

**UNITED NATIONS COMMITTEE ON THE ELIMINATION OF ALL FORMS OF
DISCRIMINATION AGAINST WOMEN**

SUPPLEMENTAL INFORMATION RE:

A.S. V. HUNGARY

COMMUNICATION NO: 4/2004

This memorandum offers comments in the case of *A.S. v. Hungary*. It is submitted by the Center for Reproductive Rights, an international non-governmental organization that uses the law to advance reproductive freedom as a fundamental right that all governments are legally obligated to protect, respect and fulfill. The Center for Reproductive Rights has done considerable work at the United Nations Treaty Monitoring Bodies and at regional human rights fora.

These comments set forth established international human rights and medical standards on the issues of sterilization and informed consent. They demonstrate that informed consent and right to information are critical components of any sterilization procedure and is a violation of international human rights when sterilization is performed without the full and informed consent of the patient. The Center for Reproductive Rights hopes that the Committee will find this information useful in its deliberations on this case.

I. Petitioner was not provided access to specific information by medical personnel at the hospital where the sterilization was performed, including information and advice on family planning in accordance with Article 10(h) of CEDAW

According to Article 10(h) of the Convention on the Elimination of All Forms of Discrimination against Women, States parties have an obligation to take “all appropriate measures,” for the purpose of ensuring “the health and well-being of families, including information and advice on family planning.”¹

In this case, the Hungarian State Party argues that the Petitioner was provided with “correct and appropriate” information, that the information with which she was provided was “appropriate in given circumstances,” that she “was in a condition in which she was able to understand the information,” and, finally, that the physician was legally permitted to deliver the sterilization “without any special procedure” because it was appropriate under the circumstances. Furthermore, the State Party argues that Petitioner “had to be familiar with the nature of the pregnancy and the childbirth without further education” because she had experienced three previous pregnancies.

The Committee on the Elimination of All Forms of Discrimination against Women, in its General Recommendation 21, stresses the importance of access to information, specifically in the context of sterilization, in stating that “in order to make an informed decision about safe and reliable contraceptive measures, women must have information about contraceptive measures and their use, and guaranteed access to sex education and

¹ Convention on the Elimination of All Forms of Discrimination against Women, *adopted* Dec. 18, 1979, G.A. Res. 34/180, U.N. GAOR, 34th Sess., Supp. No. 46, at 193, art. 10(h), U.N. Doc. A/34/46 (1979) (*entered into force* Sept. 3, 1981, *ratified by Hungary* Dec. 22, 1980) [hereinafter CEDAW].

family planning services, as provided in article 10 (h) of the Convention.”² Here, medical personnel did not provide Petitioner with information about contraceptive measures and their use. The lack of a medical record to substantiate that adequate information was given further supports the Petitioner’s claim. Specifically, Petitioner was not provided with information or advice concerning sterilization, and its effects, risks, or consequences. Nor did she receive information or advice about alternative methods of contraception and family planning. By failing to provide Petitioner with this information and advice, the Hungarian State Party violated its obligations under CEDAW.

II. Petitioner’s right to informed consent to the sterilization procedure was violated

The CEDAW Convention states in Article 12 that States Parties must “take all appropriate measures ... in the field of health care in order to ensure access to health care services, including those related to family planning.”³ The Convention goes on to explain that “States parties shall ensure to women appropriate services in connection with pregnancy, confinement, and the post-natal period.”⁴ The Programme of Action of the International Conference on Population and Development explains that “the principle of informed choice” is one that is “essential to the long-term success of family-planning programmes.”⁵ It goes on to say that “any form of coercion has no part to play.”⁶ **International law and policy explicitly endorse the principle of informed consent which is fundamental to the exercise of one’s individual human rights** (see below).

The Hungarian State Party argues both that the Petitioner was “given correct and appropriate information” and that derogation from the information procedure was allowed because, according to the Public Health Act of Hungary, a physician is allowed “to deliver the sterilization without the information procedure generally specified when it seems to be appropriate in given circumstances.” The State Party goes on to argue that “preference is given to patient’s life and the information procedure may be simplified” and that because this sterilization “had life saving function,” simplification of the information procedure was permissible. These arguments have no support in international law or acceptable medical standards.

