

A person with a physical disability, wearing a dark jacket and a pink skirt, is walking away from the camera on a set of train tracks. They are carrying a small orange doll in their right hand and a pair of scissors in their left hand. The background shows a cloudy sky and some distant structures.

ENDING FORCED STERILISATION OF WOMEN AND GIRLS WITH DISABILITIES



EUROPEAN DISABILITY FORUM REPORT

ENDING FORCED STERILISATION OF WOMEN AND GIRLS WITH DISABILITIES

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EDF draft report 'Ending forced sterilisation against women and girls with disabilities'
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Introduction

This report presents the European Disability Forum's recommendations on how to prevent and end forced sterilization against women and girls with disabilities. It explains the given societal reasons and negative consequences of forced sterilization on the enjoyment of all human rights for all women and girls with disabilities. It highlights the close relationship between this practice and deprivation of legal capacity, and describes the current situation in Europe. Finally, it gives an overview of the current human rights standards and jurisprudence on the topic.

The information and recommendations presented in this report are the outcome of a campaign that EDF is undertaken since 2015 to raise awareness on the practice of forced sterilization. As part of its Gender Equality Plan 2015-2017, the campaign has so far included the drafting of this report and a photo competition in close cooperation with our Spanish member CERMI's Women's Foundation. In 2017, a video will be produced and a hearing in the European Parliament will be organised.

This important topic has been at the center of EDF and its Women's Committee's work. In 1997, EDF released the Manifesto by Women with Disabilities on how to mainstream the rights of women and girls with disabilities. In 2011, EDF presented the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union: a toolkit for activists and policymakers. Both documents represent a key tool for ensuring that the rights of women and girls with disabilities are fully respected in practice, including with regards to reproductive rights and legal capacity.

Finally, it is important to remember that this report is written with a human rights based approach to disability according to which all people with disabilities, including women and girls with disabilities are active subjects with legal claims and rights. They are entitled to participate in all spheres of society on an equal basis with their non-disabled peers.

The Convention on the Rights of Persons with Disabilities (CRPD) recognizes the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities. Persons with disabilities are part of the diversity of society, have always been and will remain. The promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty.

Against this background, it is crucial to recognize the reproductive rights of women and girls with disabilities, their right to have a family life and to have their full legal capacity recognised in all areas of life, and provide the necessary means and support to enable them to exercise these rights in line with the CRPD.

1. Definition and consequences of sterilisation

The term 'sterilisation' refers to a surgical procedure which, either directly or indirectly, results in a person being unable to reproduce. 'Forced sterilisation' refers to undertaking this procedure without the consent or authorisation of the person who is subjected to the practice, and when it takes place without there being a serious threat or risk to health or life.

In the latter case we are talking about a practice that is carried out on (or, rather, perpetrated against) many people with disabilities, especially women and girls with disabilities, and mainly women and girls intellectual disabilities, violating and disregarding their most fundamental rights: freedom, respect and personal integrity.¹

When referring to this kind of sterilisation some terms have been used - such as 'unauthorised', 'non-consensual', 'involuntary' or 'non-therapeutic' sterilisation - that lend it a certain camouflage what is really happening to women and girls with disabilities in terms of their reproductive options.

For many women and girls with disabilities the experience means they are denied access to suitable services, forced against their will, intimidated, pressured, violated and even deprived, without knowing it, of their most basic human rights, such as safeguarding their corporal integrity and retaining control of their reproductive health.

That is why using the language of violence is, in our judgment, a fairer way to talk about these particular experiences.

'Forced sterilisation' refers to undertaking this procedure without the consent or authorisation of the person who is being subjected to the practice, and when it takes place without there being a serious threat or risk to health or life.

The fact that the procedure may have been authorised by law does not hide

¹ World Health Organization: Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO (2014).

the reality that a woman with a disability, and normally a very young woman, has been subjected to a medical intervention to remove parts of her body that were not sick and are essential to retain her overall health.² In fact, the negative long-term social and psychological consequences have never been considered. Whether authorisation to sterilise is granted by means of a legal ruling or not, if sterilisation does not have the informed consent of the person who is going to endure it then it is always unconsented and, consequently, unethical.

It is worth mentioning that, according to the recommendations from the International Federation of Gynecology and Obstetrics, no women may be sterilized without her own, previously-given informed consent, with no coercion, pressure or undue inducement by healthcare providers or institutions. By contrast, women considering sterilisation must be given information of their options in the language in which they communicate and understand.³

Moreover, we must bear in mind that sterilisation has permanent lifelong consequences, although these normally become more apparent in adult life.

In addition to an inability to reproduce, sterilisation can cause premature menopause, osteoporosis and cardiovascular conditions if it is performed before the girl begins to menstruate or during puberty. It can also lead to diminished sexual pleasure as the uterus and cervix play an important role in sexual satisfaction. Since women who have been sterilised are perceived socially to be asexual, the normal gynecological tests that all women should undergo are often overlooked⁴.

