The Ethics of Inheritable Genetic Modification

A Dividing Line?

"For who is harmed by the genetic supermarket? The parents are not harmed by having the healthier, handsomer, and more intelligent children that they want. Are the children harmed?"

From the Foreword by Peter Singer: *Shopping at the Genetic Supermarket*.

These provocative questions, and their possible answers from biomedical science, ethics, sociology and philosophy, are the subject of this searching investigation. In seeking to establish whether inheritable genetic modification is the new dividing line in gene therapy, the editors, themselves representing clinical medicine, public health and biomedical ethics, have brought together a distinguished team of scientists and scholars to address the issues from the perspectives of biological and social science, law and ethics. Their purpose is to consider how society might deal with the ethical concerns raised by inheritable genetic modification, and to re-examine prevailing views about whether these kinds of interventions will ever be ethically and socially justifiable. The book also provides background to define the field, and discusses the biological and technological potential for inheritable genetic modification, its limitations and its connection with gene therapy, cloning, and other reproductive interventions.

For scientists, bioethicists, clinicians, counsellors and public commentators, this is an essential contribution to one of the critical debates in current genetics.

John E.J. Rasko holds a personal chair in the Faculty of Medicine, Centenary Institute, University of Sydney and practises as a hematologist at Royal Prince Alfred Hospital, where he is Director of Cell and Molecular Therapy.

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"This thoughtful and stimulating book will excite a vision of the likely future of the human species or give you nightmares about the brave new world. It is timely, readable and very important. Despite the puzzles it presents, the book affirms that human intelligence can think these issues through and come to rational and moral decisions about them. The book shows how exciting it is to live in an age when technology, moral philosophy and values are suddenly the stuff of politics and a global civic debate. The puzzles will not go away because we ignore them. To look the other way is to make a decision to do nothing."

Justice Michael Kirby, AC CMG, Justice of the High Court of Australia and Member of the International Bioethics Committee of UNESCO.

"The time to think clearly about germline gene therapy is now. The distinguished group of scholars contributing to this volume have much to offer readers who want to reflect seriously on animal research in genetic modification, and on the prospect of human germline genetic alteration."

Thomas H. Murray, PhD, President, The Hastings Center, New York, U.S.A.

"I think this is a rather wonderful collection. It is put together exactly as these things should be, but rarely are – with a good mix of science, social science, law, and ethics. Anyone seriously interested in the issues around germline gene therapy (inheritable genetic modification, human genetic engineering) will find this the most helpful and insightful resource. I think any of these papers could be published in a good peer-reviewed journal. There is no wasted material or lightweight material. Ethicists may find some of the science hard going, but there is nothing there that cannot be understood (as I judge it!) and ethicists ought to understand the scientific issues properly before wading in to pronounce on the ethics."

Richard Ashcroft, Reader in Biomedical Ethics, Imperial College, London, U.K.

"This is a very high quality work in at least two senses. First, it is scientifically sophisticated. This is important, because there is too much discussion of the ethics of genetics that is not accurately anchored in an understanding of the scientific situation of research. Second, it is conceptually quite advanced. I could easily see using this text in a graduate seminar. The work coheres very well, which is often missing in some edited works."

George Agich, Department of Bioethics, Cleveland Clinic, Cleveland, U.S.A.

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JEJR: To three generations of my tolerant family connected by shared genes and joy: Helen, Simone, Nathalie, and Adam.

GMO'S: To my beloved courageous parents, Margaret and James, who have cherished me boundlessly. To Dermot, Emmet, Caoimhe, Eimear, and Eoin who make my world shine.

RAA: To my extended family, near and far.

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Foreword: shopping at the genetic supermarket

Peter Singer

> Consider … the issue of genetic engineering. Many biologists tend to think the problem is one of *design*, of specifying the best types of persons so that biologists can proceed to produce them. Thus they worry over what sort(s) of person there is to be and who will control this process. They do not tend to think, perhaps because it diminishes the importance of their role, of a system in which they run a "genetic supermarket," meeting the individual specifications (within certain moral limits) of prospective parents … This supermarket system has the great virtue that it involves no centralized decision fixing the future of human type(s).[1]

The genocide of deaf culture?

Robert Nozick's genetic supermarket has arrived on the wings of angels brought to us by Ron Harris, the founder of ronsangels.com, "the only website that provides you with the unique opportunity to bid on eggs from beautiful, healthy, intelligent women."[2] How should we respond to this and other options that will soon be beckoning? To assist us in answering these questions, I shall begin by considering a technique that has been with us for some time, but that has the effect of changing the nature of children. Understanding the basis on which this technique can be supported may help us to grapple with the more difficult question of what we should do about newer options that also change the nature of our children. It is not, however, my aim here to deal with all the objections that could be urged against these options. My purpose is the narrower one of developing a clear understanding of the central values at stake.[3]

In the deaf community there has, for some years now, been a debate over attempts to alleviate some of the effects of deafness by the provision of cochlear ear implants in children. Although this is not a technique that makes use of genetics, the issues raised are in many respects similar to those that would be raised by the discovery of a genetic marker for congenital deafness. Cochlear implants do not restore normal hearing; instead they transform speech and other sounds into electrical impulses, and transmit these impulses to auditory nerve fibers in the inner ear. When implanted in children below the age of 3 years, they make it possible for them to grow up "hearing" speech and thus to be able to take part in the speaking community as if they could hear.[4] In children who have been deaf from birth, the implants are less successful when implanted at a later age.