General Components of Informed Consent

Under European law and international human rights and medical standards, there are certain objective criteria that medical providers must follow in every case of informing a patient about his or her proposed medical treatment. The European Convention on Human Rights and Biomedicine obligates the medical provider to give each patient objective and comprehensive information about his or her contemplated treatment, including its purpose, nature, consequences and risks, in order to enable the patient to make an informed decision.⁷ Information on risks should include those inherent in the type of intervention as well as any risks related to the specific characteristics of the patient.⁸ The patient should also receive information about alternatives to

² CEDAW General Recommendation 21, para 22.

³ CEDAW, art. 12.

⁴ *Id.*

⁵ *Programme of Action of the International Conference on Population and Development*, Cairo, Egypt, Sept. 5-13, 1994, Para. 7.12, U.N. Doc. A/CONF.171/13/Rev.1 (1995) [hereinafter *ICPD Programme of Action*].

⁶ *Id.*

⁷ European Convention on Human Rights and Biomedicine, *supra* note 12, art. 5, *Explanatory Report*, para. 35.

⁸ *See id.*

the proposed treatment, including the effect of non-treatment.⁹ The World Health Organization (WHO) clearly states in its Declaration on the Promotion of Patients' Rights in Europe, that "the informed consent of the patient is a prerequisite for any medical intervention,"¹⁰

In its Declaration on the Promotion of Patients' Rights in Europe, WHO explains that "information must be communicated to the patient in a way appropriate to the latter's capacity for understanding, minimizing the use of unfamiliar technical terminology. If the patient does not speak the common language, some form of interpreting should be available."¹¹ **The European Convention on Human Rights and Biomedicine reinforces this by obliging that all information should be communicated to the patient using terminology the patient can understand; where there are language barriers, some form of interpreting should be available.**¹² The FIGO Informed Consent Guidelines specifically note that the difficulty or time-consuming nature of providing such information, for example, to patients who have had "little education," does not absolve medical providers from striving to fulfill these criteria for informed consent.¹³ **The Guidelines also emphasize that "informed consent is not a signature but a process of communication and interaction."**[emphasis added]¹⁴

In this instance, the barely-readable hand-written consent form which, as stated above, contained the Latin, rather than Hungarian word for sterilization, while signed, did *not* indicate informed consent to the sterilization procedure. The medical personnel in this case violated these requirements when they did not communicate to the Petitioner in a way that she was capable of understanding. Moreover, they did not take into account the petitioner's state of shock after losing her child and her very weak physical condition after having lost substantial amounts of blood.

Components of Informed Consent with Regards to Sterilization

That several international medical bodies, including WHO, have created specific guidelines and considerations to ensure informed consent in cases of sterilization demonstrates just how crucial it is that informed consent is obtained prior to delivering the life-altering procedure of sterilization that seriously impacts upon an individual's human rights.

In its "Ethical Considerations in Sterilization," the International Federation of Gynecology and Obstetrics (FIGO) stresses that surgical sterilization *must* be preceded by informed choice.¹⁵ Specifically, individuals must be made aware of and have the opportunity to

⁹ See *id.*; WHO, *Declaration on Patients' Rights*, *supra* note 14, para. 2.2.

¹⁰ WHO, *Declaration on Patients' Rights*, *supra* note 8, at para. 3.1.

¹¹ Regional Office for Europe, World Health Organization (WHO), *A Declaration on the Promotion of Patients' Rights in Europe*, European Consultation on the Rights of Patients, Mar. 28-30, 1994, art. 2.4, WHO Doc. EUR/ICP/HLE 121 (1994) [hereinafter WHO, *Declaration on Patients' Rights*].

¹² See European Convention on Human Rights and Biomedicine, *supra* note 12, art. 5, *Explanatory Report*, para. 36; WHO, *Declaration on Patients' Rights*, *supra* note 14, art. 2.4.; see also *id.*, art. 2.2.

¹³ FIGO, Recommendations on ethical issues in obstetrics and gynecology by the FIGO Committee for the Ethical Aspects of Human Reproduction and Women's Health, Guidelines Regarding Informed Consent, para. 3 (2000) [hereinafter FIGO, Guidelines Regarding Informed Consent].

¹⁴ *Id.*, para. 4.

