



## Background

### Year

1915

### Description

Part of unit 6 of the [Course on Genomics Ethics and Society](#), this section provides a background on the ethics of genetics, genomics, therapy and enhancement.

### Body

## Genetics, Genomics, Therapy, & Enhancement

### 1. Defining Therapy and Enhancement

Typically, therapy is understood to be the practice of *restoring* biological functions or health to some level that's "normal" either for the individual or people in general. Enhancement, by contrast, is thought of as *going beyond* biological functions and anatomical limits, extending what is "normal" either for the individual or for people in general.

However, the distinction between therapy and enhancement is often difficult to draw very clearly. So, for instance, drugs such as Ritalin, developed to treat individuals with attention deficit hyperactivity disorder (ADHD), are often used (illicitly) by individuals without this disorder to increase alertness and improve attention. So the same drug, creating the same effects, could be seen as therapy for one individual,

but enhancement for another.

But alternatively, one might view this as therapeutic – or even as an enhancement – in both cases. For instance, imagine a case where two individuals, one with ADHD and one without, both take Ritalin. After taking it, both have increased alertness and attention compared to what is possible for them as individuals without Ritalin; but neither has alertness or attention beyond what is ‘normal’ across human populations. If the marker of ‘normality’ is the human population in general, rather than the individual, Ritalin could be viewed as therapeutic in both cases (it’s not going beyond species-level normal biological function).

Related questions arise about a range of everyday items. For instance, are reading glasses a form of therapy or enhancement? Reading glasses return sight to individuals who have lost the capacity to read small print—in this sense they are restorative therapy. But at the same time, it’s ‘normal’ for people over 50 to lose the capacity to read small print. So, if the class of ‘normal’ here is what people of a similar age can do, then reading glasses look more like enhancement than therapy.

Of course, there are some things that look clearly like therapies (e.g., giving antibiotics to someone with an infection) and others that look clearly like enhancements (e.g., implanting chips in someone’s brain so that they can read a thousand words a minute). But the debate over when something is a therapy and when it’s an enhancement is an important backdrop to ethical questions raised here. In general, people are more willing to accept a need for therapy (understood as getting back something that has been lost or bringing someone up to what’s ‘normal’) than for enhancement (understood as moving beyond what’s biologically ‘normal’ for an individual or humans in general).

## **2.Genomic Medicine and Gene Therapy**

Genetic and genomic science have created entirely new possibilities for the treatment of various diseases. Genomic medicine involves both the use of large-scale population-wide genomic data to better understand disease, and the sequencing of individuals’ genomes, for use in preventative, diagnostic, and therapeutic decisions. The identification of a faulty gene against a reference sequence, for instance, may lead to the recommendation of *gene therapy* as an appropriate intervention.

Gene therapy, according to the Center for Genetics Education, is

“the use of genes as medicine involving the transfer of a therapeutic or working copy of a gene into specific cells of an individual in order to replace a faulty gene copy...or to introduce a new gene whose function is to cure or to favorably modify the clinical course of a condition.”

(<http://www.genetics.edu.au/Publications-and-Resources/Genetics-Fact-Sheets/Fact>)

While such treatments have huge promise, as yet they are not well developed, owing to the difficulties of identifying relevant genes and finding mechanisms to deliver the therapeutic genes into the body. So far, gene therapies have only been “somatic” – that is, they target genes in a particular individual’s body, and not “germline” – where therapies have inheritable effects on an individual’s offspring. Germline changes raise significant ethical issues, which we’ll consider below.

