that *the practice* of genetic enhancement would be more widespread and have greater ultimate impacts on legitimate social goals such as aggregate utility and equality. One might expect genetic intervention to be more *consequential* than cosmetic surgery because of the potentially large number and wide variety of traits that might turn out to be – or will likely in any case be claimed to be – subject to genetic influence. The expected *consequences* of tolerance towards the *practice* in question need to be taken into consideration. The fact that two kinds of actions are similar *per se* does not mean that the two kinds of practices would ultimately have the same aggregate consequences. To those who are worried about the *consequences* of a widespread practice of genetic engineering in particular, arguments from precedent should not be considered conclusive.

A fourth response to at least some uses of the argument from precedent points out that there may sometimes be *context dependent differences* between two kinds of cases. Suppose someone says “we already allow the rich to provide their children with competitive advantages by sending them to special sports camps, so we should therefore permit them to provide their children with genetic advantages too.” One avenue for responding to

this argument is found if there are reasons for thinking that equality is more important in some contexts than it is in others. There may be good reasons for thinking that equality is especially important in the context of health care, for example, in comparison with other contexts or realms. The existence of public health care systems in many parts of the world reflects that there *are* good reasons for thinking that this is the case. Equal access to (at least some level of) health care, but not soccer training, is presumably guaranteed to all in many countries precisely because there are good reasons for thinking that equality is more important in the context of health care than it is in the context of soccer.⁷² For now, however, the point is to show that arguments from precedent should not, generally speaking, be considered conclusive when relevant context dependencies apply.

2. *Direct (i.e. Not Merely Positional) Genetic Advantage*

Some traits that could imaginably become (somewhat) subject to genetic enhancement may, of course, provide more direct (i.e. not merely positional) benefits to children. Suppose, for example, that it becomes possible to influence intelligence. In comparison with merely positional advantages, we might think that intelligence (broadly speaking) is worth promoting for reasons independent of the competitive advantages it might confer.⁷³ According to ordinary ideas of the good life – which place a value on things like creativity, rationality, and awareness – intelligence itself (not just being *more intelligent* than others) would be considered advantageous. Or suppose that it becomes possible to genetically engineer the “new breed” envisioned by John Harris in *Wonderwoman and Superman*. Harris invites us to imagine

that we have made the breakthroughs
necessary to achieve a number of different
sets of modifications. We will assu-

⁷² I shall discuss what such reasons might look like later. In the meantime see Norman Daniels, *Just Health Care*, hereafter referred to as ‘Daniels JHC’ (New York: Cambridge University Press, 1985).

⁷³ I am assuming, for the sake of argument, that it does make sense to talk about intelligence in such general terms. Stephen J. Gould argues that we should be skeptical about the idea that there is such a thing as general intelligence. See his *The Mismeasure of Man* (New York: W. W. Norton & Company, 1981).

me we can insert new genes coded for antibodies to major infections including AIDS, hepatitis B, and malaria. We will also assume that we can insert genes coded for enzymes which will repair damage from carcinogens or environmental pollutants of various kinds and others which might remove predispositions to heart disease. Finally we will assume that we can insert genes which will repair DNA and so, among other things, retard ageing ... a balanced lifespan will be increased by twenty years on average.⁷⁴

Being a member of the new breed, like having increased intelligence, sounds worthwhile for the direct contribution it would make to the quality of one's life. It would not merely be a positional advantage which would only be beneficial to the extent that others are excluded. Harris' example also sounds *prima facie* acceptable because the intervention imagined ultimately aims at what we would ordinarily consider to be legitimate targets of medical intervention: i.e. the prevention of disease and the promotion of health.⁷⁵

Should these kinds of enhancements be considered socially acceptable if they become technically attainable? Again, I'm not so sure. I would want to ask what kind of research would be required to make them possible in the first place; and, I would want to know who exactly would have access to these technologies if they were in fact available. Harris assumes that the research and development of the new breed has already taken place. There is a prior question, however, about the justice of the research which would in fact be required to make the new breed possible. Would the research take place at public institutions with financial support from

⁷⁴ Harris WS, p. 186.

⁷⁵ To avoid, for the moment, a complex discussion of concepts of disease and health, my point is that the imagined intervention aims at what we prototypically consider to be diseases and what we prototypically consider to be health.

taxpayers' money? Will everyone get to become a member of the new breed, or will many innocent people be left sick and suffering? To what extent would the research required to make the new breed possible demand major sacrifices of other research programs which would have led to the treatment and/or prevention of the sickness and suffering of others? Would those who benefit as members of the new breed have been likely to live relatively high quality lives even if they had not been enhanced?

It is vitally important to recognize that technological abilities do not just fall out of the sky and into our labs. The development of one technological ability involves opportunity costs with regard to others we might pursue instead. If the development of the imagined technology requires the use of public resources, then society as a whole needs to ask (1) Would only the privileged few get to benefit from the research, or would it benefit society as a whole more generally speaking?,⁷⁶ (2) Is this the best and most appropriate use of limited (public) health care resources, or would other research programs ultimately be more fruitful towards the ultimate goals of medicine?, (3) Is the required research likely to have unacceptably adverse effects on equality and aggregate utility?

