Anti-Discrimination Working Group

Meeting #5

Friday, 15 September 2023

9.00, NCRR main meeting room (and online)

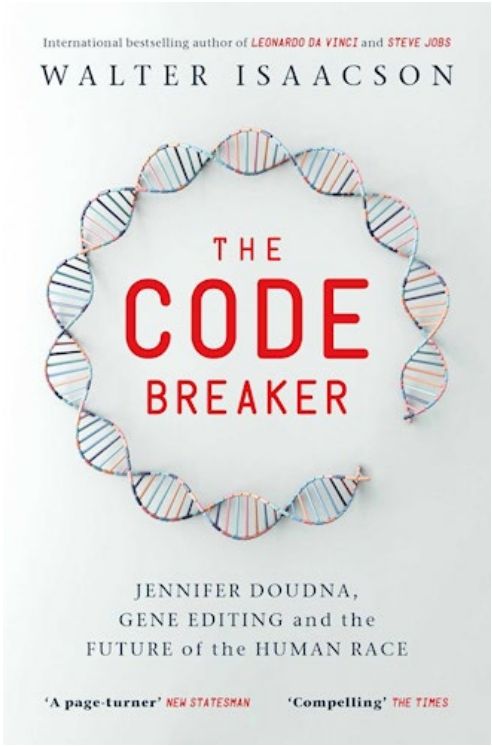
Agenda

1. Introduction round (5 min)
2. Recap: Thought experiments (monogenic diseases, disadvantage vs. disability) (5 min)
3. Thought experiments (physical traits, psychological traits) & discussion (70 min)
4. Ideas for next meeting (5 min)

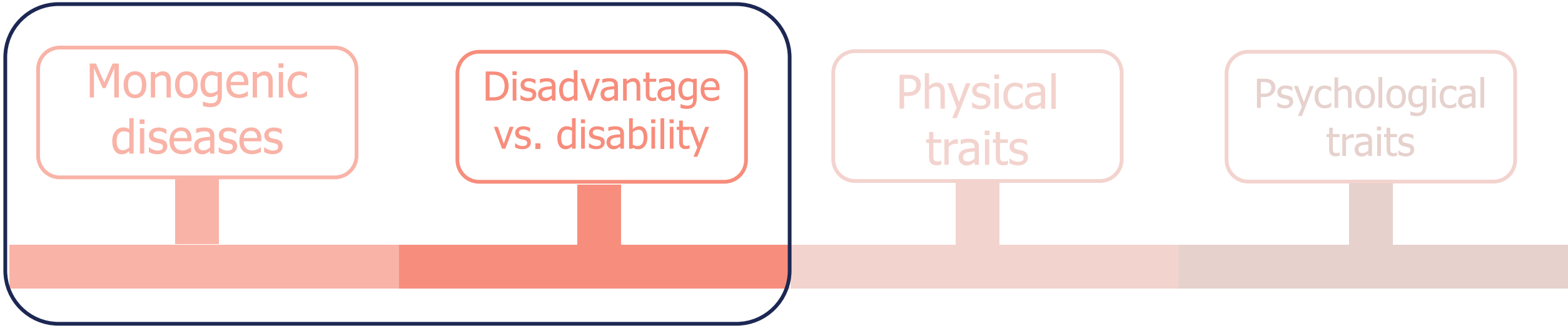
Introductions

Recap: Bioethical thought experiments

- Monogenic diseases
- Disadvantage vs. disability



Thought experiments



Huntington's disease:

- Autosomal dominant disease
- No benefit
- No evolutionary role

Sickle-cell anemia:

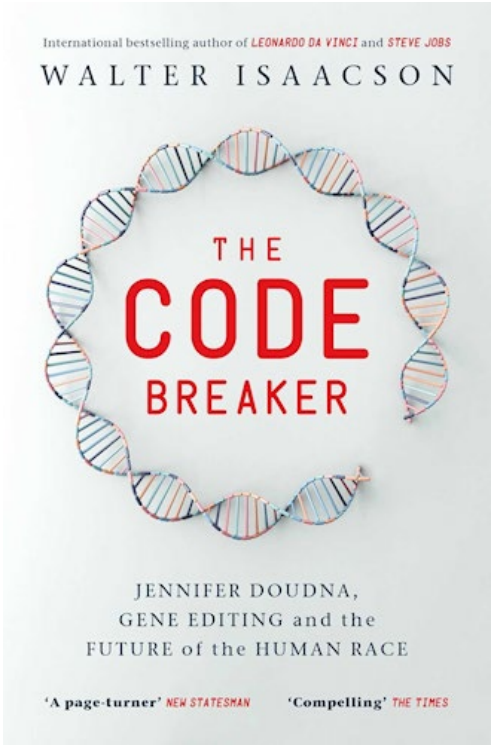
- Recessive disease
- One copy of gene leads to immunity to most forms of malaria

Deafness:

- Deaf lesbian couple wants to have a baby who is also deaf
  - Find congenitally deaf sperm donor?
  - Select embryo with genetic mutation via PGT?
  - Gene edit embryo to be deaf?
  - Rupture child's eardrums after birth?

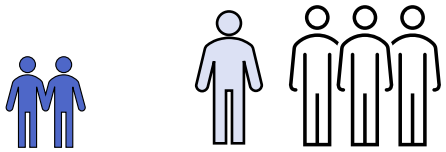
Bioethical thought experiments cont.

