



FUNDACIÓN CERMI MUJERES

Ending forced sterilisation of women and girls with disabilities

TABLE OF CONTENTS



EASY TO READ - PAGE 4

SUMMARY	11
INTRODUCTION	16
I. DEFINITION AND CONSEQUENCES OF STERILISATION	18
II. STERILISATION OF GIRLS WITH DISABILITIES	21
III. WHAT ARE THE MYTHS BEHIND FORCED STERILISATION?	22
IV. THE POTENTIAL IMPACT OF STERILISATION ON WOMEN AND GIRLS WITH DISABILITIES	25
V. FORCED STERILISATION AROUND THE WORLD	26
VI. RELATIONSHIP BETWEEN LEGAL CAPACITY AND FORCED STERILISATION	33
VII. FORCED STERILISATION FROM THE HUMAN RIGHTS PERSPECTIVE	37
7.1. The UN Convention on the rights of persons with disabilities	37
7.1.1 Concluding observations issued by the UN Committee on the rights of persons with disabilities to the European Union	38
7.1.2 Concluding observations issued by the UN Committee on the rights of persons with disabilities to European countries	39
7.2. General Comment No. 3 of the UN Committee on the rights of persons with disabilities	41
7.3. Other UN human rights treaties and the Special Rapporteur against torture	42
7.4. Council of Europe Convention on violence against women and domestic violence	44
VIII. CONCLUSIONS AND RECOMMENDATIONS	49
8.1. Recommendations to EU institutions	49
8.2. Recommendations to EU member states	50
8.3. Recommendations to persons with disabilities and their families, representative organisations, women's rights organisations and wider civil society	52

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EASY TO READ

Easy-to-read is one of the accessible information formats along with large print, Braille and audio recordings. It is mostly used by people with intellectual disabilities, as well as other groups like older people and speakers of other languages. Sentences are short and simple using words which are easy to understand. The design is clear and avoids complicated page settings.

ENDING FORCED STERILISATION OF WOMEN AND GIRLS WITH DISABILITIES

WHAT THIS REPORT IS ABOUT

The **European Disability Forum** and **CERMI Women's Foundation** have written a report together.

The **European Disability Forum** is an organisation of people with disabilities in Europe.

In short, we call it EDF.

EDF was created by people with disabilities in 1996.

EDF works to protect the rights of people with disabilities in Europe.

The **CERMI Women's Foundation** is a Spanish organisation that helps protect the rights of women and girls with disabilities.

This report looks at how to stop **forced sterilisation** of women and girls with disabilities.

Sterilisation is when women and girls have an operation that stops them having babies.

Forced sterilisation is when women and girls are forced to have this operation.

This report also looks at **legal capacity**.

Capacity is when you can make a decision or choice at one moment.



There are laws about how to decide if someone has capacity.

Then it is called legal capacity.

Legal capacity means that people with intellectual disabilities can do things on their own.

These are some of the things they can do:

Make choices about their lives.

Get married, start a family and raise children.

Make decisions about their health.

WHY FORCED STERILISATION IS BAD

Forced sterilisation is a crime says the **Council of Europe**.

The **Council of Europe** is an organization made up of different European countries.

It has 47 members.

The Council of Europe works for human rights and equality for all.

The Council of Europe does not make laws.

It can just make countries follow some international agreements.

Forced sterilisation happens a lot to women with disabilities and it happens the most to women with intellectual disabilities.

It also happens a lot to girls with disabilities.

It is against their rights and must be stopped.

Forced sterilisation shows that lots of women with disabilities are denied their human rights because they are women.

Women with disabilities often do not get the right healthcare.

For example, if they want to have babies.

Or when it comes to other things that only affect women.

Sterilisation is can be bad for women and girls with disabilities.

It can affect their health very badly.

Forced sterilisation is very bad because people must know what is happening to them.

This is called **informed consent**.

Informed consent is when you fully understand something.

In order to fully understand something

it can be important to have access to information that you understand.

For example, information in easy-to-read.

HOW WE CAN STOP FORCED STERILISATION

There are some documents which can help stop forced sterilisation.

One of these documents is the

United Nations Convention on the Rights of Persons with Disabilities (in short, UN CRPD).

This document tries to make sure that the rights of people with disabilities are respected.

The UN CRPD says that people should be able to make their own choices and not have someone make them for them.

The State should help people with disabilities

to use their legal capacity and make their own choices.

This means that forced sterilisation must be stopped.



Because forced sterilisation is not a choice.

Another of these documents is the **Istanbul Convention**.

The Istanbul Convention is about how to stop violence against women and girls with disabilities.

Forced sterilisation is violence.

The Istanbul Convention says that forced sterilisation should stop.

WHAT EDF AND CERMI WOMEN'S FOUNDATION WANT

The CERMI Women's foundation and EDF want all the countries in the **European Union** to accept the Istanbul Convention.

This will help to stop forced sterilisation.

The **European Union** (in short, EU) is a group of 28 countries.

We call these countries "member states".

They have joined together to be stronger.

The EU makes laws on many important things for the people who live in those countries.

The CERMI Women's Foundation and EDF wants countries to make violence against women and girls to be illegal.

This means that forced sterilisation should be illegal.

They also want countries to make sure that health services are helping people with disabilities.

For example by making information **accessible**.

Accessible is something that is easy to use for people with disabilities.

Such as:

- Ramps to get into a building.
- Information in easy-to-read.
- Information in sign language.

CERMI Women's Foundation and EDF want sterilisation of girls under 18 to be illegal.

It should only be legal if it must be done to save their life.

It is important for organisations of people with disabilities to help stop violence against women and to help end forced sterilisation.

- 10 -

“It has meant a loss of confidence, especially in physicians, in whom women with disabilities often need to trust.”

SUMMARY

ENDING FORCED STERILISATION OF WOMEN AND GIRLS WITH DISABILITIES

SCOPE AND STRUCTURE OF THE REPORT

The European Disability Forum (EDF) and CERMI Women's Foundation have released a comprehensive report which raises awareness on how to prevent and end forced sterilisation of women and girls with disabilities. It explains the justifications given for forced sterilisation and the negative consequences of forced sterilisation on the enjoyment of all human rights for all women and girls with disabilities. It highlights the close relationship between this practice and the deprivation of legal capacity, and describes the current situation in Europe and beyond. Finally, it gives an overview of the current human rights standards and jurisprudence on the topic.