The scientists who first developed cochlear implants assumed that they would be enthusiastically embraced by the deaf community, and especially by the parents of congenitally deaf infants. Some parents of deaf children do have exactly this response. But others have a very different response, as the following statement indicates:

> THE GENOCIDE OF DEAF CULTURE
> FACT: The law says that genocide is the destruction of an ethnic group.
> FACT: The law says that an ethnic group is "a set of individuals whose identity is distinctive in terms of common cultural traditions or heritage."
> FACT: Deaf people are "a set of individuals whose identity is distinctive in terms of common cultural traditions or heritage."
>
> Cochlear implants are an attempt to eliminate the trait of Deafness.
>
> Eliminating the trait of Deafness will destroy "a set of individuals whose identity is distinctive in terms of common cultural traditions or heritage." (That "set" of individuals will no longer exist.)
>
> THEREFORE – COCHLEAR IMPLANTS ARE GENOCIDE.[5]

Though extreme in its language, this is not an isolated point of view. A significant number of deaf parents are refusing to allow their deaf children to have the implants. They argue that the implants will cut them off from the Deaf community and from Deaf culture, which survives because of its distinctive language and its separation from the world of hearing people. The Deaf community expresses the idea that it has a distinctive culture by the use of capitalization. To be Deaf is to be part of a culture (like being French or Jewish) whereas to be deaf is to be unable to hear. As one parent said: "If somebody gave me a pill to make me hear, would I take it? No way. I want to be deaf."[6]

Something similar is happening among people with the short, stocky body shape known as achondroplasia, or dwarfism, since the discovery of the gene for this condition raised the prospect of prenatal diagnosis and selective termination. Little People of America, an association for those with short stature, has issued a position statement asserting that some of its members fear "genetic tests such as these will be used to terminate affected pregnancies and therefore take the opportunity for life away from children such as ourselves and our children." In response, they remind the rest of us that they are productive members of society who "face challenges, most of them are environmental (as with people with other disabilities)" and "value the opportunity to contribute a unique perspective to the diversity of our society …" They have "a common feeling of self-acceptance, pride, community and culture."[7]

For a final example, consider the contrasting views taken of Down syndrome. In both the U.S.A. and the U.K., at least 90% of women tested will terminate a pregnancy after prenatal diagnosis shows that they are carrying a child with Down syndrome.[8] Yet others have described people with Down syndrome as "stars in an increasingly materialistic world," "without exception magic children," and capable of "unconditional love." One parent has said:

> Those of us with a Down syndrome child (our son, Robert, is almost 24) often wish that all our children had this extraordinary syndrome which deletes anger and malice, replacing them with humour, thoughtfulness, and devotion to friends and family.[9]

Consistent with this view, Diane Beeson has opposed present practices of prenatal diagnosis on the grounds that:

> The central assumption behind the deployment of prenatal diagnosis is that life with a disability is not worthwhile and is primarily a source of suffering … From a disability-rights perspective, prenatal testing for fetal anomalies gives a powerful message that we seek to eliminate future persons with disabilities, fails to recognize the social value of future persons with disabilities, and conveys a devaluation of those now living with disability … By focusing so many resources on the elimination of potential persons with disability, we are drifting toward a eugenic resurgence that differs only superficially from earlier patterns. In the process we are seriously distorting the historical purpose of medicine as healing. We are creating a society in which disability is becoming increasingly stigmatized, with the result that human imperfection of all kinds is becoming less tolerated and less likely to be accepted as normal human variation.[10]

The cochlear ear implant, the discovery of the gene for achondroplasia, and the use of selective abortion to prevent the birth of children with Down syndrome serve to test the outer limits of our support for the politics of equality and diversity. We say that we believe that all humans are equal, and we value diversity. Does our belief in equality go so far that we hesitate to say that it is better not to have a disability than to have one? Does the value we place on diversity mean that we should oppose any measures that might weaken Deaf culture, or reduce the number of people born with Down syndrome or achondroplasia? Should we stop the use of public funds for prenatal diagnosis or cochlear ear implants?

To assess these criticisms of prenatal diagnosis, it will help to think for a moment about two related questions. First, how important is it to most parents to give their child the best possible start in life? Second, how serious a reason does a woman need in order to be justified in ending her pregnancy?

The answer to the first question is that, for most parents, giving their child the best possible start in life is extremely important. The desire to do so leads pregnant women who have smoked or drunk heavily to struggle to kick the addiction; it sells millions of books telling parents how to help their child achieve her or his potential; it causes couples to move out to suburbs where the schools are better, even though they then have to spend time in daily commuting; and it stimulates saving so that later the child will be able to go to a good college.

The answer to the second question must begin with the fact that, in accordance with the decision in *Roe v. Wade*, a woman in the U.S.A. can, in the first and second trimesters, or at least until the fetus is viable, terminate her pregnancy for any reason whatsoever. This does not, of course, mean that she is ethically justified in doing so. Some say that she is *never* ethically justified in terminating her pregnancy, and others that she is justified in doing so only to save her own life, or in cases of rape and incest. Beeson and many others who are concerned about prenatal diagnosis, however, do not rest their argument on opposition to abortion. So rather than argue this point in detail here, I shall simply state that, as I have argued elsewhere, I do not think that a fetus is the kind of being that has a right to life.[11] Hence it is not hard to justify terminating a pregnancy. For example, suppose that a couple plan to have children, but an unplanned pregnancy has occurred before they feel ready to do so – let us say that at present they are sharing a studio apartment and cannot afford anything larger, but in 5 years they will be able to move to a larger home. In my view, they would not be acting unethically if they decide to obtain an abortion.