¹⁵ International Federation of Obstetrics and Gynecology, Recommendations on Ethical Issues in Obstetrics and Gynecology by the FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, November 2003, Ethical Considerations in Sterilization, para 6, at http://www.figo.org/content/PDF/ethics-guidelines-text_2003.pdf (last visited Oct. 21, 2005) [hereinafter FIGO, Ethical Considerations in Sterilization].

consider alternatives to sterilization, particularly family planning methods that are reversible and equally effective.¹⁶ According to FIGO's guidelines, the physician who performs the sterilization is responsible for ensuring that the individual has been counseled regarding risks, benefits, and alternatives to sterilization.¹⁷ **FIGO also lays out information that must be conveyed during counseling, including that sterilization is intended to be permanent; that life circumstances may change as a result of the procedure; and that the patient may later regret her state of sterility.**¹⁸ Similarly, the World Health Organization, in its "Medical Eligibility Criteria for Contraceptive Use" explains that "all clients should be carefully counseled about the intended permanence of sterilization and the availability of alternative, long-term, highly effective methods."¹⁹ Here, Petitioner's physician did not counsel her regarding risks, benefits, or alternatives. Without conveying any of the information that constitutes comprehensive counseling, the Hungarian State Party, through medical personnel at the hospital, failed to ensure that Petitioner provided informed consent to the sterilization.

In its handbook for clinic staff, entitled "The Essentials of Contraceptive Technology," the World Health Organization, declares that "the decision about female sterilization belongs to the woman herself."²⁰ **It goes on to stress that this decision is not one that can be made for her by her husband, a health care provider, a family member, or anyone else.**²¹ In this case, Petitioner did not have the opportunity to make this decision for herself. Rather, medical personnel made the decision *for her*.

Further, the handbook recommends specific methods by which health care providers can assist a woman in deciding whether to be sterilized. These recommendations include providing clear and balanced information as to both sterilization and other family planning methods; thoroughly discussing an individual's feelings about sterilization; arranging for her to speak with women who have undergone sterilization; and reviewing the "six key points of informed consent" in order to ensure that "the woman understands the sterilization procedure."²² These six points are: temporary contraceptives also are available to the client and her or his partner; voluntary sterilization is a surgical procedure; there are certain risks in the procedure as well as benefits (both risks and benefits must be explained in a way that the client can understand.); if successful, the operation will prevent the client from having any more children; the procedure is considered permanent and probably cannot be reversed; and the client can decide against the procedure at any time before it takes place (without losing rights to other medical, health, or other services or benefits).²³ The fact that the handbook specifically and extensively defines the information that should be communicated to a patient demonstrates just how crucial it is that the patient be armed with the information necessary to make a fully informed choice as to whether to be sterilized.

It is not feasible that in the 17 minute time span between Petitioner's arrival at the hospital in the ambulance and the completion of both the operation to remove the remains of the dead fetus and the sterilization, that the health care personnel provided thorough information

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ FIGO, Ethical Considerations in Sterilization, *supra* note 9, at Specific ethical considerations, para 6.

¹⁹ World Health Organization, Medical Eligibility Criteria for Contraceptive Use, Third edition, 2004, p. 1, at <http://www.who.int/reproductive-health/publications/mec/mec.pdf> [hereinafter WHO Medical Eligibility Criteria].

²⁰ Johns Hopkins Population Information Program, The Essentials of Contraceptive Technology A Handbook for Clinic Staff, July 1997, §9-12 [hereinafter Handbook for Clinic Staff].

²¹ *Id.*

²² *Id.* at §9-23.

²³ *Id.* at §9/10-1.

about sterilization as well as alternatives, risks and benefits in accordance with international human rights and medical standards. Without this information, Petitioner could not have made a well-considered and voluntary decision. Further, the fact that Petitioner asked the doctor when it would be safe to have another child clearly indicates that it was *not* explained to Petitioner that she would be prevented from having any more children after the procedure.

Health Risk not an exception to full and informed consent in the case of sterilization

International medical standards clearly note that patients must always give their informed consent to sterilization procedures, even in cases that pose a health risk. **The World Health Organization states that in situations where pregnancy poses a serious health risk and contraception is therefore recommended for medical reasons, sterilization is often considered and that, as in other cases “these women should make voluntary, informed, well-considered decisions about contraception; family planning counseling is necessary...informed consent is necessary.”**²⁴ According to the International Federation of Gynecologists and Obstetricians, it is for the patient to weigh the risks of continued fertility or a future pregnancy and decide whether to undergo sterilization.²⁵ The Federation makes it clear that it is “never appropriate” for a doctor to make this decision for an individual, regardless of any medical reasons that may weigh in favor of sterilization.²⁶

The above-noted standards directly refute the Hungarian State Party’s argument that a physician can “deliver the sterilization without the information procedure generally specified when it seems to be appropriate in given circumstances.”