Genomic medicine and gene therapy raise a number of social and ethical issues we consider elsewhere in this course. For instance, genomic medicine raises questions about privacy and genetic data (see unit 7). Gene therapies may be tested on animals, and raise questions about animal welfare and rights (see unit 4). Our focus in this module will be on the social and ethical effects of technologies likely to emerge from research in medical genetics and genomics that offer the prospect of changing human beings in potentially radical ways, usually termed “genetic enhancements.” Many of the more radical possibilities here are just this: possibilities. But these possibilities raise ethical issues that should be explored now, since research that could lead to such enhancement is already underway. For instance, in March 2014, Crag Venter – a pioneer in human genomic research – announced an initiative to use genomics and stem-cell therapies to tackle age-related disease. Success in this area would have transformative effects on human societies. <http://www.humanlongevity.com/human-longevity-inc-hli-launched-to-promote-healthy-aging-using-advances-in-genomics-and-stem-cell-therapies/>

### **3. Existing & Future Enhancements**

Genetic intervention is just one form of enhancement (or therapy). There are also mechanical enhancements (e.g., prosthetic limbs), cosmetic enhancements (e.g., plastic surgery) and drug enhancements (e.g., Ritalin as a study aid – though with the reservations noted above).

This list of “enhancements” raises questions not only about enhancement/therapy distinctions, but also enhancement/tool distinctions. Should we see a prosthetic limb as an enhancement? What about a smart phone?

There’s clearly no bright line between tools or aids and enhancements. But one distinction often proposed here is that enhancements should be distinguished from tools or aids by taking “enhancements” to be actually incorporated in some way into the body – sometimes called “internal” – while “tools” are outside the body (“external” technologies.) We’ll adopt this distinction here (though interesting debates about the importance of the internal/external distinction do exist - see Allhoff et al. 2009).

Here we’ll outline some of the most widely discussed and controversial potential forms of human genetic enhancement (or, again, therapy). We’ll outline the social and ethical issues that each form raises, and conclude by considering some more general arguments for and against human genetic enhancement.

### **3.1. Selecting Children**

Genetic testing for diseases in newborn infants has become routine. However, it is now possible to test for gene-based diseases, as well as many other traits, long before birth. One recent development that raises a number of ethical issues is *pre-implantation genetic diagnosis* (PGD). This is the process of testing and selecting embryos prior to their implantation in the uterine wall. PGD allows parents to select against genetic disease and disabilities (and also to choose a child’s sex). Though the technology is not yet sufficiently developed, in the future it may be possible to select for other traits, such as beauty or intelligence.

There are several important ethical considerations here. Forms of PGD that avoid serious genetic disease and disabilities can be justified fairly simply on the basis of avoiding human suffering and giving children the best chance at a good life. It’s worth noting, though, that PGD doesn’t actually benefit any particular human individual in terms of improving his or her health; rather, the process determines who, of a number of potential genetic individuals, actually comes into being. It is a process of embryo *selection*, not embryonic *therapy* or change. So, while PGD may reduce overall suffering in the world, it doesn’t benefit particular genetic individuals and reduce the suffering they as individuals would have undergone (unless one thinks that one is benefited by being brought into existence).

The commonest ethical objections to PGD apply more generally to *in vitro* fertilization and other reproductive technologies that involve the discarding of embryos. Those who consider human embryos the equivalent of human persons, for instance, consider the discarding of embryos to be morally problematic. However, since this is not a specific *genetic* concern, we won't consider it further here.

Other ethical objections also exist. Depending on the social context in which PGD is carried out, it may be argued that PGD may be unjust in practice. Since the technology is expensive, it's likely that only the affluent will have access to it; on some accounts of justice, this would be problematic. It's also sometimes argued that selection against particular diseases or disabilities arises from, or promotes, discrimination against those living individuals who actually already have those diseases, suggesting that their lives are worth less than the lives of those without the disease. Unequal access to the technology might add to this problem: if certain genetic diseases or disabilities become confined to the children of those who are insufficiently wealthy to afford PGD, then it's plausible that research into those diseases, and help for those who have them, may diminish because of a lack of financial and political support.