Now think about a couple who are told that the child the woman is carrying will have a disability, say Down syndrome. Like most parents, the couple think it important to give their child the best possible start in life, and they do not believe that having Down syndrome is the best possible start in life. Is it true that this couple must be making the assumption that "life with a disability is not worthwhile and is primarily a source of suffering"? There is no more reason to believe that these parents make that assumption, than there is to believe that parents who terminate a pregnancy because they cannot afford a larger apartment believe that "life as a child in one room with one's parents is not worthwhile and is primarily a source of suffering." In both cases, all that the parents need assume is that it would be *better* to have a child without Down syndrome, or to have a child who can have a room of her own. After all, in neither case are the parents choosing whether or not to have a child at all. They are choosing whether to have *this* child or another child that they can, with reasonable confidence, expect to have later, under more auspicious circumstances.[12]

Thus it is possible to justify abortion in these circumstances while accepting Beeson's claims that people with congenital disabilities "often achieve the same high levels of life satisfaction as non-disabled persons." A couple may reasonably think that "often" is not good enough. They may also accept – as I do – that people with Down syndrome often are loving, warm people who live happy lives. But they may still think that this is not the best they can do for their child. Perhaps they just want to have a child who will, eventually, come to be their intellectual equal, someone with whom they can have good conversations, someone whom they can expect to give them grandchildren, and to help them in their old age. Those are not unreasonable desires for parents to have.

What of the "powerful message that we seek to eliminate future persons with disabilities" that Beeson tells us is sent by prenatal diagnosis and abortion to people with disabilities? Her concern seems highly selective. She has surely noticed that every bottle of alcoholic beverage sold in the U.S.A. bears the words:

> GOVERNMENT WARNING: (1) ACCORDING TO THE SURGEON GENERAL, WOMEN SHOULD NOT DRINK ALCOHOLIC BEVERAGES DURING PREGNANCY BECAUSE OF THE RISK OF BIRTH DEFECTS.

Does not that warning – much more visible to ordinary Americans than prenatal diagnosis – send out a “powerful message” that we should prevent the birth of children with defects? What about the message sent by programs that immunize girls against rubella? Is anyone seriously proposing to withdraw such government warnings, or end such immunization programs?

The Surgeon General’s desire that women should not, through alcohol consumption, give birth to people with disabilities, does not in any way imply that he has less concern for the interests of people living with disabilities than he has for those without disabilities. As I have argued elsewhere, we can and should have equal consideration for the interests of all beings that have interests.[13] Although this is, in my view, the fundamental basis of equality both within our own species and between our species and beings of other species that have interests, for that very reason it may not satisfy the advocates of people with disabilities. But what other defensible sense can we give to the idea of equal worth?

Ani Satz has argued that measures to prevent the birth of people with disabilities are compatible with regarding people with disabilities as having equal worth, because these practices do not imply any judgments about the value of life with a disability:

> The obese are not devalued by overweight individuals who join Jenny Craig on the belief that obesity detracts from quality of life … Organizations actively try to prevent workplace, automobile, household, and sporting accidents, contributors to disabling conditions. These precautions do not judge the moral worth of disabled individuals. To argue otherwise would be to assume, reductio absurdum, that industrial workers or rock concert-goers who wear earplugs are indicating that membership in the deaf community would be of less value than membership in the hearing community.[14]

We should distinguish two different kinds of judgment that are in danger of being conflated in this passage: judgments about “the moral worth of disabled individuals” and judgments about the general quality of life, or even the value of life, with a given disability. The moral worth of individuals is not dependent on their abilities, except where they have very limited intellectual capacities; but the *reductio* with which Satz ends her argument in the passage quoted above is, in my view, not at all *absurdum*. If I take precautions to prevent deafness, I do so on the grounds that I think life with the ability to hear is, in general, better than life without the ability to hear. Is this perhaps just because I have been able to hear for the first 50 years of my life, and would have difficulty in making the adjustment to being a member of the Deaf community? That may be part of the story, but it is not the whole story. Imagine that shortly after the birth of our child, a doctor tells us that it has an ear infection, which unless treated will cause deafness. Fortunately, the doctor adds, there is an antibiotic that will clear up the infection in a few days. Would we contemplate for a moment saying: "Wait a minute, Doctor, we need to think about whether we value membership of the hearing community more highly than membership of the Deaf community"? Obviously not: but the reason we would not is not that we are judging membership in the Deaf community to be less desirable than membership in the hearing community, but because we take it for granted that it is less desirable.

To make this point correctly, we need to be very precise in our language. Jonathan Glover has said: "Medical treatment presupposes that health is better than sickness, but those who believe in it are able to treat sick people as their equals."[15] That is true, of course, but the sense in which the sick are our equals needs to be specified. As Glover himself has pointed out, if we do not have enough resources to treat all the sick, we have to decide who to treat. He has supported the view that in making this decision we should take into account both the expected life-span of the sick person, and the quality of that person's life, at least when it is clear that it is not worth living.[16] So while we treat the sick as our equals, socially, morally, and politically, when it comes to tough decisions about saving their lives, some of the sick are less equal than others.

