BONUS INTRODUCTORY LECTURE ON BIOETHICS

DESIGNER BABIES: CHOOSING OUR CHILDREN'S GENES

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EXISTING WAYS OF DETERMINING OFFSPRING GENOME

- Old school: choosing a mate
  - Steven Pinker: "Anyone who has been turned down for a date has been a victim of the human drive to exert control over half the genes of one's future children."
- New way: In vitro fertilization (IVF), preimplanation genetic testing (PGD), and discard of affected embryos
  - IVF burdensome and expensive

REASONS FOR GENETIC TESTING OF EMBRYOS

- To prevent the birth of a child with genetic disease
  - E.g., Tay-Sachs, cystic fibrosis, thalassemia, sickle cell anemia
- Non-disease use
  - Determine sex
    - Medical: to avoid sex-related disease, e.g., hemophilia
    - Non-medical: preference
- Possible future uses
  - Selection of embryos for non-disease traits
    - Dr. Jeffrey Steinberg (2009) claimed he could give parents 80% chance of getting desired hair or eye color
    - Is it possible? Would it be ethical?

GENE THERAPY

- Replacing/modifying defective disease-causing genes with healthy ones
- Has had some successes and many failures
- All medicine is hard
- Gene therapy poses special challenges

CHALLENGES OF GENE THERAPY

- Most genetic diseases are caused by multiple genes, not just one
- All of them interact with each other and the environment
- Gene editing requires targeting exactly the right location on the gene
- No trait is solely a matter of the existence of genes
- Genes need to be expressed (epigenetics)
- Need to figure out how the genes interact with each other and the environment to produce disease
- Avoid unforeseen, unwanted side effects

CRISPR-CAS9

- A promising new gene editing technology
- Has been used to modify mosquitos to prevent transmission of malaria
  - Release into the wild a decade away
- Editas hopes to use CRISPR in a clinical trial by 2017 to treat a rare form of blindness, Leber congenital amaurosis
  - Good case because the exact gene error is known, the eye is easy to reach
- Still, don't know if it will work, and may cause unintended side effects

FROM THERAPY TO ENHANCEMENT

- Biggest ethical problems in genetic modification: **safety and efficacy**
- But if these can be solved, few people have a problem with gene therapy intended to cure or prevent disease
- Bigger concern with genetic enhancement intended to make us “better than well”

ENHANCEMENT: HOW TO DEFINE

- Line between therapy and enhancement not always clear
  - Some means of preventing disease (vaccination) work by enhancement (enhancing the immune system)
- What counts as normal/baseline?
- Not all improvements count as enhancement
  - Training regimen, diet to improve strength
- Hard to define, but we know it when we see it!

TYPES OF ENHANCEMENT

- Appearance
  - Cosmetic surgery
    - Medication
    - E.g., for male-patterned baldness
- Mental or physical performance
  - Legal drugs
    - E.g., Ritalin, steroids
  - Illegal drugs
    - Speed
- Society often willing to tolerate use of some enhancements
  - Cosmetic surgery
  - May impose some controls
  - virtually never willing to pay for them

WHAT IS *GENETIC* ENHANCEMENT?

- Using genetic means to get or avoid non-disease traits
  - Might be done by genetic testing and discard
  - Might be done by modification of embryos: "designer babies"
- Can it be done?
- Should it be done?

TECHNICAL DIFFICULTIES OF GENETIC ENHANCEMENT

- All the problems in gene therapy and more
  - There are some single-gene diseases (Huntington's)
  - There are no single-gene non-disease traits
  - No "gene for" intelligence, etc.
- How would you know if genetic intervention to enhance intelligence worked?
  - At least in clinical trial for disease, success would be clear
  - How would you know if an enhanced child was smarter than he would have been?

MISCONCEPTIONS ABOUT GENETIC ENHANCEMENT

- Genetic enhancement would not automatically make someone smart or athletic
  - Any more than the child of two brainy people is automatically a star student or an athlete
- At best, it might give a "genetic edge" for the desired trait
- If we don't understand this, we'll never be able to talk sensibly about the ethics of genetic modification
- Risk of unjustified banning
  - E.g., GMO foods

OTHER THAN SAFETY AND EFFICACY, WHAT ARE THE ETHICAL OBJECTIONS?