PGD also allows for sex selection. There may be medical reasons for sex selection (where a genetic disease only appears in one sex). However, sex selection might also be practiced simply because parents want a child of a particular sex. In these cases PGD may be used to support and promote sex discrimination, also a significant justice concern.

Other significant questions arise over forms of enhancement not yet widely practiced. For instance, in the future, embryos (or zygotes) might be selected for particular capacities or traits (such as height or eye color), or (potentially) could be genetically altered to manifest capacities or traits they do not already possess. These kinds of enhancements intensify extrinsic concerns about the social effects of such technologies (in terms of concerns about justice and discrimination, for instance) to which we will return below. But they also raise "intrinsic" concerns – about the use of the selective technologies themselves.

One specific concern here is that selecting traits or capacities for children makes them more like consumer products than our children. The philosopher Michael Sandel, for example, has argued that loving one's children is inconsistent with wanting to shape their genetic constitution. Loving one's children, he suggests,

consists in appreciating them regardless of their genetic constitution. See one of our readings for this unit, Sandel (2004) in *The Atlantic*:

<http://www.theatlantic.com/magazine/archive/2004/04/the-case-against-perfection/302927/>

### **3.2. Physical Enhancement**

Techniques for physical enhancement – in particular, enhancements in strength and speed – are already in use among athletes. Many of these enhancements are based on pharmaceuticals, and are currently illegal or banned in professional sports, either because there are concerns about short and long term health impacts, or because these drugs change or increase competitiveness, or both. Future genetic and genomic technologies offer a variety of physical enhancement possibilities, from PGD selection for height or strength, to the use of techniques originally developed as gene therapies to promote or inhibit the production of various hormones and proteins important in sports performance (called “gene-doping”). Such physical enhancement techniques are also of interest to the military, where speed and strength are also important, as well as capacities to continue with little sleep.

These techniques raise general ethical questions (e.g., about health risks and injustice based on access) that we’ll consider below. But there are also more specific issues. Suppose, for instance that gene-doping was cheap, safe, and available to all professional athletes (so that it did not present an uneven playing field) – would there still be a problem with athletes using it? And suppose the military did succeed in creating successful physically enhanced soldiers – would this be ethically and socially problematic? Could such enhanced soldiers actually be considered as weapons? See Lin in *The Atlantic*:

<http://www.theatlantic.com/technology/archive/2013/01/could-human-enhancement-turn-soldiers-into-weapons-that-violate-international-law-yes/266732/#>

### **3.3. Mood/Personality Enhancement**

A number of recent enhancement proposals outside the realm of genetics have focused on altering mood. For instance, injecting oxytocin intra-nasally has been found to increase feelings of affection and attachment behaviors, and debates in neuroscience have considered whether we should use neuroenhancement drugs to improve our relationships (for instance,

<http://martoman.blogspot.com/2014/04/should-we-use-neuroenhancement-drugs->

[to.html?spref=tw\)](#)

Genetic enhancement technologies may, at some point in the future, offer the possibility of changing mood and affect (e.g., by making shy people bolder or increasing the confidence of those with low self-esteem). Carrying out such enhancements, though, would be highly controversial. Arguments in favor of such enhancements include the argument that freely allowing people to choose self-enhancement respects their autonomy (we'll consider these kinds of arguments shortly); and that human welfare would be improved if people could alter their affect in positive ways. But there are both intrinsic and extrinsic ethical objections. Some argue that mood- and affect- changing enhancements are intrinsically problematic, both because people would no longer have to learn how to reach certain desired states through effort and engagement with others, and because these changes threaten human authenticity. (Further arguments are needed to explain why effort and authenticity in this context matter, however.) Extrinsic objections concern the unknown and potentially negative long-term effects of such enhancements, both on individuals and on society.

