



EDF input to the general discussion of the CESCR on sexual and reproductive rights

October 2010

“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.”

Article 4 § 3 of the United Nations Convention on the Rights of Persons with Disabilities

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1. Introduction

The **European Disability Forum (EDF)** is the European umbrella organisation representing the interests of 65 million women and men with disabilities in Europe, of whom more than 50 % are women with disabilities. The mission of EDF is to ensure women and men with disabilities full access to fundamental and human rights through their active involvement in policy development and implementation in Europe. EDF is a member of the Social Platform and works closely to the European institutions, the Council of Europe and the United Nations.

EDF welcomes the fact that the general discussion of the Committee on Economic, Social and Cultural Rights is focusing this year on the right to sexual and reproductive health. We would wish to highlight with this statement the specific situation faced by girls and women with disabilities worldwide as regards these rights. It will become clear that actions are urgently needed for addressing the barriers that women with disabilities face all too often to benefiting from these rights.¹

Girls and women with disabilities, like all people, are covered by the full set of human rights that are secured by International law and custom, and they should be protected against infringements of these rights. Despite this, girls and women with disabilities are discriminated in many areas of life. Persons with disabilities in general, but to a greater extent women with disabilities, experience a great degree of marginalisation that may be translated into: higher levels of illiteracy, lower education levels, lower employment activity and/or jobs with a lower level of responsibility and with lower salaries, more social isolation, lower levels of self-esteem, more financial dependency on the family and/or the persons responsible for supporting them, greater socio-emotional dependency and support needs, greater risk of suffering any kind of

¹ Whilst concentrating in this document on the specific situation of women with disabilities, EDF recognises that men with disabilities also face clear barriers to benefiting fully from their sexual and reproductive rights. Some of those barriers are similar to the ones faced by women with disabilities, but some are specific for men with disabilities. It is essential to recognise the right of men with disabilities to parenthood, to gain full access to health services and information campaigns etc. Men with disabilities should have the same access to their rights as any women or men with or without disabilities.

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gender violence, lower levels of personal and social development, lack of awareness on sexuality and numerous and very dangerous myths in this regard, lack of social and health protection, low consideration of self body image, etc. Women with disabilities are often isolated and at great risk of poverty.

Society remains unprepared for persons with disabilities becoming parents, and particularly women with disabilities becoming mothers, as this directly challenges the social representation of their asexual “rolelessness” to such an extent that there is often no 'place' (physically, attitudinally or emotionally) left for them in reproductive spaces. Professionals' misgivings or questioning of their presence in reproductive space; a displayed disapproval of their pregnancy, or verbalized misgivings regarding a woman's caring abilities: all of these become directed at disabled women.²

Reproductive rights include the right to equality and non-discrimination, the right to marry and found a family, the right to decide freely and responsibly on the number and spacing of their children, the right to comprehensive reproductive health care including family planning and maternal health services, education and information, the right to give informed consent to all medical procedures including sterilisation and abortion, and the right to be free from sexual abuse and exploitation.³

This statement focuses on barriers for girls and women with disabilities to accessing these rights, and will concentrate in particular on forced sterilisation and coerced abortion of women with disabilities.

² Disabled Women and Socio-Spatial 'Barriers' to Motherhood, Hazel McFarlane, 2004

³ For a comprehensive overview of the International legal framework and the reproductive rights of women with disabilities, please see <http://reproductiverights.org/en/document/reproductive-rights-and-women-with-disabilities-a-human-rights-framework>

2. Forced sterilisation

In light of the *United Nations Convention on the Rights of Persons with Disabilities*⁴ EDF recognises that forced sterilisation is a form of violence that violates the rights of person with disabilities to form a family, decide on the number of children they wish to have, gain access to information on family planning and reproduction, and retain their fertility on an equal basis with others.

As the international community moves toward a more general recognition of both the human rights of persons with disabilities and the reproductive rights of women, the intersection comprising the rights of women with disabilities to reproductive freedom must be given full attention.