More serious still, forced sterilisation may increase vulnerability for the girl, adolescent or young woman with disabilities in the face of sexual abuse. Indeed, although it is often used as an argument to justify exactly the opposite, sterilisation may be used to cover up sexual abuse because pregnancy is often the only indication that helps to identify this type of situation.

2. Sterilisation of girls with disabilities

Girls and adolescents with disabilities face an even more enhanced

² WWDA Policy & Position Paper: 'The Development of Legislation to Authorise Procedures for the Sterilisation of Children with Intellectual Disabilities (June 2007).

³ FIGO (International Federation of Gynecology and Obstetrics), Female Contraceptive Sterilization; available online at: <http://www.wwda.org.au/FIGOGuidelines2011.pdf>

⁴ A scientific reference will be added to substantiate this claim

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vulnerability with regards to forced sterilisation that leads us to reflect on a number of questions.

Firstly, sterilisation is an issue that must be addressed during adult life and not childhood. All sterilisation of people under the age of 18 should be banned unless it is performed to save lives or in the event of a medical emergency.

We believe it is impossible to expect a person to give informed consent to sterilisation during this stage of life. Therefore, it should never be carried out until the individual involved is old enough to be able to grant informed consent.

Secondly, as the majority of EU Member States has ratified both the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, all sterilisation of boys and girls should be banned, with exception made for those cases where there is a serious risk to health or life.

All sterilisation of people under the age of 18 should be banned unless performed to save lives or in the event of a medical emergency. We believe it is impossible to expect a person to give informed consent to sterilisation during this stage of life.

3. What are the reasons given for forced sterilization?

Throughout the years, women with disabilities have been sterilised on a number of grounds and reasons:

- **For the good of society, the community or the family:** based on the idea that having to care for an 'abnormal child' is a burden, or the trouble it causes a woman with disabilities to manage her reproductive functions, and especially menstruation. The argument is also founded on financial and social factors as the extraordinary financial expense for the state to provide social services for persons with disabilities. However, should respect for human rights really be based on the potential cost of fulfilling them? With regard to the family burden, many mothers and fathers of a daughter with disabilities do not receive sufficient information or support. They find themselves alone and without support due to the lack of the services and resources they need. Faced with this difficult situation, which stems from the fact that services are inaccessible and a lack of specialist training on reproductive health and menstruation management, the family sees sterilizing their daughter as the

only solution.

- **Women with disabilities are incapable of being mothers:** it is a widely-held belief that women with disabilities cannot be mothers, even in the face of evidence demonstrating that many in fact are successful mothers of happy sons and daughters. Apart from there being few objective criteria to judge or determine the skills or lack of skills of a father or mother, there is a tendency to stray into areas of emotion and use subjective ideas about what is right and wrong. This belief prevails even despite the fact that research has shown no clear relationship between the level of education or intelligence of fathers and mothers and being a good father or mother. This negative social perception towards people with disabilities is even worse in the case of women with disabilities because they are thought to have a greater responsibility for taking care of a son or daughter. In fact, value judgments in this respect are even more hurtful and negative.

The reasons used to legitimise forced sterilisations allude mainly to questions of the good of society, the community or the family, or the inability of women with disabilities to be mothers.

Most research on forced sterilisation has focused on the sterilisation of girls with intellectual disabilities under the age of 18 and with high support needs. There is a wide range of medical, legal and academic papers addressing this issue, yet there are very few written testimonies by people who have been subjected to this type of irreversible and invasive surgical intervention. This leads us to wonder to what extent women with intellectual disabilities still find themselves in a situation of greater vulnerability and disempowerment because of how difficult it is for them to access this kind of information.

4. The potential impact of sterilisation on women and girls with disabilities

Women with Disabilities Australia's (WWDA) advocacy work on the rights of women and girls with disabilities is based on the voices and experiences of the women involved.⁵ These women have described sterilisation as a life sentence, a loss or a betrayal, and they have spoken out about the consequences for their health. The clear message is that we must listen to women and learn from them in order to heal the women already affected, and put safeguards in place to prevent other women being denied their human rights.

⁵ Leanne Dowse for Women With Disabilities Australia (WWDA). 'Moving Forward or Losing Ground? The Sterilisation of Women and Girls with Disabilities in Australia', this paper was presented to Disabled Peoples' International (DPI) World Summit, Winnipeg, September 8-10, 2004.

In addition, the experiences of the women affected have also shown that forced sterilisation forms part of a wider model in which women with disabilities are denied their human and reproductive rights. This denial includes also exclusion from suitable healthcare for reproductive health and sexual health screening programmes, restrictions in the choice of types of contraceptives, a tendency to suppress menstruation, shortcomings in pregnancy and birth management, selective or forced abortions, and denial of the right to be a mother.

