

# Would genome editing harm or benefit the person born as a result?



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## Outline...



§1. Motivations

§2. A bit of history

§3. Person affecting vs identity affecting acts

§4. Would GE be person affecting?

§5. A cynical reflection

§6. What's at stake?

§7. A political reflection....



# Why edit human genomes?

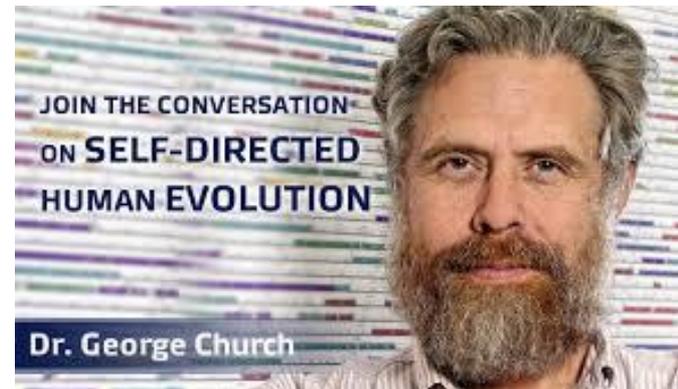
**Health?**

**(“curing” genetic diseases)?**



**Genetic relatedness?**

**Human enhancement!**



# The “therapeutic” case for genome editing is very weak....



Preimplantation genetic diagnosis (PGD) already allows couples at risk of transmitting a genetic disease to their offspring to give birth to healthy children



Only when a couple is unable to produce viable embryos that do not carry genes for a disorder using their own gametes would there be any grounds for attempting to cure affected embryos by editing their genomes.

Even in such cases, couples could always have children using donor sperm and/or donor ova.



Rather than a cure for a disease, then, genome editing would function solely as a means to satisfy the preferences of couples to raise children who were their genetic offspring.

**“Therapeutic” genome editing is a Trojan horse for human enhancement....**



# Who (or what) is being treated?

**Not the child....**

The use of donor gametes would allow a healthy child

**Not the parents....**

They will continue to have a genetic disease

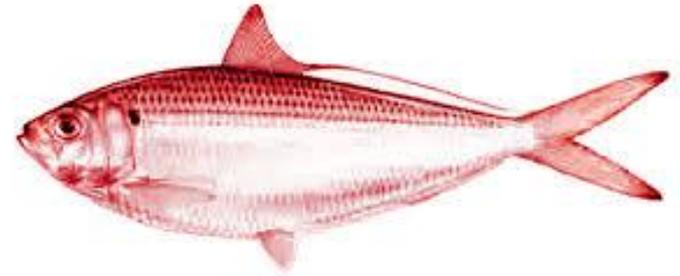
**The relationship!**

It will make possible a “normal” (genetic) relationship (?) between parents and children

**None of this is to deny that some parents will care deeply about having a “genetically related” child**



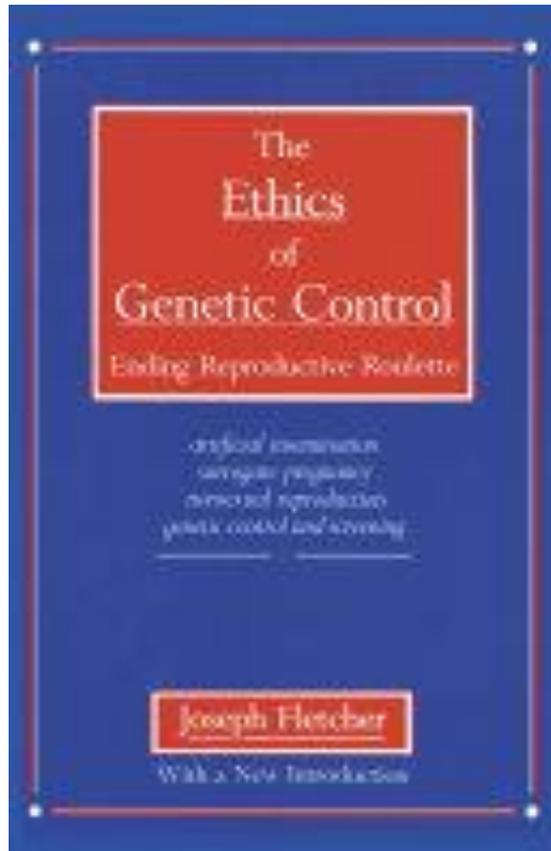
# Why the argument about risk is a red herring...