WHAT IS STERILISATION?

The term 'sterilisation' is defined for the purpose of this report as "a process or act that renders an individual permanently incapable of sexual reproduction". 'Forced sterilisation' refers to when this procedure is undertaken without the knowledge, 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.

- 11 -

Forced sterilisation constitutes a crime based on the definition of the Council of Europe Convention on preventing and combating violence against women and domestic violence (Istanbul Convention).

Forced sterilisation is carried out on (or, rather, perpetrated against) many persons with disabilities, especially women and girls with disabilities, and mainly women and girls with intellectual and psychosocial disabilities. It violates and disregards their most fundamental rights: freedom, respect and personal integrity. In particular, girls and adolescents with disabilities face a greater risk of undergoing this forced practice. Sterilisation is an issue that must be addressed during adult life and not childhood.

WHAT IS THE IMPACT OF STERILISATION ON WOMEN AND GIRLS WITH DISABILITIES?

Sterilisation represents a life sentence, a loss and a betrayal for women and girls with disabilities. It can also cause serious health consequences. Forced sterilisation forms part of a wider paternalistic model and patriarchal system in which women with disabilities are denied their human and reproductive rights. This includes exclusion from suitable healthcare for reproductive health and sexual health screening programmes, restrictions in choice of contraceptive type, a tendency to suppress menstruation, shortcomings in pregnancy and birth management, selective or forced abortions and denial of the right to have a family life.

WHERE IS IT PRACTICED?

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 continued, and continue, to take place in modern democracies throughout Europe.

For example, Sweden set up a eugenic sterilisation programme in 1934 and abolished it in 1976. Under this programme 21,000 people were forcibly sterilised and 6,000 were coerced into 'voluntary' sterilisation. In Spain, according to data from the General Council of the Judiciary (2010-2013), there was an average of 96 court rulings authorising sterilisation of persons with disabilities who were deprived of their legal capacity. Other countries that have previously had active sterilisation programmes include Denmark, Norway, Finland, Estonia, Switzerland and Iceland.

HOW DOES INTERNATIONAL HUMAN RIGHTS LAW ADDRESS FORCED STERILISATION?

International human rights standards and jurisprudence stress that forced sterilisation 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.

The UN Convention on the Rights of Persons with Disabilities (CRPD) enshrines relevant provisions to address the rights of persons with disabilities and tackle the issue of forced sterilisation (Articles 12-17-23-25). The CRPD legal framework shows that an 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 regarding medical treatment, and 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.

It is also 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 as a crime 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."

EDF'S RECOMMENDATIONS AND CERMI WOMEN'S FOUNDATION

EDF and CERMI Women's Foundation strongly urge the EU and EU countries to swiftly ratify the Council of Europe's Convention on the prevention and combating of violence against women and domestic violence. Its governments should adopt legislative reforms founded on the principle that the non-consensual sterilisation of persons with disabilities is a denial of their human rights. These reforms should include the adoption of an EU strategy and Directive criminalising all forms of male violence against women and girls (including forced sterilisation), and providing assistance and support to all women and girls victims. The reforms should also include 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. In addition, and because of the higher incidence due to gender, reforms must address the particular situation of women and girls with disabilities, including women with intellectual and psychosocial disabilities. A ban should be secured on all sterilisation of people under the age of 18, unless it is performed to save life or in a medical emergency.

Organisations of persons with disabilities, and especially of women with disabilities or those that have working areas focusing on women's issues, must play a leading role to accomplish the recommendations above, both at national and EU level, in line with the principles of the CRPD. This is especially important in designing services and support for victims.

INTRODUCTION

This report presents recommendations from the European Disability Forum (EDF) and CERMI Women's Foundation on how to prevent and end forced sterilisation of women and girls with disabilities. It sets out the justifications given for forced sterilisation and the negative consequences of forced sterilisation on the enjoyment of all human rights by all women and girls with disabilities. It highlights the close link between this practice and the deprivation of legal capacity, and describes the current situation in Europe and beyond. Finally, it provides 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 has been undertaking since 2015 to raise awareness of the practice of forced sterilisation. As part of its Gender Equality Plan 2015-2017, to date the campaign has seen the drafting of this report, deliberations in the EDF Women's Committee, a discussion at the EDF Board, and a photography competition organised by CERMI Women's Foundation.

The important topic of forced sterilisation has been central to the work of EDF and its Women's Committee. 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 are key tools to ensure the rights of women and girls with disabilities are fully respected in practice, including the right to make one's own decisions, reproductive rights and the right to legal capacity.

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

The United Nations (UN) Convention on the rights of persons with disabilities (CRPD) recognises 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 a diverse society, have always been so and will remain so. Promoting full enjoyment of their human rights, and their full participation in all spheres of life, will result in an enhanced sense of belonging and significant advances in the human, social and economic development of society.

The practice of forced sterilisation is part of a broader pattern of denial of the human rights of women and girls with disabilities. This denial also includes systematic exclusion from comprehensive reproductive and sexual health care, limited voluntary contraceptive choices, a focus on menstrual suppression, poorly-managed pregnancy and birth, involuntary abortion, and the denial of rights to parenting.¹

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

It is also important to address and acknowledge the sterilisation of men with disabilities. However, this occurs on a smaller scale than forced sterilisation of women (proportionally to the problem),² and this is the reason why this report focuses on the situation of women and girls with disabilities.

¹ / Open Society Foundations. (2011). Sterilisation of Women and Girls with Disabilities Public Health Program. Available at: <https://www.opensocietyfoundations.org/sites/default/files/sterilisation-women-disabilities-2011101.pdf>
² / Human Rights. (2011). Sterilisation of Women and Girls with Disabilities: A Briefing Paper. Available at: <https://www.hrw.org/news/2011/11/10/sterilisation-women-and-girls-disabilities>

I.

DEFINITION AND CONSEQUENCES OF STERILISATION

The term 'sterilisation' is defined for the purpose of this report as "a process or act that renders an individual permanently incapable of sexual reproduction".³ 'Forced sterilisation' refers to when this procedure is undertaken without the knowledge, 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.