5. Forced sterilisation in Europe

Across Europe, the practice of forced sterilisation of women from marginalised groups such as Roma women and women with disabilities has a long history. Such practices were not confined to the eugenic policies of World War II, but also continue to take place in modern democracies throughout Europe.⁶

Sweden set up an eugenic sterilisation program in 1934 and abolished it in 1976. According to the 2000 governmental report, under this program, 21 000 persons were forcibly sterilized, 6 000 were coerced into a 'voluntary' sterilization while the nature of a further 4 000 cases could not be determined. The Swedish state subsequently paid out damages to many of the victims of these practices of forced sterilisation.⁷

In the late 1990s, media and non-governmental organisations reports highlighted the practice of forced sterilisation of women with intellectual disabilities in **France**. In 1997, it was revealed that 15 000 women had been forcibly sterilised in French institutions for persons with intellectual disabilities. Another report showed that 211 disabled women or women in a difficult social situation were forcibly sterilised in French public hospitals in 1996.⁸

On the 16 August 2011, the Center for Reproductive Rights, European Disability Forum, Interights, International Disability Alliance and Mental Disability Advocacy Center, jointly submitted written comments to the European Court of Human Rights in the case of *Gauer and Others v. France*.⁹ This case was brought by five women with intellectual disabilities who were forcibly sterilised alleging that they underwent a process of tubal ligation

⁶ G. Aly, Peter Chroust, and Christian Pross, *Cleansing the Fatherland: Nazi Medicine and Racial hygiene* 295 (1994).

⁷ Sweden admits to racial purification Forced sterilisation of 'inferior' women unchecked for 40 years, *The Independent*, August 25, 2007; available on the website <http://www.independent.co.uk/news/world/sweden-admits-to-racial-purification-1247261.html>

⁸ La sterilization des Handicapees est faible, mais non marginale, Selon l'IGAS, *Le Monde*, (Oct. 2, 1998).

⁹ European Court of Human Rights, Application no. 61521/08, *Joelle Gauer and Others v. France*, 2011.

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without their informed consent and against their wishes. The judgment of the European Court of Human Rights could have been a crucial statement concerning the reproductive rights of persons with disabilities and the States' obligations in preventing abuses against persons with disabilities. However, the Court found that the application had been lodged out of time and therefore declared it inadmissible pursuant to Article 35 of the Convention.

Also in **Spain** forced sterilisation continues to be performed on women and girls with disabilities, and especially those with intellectual or psychosocial disabilities, without their consent or their understanding the purpose of the surgical intervention, under the pretext of their welfare. According to data from the General Council of the Judiciary (2010-2013), there is an average of 96 court rulings authorising sterilisation of people with disabilities subject to prior incapacitation.

A Spanish Constitutional Court ruling 215/1994 concluded in a sterilisation procedure carried out on the grounds that "sterilisation allows her (the incapacitated individual) to be freed from constant surveillance, which could turn out to be contrary to her dignity and moral integrity, and enables her to exercise her sexuality". The ruling states that the measure is "simply beneficial for the health of persons with severe mental impairments".

In 2015, the Court of Protection of the **United Kingdom** ruled that a woman with intellectual disabilities should be sterilized for her own safety because another pregnancy would have been a "significantly life-threatening event" for her and the fetus.

Other countries that had previously active sterilisation programmes include Denmark, Norway, Finland, Estonia, Switzerland and Iceland.¹⁰

6. Relationship between legal capacity and forced sterilisation

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) declares literally that "States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law." The article goes on to assert that "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."

The CRPD enshrines a paradigm shift according to which persons with

¹⁰ Gunnar Broberg and Nils Roll-Hansen, eds., *Eugenics And the Welfare State: Sterilization Policy in Denmark, Sweden, Norway, and Finland* (Michigan State University Press, 2005).

disabilities are holders of rights on an equal basis with others. The CRPD therefore acknowledges that persons with disabilities are “persons before the law” and have legal capacity on an equal basis with others. This approach implies a shift away from a ‘substituted decision-making’ towards more individually tailored systems of support.

General Comment No. 1 of the CRPD Committee¹¹ confirms that “women with disabilities are subjected to high rates of forced sterilization, and are often denied control of their reproductive health and decision-making, the assumption being that they are not capable of consenting to sex. Certain jurisdictions also have higher rates of imposing substitute decision-makers on women than on men. Therefore, it is particularly important to reaffirm that the legal capacity of women with disabilities should be recognized on an equal basis with others”.

Moreover, article 15, sections 2 and 3 of the United Nations Convention on the Elimination of all Forms of Discrimination against Women establishes that in civil affairs States Parties shall afford women a legal capacity identical to that of men and the same opportunities to exercise that capacity.

