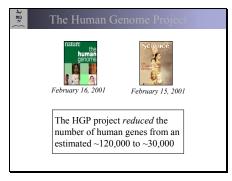


Introduction

- The Human Genome Project (HGP)
- Human genetic normalcy medicine?
- Human genetic normalcy eugenics?
- HGP in reproductive technology a defense
- \blacksquare The slippery slope to cloning?

Slide 3





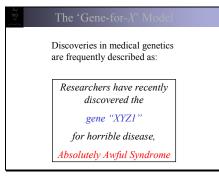
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Goals of the HGP

- Describe disease at the molecular level
- \blacksquare Use a molecular concept of the gene
- Develop a profile of human genetic normalcy

Slide 6



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Function and Normal

- Health ideals for a human body (parts or systems) means that the body is functioning as it should
- Proper functioning is an adaptationist account of gene selectionism
- Normalcy, on the HGP account, means that one is well-functioning as one should given one's evolutionary past

Slide 8

Disease at the DNA Lev

"[I]nherited defects would be caused by changes in the sequence of DNA, perhaps by a change in a single nucleotide. Such change might result in the replacement of one amino acid by another in a protein at a critical location, making the protein biologically useless." (Jukes, quoted in Lloyd p.555)

Slide 9

Biochemical Pathway Model

James Watson: "[W]hat is desired is some complete set of causal steps yielding a living organism. But variation plays no role in this model. It is an uninteresting and even distracting feature of the processes on which the explanatory theory is focused."



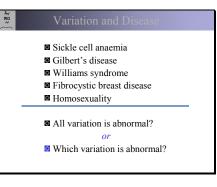
James Watson

(quoted in Lloyd p. 556, Ruse and Hull, Philosophy of Biology OUP)

What's the Problem

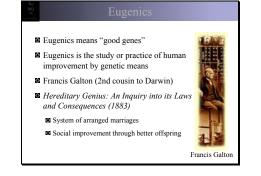


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The alternative is a developmental model that tracks an expected range of outcomes relative to a background developmental context.

Slide 12



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Ethical Ou

Individual: Should individuals have the freedom to determine their own genetic future? (eg. offspring or themselves)

Family: Do prospective parents have a duty to their future children to get tested? Should children be able to sue? (Tay Sachs)

Patient-Physician: Should physicians recommend genetic testing? (eg. Huntington's, Tay Sachs, Cystic Fibrosis)

Slide 14

Ethical Quest

Individual-Corporation: Should life insurers or employers be able to discriminate against carriers of genetic diseases? (HGP and Insurance)

State-Individual: Is it permissible to over-ride individual reproductive autonomy to achieve social goals? (Eg. Carrie Buck)

State-Society: Should the state play an active role in recommending an ideal genetic make-up of the population? (Bell-Curve, Nazi Germany)

Global-Social-Individual: Is there are global need to limit certain individuals' reproductive autonomy in some societies? (eg. China's one-child policy)

Slide 15

Voluntary Common social ideal Voluntary testing / voluntary action CF screening

- Coerced / State Mandated
 - Enforced social ideals
 - $\blacksquare Compulsory testing / compulsory action$
 - Canada, US, Germany, China, India

Defining Euger

- Diane Paul is concerned that we are overly broad in what counts as eugenics:
 - intention is the purpose of every pre-natal genetic test eugenic?
 - consequence are all actions that change gene frequencies eugenic?

Slide 17

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When is Eugenics Ba

Positive eugenics - active trait selectionNegative eugenics - trait avoidance

- Good eugenics no coercion
- Bad eugenics coercion
- Freedom from coercion (conservativism)Freedom of opportunity (liberalism)

Slide 18

Direct Eugenics Pre

- Slippery slope arguments about the HGP*
- Cost-benefit analysis drives pre-natal testing
- Testing drives selective abortion
- Negative eugenics works on recessive traits that are 'hidden' - slow process

Imagine a case in which pre-natal diagnosis shows a fetus is severely disabled

the conservative response is that parents would be uncoerced if free to abort or bring to term

the liberal response is that parents lack that freedom if the social burden of caring for a severely disabled child are overwhelming

In which of the two cases are we really free?

Pauling on tattoos:

"If this were done, two young people carrying the same seriously defective gene in a single dose would recognize this situation at first sight, and would refrain from falling in love with one another. It is my opinion that legislation along this line, compulsory testing for defective genes before marriage, and some form of public, or semi-public display of this possession, should be adopted"



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Indirect Eugenics Pres

- Insurers and employers have a clear costbenefit justification for genetic testing
- Consensual testing carries no liability for physicians, insurers or employers
- Is it possible to give "informed no's"?

Slide 20

Consumer Pressure

People want perfect babies

- They have duties, once babies are in the world, to make their conditions as good as possible
- Paul: "once the principle of choice in respect to a non-medical condition is admitted, it is hard to know on what grounds it can be denied to parents who want to give their child a competitive advantage with respect to intelligence, height, or other socially desired characteristics."