Forced sterilisation constitutes a crime based on the definition of the Council of Europe Convention on preventing and combating violence against women and domestic violence (hereafter, the Istanbul Convention). Article 39 criminalizes performing surgery which terminates a woman's capacity to naturally reproduce without her prior and informed consent.⁴

Forced sterilisation is carried out on (or, rather, perpetrated against) many persons with disabilities, especially women and girls with disabilities, and mainly women and girls with intellectual and psychosocial disabilities. It violates and dismisses their most fundamental rights: to freedom, respect and personal integrity.⁵ Forced sterilisation is now globally recognised as an act of violence,⁶ a form of social control and a documented violation of the right to be free from torture and other cruel, inhuman or degrading treatment or punishment.⁷

When referring to this kind of sterilisation, terms such as 'unauthorised', 'non-consensual', 'involuntary' or 'non-therapeutic' sterilisation have been used which mask 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 that they are denied access to suitable services and 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.

The fact that the procedure may have been authorised by law cannot hide the reality that a woman with a disability, and usually a very young woman, is subjected to an unnecessary and non-therapeutic medical intervention to remove an organ that is essential for sexual and reproductive health.⁸ There is considerable stigma attached to sterilisation and loss of fertility.⁹ In addition, forced sterilisation of women and girls with psychosocial disabilities can be (re)traumatising and have lifelong implications for mental health. 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 recommendations issued by the International Federation of Gynecology and Obstetrics (FIGO), no woman may be sterilised without her own, previously-given, informed consent, with no coercion, pressure or undue inducement by healthcare providers or institutions having been applied. By contrast, women considering sterilisation must be given information of their options in the language in which they communicate and understand.¹⁰

In addition to an inability to reproduce, sterilisation can cause premature menopause, osteoporosis and cardiovascular conditions if it is performed before a girl begins to menstruate or during puberty. More serious still, forced sterilisation may lead to enhanced vulnerability to sexual abuse for a girl, adolescent or young woman with disabilities.

³ / Elsevier. (2009). Mosby's Medical Dictionary, 8th edition

⁴ / Istanbul Convention. (2011). Council of Europe Convention on preventing and combating violence against women and domestic violence. (art.39) Council of Europe Treaty Series - No. 210.

⁵ / World Health Organization. (2014). Eliminating forced, coercive and otherwise involuntary sterilisation. An interagency statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO.

⁶ / Istanbul Convention. (2011). Council of Europe Convention on preventing and combating violence against women and domestic violence (art.39) Council of Europe Treaty Series - No. 210, UN Committee on the Elimination of Discrimination Against Women (CEDAW Committee) (1992), General recommendation No. 19: Violence Against Women, art. 16 (and art. 5) of the Convention (Women and Health), para. 22.

⁷ / UN Human Rights Council, Promotion and Protection of All Human Rights, Civil, Political, Economic, Social and Cultural Rights. (2008). Including the Right to Development: Report of the Special Rapporteur on torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Manfred Nowak, 15 January 2008, A/HRC/7/3, [paras.38, 39].

⁸ / WWDA Policy & Position Paper. (2007). The Development of Legislation to Authorise Procedures for the Sterilisation of Children with Intellectual Disabilities

⁹ / Ripke, K. (2015). The Stigma attached to infertility. Frozen Egg Bank. Available at: <https://www.eggfreezing.com/stigma-attached-to-infertility/>

¹⁰ / FIGO (International Federation of Gynecology and Obstetrics). (2011). Female Contraceptive Sterilisation. Available at: www.wwda.org.au/FIGOGuidelines2011.pdf.

- 20 -

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

II. STERILISATION OF GIRLS WITH DISABILITIES

- 21 -

Girls and adolescents with disabilities face a greater risk of subjection to forced sterilisation. This leads to a number of considerations.¹¹ First, sterilisation must not be performed on children. The UN Committee on the rights of the child has identified forced sterilisation of girls with disabilities as a form of violence and noted that states parties to the Convention on the rights of the child are expected to prohibit by law the forced sterilisation of children with disabilities. The Committee has also stated that the principle of the “best interests of the child” cannot be used “to justify practices which conflict with the child’s human dignity and right to physical integrity.”¹²

Second, as the majority of European Union (EU) member states have ratified both the Convention on the rights of the child (CRC) and the CRPD, 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.

¹¹ / European Conference, Madrid .(2007). Situations about the sterilisation of girls and women with disabilities in different countries in Europe are gathered in: Recognising the rights of girls and women with disabilities: an added value for tomorrow's society. Available at: <http://www.cermi.es/es-ES/ColeccionesCermi/Cermi.es/Lists/Coleccion/Attachments/45/Reconociendolosderechosdelasniasyjerescondiscapa.pdf>.

¹² / Open Society Foundations. (2011). Sterilisation of Women and Girls with Disabilities Public Health Program. Available at: <https://www.opensocietyfoundations.org/sites/default/files/sterilisation-women-disabilities-20111101.pdf>

III. WHAT ARE THE MYTHS BEHIND FORCED STERILISATION?

A number of myths have been used traditionally to justify the sterilisation of women and girls with disabilities:

FOR THE GOOD OF SOCIETY, THE COMMUNITY OR THE FAMILY:

this justification is based on the idea that having to care for an 'abnormal child' is a burden, or on the difficulty a woman with disabilities might experience in managing her own reproductive functions, and especially menstruation. The argument is also founded on economic and social factors because of the extra expense of the state having 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 burden on families, mothers and fathers of girls with disabilities are often not given sufficient information or support. They find themselves alone due to a lack of services and resources. Faced with this difficult situation, which stems from services being inaccessible and a lack of specialist training on reproductive health and menstruation management, a family may see sterilising their daughter as the only solution.

WOMEN WITH DISABILITIES ARE INCAPABLE OF BEING MOTHERS:

there is a widely-held misconception 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 despite the fact that research has shown no clear relationship between educational attainment or intelligence of fathers and mothers and being a good father or mother. This negative social perception towards persons with disabilities is worse in the case of women with disabilities because of the greater responsibility for parental care they are considered to have. In fact, value judgments in this respect are even more hurtful and negative.

