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Session 3: Sexuality, Reproductive Rights and Independent Living

Legacy of Eugenics:

Reproduction, Female Body, and Medical Technologies

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Eugenics Today

The Science Council of Japan, the Subcommittee on Bioethics and Humanities of the Philosophy Committee (2020) *Ethical Justification for the Use of Genome Editing Technology for Human Reproduction (Executive Summary)*, p.6 * Matsubara is one of the members who prepared this report.

“...eugenics and social discrimination, there is a widespread understanding today that decisions concerning reproduction are entrusted to the autonomy of the parents and to individual judgment, rather than the state, and that as long as all people’s rights are protected, there will be no issues like the evils of eugenics in the past.”

“Against the backdrop of this understanding, the expectation of treatment and medical support for people suffering from genetic diseases is discussed in relation to the use of genome editing technology in reproduction.”

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- Eugenics is consistent in that it intervenes in reproduction based on biological and medical characteristics.
 - In this presentation, I focus on the intervention of medical technology on women's bodies.

1. Two Ways to Achieve Eugenics Goals

Positive eugenics:

Efforts aimed at increasing desirable traits

Negative eugenics:

Efforts aimed at decreasing undesirable traits

Source:

<https://eugenicsarchive.ca/discover/encyclopedia/5233c3ac5c2ec500000000086>

● Medical Technologies Used for Eugenic Interventions in Reproduction

Negative eugenics:

- Sterilization (tubal ligation, tubectomy, vasoligation, and vasectomy)
- Hysterectomies, oophorectomies, and orchidectomies
- Irradiation to gonads
- Induced abortion
- PGD (Preimplantation Genetic Diagnosis)
- Prenatal testing

Positive eugenics:

- PGD
- Heritable human genome editing or germline genetic modification

2. Negative Eugenics: Sterilization

Eugenic sterilization laws in Japan

National Eugenics Law (1940-1948)

Article 1: This Law has the aim of national betterment by preventing the increase of persons with bad hereditary characteristics and by intending to increase the persons with healthy characteristics.

Eugenic Protection Law (1948-1996)

Article 1: The object of this Law is to prevent the increase of the inferior descendants from the eugenic point of view and to protect the life and health of the mother as well.

●JDF's Parallel Report for the List of Issues for Japan, June 2019

Submission to the Committee on the Rights of Persons with Disabilities

Article 17 Protecting the integrity of the person

Forced sterilization:

- About 25,000 sterilizations for eugenics reasons
- About 16,500 forced sterilizations for eugenic reasons
- About 70% of them were women. ...

Table 1. Number of sterilizations performed in accordance with Articles 4 and 12 of the Eugenic Protection Law. (1949–1996)

	Art. 4	Art. 12	Total
Women	9,711	1,601	11,312
Men	4,855	308	5,163
Total	14,566	1,909	16,475 (Percent of women 68.7)

Source: Toshimitsu K, 2016, *Forced Sterilization of Disabled Women in Postwar Japan* (In Japanese), Institute of Ars Vivendi, Ritsumeikan University, p. 11.

● Reproduction Control Through Invasion of Women's Bodies

The total number of sterilizations (for eugenic and maternal protection purposes) performed under the Eugenic Protection Law is about 845,000.

About 98% of these are performed on women.

Forced sterilization is still practiced even after the Eugenic Protection Law was revised.

