

# A.S. v. Hungary:

## Informed Consent: A Signature is Not Enough

### WHAT HAPPENED

A.S., a Hungarian woman of Roma origin, underwent surgery at a public hospital in connection with a miscarriage. Minutes after being admitted to the hospital in a “state of shock” and while on the operating table, A.S. was asked to sign a statement of consent to a caesarean section. The statement also contained a barely legible handwritten note using the Latin word for sterilization. A.S. did not know that she was signing a form authorizing her sterilization (by tubal ligation); she learned that she had been sterilized only after the surgery, when she asked when it would be safe for her to try to have another baby. A.S. was not provided with information or advice concerning sterilization and its effects, risks, or consequences, nor was she provided with information or advice about alternative family planning methods. A.S.’s inability to have more children has caused her and her partner great suffering.

After failing to obtain a domestic remedy in Hungary, A.S. subsequently brought a complaint before the United Nations Committee on the Elimination of Discrimination against Women (CEDAW Committee) alleging that sterilization is never a life-saving intervention that needs to be performed without consent and that Hungary, by failing to fully inform A.S. about the risks and consequences of sterilization and obtain her informed consent, violated rights protected under the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), including her right to information on family planning [Article 10(h)], her right to access health care services [Article 12], and her right to decide freely on the spacing and number of her children [Article 16(1)(e)].<sup>3</sup>

### THE DECISION

On August 14, 2006, the CEDAW Committee determined:

- Despite the fact that A.S. was sterilized before

### Why This Case is Important

On August 14, 2006, the CEDAW Committee determined that Hungary had failed to protect A.S.’s reproductive rights. The *A.S. v. Hungary* decision establishes that sterilizing a woman without her full and truly informed consent is a violation of her basic human rights. It marks the first time that an international human rights tribunal has held a government accountable for failing to provide necessary information to a woman to enable her to give informed consent to a reproductive health-related medical procedure. The impact of this decision extends well beyond sterilization.

The CEDAW Committee’s decision also affirms international ethical standards recognizing that informed consent is more than just a signature. In fact, Informed Consent Guidelines from the International Federation of Gynecology and Obstetrics assert that “informed consent is not a signature but a process of communication and interaction,” and that the “difficult and time-consuming” nature of obtaining informed consent does not “absolve physicians caring for women from pursuing ... informed consent.”<sup>1</sup> The World Health Organization has also indicated that “[a]ll clients should be carefully counselled about the intended permanence of sterilization and the availability of alternative, long-term, highly effective methods.”<sup>2</sup>

the Optional Protocol to CEDAW came into force in Hungary, the Committee would move forward with an examination of the merits of the complaint. The Committee was convinced that *sterilization is permanent, since it is intended to be irreversible* and since surgery to reverse sterilization carries a low success rate, is dependent on many factors, and carries risks. On this basis, the Committee decided that the continuous nature of the facts and alleged violations allowed it to consider the merits of the complaint.<sup>4</sup>

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- Article 10(h) of CEDAW grants a right to “specific educational information to help ensure the health and well-being of families, including information and advice on family planning.” The “failure of the State party ... to provide appropriate information and advice on family planning” violated this right.<sup>5</sup>
- Article 12 of CEDAW grants a right to “appropriate services in connection with pregnancy, confinement and the post-natal period.” The state’s failure to provide A.S. with thorough information about sterilization “in a way in which she was able to understand it...as well as [information about] alternatives, risks and benefits, to ensure that [she] could make a well-considered and voluntary decision to be sterilized” violated this right to health care services.<sup>6</sup>
- Article 16(1)(e) grants a right to “decide freely and responsibly on the number and spacing of ... children and to have access to the information, education and means” to do so. Sterilization without a woman’s full and informed consent “must be considered to have permanently deprived her of her natural reproductive capacity,” thereby violating this right.<sup>7</sup>

### WHAT THE GOVERNMENT MUST DO NOW<sup>8</sup>

The CEDAW Committee called on Hungary to provide financial compensation to A.S. for the rights violations that she suffered. In addition, the Committee recommended that the state:

- Ensure that both public and private health care providers understand and respect the provisions of CEDAW and the Committee’s general recommendations pertaining to women’s access to health care services and information. The Committee highlighted the following principles:
  - o compulsory sterilization and abortion negatively affect women’s physical and mental health and violate their rights to reproductive autonomy;
  - o women must be able to make informed decisions about contraceptive use, and must have access to sexuality education and family planning services;
  - o women have the right to be fully informed

of their options in agreeing to treatment, including potential benefits, adverse effects, and alternatives; and

- o states should ensure access to quality health care for women, which should be delivered in a way that ensures informed consent, respects a woman’s dignity, and is sensitive to her needs and perspectives.<sup>9</sup>
- Review domestic legislation on the issue of informed consent and ensure that this legislation conforms to international human rights and medical standards.
- Monitor public and private health centers, including hospitals and clinics, to ensure that no sterilization procedures are carried out without the patient’s informed and voluntary consent.

