

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), preimplantation genetic testing (PGD), and discard of affected embryos
 - IVF burdensome and expensive

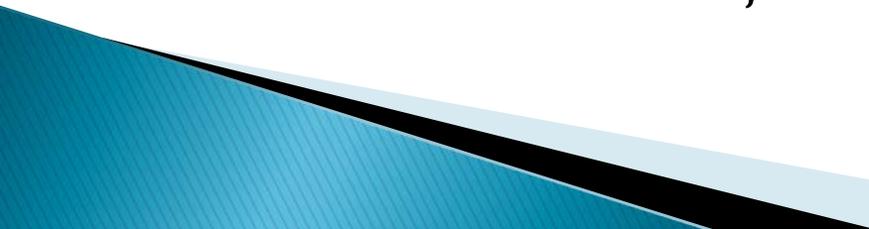
REASONS FOR GENETIC TESTING OF EMBRYOS

- ▶ 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
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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
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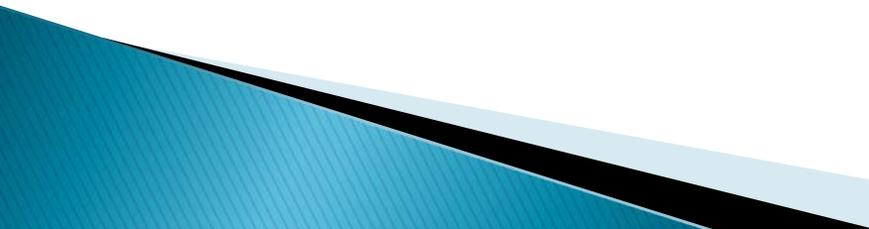
CRISPR-CAS9

- ▶ 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”
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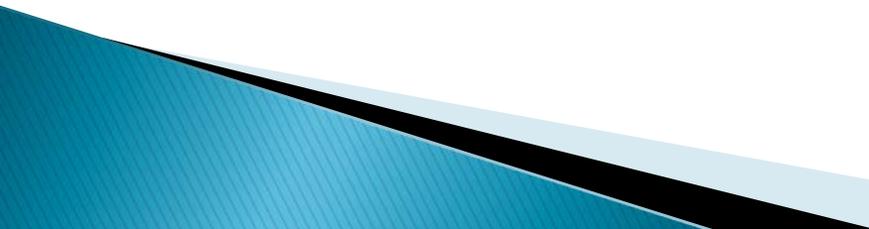
ENHANCEMENT: HOW TO DEFINE

- ▶ 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!
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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?
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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
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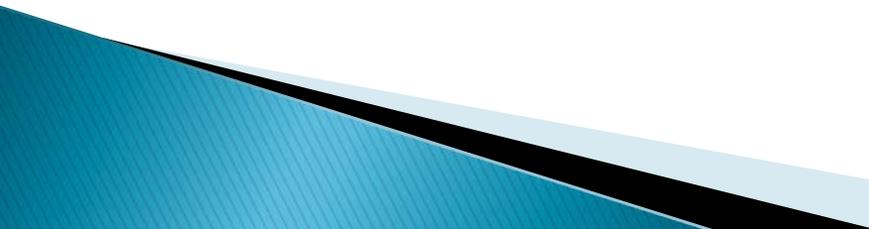
ARGUMENT AGAINST DESIGN

- ▶ 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
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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

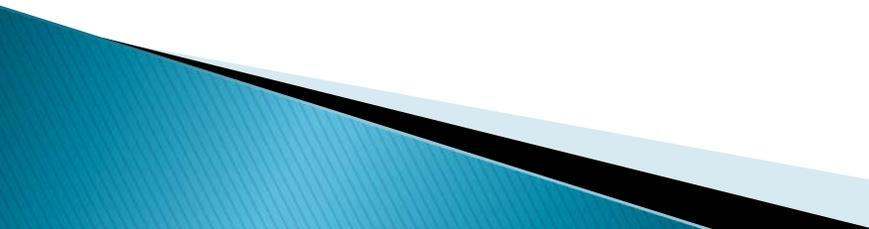
ARGUMENT FROM SOCIAL JUSTICE

- ▶ “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
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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