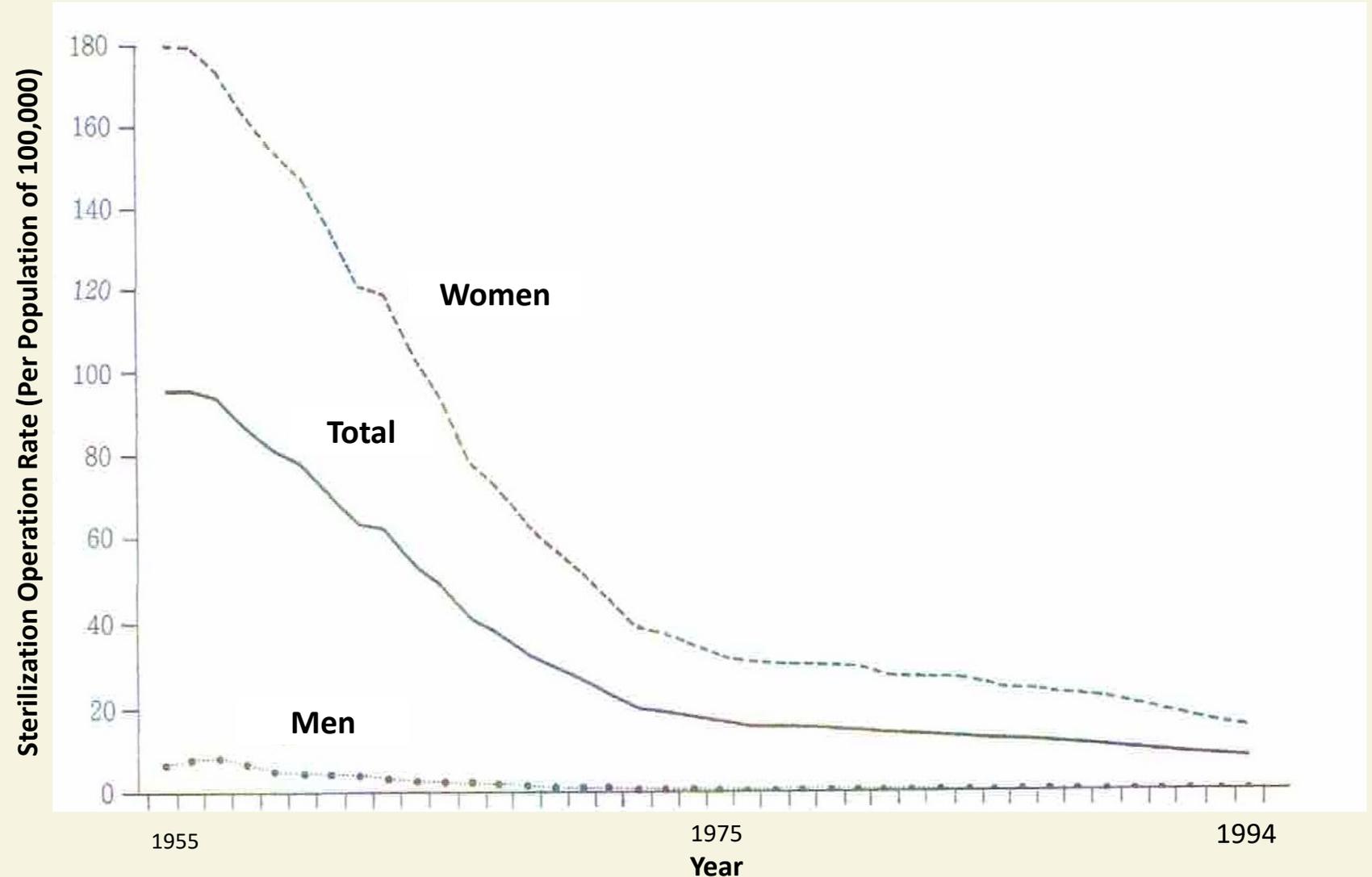


Figure 1. Annual Changes of Sterilization Operation Rate (Per Population of 100,000)

Source: Ministry of Health and Welfare, Eugenic Protection Statistical Report (1994)

3. Positive Eugenics: Heritable Human Genome Editing

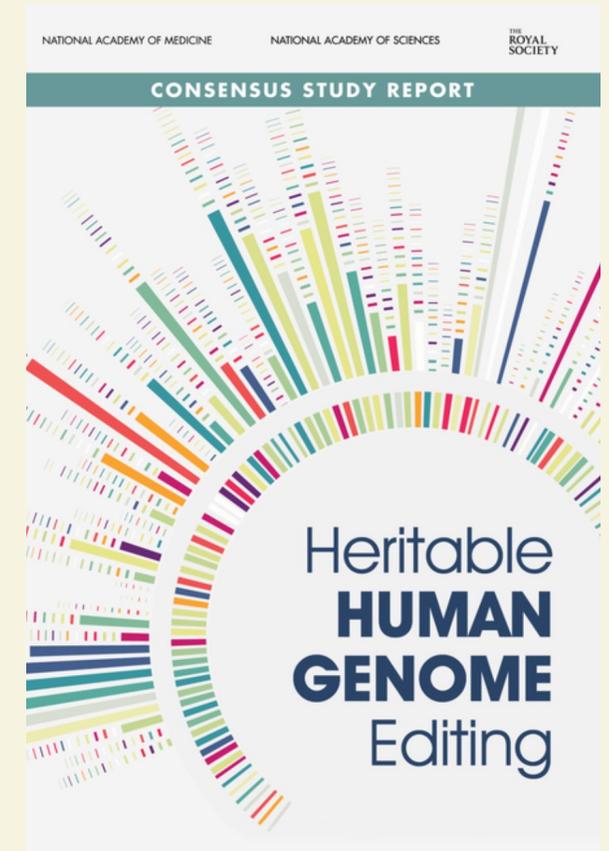
- In the international scientific community, heritable human genome editing (HHGE) or germline genetic modification has not been implemented due to safety concerns and ethical issues.
- He Jiankui(賀建奎)announced in November 2018 that he had created the world's first genetically edited babies in China. This experiment violated international and Chinese ethical guidelines for embryonic genetic research.
- Leading scientists have called for an international moratorium on the clinical research of HHGE.
- At the same time, however, the international scientific community has begun to discuss clinical pathways for implementing HHGE.