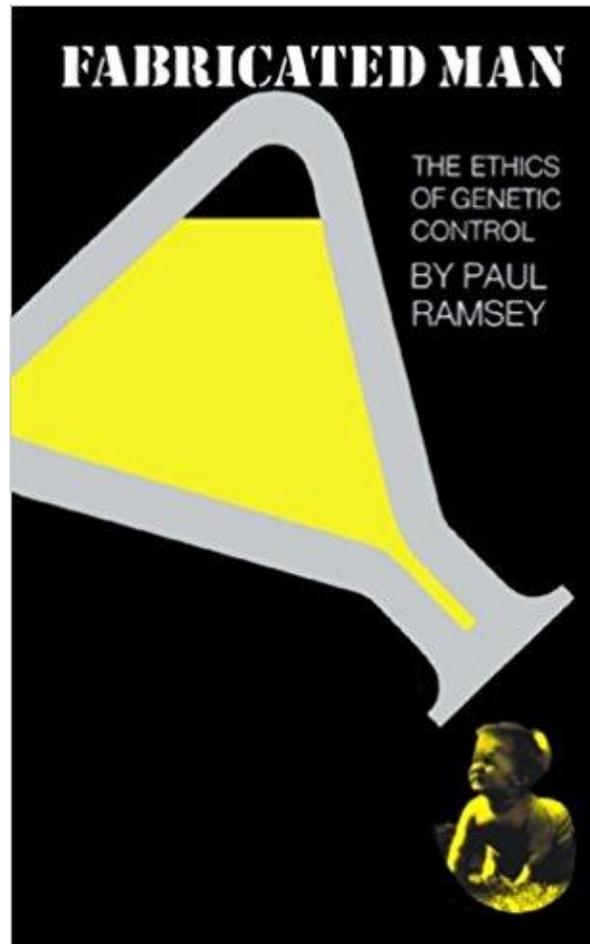
- First use will inevitably be experimental
  - Risk of children being born with disabilities
- But this risk is endemic to reproductive technologies
  - We still don't know if IVF is safe
  - “Natural” pregnancy involves significant risks
- Coming into existence is risky!



A bit of history...



1974



1970

WHAT IS EUGENICS?

by  
MAJOR LEONARD DARWIN

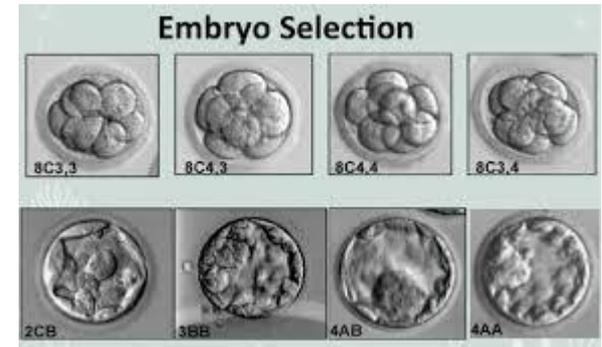
LOTHIAN PUBLISHING CO. PTY. LTD.  
MELBOURNE and SYDNEY  
1930

1930

# The frame of the debate: Two types of technology

## Technologies of genetic selection

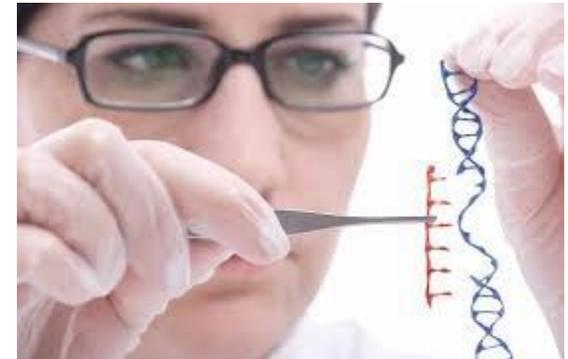
(Sperm sorting, selective abortion, preimplantation genetic diagnosis)