For women with psychosocial disabilities, the misconception that they might harm their children should be mentioned. The 'dangerousness' justification is used to limit their rights in many areas of life, despite clear evidence that they are more often the victims, rather than the perpetrators, of violence.¹³

FOR THE "GOOD OF WOMEN WITH DISABILITIES":

protecting women with disabilities against abuse and from future pregnancies as a result of possible future abuse. As protection against menstrual difficulties for women with disabilities, such as autism and severe learning disabilities, and in particular when they experience seriously distressing symptoms or 'challenging behaviour'.¹⁴

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 literature addressing this issue, yet there are very few written testimonies from the people who have been subjected to this type of irreversible and invasive surgical intervention. Lack of access to this kind of information leads us to question the extent to which women with intellectual disabilities still find themselves in a situation of great vulnerability and disempowerment.¹⁵

¹³ / Peterson et al. (2014). How Often and How Consistently do Symptoms Directly Precede Criminal Behavior Among Offenders With Mental Illness?, Columbia University, Law and Human Behavior.

¹⁴ / See Albanese, A. and Hopper, N.W. (2007). Suppression of menstruation in adolescents with severe learning disabilities, Arch Dis Child.; 92(7): 629-632.

¹⁵ / See Servais L. (2006). Sexual health care in persons with intellectual disabilities. Mental Retardation and Developmental Disabilities Research Reviews,12: pp. 48-56.

- 24 -

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

IV. THE POTENTIAL IMPACT OF STERILISATION ON WOMEN AND GIRLS WITH DISABILITIES

- 25 -

The advocacy work carried out by Women with Disabilities Australia (WWDA) on the rights of women and girls with disabilities is based on the voices and experiences of women affected by sterilisation.¹⁶ These women have described sterilisation as a life sentence, a loss or a betrayal, and they have shared their personal experiences and the consequences for their mental and physical health and their life in general. The clear message is that we must listen to women and learn from them in order, first of all, to help those already affected and, secondly, to put safeguards in place to prevent other women being denied their human rights.

In addition, the experiences of women affected show that forced sterilisation forms part of a wider paternalistic model and patriarchal system in which women with disabilities are denied their human and reproductive rights. This includes exclusion from suitable healthcare for reproductive health and sexual health screening programmes, restrictions in their choice 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.¹⁷

¹⁶ / Dowse, L. for Women With Disabilities Australia (WWDA). (2004) Moving Forward or Losing Ground? The Sterilisation of Women and Girls with Disabilities in Australia', Disabled People's International (DPI) World Summit, Winnipeg.
¹⁷ / World Health Organization and The World Bank. (2011). World Report on Disability, pp. 78. Available at http://www.who.int/disabilities/world_report/2011/report.pdf. Cites: Dyer O. Gynaecologist is struck off for sterilising women without their consent. British Medical Journal (2002) ,325:1260.

V. FORCED STERILISATION AROUND THE WORLD

Forced sterilisation has been common practice in many countries around the world. The most notorious example are the eugenics programmes in the early 20th century that aimed to ensure only the 'fit' and 'productive' were a part of societies and that others did not exist and/or reproduce. Their purpose was to deprive women with disabilities or women from other excluded groups such as LGBTI women and Roma women of their reproductive rights.¹⁸ European and international human rights standards and jurisprudence stress that forced sterilisation is a form of violence, and a violation of many human rights.

Forced sterilisation of women with intellectual disabilities was extensively practised in **Canada** and the **USA** in the early to mid-twentieth century,¹⁹ when individuals with intellectual disabilities were considered incapable of parenting. Resort to sterilisation was to enable them to live outside institutions without the danger of pregnancy.²⁰ In Minnesota, during the interwar period, "sterilisation policy was as much about preventing child rearing by the so-called feeble-minded as it was about preventing child bearing".²¹ Moreover, forced sterilisation was prescribed by law for certain categories of individuals, including "criminals", "rapists", "epileptics", and "the insane and idiots".²² The first US state to legalise compulsory sterilisation in 1907 was Indiana and, by the end of the 1920s, twenty-four US states had introduced the practice.

Currently, **Australia** still does not have any laws in place to prohibit the forced sterilisation of women or children with disabilities. However, there is evidence which suggests that the majority of girls who are sterilised have an intellectual disability.²³ In September 2012, the Senate Community Affairs References Committee established an inquiry into the involuntary or coerced sterilisation of people with disability and intersex people in Australia, and released two Inquiry Reports in 2013.²⁴ The Committee only recommended implementing a prohibition of forced sterilisation in cases where an adult with disability has the 'capacity' to provide consent.

Across **Europe**, the practice of forced sterilisation of women with disabilities has a long history. Such practices were not confined to the eugenic policies of World War II, but continued, and continue, to take place in modern democracies throughout the continent.²⁵

Sweden set up a eugenic sterilisation programme in 1934 and abolished it in 1976. According to a 2000 Swedish government report, under this programme 21 000 people were forcibly sterilised and 6 000 were coerced into 'voluntary' sterilisation. The nature of a further 4 000 cases could not be determined. The Swedish state subsequently paid out damages to many victims of these practices of forced sterilisation.²⁶

In the late 1990s, reports from the media and from non-governmental organisations 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 women with disabilities or women in a difficult social situation were forcibly sterilised in French public hospitals in 1996.²⁷

¹⁸ / American University. Washington College in Law. (2014). Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture's 2013 Thematic Report. center for human rights & humanitarian law Anti-Torture Initiative, pp. 76 http://antitorture.org/wp-content/uploads/2014/03/PDF_Torture_in_Healthcare_Publication.pdf

¹⁹ / Tilley, E., Earle, S., Walmsley, J., and Atkinson, D. (2012). 'The Silence is roaring': sterilisation, reproductive rights and women with intellectual disabilities. *Disability and Society*, 27(3) pp. 413-426.

²⁰ / Engwall, K. (2004). Implications of being diagnosed as a "feeble-minded woman". In eds Kristiansen, K. and Traustadottir, R. *Gender and Disability Research in the Nordic Countries, Sweden*: Studentlitteratur.

²¹ / See Ladd Taylor, M. (2004). The "sociological advantages" of Sterilisation Fiscal Policies and Feeble-Minded Women in Interwar Minnesota. In Eds. S. Noll and J. Trent J. *Mental Retardation in America*, pp. 281-302. New York: New York University Press

²² / Kevles, D. (1995). *In the Name of Eugenics*. Cambridge, Mass: Harvard University Press (2nd revised edition).

