

Ethics and Intellectual Disability

Eugenic Sterilizations in Japan and Recent Demands for An Apology: A Report

Takashi Tsuchiya

In Japan, a "eugenic" law permitted involuntary sterilization of people with intellectual or mental disability from 1948 to 1996. More than 16,500 women and men were sterilized against their will. On September 16, 1997, 17 civic groups, representing women and people with disability, and dozens of interested persons demanded from the Minister of Health and Welfare an apology, compensation, and investigation, but the Ministry refused with the excuse that these sterilizations were legal at that time.

The Eugenic Protection Law and its Enforcement

The objective of the "Eugenic Protection Law (EPL)," established in 1948, was "to prevent birth of inferior descendants from the eugenic point of view, and to protect life and health of mother, as well." (Article 1) This reflected the Japanese Government's worry not only about over-population

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Tara's Petition

Julie Eddinger

When Tara Lanigan, an 18-year-old Special Education student at Chantilly High School in Fairfax, Virginia, wanted to participate in the commencement ceremony with her friends, she was told by Fairfax County school officials that she could not. Tara had completed all of her 23 credits for her IEP (Individualized Education Plan). Tara's mother protested on behalf of her daughter whom she felt was unfairly denied the opportunity to participate in commencement exercises with the rest of her class. Her mother was not insisting on a regular diploma. She acknowledged that Tara had not completed all the standard requirements. She merely wanted her daughter to attend the ceremony with the rest of her class. In a dramatic story, chronicled over three months last spring by a local newspaper, *The Fairfax Journal*, Tara and her mother fought this school regulation along with supportive members of their community.

Tara had been diagnosed as moderately retarded, but it never stopped her from realizing her goals. Tara's mother, Diane Lanigan, continuously fought for her daughter to have a "normal" life. Yet, Fairfax County school officials would not let Tara

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and the predicament of mothers and pregnant women in the post-war baby boom, but also the "deterioration" in quality of offspring. In fact, EPL called sterilization a "eugenic operation," which was done either voluntarily or involuntarily.

In Article 3 EPL permitted a physician to sterilize the person with his/her own and the partner's consent. Under this Article anyone could be voluntarily sterilized if: (1) he/she or the partner had hereditary "psychopathia," "bodily disease" or "malformation," or the partner "has mental disease or feeble-mindedness"; (2) he/she or the partner's relative within the fourth degree of kinship had hereditary "mental disease," "feeble-mindedness," "psychopathia," "bodily disease," or "malformation"; (3) he/she or the partner was "suffering from leprosy, which is liable to carry infection to the descendants"; (4) she was a mother whose life was "endangered by conception or by delivery"; or (5) she was a "mother actually having several children" whose health condition was "feared to be seriously affected by each occasion of delivery."

On the other hand, Articles 4 and 12 provided involuntary sterilization. It was performed without the patient's own consent. Article 4 required a physician to apply to the prefectural "Eugenic Protection Commission" to examine the propriety of sterilization when a patient was suffering a disease on the Annexed

List and the physician considered that sterilization was necessary "for the public interests in order to prevent hereditary transmission of the disease." All diseases on the Annexed List were those that were then regarded to be hereditary, such as schizophrenia, manic-depressive psychosis, epilepsy, "remarkable abnormal sexual desire," "remarkable criminal inclination," Huntington's disease, muscular dystrophy, albinism, achromatopsia, deafness, hemophilia, "rupture of hand," "rupture of foot," etc. Moreover, Article 12 (added in 1952) permitted a physician to apply for a patient with "psychosis or mental deficiency" that was neither hereditary nor on the Annexed List, provided the patient's parent or guardian gave consent.

On receiving the application from a physician, the prefectural Eugenic Protection Commission was to notify the patient, examine the case, decide the propriety of sterilization, and finally notify both the patient and the applicant physician (Article 5). The patient or applicant physician who objected to the decision could apply for review by the Eugenic Protection Commission within two weeks (Article 6). The Commission then would review the case, decide the propriety, and notify the patient, applicant physician, prefectural Commission, and the physician who was to perform the surgery (Article 7). Those who objected to the decision could institute a lawsuit for its rescission (Article 9).

However, these provisions for

notification, review, and lawsuit did not apply to the patient with mental or intellectual disability mentioned in Article 12. In this case notice was only sent to the applicant physician and the parent or guardian who had consented (Article 13). In addition, the Ministry of Health and Welfare (MHW) issued a guideline "On the Enforcement of the Eugenic Protection Law" in 1953 saying that "a eugenic operation can be performed against the patient's own will" when the commission had judged it necessary. This guideline stated "It is permissible to restrain the patient's body, to administer an anesthetic, or to deceive the patient, etc." These new provisions in the early 1950s enabled and authorized forcible and deceitful sterilization, which was the common way of practice.