The same point applies to a claim made by Allen Buchanan:

> We devalue disabilities because we value the opportunities and welfare of the people who have them – and it is because we value people, all people, that we care about limitations on their welfare and opportunities. We also know that disabilities, as such, diminish opportunities and welfare, even when they are not so severe that the lives of those who have them are not worth living. Thus, there is nothing incoherent or disingenuous in our saying that we devalue the disabilities and wish to reduce their incidence *and* that we value all *existing* persons with disabilities – and value them equally to those who are not disabled.[17]

The argument of this passage is compelling, until we get to the word "equally" in its final clause. Suppose that there are two infants in the neonatal intensive care unit, and we have the resources to save only one of them. We know nothing about either of them, or their families, except that one infant has no disabilities, and the other has one of the disabilities that Buchanan mentions – a disability that will limit the child's "welfare and opportunities." In these circumstances, it seems rational, for precisely the reasons Buchanan gives, to save the life of the child without disabilities – but this shows that there is a clear sense in which we do not value both children equally.[18]

In our very commendable concern to give equal consideration and respect to every member of our community, and to avoid the least appearance of bias against those with disabilities, we are in danger of going to what is a truly absurd conclusion: that the abilities we have – to hear, to see, to walk, to speak, to understand, and reflect upon information given to us – are of no value. We must not deny the obvious truth that most people, disabled or not, would prefer to be without disabilities, and would prefer to have children without disabilities. There may be some members of the Deaf community and some people with achondroplasia who disagree, and of course there are many people with intellectual disabilities who are incapable of expressing an opinion, but to the best of my knowledge advocates for people in wheelchairs accept that they would be better off if they could walk; at least I am not aware of them ever calling for governments to stop wasting their taxes by supporting research into ways of overcoming paralysis.

If the use of cochlear implants means that there are fewer Deaf people, is this "genocide"? Does our acceptance of prenatal diagnosis and selective abortion mean that we are "drifting toward a eugenic resurgence that differs only superficially from earlier patterns"? If the use of the term "genocide" is intended to suggest a comparison with the Holocaust, or Rwanda, it overlooks the crucial fact that cochlear implants do not have victims. On balance, it seems that they benefit the people who have them; if this judgment is contestable, it is at least not clear that they are worse off for having the implant. Imagine a minority ethnic group in which all the parents reach separate decisions that their children will be better off if they marry a member of the majority group, and hence urge them to do so. Is this encouraging "genocide"? If so, it is genocide of such a harmless form that the term should be divorced from all its usual moral associations.

Similarly, if Beeson's reference to "earlier patterns" of eugenics is a veiled reference to Nazi policies that led to the murder of tens of thousands of disabled people, she is guilty of overlooking the vast moral gulf between what happened then and what is happening now. No state is ordering anyone's death; no one who wants to go on living is being murdered; no children whose parents want them to survive are being killed. The Nazi program was based on the interests of the *Volk*, and utter indifference to the interests of the individuals most involved, including both the victim and his or her family. Even if Beeson has in mind not Nazism but American eugenics in the first half of the present century, the differences are profound. That eugenics movement used compulsory sterilization of criminals, introduced an immigration policy based on belief in the superiority of the Northern European races, and became, as Dan Kevles puts it, a facade for "advocates of race and class prejudice, defenders of vested interests of church and state, Fascists, Hitlerites, and reactionaries generally."[19] There is no comparison between such state-sponsored, coercive policies, and the use of prenatal diagnosis and selective abortion by couples who choose to avail themselves of this option.

Even if cochlear implants are not genocidal, and prenatal diagnosis combined with selective abortion is not at all like past eugenic practices, they might be considered wrong. But consider the following principle:

> For any condition X, if it would be a form of child abuse for parents to inflict X on their child soon after birth, then it must, other things being equal, at least be permissible to take steps to prevent one's child having that condition.

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I propose this not as a self-evident truth, nor as a derivation from any particular moral foundation, but as something that might appeal to many people, irrespective of the foundations of their moral views. The "preventive principle," as I shall call it, requires us to reject the view that the fact that something is the outcome of the genetic lottery is enough to make it right. Why would anyone believe that? Only, I suggest, if somewhere deep down, they think of the genetic lottery as no lottery at all, but rather the workings of a divine Providence. If that were the case, then we might think it wrong to interfere with the natural order of things. But let us put that view aside, for lack of supporting evidence, and assume that the genetic lottery really is a lottery. Then, if there is no moral barrier that says we must not interfere with the way things are, the preventive principle seems sound.

Now let us apply the preventive principle to the cases we have been considering. Suppose that a Deaf couple give birth to a daughter who can hear normally. As they value very highly their membership of the Deaf community, and they fear that their daughter will not be a part of the Deaf community, they make arrangements with a sympathetic surgeon to destroy the child's hearing. The operation, performed under general anesthesia, causes the child no pain, but achieves its goal. The child will now be permanently deaf. Is this a case of child abuse? I suggest that it is. What the parents have done ensures that their child will never be able to hear Beethoven, or a babbling brook, or listen to lectures and debates delivered in spoken languages, except in translation. The child will also be at a disadvantage in countless other ways in getting through life. Admittedly, we must also take into account the benefits that the child will get from being part of the Deaf community, especially when being a part of the Deaf community means that the child grows up in the community to which her parents already belong. But that does not justify what they have done.

If you respond to this example in the way I do, and accept the principle I stated above, it follows that it must at least be permissible, other things being equal, for parents to take steps to ensure that their child will not be deaf. This argument does raise the difficulty of where to draw the line. Strictly, I could avoid this difficulty by pointing out that the preventive principle simply says that prenatal diagnosis and selective termination are permissible if they are a way of avoiding a condition that it would be child abuse to inflict on one's child. So the question could be answered with another question: would it be child abuse for a couple to ensure that their child would be a homosexual? In whatever way you answer that question, you should also answer the question whether the couple should be allowed to terminate a pregnancy on the basis of prenatal diagnosis that the child will be homosexual.