Whether or not the research required for the enhancement of intelligence or the engineering of the new breed is conducted at public institutions with taxpayers' money,⁷⁷ there is cause for social concern about such interventions if they would not be available to the general public. The reason is simply that the enhancements in question would provide competitive advantages, as well as more direct benefits towards the promotion of life quality, to those who receive them. Intelligence is presumably worth having for the direct benefits it confers towards the promotion of well-being. But increased intelligence would, quite often at least, also provide an advantage (to those enhanced over those who are not) in the competition for social goods. The vigorous health of the new breed would similarly be worth having for direct benefits conferred towards the promotion

⁷⁶ If it would only be available to the privileged few, then why should public resources be devoted to it?

⁷⁷ The development of such technologies would inevitably at least make use of much research that was supported by the community as a whole. As I argued before, it may be legitimate for society to impose limits on the ways in which public (intellectual) property might be put to use.

of well-being. But being a member of the new breed would provide competitive advantages as well. Members of the new breed would have lower health care expenses, for example; and, they would be especially attractive to employers because they would be less likely to get sick and miss work. Since they are likely to survive longer, they would be considered better investments in occupations requiring (much) training. And they would be less vulnerable to occupational health hazards.⁷⁸ Anyone who has seen the film *GATTACA* will already be familiar with the kind of concern under discussion.

The fear is that we will end up with a genetically stratified society. If parents are allowed to genetically enhance their children in (a wide variety of) ways which (whether or not they provide more direct advantages as well) provide them with positional advantages, then wealthy children are more likely to secure the goods for which there is social competition. Rich kids undeservingly end up with even more power and wealth than they likely already would have obtained. Not only will they get to enjoy better lives than those who are born into less fortunate circumstances, they will also be in an even better position to exploit and oppress those who are now considered to be genetically inferior in addition to being poor. The divide between the haves and have-nots increases dramatically and becomes more intractable. One's position in life, and one's quality of life, to a much greater extent than before, will be a function of parents' or ancestors' ability to pay.⁷⁹ Those born into the luckiest circumstances will ultimately, through no merit of their own, and to a much greater extent than is already the case, get to rule over the rest and enjoy more than their share of the good things in life. According to some writers, the challenge to equality posed by advances in genetics is almost unprecedented. Mehlman and Botkin, for example, argue that, "With the possible exception of slavery, [genetic] technologies represent the most profound challenge to cherished notions of social equality ever encountered. Decisions over who will have access to what genetic technologies will likely determine the kind of society and political system

⁷⁸ Harris WS, 187-188.

⁷⁹ This would thus appear to be a form of tyranny according the position of Michael Walzer in *Spheres of Justice* (New York: Basic Books, 1983).

that will prevail in the future.”⁸⁰ They go on to claim that the very principles upon which democratic society is founded will be threatened in the absence of equal access to genetic technologies.⁸¹ The inequalities of opportunity and well-being which might ensue, according to the scenarios envisioned by Mehlman and Botkin, are likely to have a negative impact on aggregate utility as well. They fear that the genetically stratified society would ultimately be politically unstable and subject to major social upheaval. I shall later pursue a discussion about what to make of such claims.

Even if an extreme genetic stratification of society does not occur, we might still be alarmed about the justice of a situation where the *health care system*, in particular, becomes a platform for providing one’s children with traits which would ultimately give them unfair competitive advantages over others. In *Just Health Care*, Norman Daniels argues that medicine should be viewed as an especially important social institution in virtue of its role in the *promotion of equality of opportunity* via the restoration of human functioning. Daniels argues that the social importance of equality of opportunity, and the role of health care in promoting it via the restoration of human functioning, provides (1) reason for treating health care different than other goods which are left in the hands of the free market and (2) reason for guaranteeing the provision of a basic package of health care services to all members of society. Those sympathetic to Daniels’ concern with justice via equality of opportunity will be troubled by the lack of a universal health care system in the United States; and, they should be doubly troubled if, on top of this, we will have a system where there are *no restrictions* preventing wealthy parents from exploiting health care resources in ways which ultimately promote, rather than reduce, inequalities of opportunity.

3. Allocation of Resources

Whether or not the doomsday scenarios envisioned by Mehlman and Botkin are in fact likely to occur, there are perhaps less far-fetched

⁸⁰ Mehlman and Botkin ATG, p. 6.