Articles 4 and 12 provided involuntary sterilization

EPL required physicians to send monthly records of performed sterilization and abortion to the Prefectural Governor. MHW annually published the statistics of them. According to the statistics, from 1949 to 1994, 16,520 sterilizations were performed applying Article 4 or 12, namely without the patient's own consent. 11,356 of these involuntary sterilizations were performed on women, and 5,164 on men.

In 1996 the eugenic provisions were repealed, and EPL was re-

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vised producing the "Maternal Protection Law," which allows only voluntary sterilization and abortion. This revision was formally done by accepting the proposal by National Family Members' Organization of the People with Mental Illness, but was stimulated by the criticism of foreign people who had heard about EPL from Japanese women with disabilities at the UN Conference on Population and Development in 1994 and Beijing Conference on Women in 1995. But at the time of the revision there was no criticism for the inhumane sterilizations in the Diet.

The Realities

Most of the involuntary sterilizations were performed on inmates of psychiatric hospitals and institutions for intellectually disabled people. Usually these inmates were deceived into having the surgery. For example, a young woman with mental disability had surgery in the psychiatric hospital without being informed what it was for. When she came to know she was sterilized, she was greatly shocked and her mental condition deteriorated. In this case, her parents gave consent to the surgery (newspaper Asahi Shimbun 9/17/97, p.21). Sometimes they were asked but virtually forced to consent to it, because having sterilization was often a requirement for entering an institution, which was what the parents wanted badly. If she/he had not been sterilized at entrance, sterilization was required at

leaving the institution or moving to the "mixed" section in which men and women were institutionalized together.

Not only people with intellectual or mental disability but also people with physical disability were deceived or virtually forced to consent to have sterilization. In 1996 at a public meeting in Osaka a woman with cerebral palsy told her story of being sterilized by radiation. She was required to be sterilized to enter an institution, and she could not refuse it under the pressure by her parents and employees of the institution. In case the person was a minor, sterilization was performed merely on the parent's consent, without notifying that person at all.

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Very often these sterilizations had been performed not by tying up the fallopian tube but by hysterectomy, because the purpose of the surgery was not only sterilization but also stopping menstruation in order to make the care of the inmate women easier. To stop menstruation, the surgery needs to take either the ovary or the womb, but since taking the ovary causes "loss of femininity," physicians preferred taking the

womb "on the patient's behalf." This procedure was illegal, because EPL permitted only the sterilization "without removing reproduction glands" (Article 2) and prohibited other kind of sterilization "without appropriate reason." (Article 28) It is apparent that stopping menstruation for easy care can never be appropriate reason. But no physician has been accused or punished for this practice. Some such surgeries were performed by the professors of the national universities at the university hospitals. A professor told a newspaper reporter that he firmly believed it to be legal, ethical, and the best way for the patient (Mainichi Shimbun 6/12/93, p.26).

The Demands and Responses

Against these inhumane sterilizations, people with disability and their advocates have protested to the government over the years, but gained little public attention. But when the forced sterilization in Sweden was reported internationally at the end of August 1997 and the Swedish government apologized, protesters were encouraged. On September 16, dozens of interested persons and 17 groups of women, people with disability, employees of institutions, lawyers, and researchers, sent representatives to the Ministry of Health and Welfare to meet officials and demanded from the government: (1) an official apology to all who were forcibly sterilized and all who were insulted by being called "inferior descendants" under EPL, and consideration for compensation;

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(2) an investigation into the historical facts by setting up the special investigation committee, in order to make public the infringements of basic human rights of people with disability and to find the necessary and proper form of apology and compensation, without infringing the privacy of the victims; and (3) an investigation into the facts of illegal hysterectomies of women with disability not only in the past but also at present, and proper measures to prevent such a practice and to give relief to the victims, respecting their rights and the privacy.

But to these demands, Ms. Tomoko Kitajima, an official of MHW, replied: (1) There is no need to apologize, because sterilizations were performed in accordance with EPL and legal. As an administrative organ, MHW cannot compensate for legal cases; (2) Sterilizations without the patient's own consent were not necessarily forced, since EPL required an examination and provided review. We have never heard of a case in which sterilization was performed forcibly, and there is no victim here at the meeting. If you know of a case which was illegal (without the examination, etc.), please notify us. The Ministry cannot investigate until we know of an illegal case; (3) MHW has published annually the statistics regarding sterilization. Further investigation is impossible, because Article 27 of EPL requires protection of the privacy of the patient; (4) The hysterectomies of

disabled women had nothing to do with EPL; it was not performed in accordance with EPL. It is a matter of the propriety and legality of each case, and of whether it had an appropriate reason. These must be judged individually by the court, not by MHW.