### **3.4. Cognitive Enhancement**

Cognitive enhancements are the most widely discussed group of potential human enhancements. These include “acquiring information (perception), selecting (attention), representing (understanding) and retaining (memory) information, and using it to guide behavior (reasoning and coordination of motor outputs)” (Bostrom and Sandberg 2009). Some forms of cognitive enhancement already exist. For instance, it's sometimes argued that learning to read is a cognitive enhancement; and drugs that enhance attention and alertness such as Ritalin, as we've seen, are often considered enhancements when taken by those without ADHD. Much research is currently being done to target memory enhancements (e.g., in the therapeutic context of degenerative diseases such as Alzheimer's). Successful therapies to restore memory may also be able to increase memory capacity (perhaps to enhance memory) for those who had normal memories to begin with.

Again, general ethical issues arise here: about autonomy in decision-making; about welfare improvements; about unequal access to the technology; and about unknown consequences. Justice issues are particularly significant in this case, because cognitive enhancements could convey significant advantages in terms of

employment for those who are enhanced, and make it impossible for the unenhanced to keep up. And the consequences of cognitive enhancements may not all be positive, even for those who are enhanced. If memory enhancement made it difficult to forget either trivial or unpleasant things, for instance, it is unlikely to be beneficial.

### **3.5. Extending Life and Stopping Aging**

Some enhancements already discussed might be life-extending. But recent research (e.g., at the Craig Venter Institute) has focused specifically on slowing the aging process and treating age-dependent diseases. While some genetic research focuses on the causes of particular diseases, slowing aging would have the effect of slowing susceptibility to disease in general, since many diseases, such as heart disease, are age related. It's possible that in the future a combination of these genetic therapies could allow those with access to this technology the ability to live well beyond 100 years.

Using genetics to significantly extend longevity is, unsurprisingly, highly controversial. Some ethicists oppose it in principle, on the grounds that this would be "playing God" with human lives, or interfering with "natural" human lifespans. However, plausible versions of this argument would need to explain how enhancement differs ethically from life-preserving normal medical treatment. It's also sometimes argued that living much longer would change people's perceptions both of themselves and of humanity, breaking our continuity with a "short-lived" human history, and changing human identity. While this may be true, again further arguments would be needed to explain why this change would be bad.

Objections relating to the possible *consequences* of increased longevity seem more plausible. For instance, only some people would have access to the relevant therapies, since these therapies would be expensive. This suggests potential justice issues – the ability to "buy life" (though it might well be argued that this is also true of conventional medical treatment, to some degree). In addition, if a significant proportion of people in a population lived substantially longer lives, major social issues relating to population sizes, resource consumption, social security, employment, pensions and intergenerational inheritance would be generated. Some of these consequences would, at least in the medium term, be negative. But, of course, longer lives might also increase human happiness overall, satisfying most people's fundamental preferences not to die.



## **4. General Ethical Issues Raised by Enhancement**

Genetic therapies and enhancements raise a wide range of social and ethical issues, as suggested above. These can be roughly grouped into the following concerns:

### **4.1. Welfare Concerns**

Many genetic therapies will increase the welfare of individuals that have them, reducing suffering, increasing wellbeing and/or lengthening life. Some forms of enhancement could have broader positive social impacts: for instance, people with cognitive enhancements might boost general medical and technological progress, thereby eventually benefiting everyone – making “all boats rise.”

And germline therapies, if introduced, could lead to improved welfare over generations. But there is also potential for such therapies and enhancement to have negative effects, on the health of those who are enhanced, their descendants, or on those who are not enhanced if others are. How this might work out overall is likely to depend on the therapy or enhancement.

Some philosophers consider welfare to be the overarching consideration, and the basic motivation to enhance. Savulescu (2001) for instance, develops what he calls a Principle of Procreative Beneficence: “when parents are able to do so without significant cost or inconvenience to themselves, they have an obligation to select – out of the possible children they could have – the one that they judge would have the best prospects of a good life”.