⁸¹ *Ibid.*, p. 120.

reasons for being concerned about impacts on aggregate utility if a wide range of genetic interventions are permitted in an unrestricted free market. The worry here has already been alluded to at numerous points in previous discussions and is perhaps best illustrated by recalling attention to the “10/90 divide” whereby only 10% of health care research funds are focused on 90% of the global burden of disease. At least part of the explanation for this phenomenon is presumably that it is often most profitable for the medical industry to develop and offer medical interventions which are not necessarily those which are most important and urgently needed. If there is no reason to expect that the most urgently needed health care services always correspond with those which are most profitable for industry to develop and offer, then we should not be surprised if the availability of the former is compromised in an unrestricted free market. Health care resources are subject to diversion from the most urgently needed applications to other less important – but ultimately more profitable – purposes. This is especially problematic when those with the greatest health problems also turn out to be those who are least financially fortunate – as is, in fact, usually the case.

This presents a general worry about leaving the meeting of health care needs to free market mechanisms. The implementation of a more centralized public health care system would provide one means of achieving a more deliberate focus of health care resources towards the medically most important purposes. The United States has been quite reluctant to establish a public health care system, however; and, even if one were finally adopted in the future, some kind of two-tiered system would presumably be most likely. In two-tiered systems there is a danger that an unrestricted more profitable private tier would drain resources away from the public sector and, to a certain extent at least, the general problem presented in the last paragraph would remain. Amy Gutmann shares this kind of worry about two-tiered systems:

Without restricting the free market in extra health care goods, a society risks having its best medical practitioners drained into the private market sector, thereby decreasing the quality of medical care received by the majority of citizens confined to the publicly funded sec-

tor. The lower the level of public provision of health care and the less elastic the supply of physicians, the more problematic ... will be an additional market sector in health care.⁸²

The drain of resources from the public to the private sphere in South Africa in recent years demonstrates that this kind of worry is not merely academic.⁸³

In the context of eugenics, the worry is that it will become profitable for industry to develop, and health care service providers to offer, a wide range of services that do not necessarily aim to meet centrally important medical needs. If the development and provision of such services turns out to be especially profitable, then resources will inevitably be drained away from what society as a whole might have ultimately considered to be more important purposes. Suppose, for example, that wealthy people turn out to be willing to pay lots of money for genetic services that are ultimately nontherapeutic in nature and aimed at things like increased intelligence, height, and breast size. If this is the case, and if there are no limits on the ways in which genetic technology might be used, then limited medical resources, in the way of personnel and equipment, are diverted away from more important therapeutic purposes towards which they likely otherwise would have been aimed. Given that treatment and prevention of serious disease is likely (I assume) to improve the quality of lives to a much greater extent than interventions aimed at things like greater than average height or breast size, there is reason to fear that aggregate utility would be adversely affected in the process. The threat to aggregate utility is that medical resources will, to a certain extent at least, be redirected away from the focus on the (most) sick, towards nontherapeutic, or in any case less urgent, purposes that would ultimately be less fruit-

⁸² Amy Gutmann, "For and Against Equal Access to Health Care", in *Classic Works in Medical Ethics*, ed. by Gregory E. Pence (Fairfield: McGraw-Hill, 1998), p. 375. She talks about a drain of resources in terms of physicians in particular. My point is that we should be concerned about this kind of phenomenon more generally – i.e. also taking researchers, research facilities, equipment, production facilities, etc. into account.

⁸³ See Solomon R. Benatar, "Health Care Reform in the New South Africa", in *The New England Journal of Medicine*, Vol. 336(12); and, Solomon R. Benatar and H.C.J. van Rensburg, "Health Care Services in a New South Africa", in *Hastings Center Report*, Vol. 25, No. 4, 1995, pp. 16-21.

ful. One way of preventing (or at least reducing) the drain of resources from more fruitful to less fruitful purposes, of course, would be to place limits on the ways in which genetic technologies may be used.

IV. Moderate Pluralism and Societal Decision Making

We have examined reasons for being concerned about the social consequences of a new eugenics which leaves genetically-informed reproductive decision making completely in the hands of individuals and private enterprise. In particular we have examined concerns about (1) the effects certain interventions might have on children and (2) the impact certain practices might have on equality and aggregate utility. Has a conclusive case in favor of the imposition of legislative restrictions against certain kinds of genetic interventions been made? If there is reason to believe that certain procedures would pose extreme dangers to children who would otherwise be expected to enjoy (relatively) normal, healthy, high quality lives, then, in such cases at least, I would say that the answer is yes, there should be limits to the amount of danger which parents are allowed to impose on children. If certain kinds of interventions can be expected to have extremely adverse effects on child autonomy, then I believe this would provide a legitimate rationale for legislative restraint as well.⁸⁴

Beyond that, as a philosopher it is difficult to say whether or not further restrictions would in fact be justified. I have shown why it is plausible to think that certain kinds of practices might have adverse effects on equality and aggregate utility. But I have not provided evidence showing *how likely* or *how severe* such impacts might be. I hope that I have, however, at least provided sufficient evidence that such concerns should be taken seriously by society as a whole. It seems that further investigation is warranted. Interdisciplinary research in history, sociology, psychology, and economics could provide a better picture of how likely and severe impacts on equality and aggregate utility might be.⁸⁵ Our topic is ripe for

⁸⁴ I must leave to the side, for now, questions about *how much* autonomy diminishment and danger should be tolerated.