I will, however, say a little more on this topic. Andrew Solomon has written:

> Being Deaf is a disability and a culture in modern America; so is being gay; so is being black; so is being female; so even, increasingly, is being a straight white male.

> So is being paraplegic, or having Down syndrome. What is at issue is which things are so "cultural" that you would not think of "curing" them, and which things are so "disabling" that you must "cure" them – and the reality is that for some people each of these experiences is primarily a disability experience while for others it is primarily a cultural one.[20]

Is being black a disability? Is being gay a disability? The racial case is easy to distinguish from the case of deafness, because although it may be true deaf people must contend with some socially constructed barriers, it is also indisputable that they lack the ability to hear. African-Americans do not lack any ability that people of other races possess. There are only patterns of discrimination or prejudice. Hence being black is not a disability.

What about being gay? While gays and lesbians lack the ability to be sexually attracted to the opposite sex, straight people lack the ability to be sexually attracted to their own sex. This line of argument implies that unless we are bisexual we are suffering from an erotic disability. Is it possible to argue that homosexuals are disabled because they cannot enjoy "normal" sexual intercourse, involving a penis and a vagina? That would require an argument to the effect that this mode of sexual intercourse is superior to others that are available to gays and lesbians, and I do not know how, in the absence of an argument from "natural law," such an argument could be grounded. Nor do I think that an argument based in natural law would be satisfactory.[21]

Stephen Macedo has suggested a more plausible ground for seeing homosexuality as a disability:

> Even if we were to wipe away all the prejudice in the world and even if homosexuals had all of the same opportunities as heterosexuals – including marriage and adoption – homosexuality would still be a misfortune: a misfortune resembling marriage to a sterile partner. Sterility is properly regarded as a misfortune (though *not*, it should be stressed, an especially grave one) and homosexuality can likewise be regarded as one, insofar as some of the great goods of marriage – the shared participation in pregnancy and new life – are not fully available to homosexual couples.

In a footnote, Macedo adds:

> … because some gays and lesbians are likely to take (unjustified, I believe) offense on this score, I should emphasize that to the extent that there is misfortune here, it is a misfortune that I share.[22]

If infertility is a disability, it is one that seems in principle soluble for lesbians at least, once we learn how to mix gametes from same sex partners and inject them into a denucleated egg. Male homosexuals would still have to find a surrogate willing to carry the child for them. But perhaps at present, infertility within the relationship does mean that homosexuality remains a disability, though as Macedo says, not an especially grave one.

Shopping for beauty and brains

In February 1999, advertisements in newspapers in some of America's most prestigious universities offered \$50,000 to an egg donor who was athletic, had scored extremely well in scholastic aptitude tests, and was at least 5′10″ tall.[23] Later in the same year Ronsangels.com opened with a splash of publicity. It featured eight "models," offering "beauty and brains to the highest bidder." Visitors to the site can see a photograph of each model, together with her vital statistics, the ages of her mother and grandmother, a brief biography, and an indication of the minimum bid required to obtain an egg, which ranges from \$15,000 to \$90,000. To provide some gender balance, the site also has a "sperm auction" featuring a well-muscled man in a brief bathing suit. His sperm is available for a minimum bid of \$15,000.

The "Ron" in Ron's Angels is Ron Harris, no mere egg and sperm auctioneer but also something of a philosopher, as an "Editorial" that he has added to the site reveals:

> It is human nature to strive to improve everything. From fruits and vegetables, to medicine, and even to plant and animal genes, we modify everything to produce the best we can. Now, modern science presents the miraculous possibility of improving ourselves. Currently, our means is *in vitro* fertilization, wherein your eggs or sperm are combined with the eggs or sperm of superior genetic background … Of course, there are no guarantees that the children produced from superior genes combined with your own will result in similarly superior children – but our striving reflects the determination to pass every advantage possible along to our descendants.
>
> It is not our intention to suggest that we make a super society of only beautiful people. This site simply mirrors our current society, in that beauty usually goes to the highest bidder. There are of course many other attributes that impart an advantage in our increasingly competitive society: intelligence, talent, personality, and social skills … This is the first society to truly comprehend how important beautiful genes are to our evolution. Just watch television and you will see that we are only interested in looking at beautiful people. From the network anchors, to supermodels that appear in most advertisements, our society is obsessed with youth and beauty. As our society grows older, we inevitably look to youth and beauty … If you could increase the chance of reproducing beautiful children, and thus giving them an advantage in society, would you?
>
> Any gift such as beauty, intelligence, or social skills, will help your children in their quest for happiness and success.

Some may, admittedly, have their suspicions about ronsangels.com. The models and bids went unchanged for months. Bids were listed, but none exceeded the specified minimum. When I began work on this paper, the auctions had closing dates, some of which had already passed. Subsequently the closing dates disappeared from the site, and later the models offering their eggs became accessible only to subscribers. A clue to why this may be the case could be found in a link, no longer present, that once took you, in two clicks, to another Ron Harris site, where the interest in women was explicitly sexual rather than reproductive. Another click took you to Harris's very candid advice on "how to make money with an adult web site." Prominent here is the injunction to: "Get traffic, any way you can! … do whatever you have to do to get traffic. Traffic is the e-porn industries' currency. The more you have the more money you will make."