### **4.2. Concerns about Justice and Inequality**

While many worries about genetic therapy and enhancement focus on potential injustices, we should also note ways in which they could promote equality. Genetic therapies could be used, for instance, to move those with genetic diseases or inherited disabilities into a “normal” range, and thus prevent the existence of “natural” inequalities, removing barriers to opportunity such ‘natural’ disadvantages present. Since the distribution of genetic disease and inherited disability is not chosen, nor a matter of desert, therapy or enhancement for relative equality in this respect could be seen as leading to more “fairness” in human society.

However, most concerns here are about potential injustices arising from enhancements: if only the wealthy can access therapies to cure disease, enhancements to make them more intelligent, and to increase longevity, it seems

very likely that the availability of enhancement would increase and entrench inequalities between those who are wealthy and those who are not.

#### **4.3. Concerns about Autonomy and Freedom**

From some political and philosophical perspectives, people should be free to choose whatever therapies and enhancements they like, as long as their choices don't harm others or significantly restrict the decisions others can make. This freedom may also be understood to extend to their own children—people should be free to select whatever characteristics they want their children to have, provided those characteristics would not give their children miserable lives. From this perspective, restrictions on individual selection of enhancements should be minimal. Just as individuals are currently free to opt for expensive education, cosmetic surgery, etc., so they should be free to choose to be enhanced or to select and enhance their children.

However, even those who think that autonomy is important may argue for restrictions on options for enhancement. Where there are doubts about the health implications of particular enhancements, even those with strongly autonomy-oriented views might support paternalistic legislation to prevent individuals from adopting enhancements (as there are currently paternalistic restrictions on the use of many drugs). And there are also plausible arguments that at least some forms of enhancement would harm others and restrict their decisions. If cognitive enhancements were only available to the wealthy, and this led to a super-class of cognitively superior individuals, there are likely to be harmful effects on those who could not afford enhancements. In other cases, such as in sport, if some individuals choose enhancement, others will also feel pressured to be enhanced, thus reducing their autonomy. Even though children don't currently choose their own genetic make-up, having it selected on their behalf by their parents may seem to threaten their autonomy. Finally, any germ-line therapies or enhancements that affect unborn generations could be regarded as restricting the freedom of the future.

#### **4.4. Concerns about Naturalness, Humility and Playing God**

A variety of intrinsic concerns surround human genetic therapies and, in particular, human enhancements, similar to those we've seen with other forms of genetic engineering. One argument concerns the "unnaturalness" of human genetic enhancements. In the context of human enhancement, this is based on the idea

that there's something special about human nature, as it has been created or has evolved without human intervention; to enhance human nature is to deny its natural "specialness." A related argument appeals to human virtues and vices, maintaining that it's hubris—where hubris is understood to be a vice—to attempt to redesign human nature. And a third argument appeals to virtues and vices in a different way, suggesting that genetic enhancements will entail the loss of both meaning-giving and character-building aspects of life, since enhancement will provide us with characteristics (such as health, good memories, strength, and confidence) for which we previously had to strive. So, if enhancement makes this all easy, we won't be able to develop virtues of determination, grit, dealing with suffering graciously (and so on) that play a significant role in creating good character in an unenhanced world.

## References

- Allhoff, F., Lin, P., Moor, J., Weckert, J. (2009). Ethics of Human Enhancement: 25 Questions & Answers. US National Science Foundation.
- Bostrom, N. & Sandberg, A. (2009). Cognitive Enhancement: Methods, Ethics, Regulatory Challenges. *Science and Engineering Ethics*, 15, 311-341.
- Savulescu, J. (2001). Procreative Beneficence: Why We Should Select the Best Children. *Bioethics*, 15, 413-426.

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## Rights

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## Resource Type

Instructor Materials

## Topics

Privacy and Surveillance

Confidentiality

Emerging Technologies

Informed Consent

Human Enhancement

Human Subjects Research

## Discipline(s)

Genetics and Genomics

Life and Environmental Sciences

Biomedical Engineering and Bioengineering