The Ethics of Genetic Technology and the Quest for Perfection

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Overview of Topics

- Genetic Testing
- Gene Therapy
- Playing God
- The Precautionary Principle
- Remedies vs. Enhancements
- Positional Goods
- Choosing Disability
- Duties to Future Generations
Uses of Genetic Testing

- Planning to have children
  - ascertaining whether a prospective parent is a carrier of genes known to cause diseases
- Assisted reproduction
  - testing embryos for genes known to cause diseases
- Pre-natal care
  - testing a fetus for genes known to cause diseases
- Preventive medicine
  - testing an asymptomatic child or adult for genes known to cause diseases
- Medical treatment
  - testing a symptomatic child or adult for genes known to cause diseases, to confirm a diagnosis suggested by other indicators

How Does Gene Therapy Work?

- Genes inserted directly into cells usually do not function.
- But certain viruses are known to be good at infecting people.
- Some of those viruses can be modified to include the desired gene and not cause illness. The resulting virus is a vector.
- Delivery options: intravenous, site injection, or tissue in a lab.
Are We Talking about Cloning?

- Cloning—copying the entire genome of a particular organism—is one of many possible applications of genetic technology.
- The vast majority of uses of genetic technology do not involve cloning.
- Instead, they involve copying or engineering small pieces of DNA.

Is It Playing God?

OH, GOD...

YES?
Analysis of the “Playing God” Concern

- As an ethical concern, “playing God” means intervening in aspects of nature that have traditionally been beyond human control and should remain under the control of God alone.
- Most ethicists think this is an unhelpful concept, because it does not tell us which aspects of nature should remain under the control of God alone and which aspects of nature it is o.k. to intervene in.

Examples:
- insulin
- appendectomy
- artificial respiration
- organ transplantation
- assisted reproduction

What about the Precautionary Principle?

- This is the principle that says that if an action, policy, or new technology has not been proven to be absolutely safe, then, as a precaution, it should not be undertaken.
- There is a grain of truth in this principle: In any kind of decision-making, we ought to exercise caution. And when new technologies are being implemented, we have to be mindful of:
  - the law of unintended consequences
  - our own tendency to overestimate the probability of the success of our ventures
What about the Precautionary Principle?

- However, it is possible to go too far:
  
  "I heard a story about this guy who went outside and got stung by a bee. So now, as a precaution, I always wear my bee suit whenever I'm outside."

- When it comes to genetic technology, there is no one right answer ("Do it" or "Don't do it"). Each step must be decided on a case-by-case basis.

Remedies vs. Enhancements

- Interventions are often divided into two categories.
  - Remedies are interventions that restore normal functioning.
    - insulin
    - organ transplantation
    - drugs for high cholesterol
    - drugs for social-anxiety disorders
    - pharmaceutical and surgical cures for ailments and diseases
  - Enhancements are interventions that improve on already-normal functioning.
    - increased height or strength (e.g., steroids)
    - greater attention span / ability to concentrate (e.g., Adderall)
The Two Sides of the Debate

- Some people think that remedies should be the exclusive focus of our efforts.
  - improvements in quality (more effective, less expensive)
  - improvements in quantity (greater coverage of diseases)
- Other people think that enhancements are just as worthwhile as remedies, and that our research efforts should be directed wherever they will do the most good.
  - On this view, remedies will usually get priority over enhancements.
  - But some enhancement efforts might take priority over some remedy efforts. For example, lengthening normal life span by forty years might take priority over lowering the cost of hearing aids by five percent.

Normal Human Functioning

- Proponents of the first view (we should focus exclusively on remedies) often appeal to the idea of “normal human functioning” and say that we should try to provide this to everyone, but not try to exceed it for anyone.
- This view is sometimes based on religion (an idea of the way humans were created by a divine being) or a non-religious conception of human nature.
Improving Human Functioning

- Proponents of the second view (we should strive for enhancements as well as remedies) often think that what we regard as “normal human functioning” is an accident of evolutionary history.
- On this view, what distant-future generations regard as normal might be very different from what we regard as normal, just as what we regard as normal is far different from what is normal for lower primates.

Positional Goods

- Even if enhancements are not ethically problematic in general, there may be a class of enhancements that are ethically problematic. These are enhancements that give certain people greater shares of positional goods.
- Positional goods are goods that are beneficial (for the people who possess them) mainly in virtue of giving people who possess them advantages over people who do not possess them.
Positional Goods: Ethical Problems

- So, the benefit someone derives from a positional good is completely or largely offset by harms experienced by other people.
- This leads to two ethical problems.
- First, from the point of view of aggregate social welfare and putting resources where they will do the most good, the costs of developing enhancements for positional goods threatens to exceed the net benefits (the relative benefits to recipients minus the relative harms to non-recipients).
- Second, if access to such enhancements is based in part on ability to pay for them, then the development of such enhancements threatens to perpetuate and widen existing inequalities of wealth and well-being.

Choosing Disability

- In 2002, a lesbian couple was planning to have a child. They were deaf, and wanted their child to be deaf, too.
- The sperm bank they were working with said people with congenital deafness would not qualify to be sperm donors in their program.
- The couple found a sperm donor from within the deaf community and had a son who is hearing impaired.
- His condition could be improved with the use of a hearing aid and his parents said they would let him make that choice himself.

Candy McCullough, Sharon Duchesneau, and their son Gauvin
Duties to Future Generations

- We will leave behind some problems for future generations to deal with. One such problem might be global warming.
- Because of this, should we—if we ever become able—change the genetic makeup of humanity to partially alleviate this and other problems? Would the following be good, if feasible?
  - reduced size
  - comfortable at wider ranges of temperatures
  - aversion to beef, pork, and chicken
  - increased empathy

Additional Resources

- Gattaca (1997), written and directed by Andrew Niccol
- Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Wikler, *From Chance to Choice: Genetics and Justice* (Cambridge University Press, 2002)
- Ronald M. Green, *Babies by Design: The Ethics of Genetic Choice* (Yale University Press, 2009)
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