²³ / Jabour, B. (2015). UN examines Australia's forced sterilisation of women with disabilities. *The Guardian*. Available at: <https://www.theguardian.com/australia-news/2015/nov/10/un-examines-australias-forced-sterilisation-of-women-with-disabilities>

²⁴ / Senate Standing Committees on Community Affairs. (2013). *Involuntary or coerced sterilisation of intersex people in Australia*. Commonwealth of Australia. Available at: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/involuntary_sterilisation/first_report/index.htm

²⁵ / Aly, G., Chroust, P. and Pross, C. (1994). *Cleansing the Fatherland: Nazi Medicine and Racial hygiene*, pp.295

²⁶ / See also Stansfield A.J., Holland A.J., and Clare, I.C.H. (2007). The sterilisation of people with intellectual disabilities in England and Wales during the period 1988 to 1999. *Journal of Intellectual Disability Research: JIDR*, 51: pp. 569-579. doi:10.1111/j.1365-2788.2006.00920.x PMID:17598870 - 26 / *The Independent*. (2007). Sweden admits to racial purification - Forced sterilisation of 'inferior' women unchecked for 40 years, Available at: <http://www.independent.co.uk/news/world/sweden-admits-to-racial-purification-1247261.html>.

²⁷ / *Le Monde*. (1998). La sterilisation des Handicapées est faible, mais non marginale, Selon l'IGAS

On 16th August 2011, the Center for Reproductive Rights, EDF, Interights, the International Disability Alliance and Mental Disability Advocacy Centre, jointly submitted written comments to the European Court of Human Rights in the case of Gauer and Others v. France.²⁸ The case was brought by five women with intellectual disabilities who were forcibly sterilised and alleged that they underwent a process of tubal ligation without their informed consent and against their wishes. The judgment of the Court could have been a key ruling on the reproductive rights of persons with disabilities and a state's 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.

In **Spain**, forced sterilisation continues to be performed on women and girls with disabilities, especially those with intellectual or psychosocial disabilities, without their consent or their understanding the purpose of the surgical intervention. This is carried out under the pretext of their welfare. According to data from the General Council of the Judiciary (2010-2013), there was an average of 96 court rulings authorising sterilisation of persons with disabilities who were deprived of their legal capacity.²⁹

A Spanish Constitutional Court ruling (215/1994) concluded that a sterilisation procedure could be 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 stated 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 sterilised for her own safety because another pregnancy would have been a "significantly life-threatening event" for her and her unborn child.

The **Croatian** Supreme Court recently allowed sterilisation of a woman with a psychosocial disability on the basis that with frequent pregnancies she was endangering her life (the new law of 2015 transferred substitute decision-making powers from guardians to the courts). Even though the law has changed, the violations of rights continue under the authority of the court.

Other countries that have previously had active sterilisation programmes include **Denmark, Norway, Finland, Estonia, Switzerland** and **Iceland**.³⁰

²⁸ / European Court of Human Rights, (2011) Application no. 61521/08, Joelle Gauer and Others v. France.
²⁹ / Data on the Sterilisation of Women and girls with Disabilities in Spain, General Council of the Judiciary.

³⁰ / Broberg, G. and Roll-Hansen, N. (2005). Eugenics And the Welfare State: Sterilisation Policy in Denmark, Sweden, Norway, and Finland. Michigan State University Press.

TESTIMONY

TESTIMONY OF A DEAF WOMAN WHO WISHED TO START A FAMILY

The woman concerned was deaf but born to hearing parents. There were communication barriers between her and her parents as her parents had no sign language skills. The woman married a deaf man and the couple decided to start a family together. After some time trying to become pregnant, the couple went to the doctor to have fertility tests. The husband completed these tests and was deemed capable of having children. However, the woman went through more rigorous examinations, only to find that she had been sterilised years previously, when she was already an adult. She had no

knowledge of this. The woman confronted her mother who told her the doctor thought sterilisation was the best thing to do to stop the deaf gene being passed down to the next generation of the family.

This has been a huge point of contention between this deaf woman and her mother. The woman was sterilised without any information and no sign language interpreter was provided. Written information would not have helped as the deaf woman's literacy skills would not have been good enough to understand the text. As time passed, this woman has unhappily accepted her situation and has since adopted a child. This is an incredibly sad story. We hope that in the future sign language interpretation and translation of written documents into sign language will be provided for deaf people to allow for informed consent*.

*Testimony kindly offered by the European Union of the Deaf (EUD)

- 32 -

**“It is a lack of respect
for our beliefs about
how we should live.”**

VI. RELATIONSHIP BETWEEN LEGAL CAPACITY AND FORCED STERILISATION

According to article 12 of the CRPD, “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 disabilities are rightsholders 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 ‘substituted decision-making’ towards more individually tailored support systems.

General comment No. 1 of the Committee on the rights of persons with disabilities (CRPD Committee)³¹ confirms that “women with disabilities are subjected to high rates of forced sterilisation, 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.”

31 / Committee on the rights of persons with disabilities, eleventh session 31st March- 11th April 2014, General comment No. 1. (2014). Available at: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>

Moreover, article 15, Sections 2 and 3 of the UN Convention on the elimination of all forms of discrimination against women (CEDAW) 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 all other private instruments with a legal effect which are directed at restricting the legal capacity of women are deemed to be null and void.

The CRPD moves away from the guardianship model and emphasises the need for supported decision-making in order to safeguard the full enjoyment of the right to legal capacity for persons with disabilities.³²

The CRPD has prompted discussions about the current legal frameworks governing legal capacity in 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 abolition of substituted decision-making regimes. Most reforms still allow some form of partial substitute decision-making regimes or partial guardianship.³³

In **Ireland** the Assisted Decision-Making (Capacity) Act came into force in 2016.³⁴ The Act provides a statutory framework for individuals to make legally-binding agreements to be assisted and supported in making decisions about their welfare, their property and other 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 will also be set up within the Mental Health Commission to provide a range of functions in relation to the new arrangements.

Sweden has replaced its guardianship system in order to promote supported decision-making measures. In regard to this, its reform of psychiatry of 1995 introduced a personal ombudsmen (PO) into the legal system.³⁵ The PO is an independent professional who works exclusively on behalf of the client on a relationship basis. The idea is for the PO to develop a trusting relationship with clients and to support people with psychosocial disabilities to make their own decisions. To this end, clients discuss their situation with the PO and jointly agree the type of support to be provided. The Swedish model is a promising practice which enhances decision-making tools that accommodate specific individuals' conditions. In 2014, 310 POs provided support to more than 6 000 people in Sweden, and 245 Swedish municipalities included POs in their social services.