The protesters organized "the Society for Demanding An Apology for Forced Sterilization"

In response to the answers by MHW, the protesters organized "the Society for Demanding An Apology for Forced Sterilization" on October 6. It will hold public meeting on November 13 in Tokyo. It also plans to collect information about the cases of involuntary sterilization from the victims by telephone for a week.

In my view, Ms. Kitajima's reply is not at all sufficient to acquit MHW. First, it was MHW that officially permitted coercion and deceit in the guideline in 1953. Even if it was not MHW but the Diet that was responsible for the legislation and the negligent revision of EPL, MHW was clearly responsible for administration and negligent abolishment of this guideline. Second, saying that EPL required examination and provided review for all sterilizations without the patients' consent is false. As I mentioned above, Articles 12 and 13 permitted sterilization of people with mental or intellectual disability only with the parent's or guardian's consent and without

notifying the patient, and did not provide for review. It was these Articles that justified deceiving the patient. Third, MHW could not have been unaware of illegal cases, for a lot of hysterectomy cases had been reported in the newspapers which seemed without appropriate reason. If MHW was unaware of the reports, it must be awful negligent in its administration. Fourth, MHW must be able to investigate the records of the examination of the Eugenic Protection Commissions respecting the privacy of the patients. That is just what the citizens are claiming. Refusing to investigate simply with the excuse of protecting privacy is absurd. Fifth, although the matter of whether each hysterectomy was illegal should be decided finally by the court, MHW cannot say the judgment has nothing to do with an administrator's task. An administrator must judge the legality of its actions, even though its propriety is finally decided by the judiciary. If it had no judgment at all, MHW could not administrate at all.

All quotations from EPL are translated by Fukio Nakane in Eugenic Protection Law, EHS Law Bulletin Series Vol. VIII, Tokyo: Japan, Eibun-Horeisha, Inc., 1962. Quotations from the 1953 guideline of MHW are translated by Tsuchiya. Special thanks to Mr. Osamu Nagase, Mr. Yasutaka Ichinokawa, Mr. Shinya Tateiwa, Ms. Aiko Tsutsumi, Ms. Kumiko Ogoshi, Ms. Tomoko Kitajima, Ms. Makiko Kato, Mr. Isao Morikawa, Ms. Junko Sakaiya, Ms. Makiko Ishihara, Prof. Robert M. Veatch, and Prof. LeRoy B. Walters.

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A Universal Declaration on the Human Genome and Human Rights

Dr. Cees van de Vate

UNESCO is presently preparing a Universal Declaration on the Human Genome and human rights. It has long encouraged reflection on the social and human consequences of scientific discoveries. In 1993 the General Conference of UNESCO decided to set up the International Bioethics Committee (IBC) in order to stimulate world-wide debate about the consequences of the growth of the life sciences. The Committee brings together some fifty prominent experts from every part of the world, who serve in a personal capacity.

UNESCO is presently preparing a Universal Declaration on the Human Genome and human rights.

The composition is very much transdisciplinary, with professors in law, medical sciences, genetics, etc., and leading persons in the international field such as the President of the International Court of Justice. To this body UNESCO entrusted the preparation of "an international instrument on the protection of the Human Genome." This instrument should be "a response to the need to protect humanity from the unprecedented risks connected with the growth of genetics." Life sciences have to develop "in a manner respectful of human rights."

The IBC has tried to fulfil this high-sounding duty in five consecutive sessions in Paris, starting in 1993. Expert groups presented reports on hot issues like human gene therapy, genetic screening and testing, genetic counseling, and human population genetics. Each session resulted in an update of the Declaration, which changed considerably, not in the least by the activities of observers from invited NGO's. The title changed, priorities changed, restrictions were added, and offensive passages removed.

Inclusion International (formerly ILSMH, or 'The League'), which is a human rights NGO advocating with and for people with an intellectual disability, has commented on the successive updates in a series of responses, which contained detailed alternative wordings.

The first update (the "Revised Outline" of 7 March 1995) was (at least from the perspective of Inclusion International) a pretty lamentable document. It sketches an overly optimistic picture of the advances and benefits of science. It chose to protect genetic research as its main objective and to use the rights of individuals as side constraints. In it science aims at "the prevention of disability and disease." In the latest update human rights appears in the title and precedes research in the rubrics of the draft. Human biological diversity is

acknowledged in Article 1. However, some important desiderata still remain to be realized. Among these desiderata are: a monitoring process that includes the composition of the monitoring body representing vulnerable groups and human rights organizations, an explicit rejection of eugenics and eugenic measures, and a prohibition of human cloning and germ-line therapy.

The official promulgation will be in 1998, at the 50th Anniversary of the Universal Declaration of Human Rights.