Slide 21

HGP - Laudable Goals? Lisa Lloyd Human genetic variability is under threat when genetic 'normalcy' is defined in medical terms Diane Paul Once genetic normalcy is defined for a population, it becomes insidiously coercive

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James Wat

- Argued that 3% of the \$200 M annual budget for the HGP should go to the study of the ethical, legal and social implications (ELSI) of the HGP
- "...I saw the need to be proactive in making ELSI's major purpose clear from its start - to devise better ways to combat the social injustice that has at its roots bad draws of the genetic dice."

Slide 23

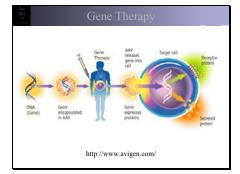
James Watso

"...past eugenic horrors in no way justify the 'Not in our genes' politically correct outlook of many left-wing academics. [...] Whether these scientists on the left actually believe, say, that the incidence of schizophrenia would seriously lessen if class struggles ended, however, is not worth finding out. Instead, we should employ, as fast as we can, the powerful new techniques of human genetics to find soon the actual schizophrenia predisposing genes...."

Slide 24

James V

"Yet anyone who proclaims that we are now perfect as humans has to be a silly crank. If we could honestly promise young couples that we knew how to give them offspring with superior character, why should we assume they would decline? Those at the top of today's societies may not see the need. But if your life is going nowhere, shouldn't you seize the chance of jumpstarting your children's future? Common sense tells us that if scientists find ways to greatly improve human capabilities, there will be no stopping the public from happily seizing them."



Slide 26

- 1. We are not morally obliged to give *all possible* children an existence.

- existence.
 But we are obliged to provide children that do come into existence a minimally satisfying life.
 A minimally satisfying life includes provision of normal health
 Genetic diseases and disabilities are conditions we all have a strong, rational preference *not* to be in.
 There is no morally significant difference between providing the conditions for normal health *prior* to birth than to provide them *after* birth.
 Failure to remove disease and disability, if it is possible to do so, is to harm children.
 We should use genetic screening and gene therapies to remove
- We should use genetic screening and gene therapies to remove disease and disability in children

Avigen's main work is on Haemophilia В

John Harris

Slide 27

Gene therapy and screening discriminate against those who presently have genetic diseases.

Response:

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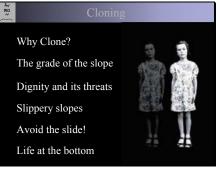
- The moral status of existing persons is equal, regardless of whether or not they have diseases or disabilities
- To remove disease in neonates is not an attack on existing persons with disease

e.g. Is setting someone's severely broken legs an attack on people in wheelchairs?



Cobjection 2 Gene therapy is just negative eugenics, and should be condemned because it will usually be coercive. *Response:* The decision is not based on race, class, age or intelligence. The point is that everyone should be discuraged from having genetically compromised children If we have the ability to use gene therapy to do good, it would be wrong not to use it. a e.g. knowing how to make airplanes safer, but not doing it would be wrong

Slide 29



Moral, not technical issues

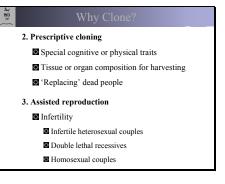
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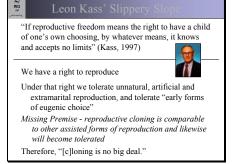


Prescriptive reproduction: Cloning is used to establish a very specific end result

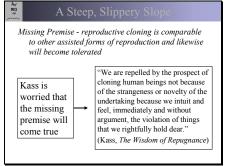
Assisted reproduction: Cloning is use to overcome some other kind of barrier







Slide 33



Kass, L. 1997. "The Wisdom of Repugnance." The New Republic, June 2: 17-26.

The repugnance objection is there to set the grade of the slope as steeply as he can set it.

Kass never shows the harmfulness of what we descend down the slope to, but instead sets the slope steeply *away* from what he thinks is "natural" for human beings.

Above all else, what Kass holds dear is his conception of human dignity, which is in large measure dependent on a view of the correct way that humans should enter the world, and how the correct process (natural reproduction) leads to unique individuals in full possession of their dignity.

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Human Value / Dignity

Dignity is sometimes defined in terms of the inherent qualities of humans
One view is that humans are unique, and have dignity because they cannot be replaced
The twins argument successfully undermines this view of dignity

Slide 35

A Different Approach

Sharing a genetic heritage with everyone else is an essential part of having moral empathy

Luck of the Lottery - we are bound together by our common exposure to the risk of not being healthy, and by recognizing the inherent contingency of lucky draws For Kant, humans acquire dignity by being rational beings who can act morally: "...autonomy is the ground of the dignity of human nature and of every rational nature."

For the challenge to this argument, see Gould, S.J. 1997. "Individuality: Cloning and the Discomfiting Cases of Siamese Twins." *The Sciences*, September/October: 14-16.