Treaty Monitoring Bodies: General Recommendations and Concluding Observations Regarding Informed Consent and Sterilization

The CEDAW Committee has, on more than one occasion, expressed concern about and issued recommendations regarding coerced or forced sterilizations that result from the lack of full and informed consent. In its General Recommendation 19, the Committee recommends that States parties “ensure that measures are taken to prevent coercion in regard to fertility and reproduction.”²⁷ **Additionally, in its General Recommendation 24, the CEDAW Committee explains that “acceptable services are those that are delivered in a way that ensures that a woman gives her fully informed consent, respects her dignity, guarantees her confidentiality and is sensitive to her needs and perspectives.”**²⁸ **The Committee urges States parties to “not permit forms of coercion, such as non-consensual sterilization ... that violate women’s rights to informed consent and dignity.”**²⁹

The Committee on Economic, Social and Cultural Rights also expresses concern about consent in stating that “the right to health contains both freedoms and entitlements. The freedoms

²⁴ See WHO, FEMALE STERILIZATION, *supra* note 2, at 72.

²⁵ See letter from International Federation of Gynecologists and Obstetricians (FIGO) to Christina Zampas, Center for Reproductive Rights, Mar. 15, 2003, available at <http://www.poradna-prava.sk/dok/figo2.gif> (last visited Dec. 12, 2003).

²⁶ See *id.*

²⁷ CEDAW General Recommendation 19, para 24(m).

²⁸ CEDAW General Recommendation 24, para 22.

²⁹ *Id.*

include the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation.”³⁰ In this instance, the Petitioner’s freedom to control her health and body, specifically her freedom to decide whether to have children in the future, was violated, as the sterilization has rendered her incapable of having any more children. Similarly, her right to be free from non-consensual medical treatment was violated when she did not consent to the sterilization procedure.

In its Concluding Observations to Slovakia, both the Human Rights Committee and the Committee on the Elimination of Racial Discrimination express serious concern about and provide recommendations regarding the violation of their respective treaties when women are not provided with sufficient information to enable them to provide full and informed consent to sterilizations. In its Concluding Observations to Slovakia, the Human Rights Committee, after expressing concern at reports of forced or coerced sterilization of Roma women, urges Slovakia to “adopt all necessary measures to investigate all alleged cases of coerced or forced sterilization, publicize the findings, provide effective remedies to victims and prevent any instances of sterilization without full and informed consent.”³¹ The Committee on the Elimination of Racial Discrimination, too, expresses concern about “reports of cases of sterilization of Roma women without their full and informed consent,” and goes on to “strongly recommend” that Slovakia “take all necessary measures to put an end to this regrettable practice,” including the adoption of a draft law on health care that “would address shortcomings in the system by specifying the requirement of free and informed consent for medical procedures.”³² The Committee goes so far as to urge Slovakia to “ensure that just and effective remedies, including compensation and apology, are granted to the victims,”³³ thus expressing the seriousness with which the Committee views the issue of lack of free and informed consent.

UN Special Rapporteur on Violence Against Women

In her report to the Commission on Human Rights, the UN Special Rapporteur on Violence Against Women communicates the gravity with which she perceives the violative nature of forced sterilization, “a method of medical control of a woman’s fertility without the consent of a woman,” by calling it “a severe violation of women’s reproductive rights.”³⁴ From the Rapporteur’s perspective, forced sterilization involves “the battery of a woman” and is thus a form of “violence against women.”³⁵

III. Petitioner’s right to decide freely and responsibly on the number of spacing of children was violated

³⁰ Committee on Economic, Social and Cultural Rights, *General Comment 14: The Right to the Highest Attainable Standard of Health (Art. 12)* (22nd Sess., 2000), in *Compilation of General Comments and General Recommendations by Human Rights Treaty Bodies*, at 90, para 8, U.N. Doc. HRI/GEN/1/Rev.5 (2001) [hereinafter CESCR, *General Comment 14*].

³¹ *Concluding Observations of the Human Rights Committee: Slovakia*, 78th Sess., para 12, U.N. Doc. CCPR/CO/78/SVK (2003).

³² *Concluding Observations of the Committee on the Elimination of Racial Discrimination: Slovakia*, 65th Sess., para 14, U.N. Doc. CERD/C/65/CO/7 (2004).