In particular, women’s equal rights to conclude contracts and to administer property are recognised, as is their right to equal treatment in all stages of procedure in courts and tribunals. In addition, all contracts and other private instruments of any kind with a legal effect which are directed at restricting the legal capacity of women are to be deemed null and void.

Several EU Member States have still in place outdated laws which provide for substituted decision-making and therefore do not comply with Article 12 of the CRPD.¹² The CRPD moves away from the guardianship model and emphasises the need of supported decision-making in order to strengthen the legal capacity of persons with disabilities.

The entry into force of the CRPD has prompted discussions about the current legal frameworks governing legal capacity in the EU Member States. Many EU Member States have recently reformed their legal frameworks and have included forms of supported decision making. However, these reforms have not led to the abolishment of substituted decision making regimes, as most reforms still include some forms of partial substituted decision making regimes or partial guardianship.

¹¹ Committee on the Rights of Persons with Disabilities Eleventh session 31 March–11 April 2014 General comment No. 1 (2014), available online <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>

¹² FRA, Legal capacity of persons with intellectual disabilities and persons with mental health problems, 2013.

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In **Ireland** the Assisted Decision Making Act went into force in 2016.¹³ The Act provides a statutory framework for individuals to make legally-binding agreements to be assisted and supported in making decisions about their welfare and their property and affairs. A number of new arrangements are covered by the Act, including Assisted Decision-Making and Co-Decision-Making. A process is also set out for the court to appoint a Decision-Making Representative for an individual. Advanced Healthcare Directives are introduced into law for the first time. As well as introducing new decision-making procedures, the Act sets out new arrangements for Wards of Court and for people who wish to make an Enduring Power of Attorney. A Decision Support Service is to be set up within the Mental Health Commission to provide a range of functions in relation to the new arrangements.

Sweden has replaced the guardianship system in order to promote supported decision-making measures. In this regard, the psychiatric reform in 1995 has introduced the Personal Ombudsmen (PO) in the Swedish legal system.¹⁴ The PO is a professional and independent person who exclusively works on behalf of his/her client on the basis of a relationship model. The PO therefore develops a trustful relation with the client and supports the person with a mental health problem for several years in making his/her own decisions about care and day to day life. To this end, the clients discuss their situation with the PO in order to jointly agree upon the type of support to be provided. The Swedish model shows the promising purpose to enhance decision-making tools that accommodate the specific individual's conditions. In 2014, 310 Personal Ombudsmen provided support to more than 6,000 individuals in Sweden and 245 municipalities included Personal Ombudsmen in their social service system.

Germany also reformed its law on the legal protection of incapable individuals by replacing the former guardianship system with an innovative system of custodianship ("gesetzliche Betreuung").¹⁵ In general, people with intellectual disabilities have full legal capacity then they turn 18. Indeed, according to the reform, national courts cannot release any order of incapacitation, but they can appoint a legal custodian who manages only those specific matters assigned by the court in relation the peculiar individual's needs. The custodian has the duty to help and assist persons with intellectual disabilities in taking decision concerning their life. The goal of this practice is to support persons with disabilities to live a self-determined life.

¹³ Number 64 of 2015 Assisted Decision-Making (Capacity) Act 2015.

¹⁴ Further information on the website <http://www.personligtombud.se/>

¹⁵ Volker Lipp, Georgia Augusta University of Göttingen, Germany "Vorsorgevollmacht" as an Alternative to Legal Guardianship 3 rd World Congress on Adult Guardianship 2014 The German

As mentioned above, these new legal reforms are a positive step towards more compliance with Article 12 of the CRPD as the recognition of the legal capacity of the person is no longer an exception, but the rule. However, the new systems still allow for the legal capacity of the person to be denied with regards to specific actions.

7. Forced sterilisation from the human-rights perspective

International human rights standards and jurisprudence underline that forced sterilization is a violation of many human rights, and that the principle of informed consent is a fundamental requirement to exercise one's individual human rights, including sexual and reproductive rights.

7.1. The UN Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) enshrines relevant provisions to respect the rights of persons with disabilities and tackle the issue of forced sterilisation. The CRPD indeed emphasises significant principles and values such as the respect for inherent dignity and autonomy, including the freedom to make one's own choices.

Article 23 sets out that States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that persons with disabilities, including children, retain their fertility on an equal basis with others.

According to Article 25(d), health professionals have the obligation to provide care of the same quality to persons with disabilities as to others, including on the basis of free and "informed consent".