There is even at least one example of conjoined twins who married a nonconjoined pair of twins. Simplicio and Lucio Godino, conjoined twin brothers who were born in the Philippines in 1908, married a pair of identical twin sisters, with whom they performed on Vaudeville. The Godina Twins (seen in the picture below) died within a few days of each other in 1936 and it is not known what happened to their wives.



Threats to D

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- Human dignity is threatened by biased draws at the Lottery
- Draws are biased when:
 someone is unfairly advantaged
 someone is unfairly disadvantaged
- Biased draws are harmful because they distort our moral empathy for one another

Slide 37

Slippery Slop

- Def'n: When it is falsely claimed that a particular action or claim will lead to undesirable consequences. These consequences are often put in the extreme.
- Ways to defeat Slippery Slope Arguments:
 Show the consequences do not logically follow from the starting point
 - Show that the consequences are not (extremely) undesirable

My argument here is that the consequences do not logically follow: That is, society is not on a slippery slope that will take them from the acceptance of therapeutic cloning of human embryos (for the sake of stem cell production, for example) to the use of cloning technologies to fully reproduce human beings.

Note: The presumption here is that therapeutic cloning does not involve the production of whole human beings. There are therapeutic uses of human reproductive cloning - say in the prevention of lethal double recessives, but I'll treat those as reproductive cases since the primary intention in using the technology is to have a whole person.

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Prescriptive Cloni

- If the intention is to endow a clone with specific mental or physical abilities, then:
 These enhancements or limitations are biased
 - samplings of the gene pool
- If the intention is to induce the traits for highly specific uses, then:
- The clones are manipulated into an unacceptably narrower range of life plans than what is available to those taking unbiased samples of the gene pool

Slide 39

Prescriptive Cloning

- Shenk approves of C.S. Lewis' position:
 "It is not that they are bad men, they are not men at all. Stepping outside of the Tao they have stepped out into the void."
- Two points:
 Shenk (and Lewis) commit the naturalistic fallacy
 They leave a moral vacuum about permissible uses of the HGP
- Contrary to Shenk's concern about a wildly unregulated human genetics industry, plausible moral injunctions against cloning are already available.

1. As the specificity of the traits goes up, and as they become increasingly realizable, the capacity to do harm by biased samplings and manipulation into a narrower range of life-plans increases. 2. Manipulated into a life-plan is not a categorical harm, but admits of degrees. Children require some manipulation and coercion. The difference here is the extent to which there is *absolute* foreclosure on particular life plans, or, in the case of the tissue/organ donors, insistence on a life plan that includes very specific activities - the expectation of the donation itself.

Slide 40

Assisted Reproducti

- Richard Wachbroit says cloning can be aligned with either:
 - assisted reproductive technology
 production of children with specific traits
- "Indeed, some commentators have called cloning asexual reproduction, which clearly suggests that cloning is a way of generating *descendents*." (i.e., not *siblings*)
- Wachbroit focus on whether descendents would be in a compromised position compared with siblings, and finds that they would not. This is supposed to remove barriers to cloning.

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Assisted Reproduct

- Assisted reproduction is technological intervention into compromised heterosexual reproduction
- Cloning is the *displacement* of sexual reproduction
- A separate argument has to be made that asexual reproduction is secured by the same protected right that assures sexual reproduction
 - Even if it is, cloning is an extraordinary measure that can be limited under the right

The infertile types (hetero-infertiles or double lethal recessives, homosexual couples) have no claim to access cloning on

the grounds that it is a form of assisted reproduction comparable to IVF, etc.

Technologically assisted reproduction assists sexual reproduction compromised for whatever reason. Cloning doesn't assist sexual reproduction, it bypasses or displaces it. It is in fact asexual reproduction, with the odd fact that the resultant

clone is in fact diploid. The assisted reproductive technologies already in place are discontinuous with cloning in this

significant way. Rather than provide arguments against reproductive cloning, a compelling argument needs to be made for the introduction of a radically new technology.

Slide 42

The Slippery Slope

Prescriptive Cloning

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Moral injunctions against biased draws in the lottery stop the descent down the slope

Assisted Reproduction

Clarity about the difference between technological *assistance* and technological *displacement* stops the descent down the slope

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Life at the Botto

- Clones will be people too!
- The biggest single threat to them is everyone else's failure to be morally empathetic
- The biggest risk is a runaway aesthetic judgment about the comparative worth of originals and forgeries

Slide 44

No Slippery Slop

So, is there a slippery slope from therapeutic to reproductive cloning?

NO:

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There are good moral reasons to prevent it

Cloning is not a technology continuous with other reproductive technologies

The bottom of the slope is not horrific

Slide 45

Conclusion

- HGP is a source of eugenic threats
- Some uses HGP knowledge in reproductive biotechnology is justified
- But uses of HGP for the sake of cloning are morally problematic