....determine WHICH individual comes into existence

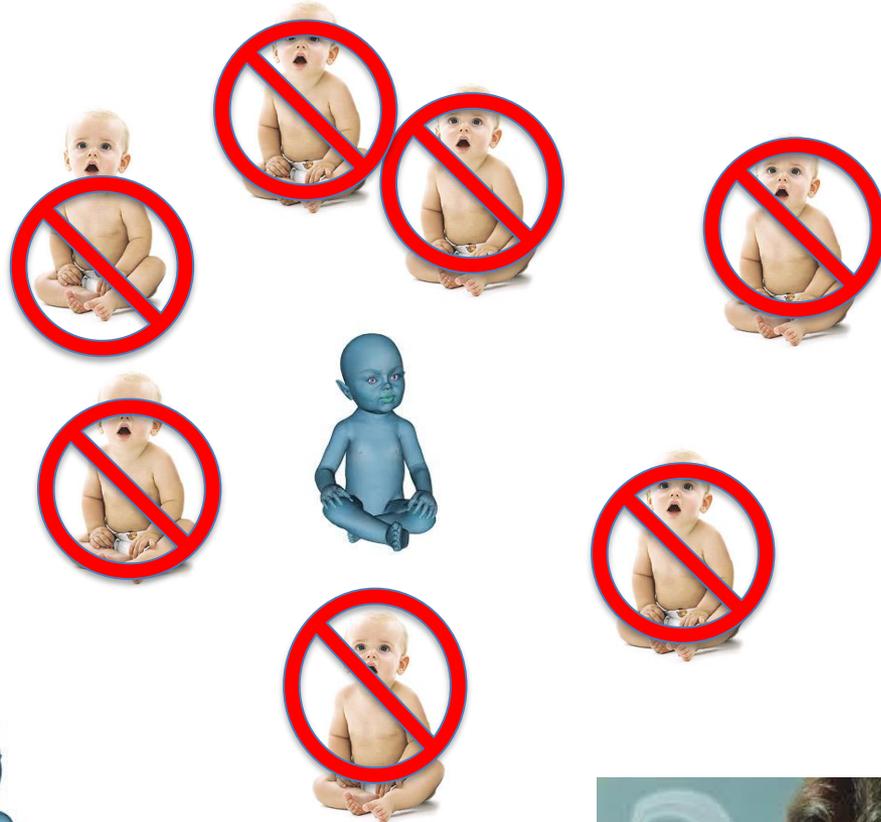
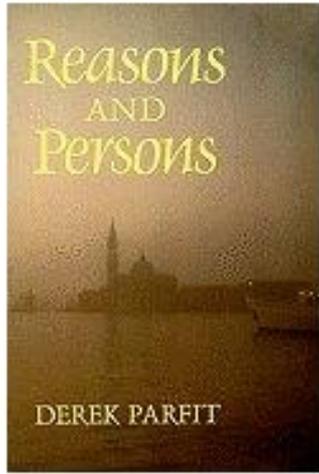
## Technologies of genetic modification

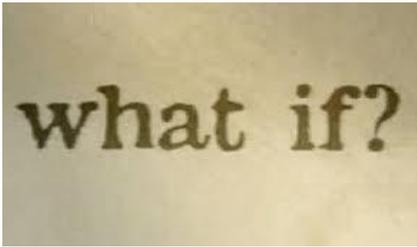
(Recombinant DNA technology, genome editing)



... would alter the capacities of particular individuals

# “person affecting” vs “identity affecting”





We normally decide whether something harms or benefits someone by asking what their welfare would have been like (A “counter-factual”) had that thing not occurred ...

But technologies of genetic selection, like PGD, determine WHICH individual comes into existence



In such cases asking what the life of the person born as a result of the technology would have been like had another choice been made involves a comparison with what their welfare would have been like if they did not exist!

“Identity affecting” choices don’t harm or benefit anyone!



If we use a technology of genetic modification it seems as though we WILL be able to ask what that individual’s welfare would have been like had we not done so

## Different sorts of reasons



For selection (identity affecting)....

Non-comparative benefits...reasons of impersonal beneficence... making a better world

Doing the “wrong” thing doesn’t make anyone worse off...