However, in many countries across the world there is clear evidence that forced sterilisation continues to be carried out on many persons with disabilities, above all on girls and women with intellectual or psychosocial disabilities, or women and girls with high support needs, without their consent or their understanding the specific purpose of the medical operation, under the pretext of the wellbeing of the person with disabilities. Women and girls living in institutions are particularly vulnerable to this unacceptable practice.

For many girls and women with disabilities this experience, to which they are forced against their will, intimidated and pressured, is a denial of their right to access appropriate services. Their fundamental human rights, including the right to safeguard body integrity and maintain control over their reproductive health, are violated and removed, at times without their realising.

⁴ The Convention can be downloaded from the UN Enable website <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> Articles 12 (Equal recognition before the law), 16 (Freedom from exploitation, violence and abuse), 17 (protecting the integrity of the person) and 23 (respect for home and the family) are of particular relevance for this statement.

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Most importantly, however, such practises constitute a violation of the right to equal recognition before the law, as set out in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, given that such “forced” medical intervention has traditionally required the consent of the parents or legal guardians following the legal incapacitation of the individual.

Action in all such cases must be based on respect for the human rights and will of the woman or girl with a disability. It is also the responsibility of the relevant medical personnel to ensure that the woman or girl with a disability is adequately informed about the fact that the surgery or medical intervention will lead to her being sterilised and the consequences of this for her future, and the girl or woman must have access to the support services she needs to take the decision as an individual.

Therefore, all public powers should revise the legal framework regulating forced sterilisation, addressing the issues of “informed consent” and “legal capacity” in order to make the necessary accommodations and fulfil the spirit of, and obligations under, the United Nations Convention on the Rights of Persons with Disabilities, which requires States to introduce legal reforms acknowledging that respect for the home and family and the dignity and integrity of persons with disabilities are fundamental rights which may not be violated. In the course of the provision of health services for all women with disabilities, the right to receive care also includes the right to refuse it.

It would be important to undertake studies to bring to light the reality of sterilisation worldwide in the case of persons with disabilities. Such studies should include the perspectives of gender, age and type of disability and offer accurate statistical data on forced and therapeutic sterilisation.

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 they listen to the voices of girls and women with disabilities during legal investigations and proceedings. These measures shall be taken in close co-operation with representative organisations of persons with disabilities.

3. Coerced Abortion

Similarly to sterilisation, coerced abortion is a severe act of violence of the rights of women but is still a reality across the world. Women with disabilities are particularly exposed to this practice. There is a common rejection of the bodies of women with disabilities as suitable reproducers and disapproval of their capability of being good parents.

In some countries where therapeutic sterilisation of women with disabilities has become illegal, the practice of coerced abortion of girls and women with intellectual or psychosocial disabilities or women and girls with intensive support needs has become even the more common, as childbearing and parenthood in relation to those individuals have continued to be described as problematic and, therefore, as best avoided.⁵

Women with disabilities sometimes have to argue with the medical personnel that they actually want to keep their baby. Testimonies also show that women often feel pushed by their own families, or persons close to them/personnel in the institutional setting where they live, to undergo an abortion.

There is sometimes also a fear among medical personnel about the consequences of a pregnancy on a woman with a disability. Therefore, as a way of protecting the woman, but also sometimes as a way of protecting themselves, medical personnel try to convince their patient to undergo an abortion. A pregnancy is a challenging and emotional period for any woman, but the attitudinal barriers and sometimes violent pressure towards an abortion makes women with disabilities fall victims of this unacceptable practice way more often than women without disabilities.

Prenatal testing of women in general is becoming more and more prevalent. Sometimes procreative technologies are a matter of routine, not choice. When it comes to women with disabilities, such testing is

⁵ "Parenthood and intellectual disability, discourses on birth control and parents with intellectual disabilities 1967-2003", J. Areschoug, September 2005.

often encouraged, but it is essential to have the right to refuse it. If the foetus is identified as having a disability, it is also the right of the mother to carry to term the foetus. Emphasising the elimination of disability through reproductive technology without addressing the social context in which they are promoted and applied has disastrous implications for persons with disabilities – and for the society as a whole. It also entrenches disability-phobic attitudes and practices.⁶

Peer support/role-model schemes targeting women with disabilities in order to strengthen their confidence and assertiveness are important for changing the situation. Sex-education targeting women with disabilities is equally essential, but also training of gynaecologists, midwives and medical personnel on the needs and situation of women with disabilities. In addition, disability awareness-training should be provided at all levels starting from school.