### THE IMPACT OF THE CASE AND WHAT IT MEANS FOR WOMEN’S HUMAN RIGHTS

The CEDAW Committee’s decision in A.S. v. Hungary marks the first time that an international human rights tribunal has held a government accountable for failing to provide necessary information to a woman to enable her to give informed consent to a reproductive health-related medical procedure. It affirms that the right to health includes the right to information about health, and that health-related information is critical to the enjoyment of the rights to life, autonomy in decision making, and all other reproductive rights of women and girls. The impact of the CEDAW Committee’s decision has implications throughout the Central and East European region, where forced and coerced sterilization of Roma women has recently been exposed.<sup>10</sup> The decision also extends beyond sterilization. According to this decision, women have a right to make autonomous, informed decisions about any of their reproductive health concerns and states are responsible for providing the information and advice that will enable women to make such informed decisions. Practices that limit this right violate CEDAW.

Specifically, the CEDAW Committee’s decision does the following:

#### With respect to Article 10(h): Right to Information and Advice on Family Planning

CEDAW protects a woman’s right “to specific information on sterilization and alternative procedures for family planning in order to guard against such

an intervention being carried out without ... a fully informed choice.”<sup>11</sup> The decision explains that counseling on family planning and contraceptives “under stressful and ... inappropriate conditions” violates women’s rights. *As such, the decision affirms the right to comprehensive information and advice on family planning and makes clear that states are responsible for providing this.*

#### **With respect to Article 12: Access to Health Care Services**

*Access to health care services includes access to information about health and the ability to make informed decisions about one’s health care.* The Committee emphasizes that the “appropriate [health-care] services” that the Convention refers to are those “services that are delivered in a way that ensures that a woman gives her fully informed consent.”<sup>12</sup> The decision also explains that to ensure “informed consent,” a patient must receive information that she can understand and be “provided ... with thorough enough counselling and information ..., as well as alternatives, risks and benefits, to ensure that [she] could make a well-considered and voluntary decision.”<sup>13</sup>

In determining whether A.S. had given her informed consent, the CEDAW Committee noted that A.S.’s signature on the consent form did not, under the circumstances, constitute consent. Instead, the Committee looked to the circumstances surrounding the surgery—such as A.S.’s physical and mental condition at the time the consent form was signed, the limited amount of time during which A.S. could have received counseling, and the fact that the word “sterilization” was written in a language A.S. did not understand—and determined that under these circumstances, “it is not plausible that ... hospital personnel provided [A.S.] with thorough enough counselling and information.”<sup>14</sup> *Accordingly, a signature alone cannot be used to determine whether a patient has given her informed consent; the circumstances under which consent is given must be considered to establish whether the consent is “informed.”*

#### **With respect to Article 16(1)(e): Right to Decide on the Number and Spacing of Children**

Women have the right to decide autonomously about the number and spacing of their children. The CEDAW Committee determined that, in sterilizing A.S. without her informed consent, Hungary “must be considered to have deprived her of her natural reproductive capacity,” violating Article 16(1)(e). In its general recommendations, the CEDAW Committee has noted that other coer-

cive practices—including forced pregnancies, forced abortions, mandatory testing for sexually transmitted diseases, or mandatory pregnancy testing as a condition for employment—similarly “violate women’s rights to informed consent and dignity,”<sup>15</sup> and may “[infringe] on the right of women to decide on the number and spacing of the bir children.”<sup>16</sup> *According to the CEDAW Committee’s decision, informed consent needs to be obtained for any medical procedure that limits a woman’s right “to decide freely and responsibly on the number and spacing of [her] children,”<sup>17</sup> not just for sterilization procedures.*

#### **RECENT DEVELOPMENTS**

The European Roma Rights Center and the Center for Reproductive Rights have continued to pursue implementation of the decision, including advocacy efforts with the CEDAW Committee during its 39th session, in July 2007, when Hungary was reviewed by the Committee. Following this session, the Committee issued concluding observations to Hungary that addressed the issue of lack of implementation of the *A.S. v. Hungary* decision.

#### **Concluding Comments of the Committee on the Elimination of Discrimination against Women: Hungary** [CEDAW/C/HUN/CO/6, 10 August 2007]

Paragraph 8: The Committee is concerned that the State party has not implemented the Committee’s recommendations, and specifically the recommendation to provide appropriate compensation to Ms. A.S., to review its domestic legislation pertaining to the principle of informed consent and ensure its conformity with international human rights and medical standards, and monitor public and private health centres which perform sterilization procedures, as contained in its views under the Optional Protocol to the Convention in respect of communication No. 4/2004, Ms. A.S. v. Hungary. The Committee is further concerned about the reasons given by the State party for non-payment of compensation to Ms. A.S. The Committee recalls that, in accordance with article 7 of the Optional Protocol, the State party is under an obligation to give due consideration to the views of the Committee, together with its recommendations.

Paragraph 9: The Committee urges the State party to reconsider its stance on the Committee’s views in respect of communication No. 4/2004, Ms. A.S. v. Hungary, and to provide appropriate compensation to Ms. A.S.