Germany also reformed its legal capacity law by replacing the former guardianship system with a system of custodianship (*gesetzliche Betreuung*).³⁶ Under this, people with intellectual disabilities generally enjoy full legal capacity when they turn 18. According to the reform, national courts cannot issue any incapacitation order. However, they may appoint a legal custodian who manages only those specific matters assigned by the court in relation to that individual's needs. The custodian has the duty to help and assist individuals with intellectual and psychosocial disabilities in taking life decisions. The goal of this practice is to support persons with disabilities to live a self-determined life.

As mentioned above, these recent legal reforms are a welcome step towards compliance with article 12 of the CRPD. Under them, 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.

³² / Fundamental Rights Agency. (2013). Legal capacity of persons with intellectual disabilities and persons with mental health problems.
³³ / For a mapping of the legal situation around supported and substitute decision-making in EU member states, please see the annex of Mental Health Europe's position paper on article 12 of the UN CRPD. Available at: http://www.mhe-sme.org/fileadmin/Position_papers/Article_12_Position_paper.pdf.
³⁴ / Number 64 of 2015 Assisted Decision-Making (Capacity) Act 2015.

³⁵ / Further information on the website <http://www.personligombud.se/>. You can also watch a video about the PO system at <http://www.mhe-sme.org/publications/videos/>.
³⁶ / Lipp, V. (2014). "Vorsorgevollmacht" as an Alternative to Legal Guardianship, 3rd World Congress on Adult Guardianship. University of Göttingen, Germany

- 36 -

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

VII. FORCED STERILISATION FROM THE HUMAN RIGHTS PERSPECTIVE

International human rights standards and jurisprudence stress that forced sterilisation is a violation of many human rights, and that the principle of informed consent is a fundamental requirement when exercising one's individual human rights, including sexual and reproductive rights.

7.1. THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The CRPD enshrines relevant provisions to respect the rights of persons with disabilities and tackle the issue of forced sterilisation. It emphasises significant principles and values, such as respect for inherent dignity and autonomy, including the freedom to make one's own choices.

ARTICLE 17 aims to protect the integrity of the person and states that every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

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, 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 that relating to 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 recognise 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 an 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 and 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.

- 38 -

7.1.1 Concluding observations issued by the UN Committee on the rights of persons with disabilities to the European Union

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

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 regards to **Croatia** that under that country's Health Act children and adults with disabilities can be sterilised without their free and informed consent if their parents or guardians request this. The Committee recommended that the Health Act be urgently amended to unconditionally prohibit the sterilisation of boys and girls with disabilities, and that of adults with disabilities, in the absence of their individual prior, fully informed and free consent.³⁷

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 authorised to give consent for the sterilisation of the person concerned, so subjecting that person to forced sterilisation. The Committee urged the Czech Republic to abolish this practice of sterilising 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 Czech Republic to provide remedies to the victims of forced sterilisation in accordance with the recommendations made by the Human Rights Committee and Committee on the Elimination of Discrimination Against Women.³⁸

- 39 -

With regards to **Germany**, the CRPD Committee was concerned about the practice of carrying out forced sterilisations and coercive abortions on adults with disabilities on the basis of substituted consent. The Committee recommended that Germany repeal section 1905 of the German Civil Code and explicitly outlaw sterilisation without the full and informed consent of the individual concerned, eliminating all exceptions, including those based on substituted consent or court approval.³⁹

The Committee also called upon **Hungary** to take appropriate and urgent measures to protect persons with disabilities from forced sterilisation.⁴⁰

³⁷ / Committee on the rights of persons with disabilities, Concluding observations on the initial report of Croatia, CRPD/C/HRV/CO/1, 15 May 2015, para. 27-28.

³⁸ / Committee on the rights of persons with disabilities, Concluding observations on the initial report of the Czech Republic, CRPD/C/CZE/CO/1, 15 May 2015, para. 36-37.

³⁹ / Committee on the rights of persons with disabilities, Concluding observations on the initial report of Germany, CRPD/C/DEU/CO/1, 13 May 2015, para. 37.

⁴⁰ / Committee on the rights of persons with disabilities, Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session, 22 October 2012, para. 38.

The concluding observations released by the Committee with regard to the initial report of **Italy** emphasised the lack of data on medical treatment, including sterilisation, administered without the free and informed consent of the person. The Committee recommended that Italy 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.⁴¹

The Committee was concerned that **Lithuania's** Civil Code of 2000 makes it possible for persons with disabilities who have been deprived of legal capacity to undergo, without their consent, surgical operations, including castrations, sterilisations, abortions and operations for the removal of organs, when authorisation by a court. It was also concerned at the lack of investigation into, and data on, the forced sterilisation of persons with disabilities. The Committee therefore recommended that Lithuania abolish all practices of forced treatment, including non-consensual castrations, sterilisations and abortions, and eliminate the possibility for third parties such as guardians, doctors and the courts to approve such practices.⁴²

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 abortion, sterilisation, scientific research, electroconvulsive therapy or psychosurgical interventions. The Committee recommended that Portugal take all possible measures to ensure that the right to free, prior and informed consent to medical treatment is respected and that it put in place assisted decision-making mechanisms.⁴³

In its concluding observations on the initial report of **Slovakia**, the Committee was concerned that the Health Care Act authorises guardians to make decisions on sterilisation and contraceptive use for women whose legal capacity has been restricted. The Committee was also concerned about the lack of investigations and redress

provisions for cases of forced sterilisation. The Committee recommended that Slovakia abolish all forms of guardianship and replace them with supported decision-making regimes, as well as investigate and provide redress for historical cases of forced sterilisation, including for Roma women with disabilities.⁴⁴

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 recognised may be subjected to sterilisation without their free and informed consent. The Committee urged Spain to abolish the administration of medical treatment, and in particular sterilisation, without the full and informed consent of the patient, and to ensure that national law especially respects women's rights under articles 23 and 25 of the Convention.⁴⁵

7.2. GENERAL COMMENT NO. 3 OF THE UN COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES

In 2016, the CRPD Committee adopted its **General comment No 3 on article 6 concerning women and girls with disabilities**.⁴⁶ The Committee identified three main subjects of concern with respect to the protection of the human rights of women with disabilities: (i) violence; (ii) sexual and reproductive health and rights, and; (iii) discrimination. Furthermore, the Committee highlighted the persistence of violence against women and girls with disabilities, including sexual violence and abuse, forced sterilisation, 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, including those related to contraception and abortion.