⁸⁵ Emerging information from genetic science itself, regarding the kinds of interventions likely to become attainable, will also be revealing.

socially important future research in these sciences. We should not, of course, expect such studies to provide either *exact* or *certain* predictions about the future of society. But the data which might be uncovered would presumably, analogous to genetic tests, allow us to attach a range of probabilities to various outcomes we might expect to result from alternative social policies. Brute philosophical speculation in the absence of further empirical data is unlikely, in any case, to provide us with answers.

If we do find compelling reasons to expect that there very likely would be severe negative impacts on equality and/or aggregate utility in the absence of restrictions, then I see no reason to think that the infringement of liberty should be considered out of the question. Liberty is just one out of many – or at least three – legitimate social aims. Why should we think that the promotion of liberty should be given absolute priority over the promotion of both equality and aggregate utility regardless of the extent to which these latter two are threatened? If we are faced with conflicting values, then we need to think more about how to make trade-offs between them.

The Good of Society

Throughout I have assumed that liberty, equality, and aggregate utility are independent, legitimate social aims which sometimes conflict – and I have assumed that none should (always) be given absolute priority over the others in situations of conflict.⁸⁶ I expect that most members of society will find these ideas to be intuitively appealing; and I believe that a wide variety of generally accepted social policies are based on the idea that they are in fact correct. In any case, the ideas in question can be supported by argument. Although I cannot pursue the relevant issues in much depth here, I *will* say something about (1) why we should explicitly embrace a framework which considers the promotion of liberty, equality,

⁸⁶ For my purposes, aggregate utility should be considered as an aggregation of life quality levels. I leave to the side Parfit's questions about the relative importance of maximizing *total* versus *average* utility. See Parfit, *Reasons and Persons* (Oxford: Clarendon Press, 1984), Part Four. I likewise do not aim to here settle the question: Equality of What? For my purposes the aim to promote equality is itself pluralistic and roughly aimed at (1) the reduction of undeserved inequalities in life quality, (2) equality of opportunity, and (3) the general improvement of circumstances of those who are worst-off.

and aggregate utility to be legitimate, independent, potentially conflicting social aims, (2) why none of these three should be given absolute priority over the others, and (3) how we might go about making trade-offs between them in cases of conflict.

The ideas that liberty, equality, and aggregate utility are each legitimate social aims has already been quite convincingly established, cumulatively, by three major strands of moral/political philosophy: i.e. libertarianism (represented by Nozick), egalitarian liberalism (represented by Rawls), and utilitarianism. Each of these theoretical traditions demonstrates the importance of the social aims they represent and emphasize. The debates that surround them, however, seem to show that not any one of the three viewpoints – each of which places special priority on one of the three social aims – is entirely correct. Debates in political philosophy, that is, reveal that (1) the social aims in question do in fact conflict and (2) that none should be given absolute priority over the others. All three theories have much that speak in their favor – because the social aims they represent do appear to be legitimate (and *sometimes* deserve priority). Hence the debate. But each appears to be *too extreme* and flawed in the face of counterexamples.

I assume that most members of society would agree that egalitarian aims should at least be taken into consideration when formulating social policy. We think that it is *unjust*, for example, if certain individuals are forced to live horribly miserable lives due to no fault of their own, while others live wonderfully high quality lives when they have no special claim, or cannot be said to deserve, to do so. If it is possible to substantially improve the lot of the undeservingly miserable at a reasonable cost to the undeservingly flourishing, then we – as a society – should try to bring this about. Rawls, however, seems to place *too much weight* on the promotion of equality. His theory of “justice as fairness” is developed specifically for a society where it is explicitly assumed that everyone is healthy.⁸⁷ If we attempt to adopt his general perspective (and the risk taking strategy he assumes should be taken by rational parties in the original position) to the context of health care, however, we are led to

⁸⁷ John Rawls, *A Theory of Justice* (Cambridge, MA: Harvard University Press, 1971).

implausible conclusions. The Rawlsian perspective, roughly speaking, holds that social structures should be arranged to ensure that the prospects of the worst-off group of individuals is maximally promoted. Inequalities should only be permitted to the degree that they benefit those who are worst-off. The general spirit of the view is that we should aim to maximally improve the prospects in life for those with the least favorable prospects in life. We should make the least favorable circumstances as favorable as possible.

In *A Theory of Justice* Rawls seems to think that the promotion of *egalitarian* aims (to benefit the worst-off groups) would not require great sacrifices regarding the *utilitarian* aim to promote aggregate well-being. In the contexts he addresses, and under the assumptions he makes, Rawls seems to think that empirically speaking these two kinds of goals – i.e. the promotion of equality and the promotion of aggregate utility – will to a reasonably acceptable extent be realized together.⁸⁸ Huge sacrifices of aggregate utility would not likely be required, according to Rawls, in order to achieve only *minimal* benefits for those who are least fortunate.