## RELEVANT HUMAN RIGHTS FRAMEWORK

The CEDAW Committee relied upon a number of CEDAW provisions in deciding this case. It is worth noting that the standards set forth in CEDAW are recognized in other international and regional human rights instruments.

### **Convention on the Elimination of All Forms of Discrimination against Women:**

*Article 10(h)*—States shall ensure “[a]ccess to specific educational information to help ensure the health and well-being of families, including information and advice on family planning.”

*Article 12*—States shall ensure “access to health care services, including those related to family planning.”

*Article 16(1)(e)*—Women have the right “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.”

*General Recommendation No. 21*—“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 family planning services.”

*General Recommendation No. 24* —“Acceptable [health-care] services are those that are delivered in a way that ensures that a woman gives her fully informed consent. ... States parties should ... ensure timely access to the range of services that are related to family planning ... including information and counseling on all methods of family planning.”

European Convention on Human Rights and Biomedicine —“An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time.” [Article 5]; “Everyone has the right to respect for private life in relation to information about his or her health. Everyone is entitled to know any information collected about his or her health.” [Article 10]

### **Other International Human Rights Law:**

*International Covenant on Civil and Political Rights* —“Everyone shall have the right to freedom of expression [including the] freedom to seek, receive and impart information.” [Article 19(2)]

*Convention on the Rights of the Child*—States shall “develop preventative health care, guidance for parents and family planning education and services.” [Article 24(2)(f)]

*Committee on Economic, Social and Cultural Rights, General Comment No. 14* —“The Committee interprets the right to health [as extending] to the underlying determinants of health, such as ... access to health-related education and information, including on sexual and reproductive health.” [Paragraph 11]

### **Regional Human Rights Treaties:**

*African Charter on Human and Peoples’ Rights* —“Every individual shall have the right to receive information.” [Article 9(1)]

*Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa*—States “shall ensure that the right to health of women, including sexual and reproductive health is respected and promoted [including] the right to be informed on one’s health status [and] the right to have family planning education.” [Article 14]

## Endnotes

<sup>1</sup> INTERNATIONAL FEDERATION OF GYNECOLOGY AND OBSTETRICS (FIGO), *ETHICAL ISSUES IN OBSTETRICS AND GYNECOLOGY* (2006), available at [www.figo.org/docs/Ethics%20Guidelines%20-%20English%20version%202006%20-2009.pdf](http://www.figo.org/docs/Ethics%20Guidelines%20-%20English%20version%202006%20-2009.pdf).

<sup>2</sup> WORLD HEALTH ORGANIZATION, *MEDICAL ELIGIBILITY CRITERIA FOR CONTRACEPTIVE USE 151* (3rd Ed., 2004), available at <http://www.who.int/reproductive-health/publications/mec/mec.pdf>.

<sup>3</sup> A.S. was represented by the European Roma Rights Center (ERRC) and the Legal Defence Bureau for National and Ethnic Minorities (NEKI). The Center for Reproductive Rights submitted an amicus brief in support of the author's arguments.

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, U.N. Doc. A/34/46 (1979) (*entered into force* Sept. 3, 1981) [hereinafter CEDAW].

<sup>4</sup> A.S. v. HUNGARY, *supra* note 3, para. 10.4.

<sup>5</sup> *Id.* para. 11.2.

<sup>6</sup> *Id.* para. 11.3.

<sup>7</sup> *Id.* para. 11.4.

<sup>8</sup> *Id.* para. 11.5.

<sup>9</sup> See, e.g., Comm. on the Elimination of Discrimination against Women (CEDAW), General Recommendation No. 19: *Violence against women*, para. 22, U.N. Doc. A/47/38 (Jan. 29, 1992) [hereinafter CEDAW General Recommendation No. 19]; CEDAW, *General Recommendation No. 21: Equality in marriage and family relations*, paras. 21 - 23 (Feb. 4, 1994) [hereinafter CEDAW General Recommendation No. 21]; CEDAW, *General Recommendation No. 24: Women and health*, paras. 20 - 23, 31(b, c) (Feb. 5, 1999) [hereinafter CEDAW General Recommendation No. 24].

<sup>10</sup> See first detailed documentation of the practice post-communism in Center for Reproductive Rights and Porad a *Body and Soul Forced Sterilization and Other Assaults on Roma Reproductive Freedom in Slovakia*. [http://www.reproductiverights.org/pub\\_bo\\_slovakia.html#report](http://www.reproductiverights.org/pub_bo_slovakia.html#report).

<sup>11</sup> A.S. v. Hungary, *supra* note 3, para. 11.2.

<sup>12</sup> *Id.* para. 11.3.

<sup>13</sup> *Id.*

<sup>14</sup> *Id.*

<sup>15</sup> CEDAW Comm, *Gen. Rec. No. 24*, para. 22. See also CEDAW General Recommendation No. 19, para. 22.

<sup>16</sup> CEDAW General Recommendation No. 19, para. 22.

<sup>17</sup> See CEDAW, ART. 16(1)(E).