⁴¹ / Committee on the rights of persons with disabilities, Concluding observations on the initial report of Italy, 6 October 2016, CRPD/C/ITA/CO/1, para. 63-64.

⁴² / Committee on the rights of persons with disabilities, Concluding observations on the initial report of Lithuania, 11 May 2016, CRPD/C/LTU/CO/1, para. 38.

⁴³ / Committee on the rights of persons with disabilities, Concluding observations on the initial report of Portugal, 20 May 2016, CRPD/C/PRT/CO/1, para. 36.

⁴⁴ / Committee on the rights of persons with disabilities, Concluding observations on the initial report of Slovakia, 17 May 2016, CRPD/C/SVK/CO/1, para. 50-51.

⁴⁵ / Committee on the rights of persons with disabilities, Concluding observations on the initial report of Spain, 19 October 2011; CRPD/C/ESP/CO/1, para. 37-38.

⁴⁶ / Committee on the rights of persons with disabilities, General comment No. 3 (2016) on article 6: Women and girls with disabilities, 2 September 2016.

The Committee emphasised 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. Instead, all women with disabilities should be able to exercise their legal capacity independently 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 sterilisation. Therefore, it is crucial to recognise 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 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 (CEDAW Committee) has clarified that forced sterilisation is a form of violence against women. The CEDAW Committee stated that "compulsory sterilisation 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."⁴⁷ The CEDAW Committee, in its General recommendation 24, also urged states parties to "not permit forms of coercion, such as non-consensual sterilisation that violate women's rights to informed consent and dignity".⁴⁸

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 outlaw the forced sterilisation of children on grounds of disability, and to provide these children with adequate information on relationships and sexual and reproductive health, as well as guidance and counselling.⁴⁹

The **Committee on economic, social and cultural rights** has also pointed out that forced sterilisation 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 sterilisation 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.⁵⁰

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 sterilisation because of discriminatory notions that they are 'unfit' to bear children is an increasingly global problem. Forced sterilisation 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."

The **Committee against torture** has indeed encouraged states to take urgent measures to investigate promptly, impartially, thoroughly and effectively all allegations of involuntary sterilisation of women, to prosecute and punish perpetrators, and to provide victims with fair and adequate compensation.⁵¹

The **UN Human Rights Council** declares that violence against women with disabilities may be structural and stem from discriminatory legislation. It also considers forced sterilisation to be a form of violence.⁵²

⁴⁷ / Committee on the elimination of discrimination against women, General recommendation No. 19 (11th session, 1992) Violence against women.
⁴⁸ / Committee on the elimination of discrimination against women, General recommendation No. 24 (20th session, 1999) on article 12: Women and health.

⁴⁹ / UN Committee on the rights of the child (CRC), General comment No. 13 (2011) On article 19: The right of the child to freedom from all forms of violence, 17 February 2011. See also, the UNICEF report The State of the World's Children 2013, Children with Disabilities (pp. 41-43).
⁵⁰ / Committee on economic, social and cultural rights (1994). Persons with disabilities: CESCR General comment 5 (31), eleventh session.
⁵¹ / UN Committee against torture (CAT Committee), Concluding observations: Slovakia, para 14, U.N. Doc. CAT/C/SVK/CO/2(2009); Czech Republic, para 6(n), U.N. Doc. CAT/C/CR/32/2
⁵² / See Human Rights Committee (HRC) general comment No. 28 (2000) on article 3, The equality of rights between men and women. See also HRC concluding observations on Slovakia, CCPR/CO/78/SVK, para. 12; on Japan, CCPR/C/79/Add.102, para. 31; and on Peru, CCPR/CO/70/PER, para. 21

On this point the mandate has asserted that “forced abortions or sterilisations carried out by state officials in accordance with coercive family planning laws or policies may amount to torture”.⁵³

The **Council of Europe's Convention on Human Rights and Biomedicine** also contains provisions that apply to the situation of forced sterilisation. However, these provisions are not in line with international and European human rights standards, in particular article 39 of the Istanbul Convention and articles 5, 12, 14, 15 and 25 CPRD as it allows for sterilisation to take place without the consent of the person. The Council of Europe's Convention states that ‘a person has to give the necessary consent for treatment expressly, in advance, except in emergencies, and that such consent may be freely withdrawn at any time’.⁵⁴ It provides that ‘the treatment of persons unable to give their consent, such as children and people with mental illnesses, may be carried out only if it could produce real and direct benefit to their health.’

- 44 -

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 to be a crime 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:

- performing an abortion on a woman without her prior and informed consent;
- 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.”

⁵³ / Méndez, J.E. (2013). Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. Human Rights Council.

⁵⁴ / Convention for the protection of human rights and dignity of the human being with regard to the application of biology and medicine: Convention on human rights and biomedicine (1997) Oviedo, 04.04.1997, CETS No.: 164

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 13th June 2017, the EU signed the Istanbul Convention⁵⁵ (which is the first step in acceding to the Convention, also called ratification).

Věra Jourová, European Commissioner for Justice, Consumers and Gender Equality, said: “Our proposal for the EU to accede to the Istanbul Convention 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.”⁵⁶

- 45 -

The European Parliament has also expressed its support in banning the practice of forced sterilisation. The Employment and Social Affairs Committee published a report on the implementation of the CRPD in the EU, highlighting that persons with disabilities should have the right to give informed consent to all medical procedures, including sterilisation and abortion.⁵⁷

The Committee on Women's Rights and Gender Equality, in its 2013 report on women with disabilities, noted 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 called on member states to prevent forced sterilisation, in particular in large institutions. It stressed 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.⁵⁸

⁵⁵ / Press release of the European Union available on 13 June 2017. Available at: https://eeas.europa.eu/delegations/council-europe/28130/eu-signs-istanbul-convention-13-june-2017_en.

⁵⁶ / Press release of the European Commission on 14 March 2016, Available at http://europa.eu/rapid/press-release_IP-16-549_en.htm.