- Physical traits
- Psychological traits



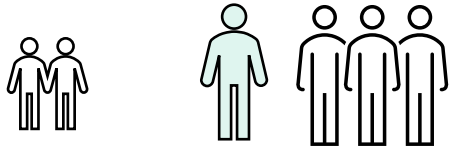
Height

Scenario 1



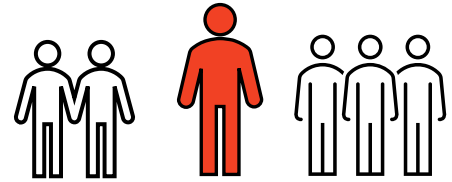
- IMAGe syndrome (stunted growth) caused by a mutation in *CDKN1C*
- Parents select against mutation so children will grow to normal height

Scenario 2



- Parents just happen to be short
- Parents select embryo for height so children will grow to normal height

Scenario 3



- Parents are average height
- Parents select embryo for extra height so children will grow to be taller

absolute improvement vs. *positional improvement*

Treatments vs. enhancements

absolute improvement vs. *positional improvement*

Enhancements that are beneficial to you even if everyone else gets them

Enhancement that are beneficial to you only if others do not get the same enhancements

Monogenic diseases

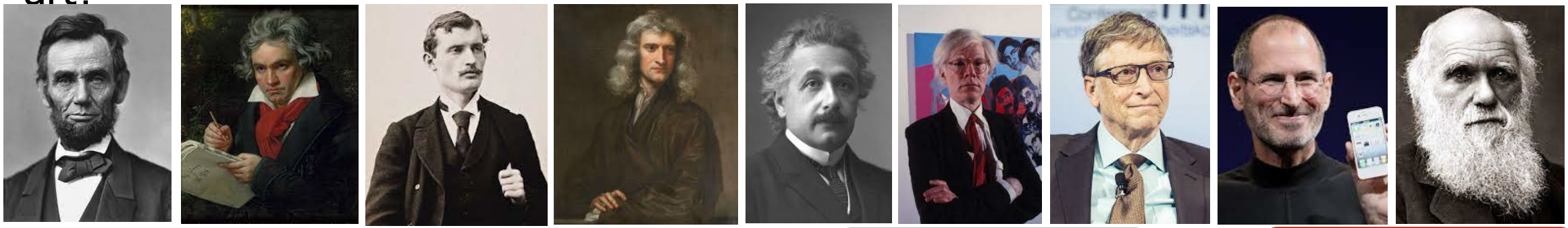
Disadvantage vs. disability

Physical traits

Psychological traits

Psychological disorders

- If genetic factors predisposing to psychological disorders could be selected against or edited, would that be a good thing?
- "Would you cure your own child from being schizophrenic if you knew that, if you didn't, he would become a Vincent van Gogh and transform the world of art?"



Monogenic diseases

Disadvantage vs. disability

Physical traits

Psychological traits

Cognitive skills

- Mouse model: enhanced memory by editing NMDA receptor genes in nerve cells
- Improve memory?
- Improve intelligence?
- What is intelligence? How do we measure it?
- Improving civilization vs. increasing number of conflicts

Monogenic diseases | Disadvantage vs. disability | Physical traits | Psychological traits

Who is going to judge you?

Scenario: There are no government regulations. You go to the fertility clinic, and they give you a list of traits for your future child.

Would you?:

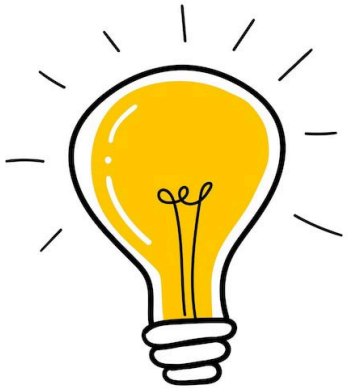
A. Eliminate Huntington's disease / sickle-cell anemia
B. Choose to not pass on genes leading to blindness / deafness
C. Choose to not pass on genes leading to below-average height / above-average weight / low IQ
D. Choose a premium-priced option for extra height / muscles / IQ

What influences how we feel about each scenario?

- Gene editing vs. genetic screening
- Monogenic vs. polygenic traits (+ pleiotropy)
- Curing “disability” vs. enhancement
- Absolute improvement vs. positional improvement
- What is good for the invidividual vs. what is good for human civilization?
- Who gets to make the decisions?

Ideas for next meeting

- **Ableism?**
- More bioethics?
- Genetic counselling?
- Equity and access to genetic testing/research?
- Other emerging technologies?
- Promoting genetic literacy?
- Discrimination at the workplace (academia/research)?



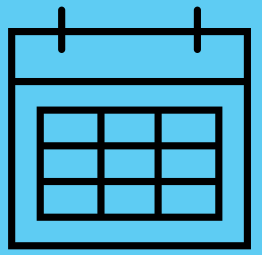
Working Group Website

https://ncrr-adwg.github.io/

- Slides
- Linked journal articles
- Additional resources: Movies, podcasts, books, etc.

Share with colleagues at other institutions!

Next meeting:
October?



Thanks!

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References & further resources

- Lencz et al., (2022), Concerns about use of polygenic embryo screening for psychiatric and cognitive traits. *Lancet Psychiatry, 9*(10), 838-844. DOI: 10.1016/S2215-0366(22)00157-2
- Isaacson, W. (2021). *The Code Breaker: Jennifer Doudna, Gene Editing, and the Future of the Human Race.* Simon and Schuster.
- Fleming, J. (2021). *How to be Human: An Autistic Man's Guide to Life.* Simon and Schuster.