Rawls' belief that the best-off, or the not-so-bad-off, would not need to make huge sacrifices in order to provide negligible, or very small, gains for the worst-off seems controversial even under the assumptions he makes for the specific contexts he addresses. In the context of medicine, however, where it is not the case that everyone is assumed to be healthy, it is extremely unlikely that the promotion of aggregative goals would always come hand-in-hand with the promotion of equality. In contexts involving health care, giving priority to the goal of maximally improving the prospects of those with the worst prospects – i.e. those who are most handicapped or diseased – take the anencephalic child as an example – would lead to the problem that Norman Daniels describes as “social hijacking”⁸⁹. Huge sacrifices *would* have to be made by those who are better-off in order to provide negligible gains for those who are worst-off. Giving absolute priority to the goal of maximally promoting the well-being (or opportunities of) the anencephalic, for example, would require

⁸⁸ I owe this interpretation of Rawls to Samuel Scheffler, in conversation.

⁸⁹ Daniels JHC, pp. 35-39.

a large-scale diversion of medical resources from treatments (and research) which provide tremendous benefits for people who are not so badly off in order to provide what would presumably be only negligible gains for a group whose situation is practically hopeless to begin with. In effect, then, the Rawlsian perspective places *too much weight* on the goal to promote *equality* and *too little weight* on the goal to promote *aggregate utility/well-being*.

Nozick's libertarianism likewise seems to place too much weight on the value of (negative) liberty and apparently too little weight on equality in particular. Counter-examples to the Nozickian perspective, I hope, have already been provided by our previous discussions. If we had every reason to believe that a completely laissez-faire eugenics would lead to *disaster* in terms of equality and aggregate utility (recall the scenarios imagined by Mehlman and Botkin for example) then it seems implausibly extreme to suppose that this must be endured because liberty always counts for more than equality and aggregate utility, regardless of the extent to which these are jeopardized. Surely no democratic society places such a high priority on negative liberties generally speaking. Negative liberties are already sacrificed in a wide variety of ways in order to promote aggregate utility and equality. Widely accepted social policies apparently aimed at the promotion of efficiency, for example, often require *minor* infringements of *non-basic* liberties. Speed limits and mandatory seat-belt laws presumably provide examples. In times of war, and other humanitarian emergencies, we also (think it is at least sometimes appropriate to) acquiesce in the violation of people's more basic liberties in order to promote and protect "the greater good". The legitimacy of progressive taxation – which according to Nozick involves the infringement of liberty – aimed at the communal provision of at least some level of welfare and education to everyone is an egalitarian measure already taken for granted as legitimate by all except for the most extreme libertarians.

The complacency with which the extreme libertarian position is willing to treat the suffering of innocent people born into unfortunate circumstances, to most of us, seems *morally disturbing*. The priority placed on the protection of negative liberty (which is supposed to justify this complacency) also seems *theoretically fetishistic*. It is theoretically odd,

that is, to place so much weight on negative rights to freedom from interference without placing more weight on the positive rights to the more basic requirements in life. If negative freedoms are so important, then why shouldn't the positive freedoms that would enable one to exercise them be considered important too? The Nozickian perspective perhaps gains more plausibility if we limit our attention to contexts where everyone is fairly well off, and at least has her most basic requirements met.

Utilitarianism, as is well known, seems almost intuitively compelling, but also intuitively not quite right. Of course efficiency and aggregate well-being are legitimate social goals. Arguments in favor of promoting liberty, in fact, often appeal to the idea that doing so will promote aggregate utility. Many arguments in favor of the free-market, for example, are at least somewhat parasitic upon the idea that aggregate utility matters and will be maximized via *laissez-faire*. Despite the intuitive appeal of utilitarianism, however, the idea that we should give absolute priority to the promotion of aggregate utility is notoriously unsatisfactory if this implies paying disregard (or merely instrumental regard) to distributive justice and the protection of (widely accepted) basic human rights.⁹⁰

Each of the three main strands of political philosophy on offer seems to suffer fatal flaws. It seems inappropriate to embrace any one of these viewpoints in particular – and inappropriate to grant absolute priority to any one of the three values which they emphasize respectively. Rather than suffering philosophical and political dismay trying to choose between the three general viewpoints – and the values they favor – we should realize that we are not forced to do so. We might, that is, pursue a more pluralistic strategy: Rather than choosing any one of the three apparently legitimate social aims in particular, and giving general priority to it over the others, we might attempt to *strike a balance* between them.⁹¹

What we need, then, is a principled way of balancing the goals to promote equality, liberty, and aggregate utility. We thus need to think more

⁹⁰ See, for example, *Consequentialism and Its Critics*, ed. by Samuel Scheffler (New York: Oxford University Press, 1988). (Also, recall that for our purposes 'utilitarianism' refers specifically to views aimed at the *aggregative* maximization of well-being.)