● Translational Pathway for HHGE 1

International Commission of the Clinical Use of Human Germline Genome Editing, National Academy of Medicine, National Academy of Sciences, and the Royal Society (2020) *Heritable Human Genome Editing*, p.1

“HHGE could represent an important option for prospective parents with a known risk of transmitting a genetic disease to have a genetically- related child without that disease and its associated morbidity and mortality.”

“However, it will be essential to establish safe and effective methodologies that could form the necessary steps in a translational pathway for any clinical uses of HHGE.”



<https://www.nap.edu/catalog/25665/heritable-human-genome-editing>

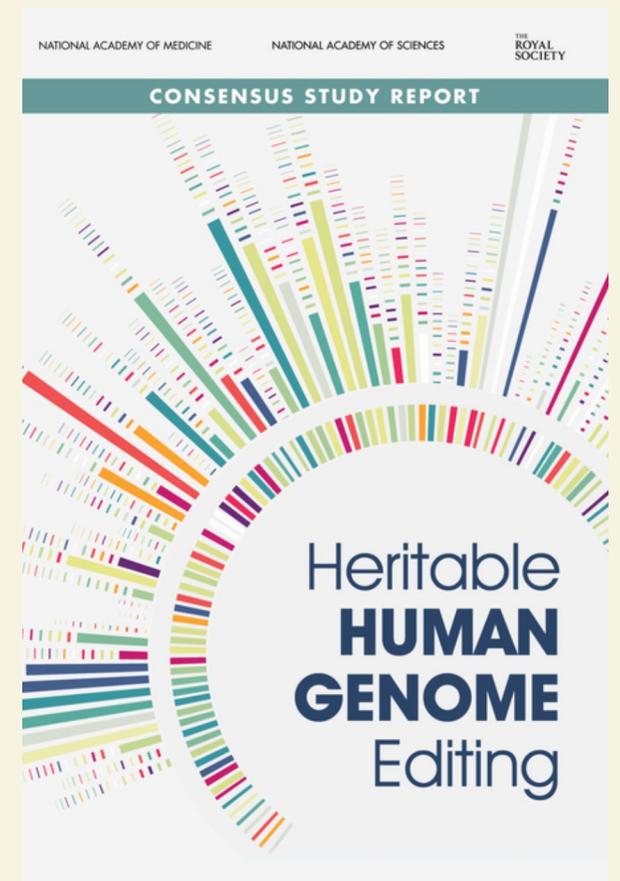
● Translational Pathway for HHGE 2

International Commission of the Clinical Use of Human Germline Genome Editing, National Academy of Medicine, National Academy of Sciences, and the Royal Society (2020)
Heritable Human Genome Editing, p.3

Recommendation 4

Criteria for initial uses of HHGE:

1. the use of HHGE is limited to serious monogenic diseases; the Commission defines a serious monogenic disease as one that causes severe morbidity or premature death;
2. the use of HHGE is limited to changing a pathogenic genetic variant known to be responsible for the serious monogenic disease to a sequence that is common in the relevant population and that is known not to be disease-causing; ...



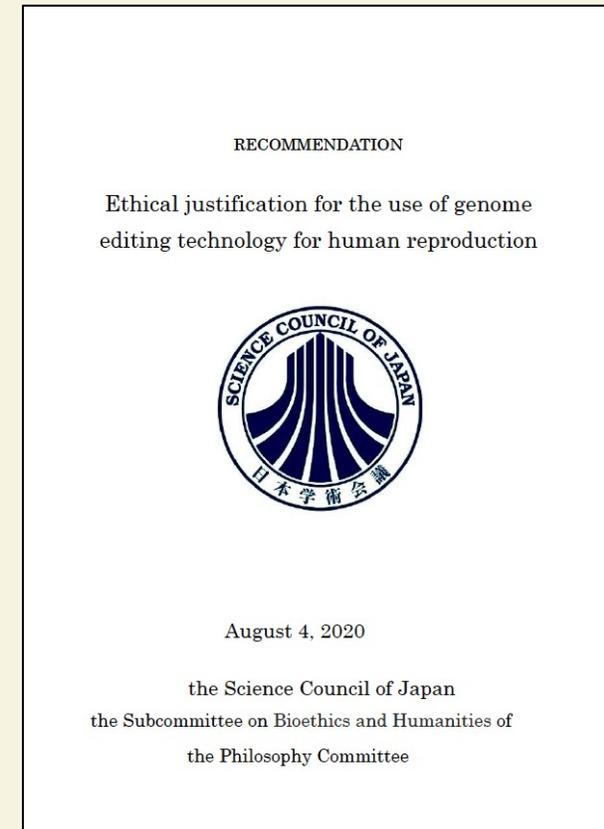
<https://www.nap.edu/catalog/25665/heritable-human-genome-editing>