⁵⁷ / Report of the European Parliament, 9 June 2016, Implementation of the UN Convention on the Rights of Persons with Disabilities, with special regard to the Concluding Observations of the UN CRPD Committee (2015/2258(INI)). Available at: <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+REPORT+A8-2016-0203+0+DOC+XML+VO//EN>

⁵⁸ / Report of the European Parliament, 14 October 2013, Women with disabilities (2013/2065(INI)). Available at: <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+REPORT+A7-2013-0329+0+DOC+XML+VO//EN>

TESTIMONY

OBLIGATORY GYNECOLOGICAL EXAMINATION AND EXTENDED TIME LIMIT FOR ABORTIONS

-46-

"I think that it would be great if forced abortions in the course of psychiatric treatment are taken up on the human rights agenda. Both of my hospitalizations (in 1985 and 1991) included obligatory gynaecological examination right after the admission. I was told that this is done in order to check whether women are pregnant. In distinction to 'regular' abortions that

could be performed within the first 3 months of pregnancy, in psychiatric hospitals this time limit was extended to up to 5 months. In 1991 I was told that this is just an internal 'institutional rule'. Both these places were not long-term institutions, these were regular closed psychiatric wards. They had their own gynaecologists. The examinations were routine and unpleasant and I can't even think of what happened to women who were pregnant. The nature of these procedures that are often not subject to any legal provision are well worth exposing."*

-47-

* Testimony kindly offered by the European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP)

- 48 -

“For many women, it means that other people are making their decisions for them.”

VIII. CONCLUSIONS & RECOMMENDATIONS

8.1. RECOMMENDATIONS TO EU INSTITUTIONS

- › The EU should swiftly ratify the Council of Europe's Convention on the prevention and combating of violence against women and domestic violence.
 - › The EU should adopt a strategy and directive criminalising all forms of male violence against women and girls (including forced sterilisation), and providing assistance and support to all women and girls victims.
 - › There should be an EU co-ordinator to end violence against women and girls, under the umbrella of the European Commission's work on equality between women and men.
 - › The EU should implement the recommendations it has been given by the CRPD Committee on forced sterilisation and legal capacity.
 - › The EU should 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 should promote and undertake research to raise awareness on the reality of sterilising persons with disabilities in member states, taking into account gender, age and type of disability and providing accurate statistics on forced and therapeutic sterilisation.
- 49 -

- > The EU should issue a communication to member states on the implementation of EU legislation on access to justice, access to goods and services, and health, voting and consumer rights provisions in line with article 12 of the CRPD. The communication should clearly prohibit discrimination on the basis of disability and/or legal capacity status in exercising rights and accessing these services, and ensure informed consent. The EU should promote access to sex education which is accessible for people with disabilities, including those who need alternative/augmentative means of communications, such as people with autism.

8.2. RECOMMENDATIONS TO EU MEMBER STATES

- > Those countries that have yet to do so should ratify and implement swiftly the Council of Europe's Convention on preventing and combating violence against women and domestic violence. In implementing the Istanbul Convention, member states should ensure that forced sterilization is considered a criminal offense, that victims have access to support services, access to justice and reparation, and that preventative measures are put in place.
- > With the support of the EU, national ministries for health, social services and equality should carry out studies on the forced sterilisation of persons with disabilities. Studies should take into account gender and age perspectives and also consider the type of disability, i.e. intellectual disability, mental health, physical disability, etc.
- > A multidisciplinary working group should be created to study forced sterilisation of persons with disabilities. It should also review legislation and protocols for intervention in line with the CRPD. A multidisciplinary approach can be assured by including practitioners from 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 to draw up standard measures that can be put in place.

- > In line with the information presented in this report, reforms should be founded on the principle that the non-consensual 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, psychosocial, 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 a life 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 this end, it is advisable to review 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: (i) people with disabilities themselves, who should have access to sex education that is accessible and responds to their communications needs, including for people with autism. It can also be achieved by facilitating peer group engagement to support sex education learning and information sharing; (ii) the families of girls and women with disabilities who are most vulnerable and at greatest risk of suffering forced sterilisation, regarding the rights and needs of their daughters, and; (iii) practitioners, and 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 should be taken in close cooperation with representative organisations of persons with disabilities.

- › Member states should advance measures to promote the right of women to have control over their own bodies and sexuality. According to the definition of the Beijing Platform for action, “[t]he human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. Equal relationships between women and men in matters of sexual relations and reproduction, including full respect for the integrity of the person, require mutual respect, consent and shared responsibility for sexual behaviour and its consequences.”⁵⁹

8.3. RECOMMENDATIONS TO PERSONS WITH DISABILITIES AND THEIR FAMILIES, THEIR REPRESENTATIVE ORGANISATIONS, WOMEN'S RIGHTS ORGANISATIONS AND WIDER CIVIL SOCIETY

Organisations of persons with disabilities, and especially of women with disabilities or those that have working areas focusing on women's issues, must play a leading role to accomplish the recommendations above, both at national and EU level, in line with the principles of the CRPD. This is especially important when designing services and support for victims.

This process will entail assigning funds for program development, and some of the main tasks of these programs should be:

- › To carry out research and develop accessible information resources for women and girls with disabilities on sterilisation and its consequences;
- › To include targeted seminars and discussion groups on these topics in their work

programmes, as well as to 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 non-consensual sterilisation and those looking for information and support regarding taking a decision on sterilisation and other more general issues regarding reproductive health;
- › To set up and maintain a national network for the reproductive rights of women with disabilities, once the target population has been identified and progress made on the tasks above;
- › To foster accessible sex education for all people with disabilities, targeted at their communication needs (e.g. in the case of women with autism).

WE CANNOT CONCLUDE THIS REPORT WITHOUT EXPLICIT REFERENCE TO THE WORK THAT SHOULD BE CARRIED OUT DIRECTLY WITH THE FAMILIES OF PERSONS WITH DISABILITIES MOST AT RISK OF HAVING THEIR SON OR DAUGHTER STERILISED. PEOPLE WITH DISABILITIES AND THEIR FAMILIES NEED TO BE GIVEN 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 space to reflect and to reach an understanding that sterilising women with disabilities is a question of human rights. Women with disabilities and their families should be given human rights-based training that empowers them to learn about and claim their rights. They should be given recommendations on other options for menstrual management and pregnancy prevention through the use of contraceptives.⁶⁰ In addition, information 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, and so that they can change their attitudes and begin to listen to them in research projects.

Only when we are able to turn around the prevailing social beliefs 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.

⁶⁰ / See for instance, Grover S.R. (2002). Menstrual and contraceptive management in women with an intellectual disability. The Medical Journal of Australia, 176: pp. 108-110. PMID:11936305.





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