Article 12 requires States Parties to reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law. States Parties shall therefore recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

The legal framework delineated by the CRPD shows that the individual's right to decision-making should not be replaced by decisions of a third party. Persons with disabilities have the right to make choices that affect their own life with regard to medical treatment, family and reproductive issues. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

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7.1.1 Concluding Observations issued by the UN Committee on the Rights of Persons with Disabilities to the EU

The UN Committee on the Rights of Persons with Disabilities considered the initial report of the **European Union** and pointed out that persons with disabilities are exposed to involuntary treatment, including forced sterilization and abortion, in the EU Member States. The Committee urged the European Union to take all possible measures to ensure that the individual's right to free, prior and informed consent to treatment is upheld and supporting decision making mechanisms are provided in the Member States. The CRPD Committee also recommended that the European Union take appropriate measures to ensure that its economic and social policies and recommendations promote support for families with persons with disabilities and ensure the right of children with disabilities to live in their communities.

7.1.2 Concluding Observations issued by the UN Committee on the Rights of Persons with Disabilities to European countries

The Committee was deeply concerned with regard to **Croatia** that children and adults with disabilities can be sterilized without their free and informed consent pursuant to the Health Act, in cases in which their parents or guardians have so requested. The Committee recommended that the Health Act be urgently amended to unconditionally prohibit the sterilization of boys and girls with disabilities, and that of adults with disabilities in the absence of their individual prior, fully informed and free consent.¹⁶

The concluding observations of the Committee to the **Czech Republic** noted with concern that under the Civil Code and the Health Care Act, guardians of persons with disabilities are authorized to give consent for the sterilization of the person concerned, thus subjecting that person to forced sterilization without his or her free and informed consent. The Committee urged the State party to abolish the practice of sterilization of persons with disabilities without their free and informed consent and to amend the Civil Code and the Health Care Act accordingly. The Committee also called upon the State party to provide remedies to the victims of forced sterilization in accordance with the recommendations made by the Human Rights Committee and the Committee on the Elimination of Discrimination against Women.¹⁷

¹⁶ <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/098/80/PDF/G1509880.pdf?OpenElement>

¹⁷ <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/098/68/PDF/G1509868.pdf?OpenElement>

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With regards to **Germany**, the CRPD Committee was concerned about the practice of carrying out forced sterilization and coercive abortions on adults with disabilities on the basis of substituted consent. The Committee recommended that the State party repeal section 1905 of the German Civil Code and explicitly prohibit in law sterilization without the full and informed consent of the individual concerned, eliminating all exceptions, including those based upon substituted consent or court approval.¹⁸

The Committee also called upon **Hungary** to take appropriate and urgent measures to protect persons with disabilities from forced sterilization.¹⁹

The concluding observations released by the Committee with regard to the initial report of **Italy** emphasised the lack of data on medical treatment administered without the free and informed consent of the person, including sterilization. The Committee recommended that the State party abolish all laws that permit medical treatment, including sterilisation, consented by a third party (parent or guardian) without the free and informed consent of the person, and that it provide related high-quality training to health professionals.²⁰

The Committee was concerned with regards to **Lithuania** about the provision of the Civil Code of 2000 that makes it possible for persons with disabilities who have been deprived of legal capacity to undergo, without their consent, surgical operations, including castrations, sterilizations, abortions and operations for the removal of organs, upon authorization by a court. It is also concerned at the lack of investigation of and data on the forced sterilization of persons with disabilities. The Committee therefore recommended that the State party abolish all practices of forced treatment, including non-consensual castrations, sterilizations and abortions, and eliminate the possibility for third parties such as guardians, doctors and the courts to approve such practices.²¹

The concluding observations of the Committee on the initial report of **Portugal** emphasised that persons with disabilities, especially those who have been declared legally incapacitated, continue to be subjected, against their will, to termination of pregnancy, sterilization, scientific research, electroconvulsive therapy or psychosurgical interventions. The Committee recommended that the State party take all possible measures to ensure that the right to free, prior and informed consent to medical treatment is respected

¹⁸ <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/096/31/PDF/G1509631.pdf?OpenElement>

¹⁹ http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHUN%2fCO%2f1&Lang=en

²⁰ http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fITA%2fCO%2f1&Lang=en

²¹ http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fLTU%2fCO%2f1&Lang=en

and that it put in place assisted decision-making mechanisms.²²

In the concluding observations on the initial report of **Slovakia**, the Committee was concerned that the Health Care Act authorizes guardians to make decisions for women, whose legal capacity has been restricted, on their sterilization and use of contraception. The Committee was also concerned about the lack of investigations and provisions of redress for cases of forced sterilization. The Committee recommended that the State party abolishes all forms of guardianship and replaces them with supported decision-making regimes, as well as investigate and provide redress for historical cases of forced sterilization, including for Roma women with disabilities.²³

The Committee considered the initial report submitted by **Spain** and issued several observations regarding protection for the integrity of the person and, more specifically, sterilisation. The Committee was concerned that persons with disabilities whose legal capacity is not recognized may be subjected to sterilization without their free and informed consent. The Committee urged the State party to abolish the administration of medical treatment, in particular sterilization, without the full and informed consent of the patient; and ensure that national law especially respects women's rights under articles 23 and 25 of the Convention.²⁴