⁹¹ This philosophical approach seems quite likely to be compatible with (and/or represent) both common sense and (at least part of) political reality.

about how to make trade-offs between these disparate social aims in situations of conflict.⁹² It would be quite difficult to say how exactly we should go about making such trade-offs. In the end, this question is perhaps best settled through democratic procedures. I will, however, offer a sketch of a suggestion that might capture commonly shared intuitions. I cannot here provide a well developed or thoroughly defended framework; but the following kind of view seems to arise naturally from debates in moral/political philosophy. The aim is to develop a framework informed by counterexamples that challenge the three central strands of political thought.

In some circumstances we might find it possible to formulate policy that seems likely to concurrently promote more than one goal, or perhaps even all three goals – and then our choice may be obvious. In other cases, however, we will find that the promotion of one goal would involve some cost with regard to the promotion of another. When such conflicts arise we must decide how much *weight* or *priority* to give the promotion of one goal as opposed to the other. Suppose that there are two policies to choose from – one which would maximally promote equality and one which would maximally promote aggregate utility. We would then need to ask how much weight should be given to each goal respectively. There may be reason to think that the weight or priority that should be given to the promotion of one goal compared to another should depend on the context in question.⁹³

How much of a decrease in inequality would be equivalent to how much of an increase in aggregate utility in its contribution to the ultimate good of society? We might not expect to find a simple conversion formula which tells us that a decrease of X units (of whatever is the measure) of inequality will be equal to an increase of Y units (of whatever is the measure) of aggregate utility in its contribution to the good of society. In some contexts we might find that a decrease of X units of inequality will contribute more to the good of society than would an increase of Y units of aggregate utility; but, in other contexts we might find that an

⁹² This general kind of idea is acknowledged implicitly or explicitly by Daniels in JHC, Griffin in WB, and Amartya Sen in *Inequality Reexamined* (Cambridge, MA: Harvard University Press, 1992). It has recently been expressed quite explicitly by Buchanan et. al. in CTC. See also, Amartya Sen, *Development as Freedom* (New York: Anchor Books, 1999).

⁹³ The spirit of the discussion that follows has been heavily influenced by discussions with, and particular suggestions of, Philip Kitcher.

increase of Y units of aggregate utility would contribute more towards the good of society than would a decrease of X units of inequality.⁹⁴ Similar things might be said when we make comparisons between equality and liberty.

Perhaps the importance, priority, or weight that should be given to the promotion of equality should depend not only on the magnitude or degree of inequality, but should also depend on the *nature* of the inequalities in question. It seems plausible to think that the promotion of equality should be given *greater* weight – i.e. will contribute more to the good of society – *to the degree* that:

- (1) there are groups of people living the *lowest*⁹⁵*quality* lives,
- (2) this is *preventable*,
- (3) there are *larger numbers* of people who avoidably live such lives, and
- (4) worst-off individuals cannot reasonably be considered to be *responsible* for their plight.

When we can reduce inequalities by substantially elevating the life quality of reasonably large numbers of innocent people living the lowest quality lives, then shouldn't we be more willing to sacrifice liberty and aggregate utility than otherwise would be the case?

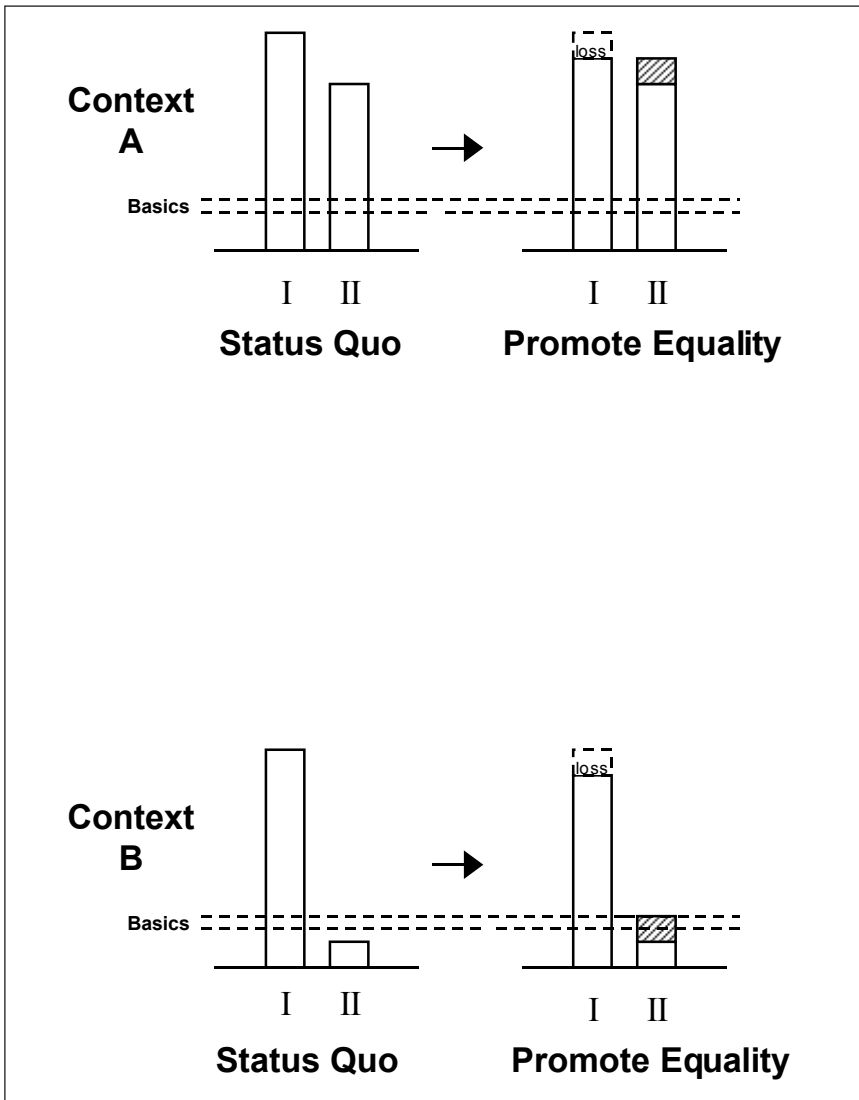
We might think that the promotion of equality should be given less weight, on the other hand, to the degree that