The issues will come for a final discussion before the General Conference in November 1997. The official promulgation will be in 1998, at the 50th Anniversary of the Universal Declaration of Human Rights. It is hoped that the delegates will reach changes for the good, so that these rights are furthered indeed.

Dr. Cees van de Vate received his doctorate in biology and has also studied theology. He is now the pastor of the Reformed Church in Zandvoort, The Netherlands.

Special Interest Research Group on Ethics

Many participants in the 10th World Congress of the IASSID in Helsinki (July 1996) showed a particular interest in ethical aspects of recent developments in research (genetic and behavioral), service management and policy. The pre-congress workshop on 'Intellectual Disability, Genetics and the Value of Life' and the session of Inclusion International on social consequences of the Humane Genome Project and other genetic research projects offered outstanding examples of the growing interest in normative reflection in the field of intellectual disability. Many researchers in the field of social science as well as the field of medicine and biology showed a consciousness of their individual and social responsibilities and an eagerness to discuss the ethical perspective of their work.

During the congress the initiative was taken to establish a Special Interest Research Group on ethics and Intellectual Disability. A Special Interest Research Group will be sponsored by the international Association for the Scientific Study of Intellectual Disability after recognition by its Board. This recognition can be obtained when a sufficient number of persons have registered as a member of this SIRG. Aim of the SIRG on Ethics and Intellectual Disability is:

- to promote exchange about key issues in the field of ethical reflection on research, services and policy regarding persons with intellectual disability
- to explore opportunities for multidisciplinary and international cooperation
- to engage in discussions on social and professional responsibilities of scientists and caregivers.

If you agree to the above mentioned set of common objectives and if you are interested in participating in regular meetings on topics as those mentioned above, then register as a member of the SIRG on Ethics by writing or e-mailing to:

Herman P. Meininger, Faculty of Theology and Philosophy Vrije Universiteit, De Boelelaan 1105, 1081 HV Amsterdam, The Netherlands.
E-mail: H.P. Meininger@esau.th.vu.nl

Please state your full name and address, the name of your organization, university or institute, and E-mail address. Also indicate whether your organization is a member of IASSID or whether you are a personal member of IASSID. Non-members of IASSID are also invited to partake in this Special Interest Group.

The Law and Retardation

Brief summaries of important legal cases will appear from time to time in the newsletter prepared by Susan Poland, J.D., National Reference Center for Bioethics Literature, The Kennedy Institute of Ethics

Pihl v. Massachusetts Department of Education, 9 F. 3d 184 (1st Cir. 1993)

Karl Pihl, age 27 at the time of the case, is emotionally disturbed and mentally retarded. He also has profound hearing loss and speech deficiencies. When he was 19, his IEP (individual education plan) was disputed between his parents and the school district and not implemented. They asserted that the state had failed to provide free public education to Karl as required by law under IDEA (Individuals with Disabilities Education Act). They sought compensatory education regardless of his age.

IDEA provides for education to disabled students between ages 3 and 21. Compensatory education is a legal remedy provided under IDEA for compensation for rights denied in the past; it differs from compliance with IDEA. The court reasoned that under IDEA compensatory education must be available beyond age 21 as a remedy regardless of age or eligibility. In Karl's case, he is entitled to two years of compensatory education despite being age 27 if he can prove that the school district denied his right to an education under IDEA.

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To add your name to the mailing list for the Network on Ethics and Intellectual Disabilities write:

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participate in the commencement ceremony with her classmates. She told the *Fairfax Journal* that Tara "sees herself as a senior and does not see herself as different. If they don't allow her to wear a cap and gown and walk across the stage like 99 percent of the others, that's just discrimination."

Mrs. Lanigan believed that the commencement ceremony was a rite of passage for Tara. "The graduation ceremonies for mentally retarded students mean saying goodbye to that segment of their education, the academic part, and the beginning of a new segment, their vocational training." Area II Superintendent, Paula Johnson, offered an alternative, "Nobody feels good about this, but we try to be fair. She can participate in the ceremony when she completes her vocational training requirement next year." She claimed fairness to other students was the main concern of school officials. If Tara participated in the ceremony, then other students who had been told they could not attend the ceremony because they failed to fulfill their course requirements would then want to participate also.

A petition filed by Tara's

mother to urge a school policy change received 1,000 signatures. She wrote letters to George Allen, Governor of the State of Virginia, and the Fairfax County School Board Chairman, Kristen Amundson, for their help. The week of graduation in June, the School Board finally changed the policy to allow Special Education students to march in commencement exercises with their graduating class even if they still had vocational training requirements left to complete.

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After three months of determined action, Mrs. Lanigan and Tara won their fight. On June 18, 1997, Tara Lanigan, in a mortarboard and graduation gown, joined 540 of her classmates in their ceremony. Most importantly, she *experienced* the rite of passage of commencement with her class.

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Pat Milmo McCarrick

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