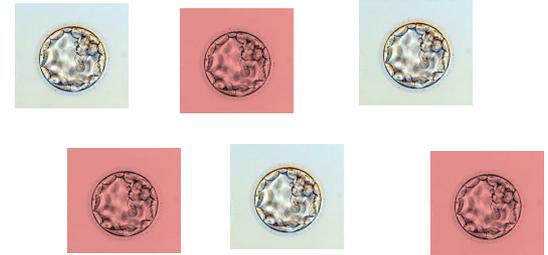
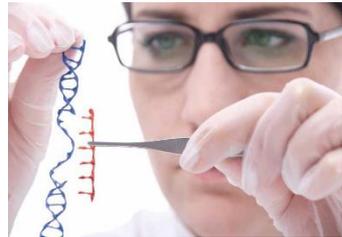
For modification (person affecting)....

Obligations to particular people, to avoid harming them, and to benefit them

**We have stronger reasons to modify than to select!**

**So would genome  
editing be person  
affecting?**

# One way to edit the human genome...



Early stage  
human  
embryo  
(blastocyst)

CRISPR/Cas9

GM embryo (?)



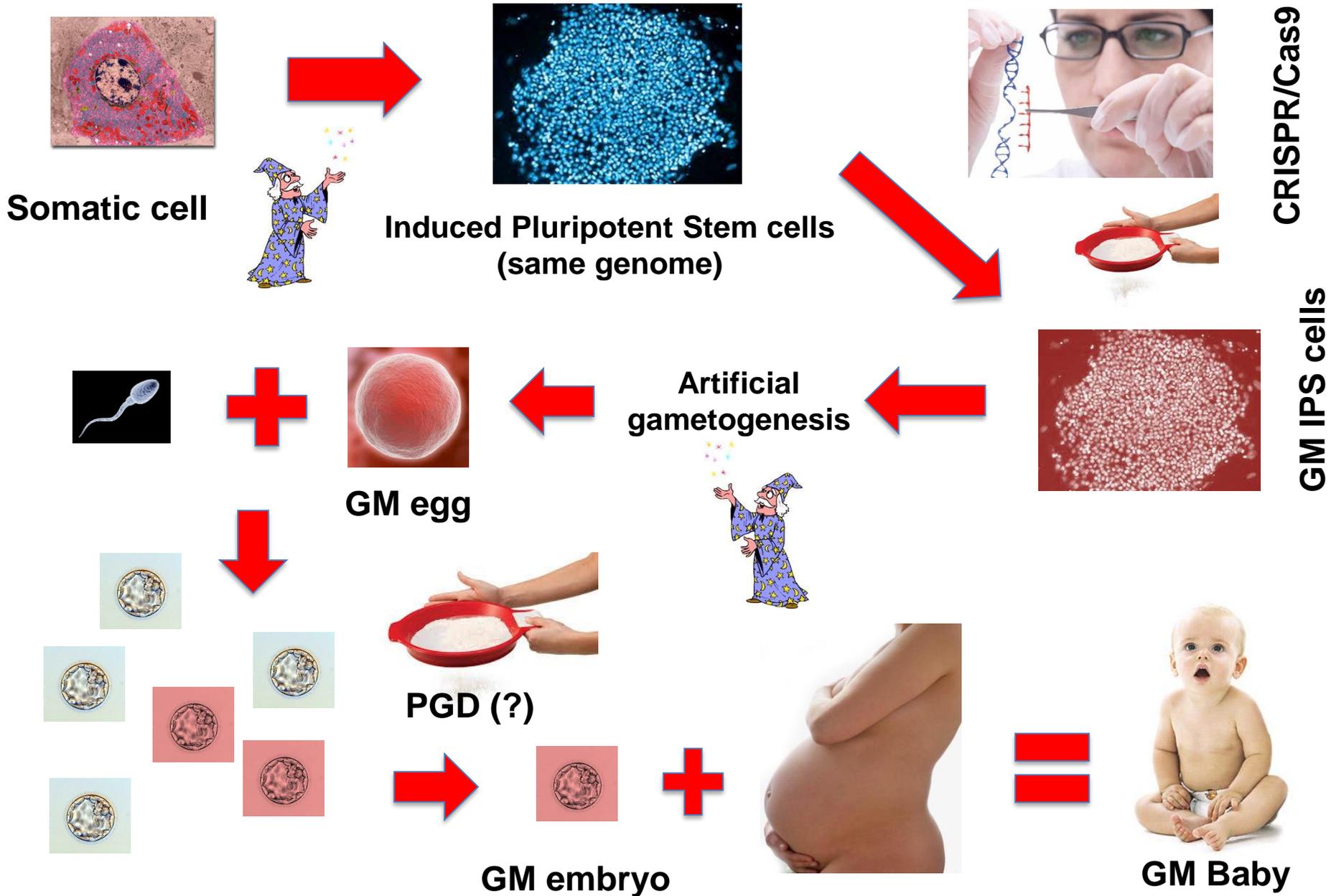
PGD (?)