Even if his egg sales are just a way of getting people to visit his porn site, Ronsangels.com is a test case for the view that the market knows best. The U.S.A. is exceptional among the industrialized nations in allowing a free market in human gametes. There are already other commercial operations selling gametes, and there can be little doubt that, unless such activities are prohibited, there will soon be more, offering couples ever more technologically sophisticated ways of improving their odds of having tall, slim children with above-average beauty, health, intelligence, and athletic, musical, and artistic talent.

There are many grounds on which we might find the ideas behind Ron's Angels distasteful, or worse. We could argue that they indicate a warped sense of how to think about one's future child, a sense shaped by a society that puts too high a premium on beauty and success. That may be, but what should we do about it? There is credible evidence suggesting that many of the things that parents look for in their children have a genetic component: physical appearance, including height and body shape, intellectual aptitude, many athletic skills, and longevity.

As we have already noted, parents already do their best to influence the environmental factors that undoubtedly also play a part in shaping these characteristics. They can now influence genetic factors as well as environmental ones, in one of three ways. By using *in vitro* fertilization, they can have the embryo screened before implantation; they can use prenatal diagnosis and selective abortion; and they can obtain eggs, sperm, or embryos from people they regard as genetically superior. All of these techniques have disadvantages. The first is costly, inconvenient, and does not always lead to a pregnancy. The second involves an abortion, which is not a pleasant procedure for a woman, irrespective of her views about the moral status of the fetus. The third means that the child will not be a biological child of the couple, but will carry the genes of at least one other person. Probably within the next two decades, however, we will have a fourth option: genetic enhancement of our own embryos.

Harris asks: "If you could increase the chance of reproducing beautiful children, and thus giving them an advantage in society, would you?" He is doubtless correct in his assumption that most of us will answer that question affirmatively. We go to so much effort to shape our children's environment to give them the best possible start in life, that once we gain the ability to select their genes, we are unlikely to reject it. What might restrain some potential parents are factors like risk, cost, and whether the children will still be their own children, in a biological sense. The last of these has up to now been a constraint on the number of couples

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willing to use donor eggs and sperm. But our rapidly increasing knowledge of human genetics will soon make it possible for us to have children who are genetically our own, and yet who are genetically superior to the children we would produce if we left it to the random process of normal reproduction. This will come initially through increasingly sophisticated genetic screening of *in vitro* embryos. Before very long, however, it will become possible to insert new genetic material safely into the *in vitro* embryo. Both of these techniques will enable couples to have a child whose abilities are likely to be superior to those offered by the natural lottery but who will be "theirs" in the sense of having their genes, not the genes of only one of them, or the genes of a third person, except (when genetic modification rather than simply genetic selection is used) to the extent necessary to produce the specific desired characteristics.

Many people say that they accept selection against serious diseases and disabilities, but not for enhancement above what is normal. There is, however, no bright line between selection against disabilities and selection for positive characteristics. From selecting against Huntington disease it is no great step to selecting against genes that carry a significantly elevated risk of breast or colon cancer, and from there it is easy to move to giving one's child a better than average genetic health profile. Similarly, if almost all of us are willing to abort a fetus that has Down syndrome, most of us will also be willing to abort one with genes that indicate other intellectual limitations, for example genes that correlate with IQ scores below 80. But why stop at 80? Why not select for at least average IQ? Or a bit above average? The existing market in human eggs suggests that some people will also select for height, which in turn correlates to some extent with income. Then, as Harris points out, there is beauty, and we will not reject the opportunity to ensure that our children are beautiful.

Choices, private and public

How should we react to the scenario that extrapolates beyond Ron's Angels? We could treat it as a slippery slope argument, one that proves that we must act now to stop prenatal screening, because otherwise we are heading toward a nightmarish future in which children are made to order, and wanted for their specifications, not loved for what they are. But taking the argument that way forces us either to reject something – current practices of prenatal diagnosis – that most people regard as a great boon, or to show that we can stop somewhere short of permitting the choices I have described. Neither is a convincing option. A second possibility is to say that the future just sketched is no nightmare, but a better society than we now have, one full of healthier, more intelligent, taller, better-looking – perhaps even more ethical? – people. There is, therefore, no "slippery slope," because the slope does not lead down to an abyss, but upward to a higher level of civilization than we have achieved so far.

Nozick's words cited at the start of this essay suggest a third possible answer: it is not up to us to judge whether the outcome of this process will be better or worse. In a free society, all we can legitimately do is make sure that the process consists of freely chosen individual transactions. Let the genetic supermarket rule – and not only the market, but also altruistic individuals, or voluntary organizations, anyone who wishes, for whatever reason, to offer genetic services to anyone who wants them and is willing to accept them on the terms on which they are offered.

That the U.S.A. should allow a market in eggs and sperm which goes some way towards fulfilling Nozick's prophecy is no accident. In other countries a practice that threatens to turn the child of a marriage into an item of commerce would meet powerful opposition from both conservative "family values" politics and from left of center groups horrified at the idea of leaving to the market something as socially momentous as the way in which future generations are conceived. In the U.S.A., however, that leftist attitude is restricted to groups on the margins of political life, and the conservatives who dominate Congress show their support for family values merely by preventing the use of federal funds for ends that they dislike; in all other respects, they allow their belief that the market always knows best to override their support for traditional family values.