³³ *Id.*

³⁴ *Report of the Special Rapporteur on Violence against Women, its Causes and Consequences*, Commission on Human Rights, 55th Sess., Provisional Agenda Item 12 (a), para 51, U.N. Doc.E/CN.4/1999/68/Add.4 (1999).

³⁵ *Id.*

The CEDAW Convention requires States parties to “take all appropriate measures ... in all matters relating to marriage and family relations.”³⁶ The Convention specifically requires that States parties ensure “the same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.”³⁷ In two of its General Recommendations, the CEDAW Committee has expressed concern about the impact of compulsory sterilization on women’s rights. **In General Recommendation 19, the CEDAW Committee states that “compulsory sterilization ... adversely affects women’s physical and mental health, and infringes the right of women to decide on the number and spacing of their children.”**³⁸ Then, in its **General Recommendation 21, the Committee reiterates: “women are entitled to decide on the number and spacing of their children.”**³⁹

By sterilizing the Petitioner without her fully informed consent, the Hungarian State, through the doctors at the public hospital, violated the Petitioner’s right to decide on the number and spacing of children by limiting her access to the information that would have allowed her to make the decision as to whether to be sterilized. As a result of the sterilization that was performed on the Petitioner without her consent, Petitioner no longer has the freedom to make decisions as to the number and spacing of children. Rather, this decision was made *for* her by medical practitioners and, as a result of the permanence of the procedure, Petitioner will indeed never have the freedom to make this decision.

IV. Petitioner’s suffered an ongoing violation of her rights as a result of the permanency of sterilization

Finally, the Hungarian State Party argues that Petitioner did not suffer a permanent violation of rights. Thus, they argue that under Article 4(e) of the Optional Protocol, her claim is inadmissible. However, the State Party has failed to support its claim in terms of reversibility and in fact, its claim, that “the Petitioner has not been bearing permanent disability since in the given way it is not an irreversible operation”, goes against internationally accepted medical standards which assert that sterilization is a permanent, non-reversible procedure.

The WHO, in its Medical Eligibility Criteria for Contraceptive Use, notes that sterilization is intended to be permanent and goes on to provide guidelines about counselling for individuals and couples who are considering sterilization that must be based on the premise that sterilization is a “permanent method.”⁴⁰ In its handbook for clinic staff, the WHO again states that “sterilization should be considered permanent.”⁴¹ While surgery to reverse sterilization is feasible, there are serious limiting factors, including cost, the availability of the procedure, and the physical state of the woman.⁴² Even if these limitations are somehow overcome, and surgery is performed, “successful reversal is not guaranteed.” Further, even if pregnancy does occur as a result of reversal surgery, there is an increased risk of ectopic

³⁶ CEDAW, Art. 16.1.

³⁷ CEDAW, Art. 16.1(e).

³⁸ CEDAW General Recommendation 19, para 22.

³⁹ CEDAW General Recommendation 21, para 21.

⁴⁰ WHO Medical Eligibility Criteria, *supra* note 13, at pp. 1 and 8.

⁴¹ Handbook for Clinic Staff, *supra* note 14, §9-22.

⁴² *Id.*

pregnancy.⁴³ (See also section above titled *Components of Informed Consent with Regards to Sterilization*).

Based on the uncertain success rates of the reversal operations only in light of the results of such operation carried out on the Petitioner one could claim with full confidence that the sterilization performed on A.S. is reversible. But possibility of reversal cannot be proven by legal means. The Petitioner cannot be required to undergo an abdominal operation with low chance of success. Thus, Petitioner's rights were, and continue to be violated as a result of the fact that she will never be able to have children.

V. Conclusion

This survey of international human rights and medical standards demonstrates that informed consent and right to information are critical components of any sterilization procedure and is a violation of international human rights when sterilization is performed without the full and informed consent of the patient. For example, The CEDAW Committee has recognized that non-consensual sterilization violates women's human dignity (see above). In addition, the permanency of the operation, and the resulting fact that the petitioner will never be able to have any more children has resulted in psychological trauma and severe negative impact on her private and family life which is continuous and ongoing, impacting her for the remainder of her life. For the reasons set forth in these comments, this Committee should find that the failure to ensure informed consent in this case is a violation of the Petitioner's basic human rights, specifically, Article 10.h, Article 12, and Article 16.1.e of the Convention on the Elimination of All Forms of Discrimination Against Women.

Respectfully,

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⁴³ Handbook for Clinic Staff, *supra* note 14, §9-5, §9-22.