In addition, appropriate schemes must be developed with the objective to ensuring both that pregnant women and girls with disabilities get support in preparing for maternity and that mothers with disabilities in need of support to take care of their children have access to adequate assistance and services.

4. Access to sexual health and maternity services

Women with disabilities face a number of specific barriers in accessing health and social services compared to men with disabilities and women without disabilities. These barriers can be grouped into categories of physical accessibility, lack of access to information in accessible formats, lack of provision to take into account augmentative and alternative means of communication, plus societal barriers based on prejudices and myths surrounding pregnancy and motherhood in the case of women

⁶ For a more comprehensive overview, see “Disability, Feminism and Eugenics: who has the right to decide who should or should not inhabit the world” by Joan Hume 1996

with disabilities, insufficient awareness levels and a lack of trained professionals.

When it comes to the barriers to motherhood and sexuality, those range from everything from lack of physical access to maternity and gynaecologist services and women shelters, meaning that you are very limited in choice as a woman in need of these services, to lack of trained staff who are aware of the specific situation and needs of women with disabilities, to lack of adequate interpreter services and information in accessible formats.

Women and men who wish to prevent a pregnancy must also receive adequate information in relation to contraception methods in order to be able to make an informed choice about methods and possible side effects or consequences of any of those methods.

There is a need for more research and studies in regard to the specific situations of women and of men with disabilities. However, there is a need for a dual approach, which means disability and gender must be mainstreamed in all initiatives taken in the field of health services in general. EDF calls for inclusive public health campaigns and information campaigns about sexuality and parenthood. Fertility treatments should be available as possible for men and women with disabilities adapted to their individual situations and on an equal basis with other citizens. EDF also wishes to see a strong focus not only on physical health but also mental health and to concentrate on the link between those. Statistics and data should be disaggregated by gender, but also by disability.

5. Recommendations to the CESCRC Committee

On the basis of the facts and situation for women and men with disabilities as described above, EDF makes the following recommendations to the CESCRC Committee:

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- To fully integrate the disability perspective, as well as the gender perspective, in all work undertaken by the committee, including in its current and future work on sexual and reproductive rights, in close cooperation with the representative organisations of persons with disabilities and with the representative women's and feminist organisations. The gender dimension must also be respected in all work by the committee on disability, and vice versa.
- To officially denounce forced sterilisation and coerced abortion of women with disabilities as clear acts of violence.
- To call on States to adopt relevant National legislation and policies on sexual and reproductive rights, where the disability and gender dimensions are clearly integrated.
- To call on States to revise the legal framework regulating forced sterilisation and coerced abortion, addressing the issues of "informed consent" and "legal capacity", in accordance with the spirit and obligations of the UN Convention on the rights of persons with disabilities
- To call on States to undertake relevant research and studies on forced sterilisation and coerced abortion of women with disabilities, and to take measures in terms of awareness-raising, information and training in order to put an end to this unacceptable practices. Those measures should be taken in close cooperation with representative organisations of persons with disabilities.
- Call on States to develop appropriate schemes, services and information campaigns, ensuring that men and women with disabilities have equal access to their reproductive and sexual rights.

APPENDIX

A.1. Other relevant EDF documents

EDF declaration against forced sterilisation of girls and women with disabilities, *25th of November 2009*

EDF resolution on active termination of life of infants with impairments and on the right to life, *adopted by the EDF Annual General Assembly on 28 May 2006 in Rome*

A.2 Contact person at the EDF Secretariat:

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More information about EDF is available on www.edf-feph.org

Should you have any problems in accessing the documentation, please contact the EDF Secretariat. (T: +32-2-282.46.00)