7.2. General Comment No. 3 of the UN Committee on the Rights of Persons with Disabilities

In 2016, the CRPD Committee adopted the **General Comment No 3 on Article 6 concerning women and girls with disabilities**.²⁵ The Committee identified three main subjects of concern with respect to the protection of the human rights of women with disabilities: (1) violence, (2) sexual and reproductive health and rights and (3) discrimination. Furthermore, the Committee highlighted the persistence of violence against women and girls with disabilities, including sexual violence and abuse, forced sterilization, female genital mutilation and sexual and economic exploitation. According to the Committee, certain forms of violence, exploitation or abuse may be considered as cruel, inhuman, degrading treatment or punishment that violates international human rights law. Among these are forced, coerced and otherwise involuntary pregnancy or sterilisation; as well as any other medical procedure or intervention performed without free and informed consent,

²² http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fPRT%2fCO%2f1&Lang=en

²³ http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fSVK%2fCO%2f1&Lang=en

²⁴ http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fESP%2fCO%2f1&Lang=en

²⁵ Committee on the Rights of Persons with Disabilities General comment No. 3 (2016) Article 6: Women and girls with disabilities 2 September 2016

including those related to contraception and abortion.

The Committee emphasized that the choices of women with disabilities, especially women with psychosocial or intellectual disabilities, are often ignored. Their decisions are replaced by third parties, including legal representatives, service providers, guardians and family members, thus violating their rights under article 12 of the CRPD. By contrast, all women with disabilities should be able to independently exercise their legal capacity by taking their own decisions, with support when desired with regard to medical and/or therapeutic treatment. Restricting or removing legal capacity can facilitate forced interventions, such as forced sterilization. Therefore, it is crucial to recognize the legal capacity of women with disabilities on an equal basis with others along with the right to found a family and have regular access to family support services.

7.3. Other UN Human Rights treaties and the Special Rapporteur against Torture

Sterilisation carried out without the full and informed consent of the individual breaches several other international human rights instruments, such as the **United Nations Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)**. CEDAW is a comprehensive international agreement that promotes women's equal attainment of economic, social, cultural, civil and political rights. The Committee on the Elimination of Discrimination against Women clarified that forced sterilisation is as a form of violence against women. The Committee stated that "compulsory sterilization or abortion adversely affects women's physical and mental health, and infringes the right of women to decide on the number and spacing of their children. States parties should ensure that measures are taken to prevent coercion in regard to fertility and reproduction".²⁶ The Committee, in its General Recommendation 24, also urged States parties to "not permit forms of coercion, such as non-consensual sterilization that violate women's rights to informed consent and dignity."²⁷

The **Committee on the Rights of the Child** has observed that forced sterilisation of girls with disabilities under the age of 18 constitutes a form of violence. The Committee has called upon states to prohibit, by law, the forced sterilization of children on grounds of disability and to provide these children with adequate information on relationships and sexual and reproductive

²⁶ Committee on the Elimination of Discrimination against Women, General Recommendation No. 19 (11th session, 1992) Violence against women

²⁷ Committee on the Elimination of Discrimination against Women, General Recommendation No. 24 (20th session, 1999) on article 12 : Women and health

health, as well as guidance and counseling.

The **Committee on Economic, Social and Cultural Rights** has also pointed out that forced sterilization of women and girls with disabilities violates Article 10, protecting the family, of the International Covenant on Economic, Social and Cultural Rights (CESCR). According to the CESCR Committee, women with disabilities have the right to protection and support in relation to motherhood and pregnancy. Both the sterilization of, and the performance of an abortion on, a woman with disabilities without her prior informed consent are serious violations of Article 10 (2) CESCR.

Forced sterilization is now globally recognised as an act of violence, a form of social control and documented violation of the right to be free from torture. The **Committee Against Torture** has indeed encouraged States to take urgent measures to investigate promptly, impartially, thoroughly, and effectively all allegations of involuntary sterilization of women, prosecute and punish the perpetrators, and provide the victims with fair and adequate compensation.

The **United Nations Human Rights Council** declares that violence against women with disabilities may be structural and stem from discriminatory legislation, and also considers forced sterilisation to be a form of violence.

Specifically, item 48 in the 2013 Report of the **Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment** points out that “some women may experience multiple forms of discrimination on the basis of their sex and other status or identity. Targeting ethnic and racial minorities, women from marginalized communities and women with disabilities for involuntary sterilization because of discriminatory notions that they are “unfit” to bear children is an increasingly global problem. Forced sterilization is an act of violence, a form of social control, and a violation of the right to be free from torture and other cruel, inhuman, or degrading treatment or punishment.”

On this point the mandate has asserted that “forced abortions or sterilizations carried out by State officials in accordance with coercive family planning laws or policies may amount to **torture**”.

