

Australian Citizens' Jury on Genome  
Editing

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# Human genome editing and disability: what are the issues?

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# Heritable genome editing and disability

- The promise of reducing genetic anomalies associated with disease or disability is the **central rationale** for all genomic medicine including HGE
- HGE aims to change individual, family and collective genetic makeup to prevent disabling genetic conditions being inherited



Around 1 billion disabled people globally (WHO), 4.4 million in Australia (AND)

# Why do we want to prevent disability?

- “Disability causes suffering, pain and disadvantage”
- “Disability is costly to society”
- “Being disabled is being less than an ideal human”



# Disability critique

- Not all disability involves suffering, pain or disadvantage; sometimes just difference not accommodated by society
  - ?Major biomedical intervention as best response...
- Not all disability entails extra healthcare or other costs
- “Less than an ideal human” = some questionable ideas about what a human being is (or should be), diversity, the life course, etc....



# Other concerns

- Ignores ***diversity of disabled experience*** and opinion
  - Some people with disabilities want to eradicate genetic disability;
  - others strongly identify with their disabling conditions;
  - others reject them as disabling at all
- Harms people with disability due to ***opportunity costs***
  - Where will finite resources go?
  - Which aims will draw most attention?



# Does HGE change attitudes?

- Harms disabled people through **increasing negative attitudes**
  - *Selecting against genes isn't the same as selecting against people...*
  - ...but “the divide between disease-free genes and faulty genes eventually tracks beyond genetics to people, essentially marking them as society’s ‘desirables’ or ‘undesirables’.”
    - *Françoise Baylis, Altered Inheritance (2019), p. 75*
- Overall increasing power to ‘select’ desired characteristics will lead to more rigid ideas about normality, **less acceptance of diversity** and difference

# Does regulation of HGE express anything?

- Law/regulation is both practical and *expressive* or *symbolic*
  - what we allow (in law, health policy) says something about what we think is generally morally right for community
- Regulating technology like HGE is not just about controlling usage but also about **forming people's moral thinking**
- *What message(s) are conveyed by decisions to permit/not permit HGE? At all? For some impairments, but not others?*

# Is HGE eugenic(s)?

- Idea that human population is improved by encouraging people considered genetically more fit to have more children
- Eugenic history of the twentieth century in Europe and North America (forced sterilisation, 'race hygiene', involuntary euthanasia)
- Historical, moral and emotional weight of 'eugenics' makes it hard to discuss







# Is HGE eugenic(s)?

- Unlike historical eugenics, HGE is constructed around the idea of **(parental) choice**, not benefit to the state...
- *...nevertheless, cost of health and social care are inevitably raised in debate*
- Unlike historical eugenics, **voluntary not compulsory**...
- *...but social expectations generate equally powerful pressures (neoliberal eugenics) – and who can predict what some state, at some time, might do?*

# Do we actually need it?

- Only about 10% disability has identifiable genetic cause
- Most disabling genetic conditions could be avoided in other ways:
  - prenatal genetic diagnosis (PND), preimplantation genetic diagnosis, egg or sperm donation, not having (genetically related) children
- HGE is not really about curing genetic disability; it's about **supporting people's wish to have genetically related children** in a familial context of genetic disability
- ***Is this a good enough reason?***

# Will HGE lower the barrier to intervention?

- We can already avoid much inherited genetic anomaly by PND or PGD
- ***Moral seriousness*** of PND and PGD interventions usually considered to be high
  - Termination
  - Embryo selection
- HGE may be considered **less morally serious**, and therefore its use considered more readily, for more trivial differences



# The importance of asking the right questions...

- Not “should we use HGE to eradicate disability?” but...
- What kind of society do we want?
- What kind of people do we want?
- What is our ultimate goal – is it ‘reducing/eliminating disability’ or something broader?
- Is HGE (or any other technology) a way to achieve that goal?
- If so, how (and how not)?
- How do we ensure these decisions are made fairly, democratically, inclusively?

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