There are strong arguments against state interference in reproductive decisions, at least when those decisions are made by competent adults. If we follow John Stuart Mill's principle that the state is justified in interfering with its citizens only to prevent harm to others, we could see such decisions as private ones, harming no one, and therefore properly left to the private realm.[24] For who is harmed by the genetic supermarket?

The parents are not harmed by having the healthier, handsomer, and more intelligent children that they want. Are the children harmed? In an article on the practice of buying eggs from women with specific desired characteristics like height and intelligence, George Annas has commented:

> What's troubling is this commodification, this treating kids like products. Ordering children to specification cannot be good for the children. It may be good for adults in the short run, but it is not good for kids to be thought of that way.[25]

But to say that this is "not good" for these children forces us to ask the question: not good compared with *what?* The children for whom this is supposed not to be good could not have existed by any other means. If the egg had not been purchased, to be fertilized with the husband's sperm, that child would not have been alive. Is life going to be so bad for this child that he or she will wish never to have been born? That hardly seems likely. So on one reading of what the standard of comparison should be, it is clearly false that the purchase of these eggs is not good for the kids.[26]

Suppose that we read "not good for kids" as meaning "not the best thing for the next child of this couple." Then whether the purchase of the egg is or is not good for the kid will depend on a comparison with other ways in which the couple could have had a child. Suppose, to make the comparison easier, they are not infertile – they bought an egg only in order to increase their chances of having a tall, athletic child who would get into a very good university. If they had not done so, they would have had a child in the normal way, who would have been their genetic child. Was it bad for their child to buy the egg? Their child may have a more difficult life because he or she was "made to order," and perhaps will disappoint his or her parents. But perhaps their own child would have disappointed them even more, by being less likely to be any of the things that they wanted their child to be. I do not see how we can know which of these outcomes is more likely. So I do not think we have grounds for concluding that a genetic supermarket would harm either those who choose to shop there, or those who are created from the materials they purchase.

If we switch from an individualist perspective to a broader social one, however, the negative aspects of a genetic supermarket become more serious. Even if we make the optimistic assumption that parents will select only genes that are of benefit to their children, there are at least three separate grounds for thinking that this may have adverse social consequences. The first is that some of the traits that people seek to ensure for their children will be advantageous for them only in comparative, not absolute terms. To increase one's children's longevity is good for them, whether or not everyone else's longevity has been increased by a similar amount. To increase one's children's height, however, is beneficial only if it also moves them up relative to the height of others in their society. There would be no disadvantage in being 5′ tall, if the average height in the community were 4′9″ and there will be no advantage in being 6′3″ if the average height is 6′6″. Arguably, it would be better if everyone were shorter, because we would require less food to sustain us, could live in smaller houses, drive smaller, less powerful cars, and make a smaller impact on the environment. Thus being able to select for height – something couples are already doing, on a small scale, by offering more for the eggs of tall women – could start the human equivalent of the peacock's tail – an escalating "height race" in which the height that distinguishes "tall" people from those who are "normal" increases year by year, to no one's benefit, at considerable environmental cost, and perhaps eventually even at some health cost to the children themselves.[27]

The second ground for objecting to a genetic supermarket is the fear that it would mean less diversity among human beings. Not all forms of diversity are good. Diversity in longevity is greater when there are more people with genes that doom them to an early death. The loss of this diversity is welcome. But what about the loss of the merely unusual, or eccentric? Antony Rao, a specialist in behavioral therapy in children, finds that many middle and upper class parents come to him when their children behave in unusual ways, wanting them to be medicated, because "they fear that any deviation from the norm may cripple their child's future."[28] If this is true of behavioral abnormalities that for many children are merely a passing phase, it is likely to be even more true of genetic abnormalities. It is easy to imagine genetic screening reports that indicate that the child's genes are unusual, although the significance of the abnormality is not well understood (usually medical shorthand for "we do not have a clue"). Would many parents decide to terminate the pregnancy in those circumstances, and if so, would there be a loss of diversity that would leave human society a less rich place, and perhaps even, in the long run, reduce the species' capacity to adapt to changing circumstances?

The third and in my view most significant ground for objecting to a genetic supermarket is its threat to the ideal of equality of opportunity. John Schaar has written: "No policy formula is better designed to fortify the dominant institutions, values, and ends of the American social order than the formula of equality of opportunity, for it offers *everyone* a fair and equal chance to find a place within that order."[29] It is, of course, something of a myth to believe that equality of opportunity prevails in the U.S.A., because wealthy parents already give their children enormous advantages in the race for success. Nevertheless, the Ron's Angels slogan of "beauty and brains to the highest bidder" points to a future in which the rich have beautiful, brainy, healthy children, while the poor, stuck with the old genetic lottery, fall further and further behind. Thus inequalities of wealth will be turned into genetic inequalities, and the clock will be turned back on centuries of struggle to overcome the privileges of aristocracy. Instead, the present generation of wealthy people will have the opportunity to embed their advantages in the genes of their offspring. These offspring will then have not only the abundant advantages that the rich already give their children, but also whatever additional advantages the latest development in genetics can bestow on them. They will most probably therefore continue to be wealthier, longer-lived, and more successful than the children of the poor, and will in turn pass these advantages on to their children, who will take advantage of the ever more sophisticated genetic techniques available to them.