- Argument against design
- Argument from genetic determinism
- Argument from autonomy
- Argument from identity
- Argument from authenticity
- Argument from giftedness/parental tyranny
- Argument from social justice

ARGUMENT AGAINST DESIGN

- Parents shouldn't strive to determine their children's traits, but should accept their children as they are
- This can't mean that parents should never try to influence the traits their children have!
- Is the objection specifically to shaping by genetic means?
  - This rests on the misconception that genes are deterministic in a way that other factors are not

ARGUMENT FROM GENETIC DETERMINISM

- The fallacy of genetic determinism: genes are different
- They are not
- Education actually changes the brain
  - Neuronal phenotype manipulation (Alex Mauron)
- Many environmental influences (diet, child abuse) make permanent changes in the child's body and mind

ARGUMENT FROM AUTONOMY

- "When parents select genes for their child, they infringe the child's autonomy."
  - They force the child to be a particular kind of person, the kind of person the parents want
  - It's not a free choice on the part of the child
- This assumes that when gene selection is natural, we make free choices – clearly false
- None of us gets to choose our own genes
- We play the hand we're dealt

ARGUMENT FROM IDENTITY

- "When parents modify the genes of offspring, they change their identity, and they have no right to do this."
- Numerical vs. narrative identity
  - Numerical: what makes me the same individual over time
  - Narrative: my life story
- Narrative identity affected by numerous factors
  - Changing places, divorce, etc.
- Might be wrong to change a child's numerical identity
  - But this can't be wrong at embryonic stage
  - Which gametes become the embryo undetermined
- Changing numerical identity impossible beyond embryonic stage
- So, either identity in morally important sense is not changed, or it's not wrongful

ARGUMENT FROM AUTHENTICITY

- "Personalities of genetically modified people would be less real or authentic."
  - Am I really cheerful or have I just been modified to be cheerful?
    - This makes no sense
- Whether you have a trait because you inherited it naturally or were modified does not matter
  - Individuals with one or two copies of the short allele of the 5-HTT gene more susceptible to depression after stressful events; those with long allele more resilient.
- Whether the gene was inherited naturally or modified, resilience is the same

ARGUMENT FROM GIFTEDNESS

- A twist on the argument against design
  - Sandel's critique of hyper-parenting: the impulse to control too much
  - Murray's critique of parental tyranny: let children find their own ways of flourishing
- These are objections to styles of *parenting*, not genetic enhancement *per se*
- Perhaps genetic enhancement would exacerbate bad parenting
- Depends on the traits chosen and the motives for choosing them

ARGUMENT FROM SOCIAL JUSTICE

- "Genetic interventions will be expensive and therefore open primarily to the rich, thus exacerbating inequality and perpetuating advantages to the wealthy classes."
- Genetic enhancement, if possible at all, would be a drop in the bucket compared to current sources of inequality
  - Housing, schooling, white privilege, etc.
- Society could choose to make genetic boosts available to the least advantage, even the playing field

TEMPTED BY THE HOT AND SEXY

- Cloning, gene editing, head transplants…
- Bioethicists have an obligation to say something about the real issues in social justice (examples from Prof. Kumta)
  - Coca Cola using up water supply in poor countries and diverting essential water to factories and then selling discounted water to the population
  - drug factories in India and China that provide 92% of the world's illicit drugs
  - farmer suicides in India due to greed, bad planning, corruption

CONCLUSION, PART 1

- Bioethicists also have an obligation to help educate the public; expose bad arguments based on misunderstanding of science
- Some of the objections – parenting, social justice – are serious ones
- Don't fetishize the technology
  - If the issue is parenting, let's discuss that
  - If the issue is social justice, let's discuss that
- Genetic interventions could be beneficial
- How we use technology is up to us

CONCLUSION, PART 2

- Plenty of reasons to be skeptical of genetic interventions, whether therapeutic or enhancement
  - Safety and efficacy
- Why would prospective parents use their money on a technology that *might* give their child a genetic edge?
  - Use resources on what we know works to boost intelligence, e.g., talk to infants, read to children, improve schools