- (1) the groups in question already live high quality lives and have their most basic needs met (See Figure 1), or
- (2) equality can primarily only be promoted by decreasing the quality of the lives of certain groups (i.e. when inequalities can only be reduced by lowering the life quality of the not-so-bad-off rather than substantially elevating the life quality of the worst-off individuals) (See Figures 2 and 3), or
- (3) there are smaller numbers of persons in the not-so-well-off groups, or
- (4) the persons who are not-so-well-off are *responsible* for the fact that they are not-so-well-off.

⁹⁴ Where X and Y are constants.

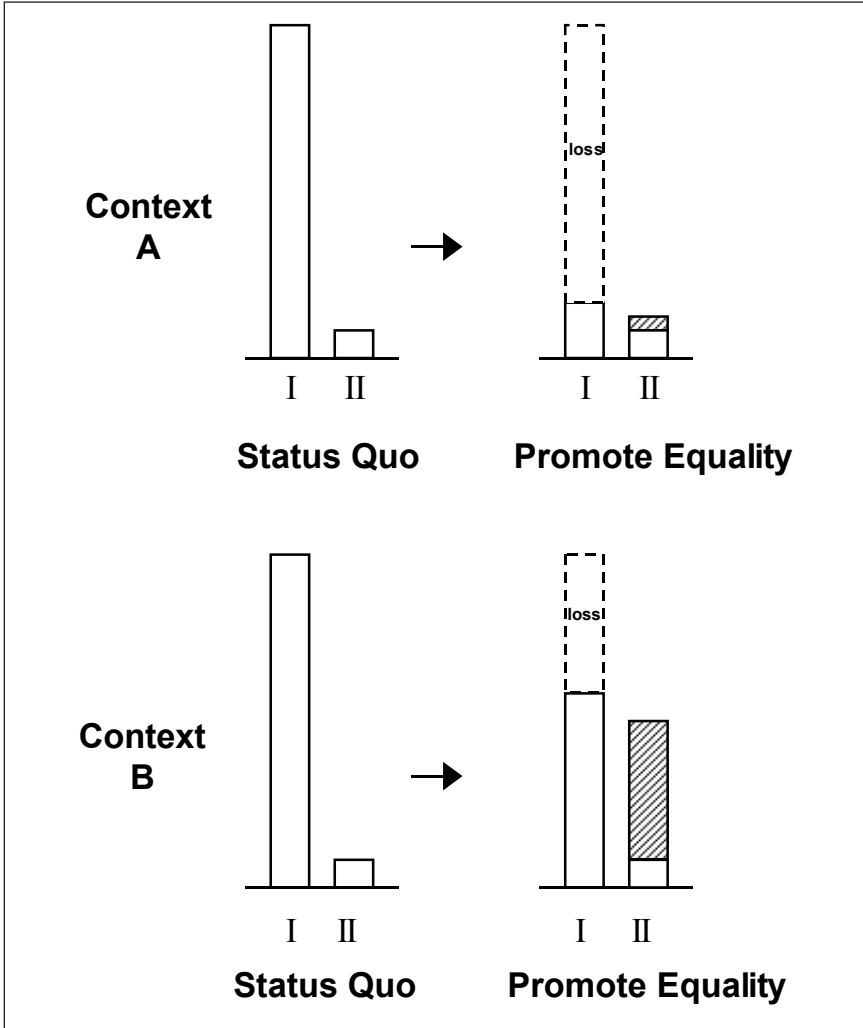
⁹⁵ On an absolute (rather than relative) scale.