7.4. Council of Europe Convention on violence against women and domestic violence

It is vital to keep in mind the provisions of the **Council of Europe Convention on preventing and combating violence against women and domestic violence** (Istanbul Convention) which considers forced sterilisation

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as criminal conduct against women.

According to article 39 of the Istanbul Convention: "Parties shall take the necessary legislative or other measures to ensure that the following intentional conducts are criminalized:

- a) performing an abortion on a woman without her prior and informed consent;
- b) performing surgery which has the purpose or effect of terminating a woman's capacity to naturally reproduce without her prior and informed consent or understanding of the procedure."

The Treaty has been signed and ratified by 14 out of the 28 EU Member States: Austria, Belgium, Denmark, France, Finland, Italy, Malta, Netherlands, Poland, Portugal, Romania, Slovenia, Spain and Sweden. Importantly, on 4 March 2016, the European Commission has proposed for the European Union to ratify the Council of Europe's Istanbul Convention.

Věra Jourová, European Commissioner for Justice, Consumers and Gender Equality said:

"Our proposal sends a clear message: victims of violence against women must be better protected across Europe. One in three women in the EU has experienced physical or sexual violence, or both. More than half of all women have experienced sexual harassment after the age of 15. These figures are unacceptable and this goes against our values. Today's proposal for the EU to ratify the Istanbul Convention is a step forward both for our fight against violence and in guaranteeing gender equality. To ensure coherent implementation at all levels, I also call on those Member States who have not yet ratified the Convention to do so swiftly."

The European Parliament has also expressed its support in banning the practice of forced sterilization. The Employment and Social Affairs Committee published a report on the implementation of the CRPD in the EU and highlighted that the persons with disabilities should have the right to give informed consent to all medical procedures, including sterilisation and abortion.

The Committee on Women's Rights and Gender Equality in its 2013 report on women with disabilities notes that forced sterilisation and coerced abortion are forms of violence against women and constitute forms of inhuman and degrading treatment that Member States must eradicate and strongly condemn. The report calls on the Member States to prevent forced sterilisation, in particular in large institutions and stresses that any sterilisation

agreement entered into by a woman or girl with disabilities must be voluntary and must be examined by an impartial third party charged with verifying that the decision was reached fairly and, in the absence of severe medical indications, without enforcement.

8. Conclusions and recommendations

8.1. Recommendations to the EU institutions

- The European Union should swiftly ratify the Council of Europe's Convention on the prevention and combatting of violence against women and domestic violence;
- The EU to implement the recommendations it has received by the UN CRPD Committee on forced sterilization and legal capacity;
- The EU to adopt public health policy measures to ensure the protection of the integrity of all persons with disabilities and in particular their right to informed consent to medical treatment;
- The EU to promote and undertake research to publicize the reality of sterilisation of persons with disabilities in Member States, taking into account gender, age and type of disability and providing accurate statistics on forced and therapeutic sterilization;
- The adoption of a Communication to Member States on the implementation of EU legislation on access to justice, access to goods and services as well as health, voting and consumer rights provisions in line with Article 12 CRPD and which clearly prohibits discrimination in exercising rights and accessing these services on the basis of disability and/or legal capacity status and that informed consent is ensured.

8.2. Recommendations to the EU Member States

- For those remaining countries, to ratify swiftly the Council of Europe's Convention on the prevention and combatting of violence against women and domestic violence;
- With the support of the EU, national Ministries for Health, Social Services and Equality must carry out a study on the forced sterilisation of persons with disabilities. The study must take into account gender and age perspectives and also consider type of disability.
- A multidisciplinary working group must be created to study therapeutic sterilisation of minors with disabilities and forced sterilisation of adults with disabilities. It should also review legislation and protocols for intervention in line with the UN Convention on the Rights of Persons with Disabilities. A multidisciplinary approach can be assured by including practitioners from

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organisations of persons with disabilities and from the fields of the judiciary, law, health and human rights, among others. The main task of the working group should be to review all current protocols and legal channels regarding sterilisation and draw up standard measures that can be put in place;

- In line with the information presented in this report, any reforms must be founded on the principle that the unconsented sterilisation of persons with disabilities (mainly women and girls) is a human rights matter. Moreover, reforms must acknowledge that any sterilisation performed without the informed consent of the person involved is forced sterilisation. As a result, any application for sterilisation must be considered a procedure that is performed 'on the person with disabilities' and not 'for the person with disabilities'. In addition and because of the higher incidence due to gender, reforms must address the particular situation regarding therapeutic or forced sterilisation of women and girls with disabilities, including women with intellectual, physical, cognitive and sensory disabilities;
- A ban should be secured on all sterilisation of people under the age of 18, unless it is performed to save lives or in a medical emergency;
- Research on 'informed consent' is needed in relation to sterilisation and other issues concerning the reproductive health of women and girls with disabilities of all ages. To achieve this, it would be advisable to check urgently those processes and procedures used in the sterilisation of people who have been declared 'incapable' of granting their informed consent. In all cases, we recommend setting up an independent mechanism to ensure informed consent is safeguarded.
- Necessary measures should be taken in terms of awareness, information and training aimed at both the families of girls and women with disabilities who are most vulnerable and at greatest risk of suffering forced sterilisation, and professionals, above all health care professionals and those involved in the legal field, to ensure that they listen to the voices of girls and women with disabilities during legal investigations and proceedings. These measures shall be taken in close cooperation with representative organisations of persons with disabilities.