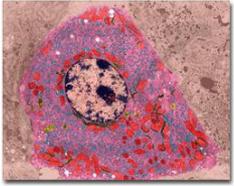
GM Baby

Problem of embryonic mosaicism. Needs multiple embryos

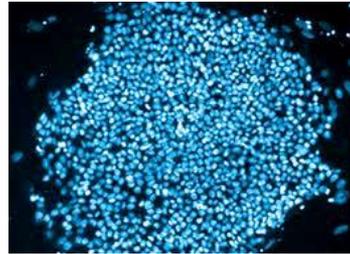
# Another way to edit the human genome...



# A still better way to edit the human genome...



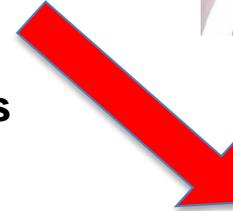
**Somatic cell**



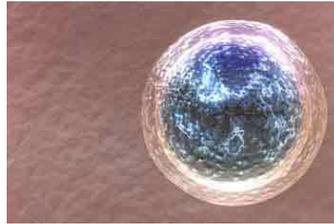
**Induced Pluripotent Stem cells  
(same genome)**



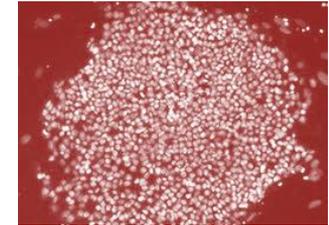
**CRISPR/Cas9**



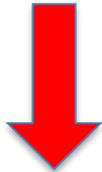
**GM IPS cells**



**de-nucleated egg**



**Somatic Cell  
Nuclear  
Transfer**



**GM embryo**



**Brave woman**



**GM Baby**

Whether these procedures are person affecting or not seems to depend on how we conceptualise the relationship between the embryo selection stage and gene editing stage....

Is it....



or....?





## Devolder and Douglas's challenge....

In "GENE EDITING, IDENTITY AND BENEFIT"

Presented at *Genome editing - biomedical and ethical perspectives: An International Conference*,  
Belgrade, 20-21 August

**What would have a couple done if they hadn't chosen to edit their child's genome....**

....well, that depends on how serious the condition they are trying to avoid...



If it's a serious condition, if they hadn't done GE they would have done PGD or used donor gametes

=> Not person affecting!

If it's not a serious condition, they might have proceeded with the same embryo

=> person affecting!

**We have stronger reasons to correct trivial conditions!**

**Why are we only discovering this now?**



Savulescu, Julian. 2001.

**Procreative Beneficence:  
Why We Should Select  
The Best Children.** *Bioethics*  
15(5): 413-426.

Savulescu, Julian. 2005.

**New breeds of humans:  
the moral obligation to  
enhance.** *Reproductive  
Biomedicine Online*, Volume 10,  
Supplement 1, Pages 36-39.

Savulescu, J., & Kahane, G. 2009. **The moral  
obligation to create children with the best  
chance of the best life.** *Bioethics* 23(5): 274-  
290.



# Parental obligation in an unjust world



Childrens' welfare will be the product of their genes and their environment

Including their social environment

Parents won't be able to change the fact that their child will grow up in a sexist, racist, homophobic environment

But they will be able to change whether they are the target of sexism or racism or (perhaps) homophobia



**The “best” baby turns out to be white, male, and straight... and blonde-haired and blue-eyed...**



Sparrow, R. 2011. A not-so-new eugenics: Harris and Savulescu on human enhancement. *Hastings Center Report* 41(1): 32-42.

# There can be only one!

“best” is a maximising notion!

- There is only one “best genome” for any given environment

Everyone will be morally obligated to have a (cloned) child with the same genome



**Savulescu has ducked these implications by insisting that, because he's been discussing PGD, the "obligation" generates only "pro tanto" reasons (we have some reason) to act...**



**VS**



**This is a strange notion of obligation....**



Sparrow, R. 2007. Procreative beneficence, obligation, and eugenics. *Genomics, Society and Policy* 3(3): 43-59

Savulescu is (pretends to be?) a libertarian



As failures to enhance do not harm anyone, laws requiring enhancement are not justified.