● Recommendation of the Science Council of Japan, the Subcommittee on Bioethics and Humanities of the Philosophy Committee, August 2020

Ethical Justification for the Use of Genome Editing Technology for Human Reproduction (Executive Summary), p.6

“The old eugenics permitted an invasion of women’s bodies in the form of sterilization or abortion on the basis of genetic characteristics that were deemed undesirable, for the purpose of preventing inheritance of such characteristics.”

“The use of genome editing in human reproduction is carried out on the basis of genetic characteristics, and on a tacit understanding that if a new genetic disease were to appear in the embryo or fetus, the birth of a child with a disease or disability would be avoided by abortion or by miscarriage/stillbirth.”



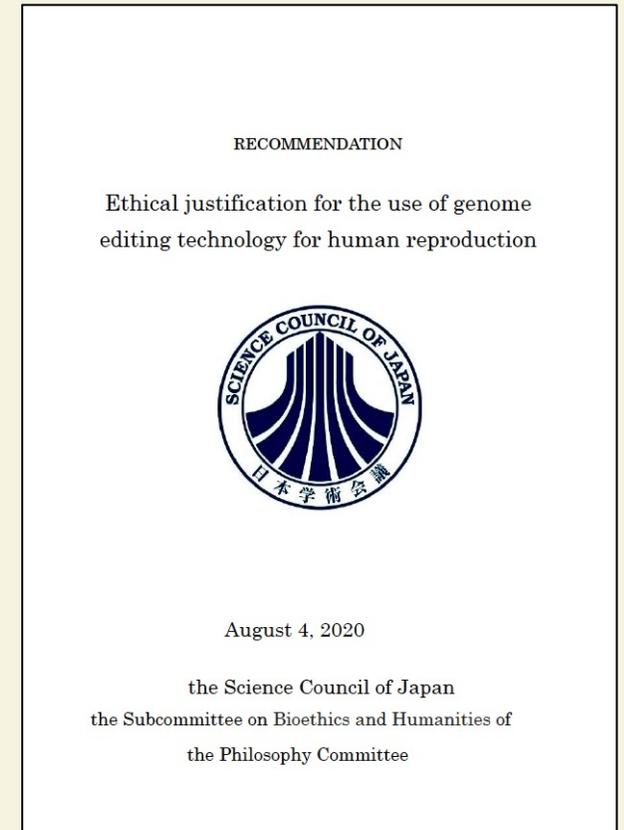
<https://www.scj.go.jp/ja/info/kohyo/pdf/kohyo-24-t292-5e.pdf>

● Recommendation of the Science Council of Japan, the Subcommittee on Bioethics and Humanities of the Philosophy Committee, August 2020

Ethical Justification for the Use of Genome Editing Technology for Human Reproduction (Executive Summary), p.7

“Particularly in relation to the challenges of the new eugenics or social discrimination, if an abnormality were to be discovered in an embryo or fetus that had undergone genome editing, eugenic coercion to proactively opt for abortion would come into play.”

“This choice would be expected in order to avoid failures of experimental treatments using genome editing, and the woman’s body thus functions as a breakwater against the results of experimental failure.”



<https://www.scj.go.jp/ja/info/kohyo/pdf/kohyo-24-t292-5e.pdf>

Summary

- Eugenics has been consistently based on the medical model of disability, which has used “hereditary disease” or “incurable disease” as a marker for invasion into the body. It has used the female body as a “breakwater” to select offspring.
- Multiple discrimination against women with disabilities is closely related to eugenic issues, not only in forced sterilization and abortion, but also in situations where assisted reproductive technologies are used.
- Behind the problem lies women’s heavy and disproportionate burden in human reproduction. The desired relationship between sexuality, reproduction, and medical technologies needs to be examined with reference to the women’s bodies.