8.3. Recommendations to persons with disabilities and families, their representative organisations, women's rights organisations and larger civil society

It is important to highlight that in the realization of the above mentioned recommendations, both at national and EU level, organisations of people with disabilities, and especially of women with disabilities or those that have working areas focusing on women's issues, must also play a leading role, and above all in designing services and support for victims.

This will entail assigning funds for programme development. Some of their main tasks should be:

- To carry out research and develop accessible information resources for women and girls with disabilities on sterilisation and its consequences;
- To include specific seminars and discussion groups on these topics in their work programmes, as well as encourage women with disabilities themselves to be speakers and mentors to other colleagues.
- To carry out research and develop service models based on best practices to support women and girls with disabilities who have suffered unconsented sterilisation and those looking for information and support regarding taking a decision on sterilisation and other more general reproductive health-related issues;
- Once the target population has been identified and progress has been made on the tasks above, to set up and maintain a national network for the reproductive rights of women with disabilities.

Finally, we cannot conclude this report without explicit reference to the work that should be carried out directly with the families of people with disabilities that are most vulnerable to the risk of having their son or daughter sterilised. These families need to be provided with guidance and support services in reproductive health, such as information on contraceptives, sexual health, fertility management, pregnancy, the menopause, and breast and cervical cancer screening programmes for women with disabilities.

However, most importantly these families need to be given a space to reflect and reach an understanding that sterilising people with disabilities is a question of human rights. They should be given recommendations on other options for menstrual management and pregnancy prevention through the use of contraceptives. In addition, informative material should be produced on the legal, medical and social ramifications of forced sterilisation and menstrual suppression practices. In the same way it is necessary to train practitioners, and in particular doctors and other healthcare staff, so that they understand the difference they can make in the lives of women and girls with disabilities, change their attitudes and begin to listen to them in research projects.

Only when we turn around the prevailing social perception concerning the right of women and girls with disabilities to take their own decisions on their own lives will we grant them the right to be themselves.

Annex – Testimonies to add later throughout the report, jointly with pictures

Loss of identity

"For me, it has meant a denial of my status as a woman."

"I have lost my identity as a woman, as a sexual being."

"I have been denied having the same enjoyment and aspirations as other women. "

"The psychological effects are enormous. They rob you of the feeling of being a woman."

Without defence

"Women with intellectual disabilities do not always understand what it means the sterilization until it has been carried out and then it is too late." "I've always been afraid to talk about it, I'm very lonely."

"I want to help other people who have no voice to stop it from happening, But I feel helpless to do so."

"They raped me."

Cultural impact

"As I will not go through an apparent menopause, in my culture it means that there is no point from which one can say "I have grown old."

"It is a lack of respect for our beliefs about how we should live. "

Effects on health

"As some fundamental parts of my body have been excised, it is difficult to know what is going on inside."

"I am concerned about the future effects on my health, such as osteoporosis and others problems."

"I will not have a way of knowing when menopause begins."

"I know that, as a consequence, there have been hormonal changes in my body that would not have happened if this had not happened. "

Effects on relationships

"It can lead to the breakdown of a relationship."

"Women who have been sterilized may be afraid of being rejected by his or her partner."

"Other people do not understand what it means for your life and it is quite difficult to explain them"

"It does not allow women to have children, even if they want to."

Lack of choice

"For many women it means that other people are making their decisions by them."

"It means depriving a woman of her right to choose what she wants to be in life."

"It implies that you are imprisoned in a forced form of birth control. You can not choose. "

Loss

"It can trigger an early menopause, a loss of things that happen in life." "For me, it is living with loss."

"It really affects my self-esteem."

"It has not allowed me to lead a normal life."

"It means losing control."

"It has meant a loss of confidence; especially in physicians, in which women with disabilities often need to trust."

"You miss having your period."

Feelings

"I feel angry."

"I have an emotional block."

"I feel alone and isolated."

"It's hard to bear the pain."

"I feel sorry that I do not see myself as having a sexual identity."

"I feel rejected."

Absence of services

"We do not have information accessible to us."

"The fact that there are no services is not a reason for sterilization."

"There are not enough services or people to listen to you."