Indeed, laws requiring therapy are not justified

**But if genome editing is person-affecting it is likely to be morally obligatory....**

GE will increase a child's welfare and openness of future

Failure to GE will reduce a child's welfare and openness of future

Failure to GE will constitute "genetic neglect"

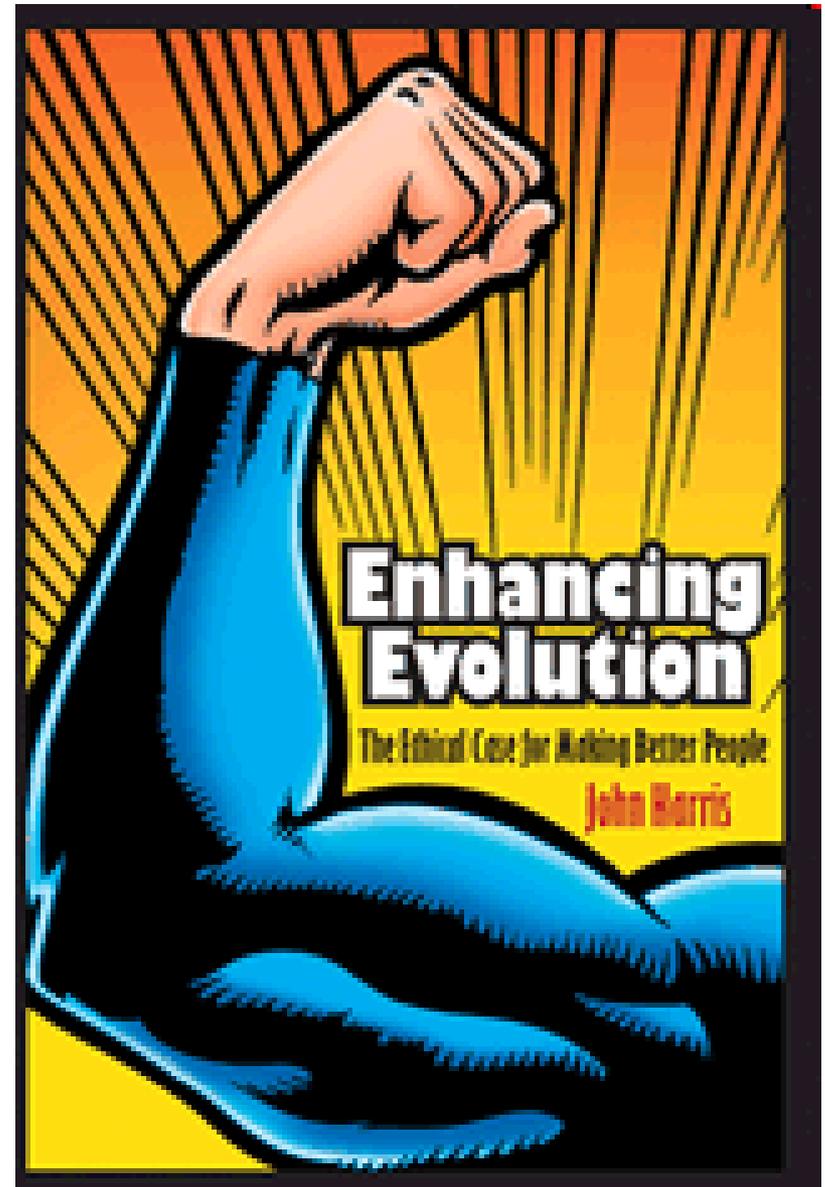
Even "genetic child-abuse"

There will be a strong case for mandatory GE, enforced by the state



“This book defends human enhancement and argues that not only are enhancements permissible but that in some cases **there is a positive moral duty to enhance**” (p. 3)

“The overwhelming moral imperative for both therapy and enhancement is to prevent harm and confer benefit. Bathed in that moral light, **it is unimportant whether the protection or benefit conferred is classified as enhancement or improvement, protection or therapy.**” (p. 50)



**So it's very important that  
we settle on the relevant  
counter-factual...**



**The more we emphasise the therapeutic potential of this technology the more people will believe it to be person affecting...**



**... and the more political support there will be for eventually making it mandatory**



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