Figure 1



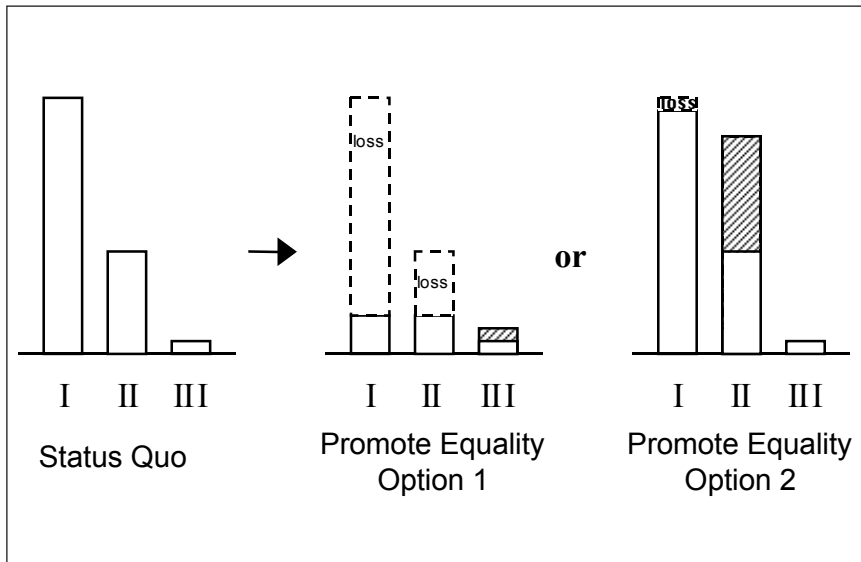
Equality and Basic Needs. Above are shown the comparative levels of life quality for two groups in two contexts. In Context A both groups are originally quite well off in comparison with Context B where the members of Group II initially live low quality lives and do not have their basic needs met. The promotion of equality seems less important in Context A than in Context B.

Figure 2



Leveling Up vs. Down (two groups). Above are shown the comparative levels of life quality for two groups in two different contexts. In Context A the promotion of equality is primarily only achievable by decreasing the life quality of members of Group I. The life quality of members of Group II cannot be substantially elevated. In Context B, however, the promotion of equality is to a greater extent achievable by elevating the life quality of members of Group II. The goal to promote equality should be given less weight in Context A.

Figure 3



Leveling Up vs. Down (three groups). The comparative levels of life quality for members of three groups are shown above. In this context it is possible to promote equality in two ways. The first option would decrease inequalities primarily by lowering the life quality of members of groups I and II. The quality of life of members of group I would be only slightly elevated. The second option would decrease inequality primarily by elevating the life quality of members of Group II. Group I would suffer only a minimal loss. We should choose, therefore, option 2.⁹⁶

To the degree that decreases in inequality would require reductions rather than improvements in life quality, to the degree that they would be focused on improving the situation of persons who are responsible for their misfortunes, and to the degree that most everyone is already quite well-off and has her most basic requirements met, then we should perhaps be less willing to make sacrifices in aggregate utility and liberty than otherwise would be the case.

⁹⁶ This diagram was suggested by Philip Kitcher.

If this rough (and admittedly sketchy) account seems correct, then it would appear that equality is especially important in the context of health care, where the condition of many innocent people is presumably to a large extent improvable. One might argue that liberty, on the other hand, is also especially important in the context of eugenics insofar as we place a very high value on *reproductive liberty* in particular. I am not convinced that this kind of objection is terribly convincing, however. It might be true that the freedom to make one's own choices about whether or not to reproduce is a centrally important basic human right; but, surely the freedom to employ limited medical resources to *design* the traits of one's offspring (beyond certain limits anyway) is not so basic or tremendously important.⁹⁷ In addition, as I have already mentioned, there is reason to think (1) that some of the interventions we have discussed would be immoral, unfair, and/or somewhat abusive to children and (2) that the liberty to pursue them should therefore count for less.

In any case, the restriction of liberty need not be absolute. Some kinds of genetic interventions would likely be more socially problematic than others, so dividing them into two and only two groups – i.e. (1) those that should be prohibited and (2) those that should be permitted – might be the wrong way to proceed. Discouragement can come in degrees. We might, for example, restrict the public funding of certain kinds of research and impose something like a vice tax on certain kinds of interventions. The implementation of procedural requirements might also make certain kinds of interventions more difficult to come by. (Which is not to say, necessarily, that some kinds of interventions should not be more strongly discouraged.) With regard to a vice tax, the funds accrued could be used for redistributive purposes in response to egalitarian concerns.⁹⁸

⁹⁷ This point is made by at least some staunch defenders of procreative liberty, such as Robertson in CC. He denies that procreative liberty includes the right to selectively enhance the traits of offspring. The reasons why reproductive freedom is important, according to Robertson, do not apply to enhancement.

⁹⁸ Peter Singer suggested the idea of using such funds for redistributive purposes to me in conversation.

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- 1 Carl Friedrich Gethmann, Armin Grunwald, Technikfolgenabschätzung: Konzeptionen im Überblick, 9/96, 2. Aufl. 7/98
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