Will this lead to a *Gattaca* society in which "Invalids" clean toilets while "Valids" run the show and get all the interesting jobs?[30] Lee Silver has pictured a United States a millenium hence in which the separation between "Gene-enriched" humans and "Naturals" has solidified into separate species.[31] That is too far in the future to speculate about, but Maxwell Mehlman and Jeffrey Botkin may well be right when they predict that a free market in genetic enhancement will widen the gap between the top and bottom strata of our society, undermine belief in equality of opportunity, and close the "safety valve" of upward mobility.[32]

Suppose that we do not wish to accept this situation: what choices do we have? We can ban all uses of genetic selection and genetic engineering that go beyond the elimination of what are clearly defects. There are some obvious difficulties with this course of action.

First, are we violating Mill's principle, and if so, can we justify doing so? We could claim that although individual reproductive decisions appear only to affect the parties to the decision, and the child who develops from it, this appearance is deceptive. Reproduction of the kind described will change the nature of society by taking away the age-old dream that anyone can make it to the top. This is, arguably, a "harm to others" serious enough to justify the intervention of the state.

Second, who will decide what clearly is a defect? Presumably, a government panel will be assigned the task of keeping abreast with relevant genetic techniques, and deciding which are lawful and which are not. This allows the government a role in reproductive decisions, which some may see as even more dangerous than the alternative of leaving them to the market.

Third, there are serious questions about whether a ban on genetic selection and engineering for enhancement purposes could be made to work across the U.S.A., given that matters regulating conception and birth are in the hands of the states, rather than the federal government. In the case of surrogacy, attempts by various states of the U.S.A. to make the practice illegal, or to make surrogacy contracts void, have had little effect because Arkansas, California, and Ohio are more friendly to surrogacy. Couples seeking a surrogate to bear a child for them are prepared to travel to achieve what they want. As Silver remarks: "What the brief history of surrogacy tells us is that Americans will not be hindered by ethical uncertainty, state-specific injunctions, or high costs in their drive to gain access to any technology that they feel will help them achieve their reproductive goals."[33]

Fourth, assuming that we could get the U.S. Congress to ban genetic selection and engineering when used for enhancement, persuade the Supreme Court that the legislation violates neither the rights of the states to legislate in this area nor any constitutional rights to privacy in reproduction, and effectively enforce the ban within the U.S.A., we would still have to deal with the fact that we now live in a global economy. A small impoverished nation might be tempted to allow enhancement genetics, thus setting up a niche industry serving wealthy couples from the U.S.A. and other countries that have banned enhancement. Moreover, in view of the competitive nature of the global economy, it may even pay industrialized nations to encourage enhancement genetics, thus giving them an edge on those that do not. On Singapore's National Day, in 1983, Prime Minister Lee Kuan Yew gave a speech about the heritability of intelligence, and its importance for Singapore's future. Shortly afterwards, the government introduced measures explicitly designed to encourage university graduates to have more children.[34] Had genetic enhancement been available to Lee Kuan Yew at the time, he might well have preferred it to the government-sponsored computer dating services and financial incentives on which he was then forced to rely.

If a ban in the U.S.A. turns out to be unattainable, ineffective, or contrary to the vital interests of the U.S. economy, a bolder strategy could be tried. Assuming that the objective is to avoid a society divided in two along genetic lines, genetic enhancement services could be subsidized, so that everyone can afford them. But could society afford to provide everyone with the services that otherwise only the rich could afford? Mehlman and Botkin propose an ingenious solution: the state

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should run a lottery in which the prize is the same package of genetic services that the rich commonly buy for themselves. Tickets in the lottery would not be sold; instead every adult citizen would be given one. The number of prizes would relate to how many of these packages society could afford to pay for, and thus would vary with the costs of the genetic services, as well as with the resources available to provide them. To avoid placing a financial burden on the state, Mehlman and Botkin suggest, the use of genetic technologies could be taxed, with the revenue going to fund the lottery.[35] Clearly universal coverage would be preferable, but the use of a lottery would at least ensure that everyone has some hope that their children will join the ranks of the elite; and taxing those who are, by their use of genetic enhancement for their own children, changing the meaning of human reproduction seems a fair way to provide funds for it.

Thus shopping at the genetic supermarket has taken us to the surprising conclusion that the state should be directly involved in promoting genetic enhancement. The justification for this conclusion is simply that it is preferable to the most probable alternative – leaving genetic enhancement to the marketplace.

NOTES

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11 See Peter Singer, *Practical Ethics*, 2nd edn, Cambridge: Cambridge University Press (1993), (Chapter 5).

12 Allen Buchanan makes the same point, using the example of a woman who postpones having a child because she is living in a refugee camp, in his Choosing who will be disabled: genetic intervention and the morality of inclusion, *Social Philosophy and Policy* 13 (1996), 18–45, 29.

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16 Jonathan Glover, *Causing Death and Saving Lives.* Harmondsworth, Middlesex: Penguin (1977), see especially pp. 220–4.

17 Buchanan, Choosing who will be disabled, p. 33.

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19 Daniel Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity.* New York: Knopf (1985), p. 164.

20 Andrew Solomon, Defiantly deaf, *The New York Times Magazine* 28 August 1994, p. 38.

21 See Peter Singer and Deane Wells, *Making Babies.* New York: Scribner (1985), pp. 24–9.

22 Stephen Macedo, Homosexuality and the conservative mind, *The Georgetown Law Journal* 84 (1995) 261–300, especially p. 269 and Note 122 at 292.

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31 Lee Silver, *Remaking Eden.* New York: Avon (1998), p. 282.

32 Mehlman and Botkin, *Access to the Genome*, Chapter 6.

33 Silver, *Remaking Eden*, p. 177.

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