# Sterilization of Women and Girls with Disabilities

### A BRIEFING PAPER

#### What is Sterilization?

In many parts of the world, women rely on access to a range of methods to control their fertility, including voluntary sterilization. However, too often, sterilization is not a choice. Sterilization is defined as "a process or act that renders an individual incapable of sexual reproduction."<sup>1</sup> Forced sterilization occurs when a person is sterilized after expressly refusing the procedure, without her knowledge or is not given an opportunity to provide consent. Coerced sterilization occurs when financial or other incentives, misinformation, or intimidation tactics are used to compel an individual to undergo the procedure. Women with disabilities are particularly vulnerable to forced sterilizations performed under the auspices of legitimate medical care or the consent of others in their name.

#### Background

Systemic prejudice and discrimination against women and girls with disabilities continues to result in widespread denial of their right to experience their sexuality, to have sexual relationships, and to found and maintain families. The right to bodily integrity and the right of a woman to make her own reproductive choices are enshrined in a number of international human rights treaties and instruments.<sup>2</sup> However, throughout the world, an alarming number of women and girls with disabilities have been, and continue to be, denied these rights through the practice of forced sterilization.<sup>3</sup> Sterilization is an irreversible medical procedure with profound physical and psychological effects. Forced sterilization is an act of violence,<sup>4</sup> 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.<sup>5</sup>

Across the globe, forced sterilization is performed on young girls and women with disabilities for various purposes, including eugenics-based practices of population control, menstrual management and personal care, and pregnancy prevention (including pregnancy that results from sexual abuse).<sup>6</sup> The practice of forced sterilization is part of a broader pattern of denial of the human rights, including reproductive

6 Brady, S., Briton, J., & Grover, S. (2001), OpCit.

<sup>1</sup> Mosby's Medical Dictionary, 8th edition, 2009, Elsevier. Voluntary sterilization refers to the process or act being undertaken with the individual's free and informed consent. Conversely, involuntary sterilization refers to the process or act being undertaken without the free and informed consent of the individual, such as when a person is forced or coerced into submitting to a sterilization procedure.

<sup>2</sup> See for example: UN General Assembly, Convention on the Rights of Persons with Disabilities, 24 January 2007, A/RES/61/106, [Art.23]; UN General Assembly, International Covenant on Civil and Political Rights, 16 December 1966, 2200A (XXI), [Art.7, 17]; UN General Assembly, International Covenant on Economic, Social and Cultural Rights, 16 December 1966, 2200A (XXI), [Art.10]; UN General Assembly, Convention on the Elimination of All Forms of Discrimination Against Women, 18 December 1979, 34/180, [Art.16]; United Nations, The Beijing Declaration and the Platform for Action: Fourth World Conference on Women, Beijing, China, 4-15 September 1995, A/CONF.177/20/Add.1; [paras.94-96].

<sup>3</sup> See for example: Brady, S., Briton, J., & Grover, S. (2001) The Sterilisation of Girls and Young Women in Australia: Issues and Progress. A report commissioned by the Federal Sex Discrimination Commissioner and the Disability Discrimination Commissioner; Human Rights and Equal Opportunity Commission, Sydney, Australia. Available online at: www.wwda.org.au/brady2.htm; Brady, S. (2001) The sterilisation of girls and young women with intellectual disabilities in Australia: An audit of Family Court and Guardianship Tribunal cases between 1992-1998. Available online at: www.wwda.org.au/brady2001.htm; Ana Peláez Narváez, Beatriz Martínez Ríos, and Mercé Leonhardt Gallego, Maternidad y Discapacidad [available in Spanish] (Comité Representante de Personas con Descapacidad, Barclays Fundación, Ediciones Cinca, 2009), p.65; Human Rights Watch interview with Dr. Lalitha Joshi, gynecologist and President of the Down's Syndrome Association, Kathmandu, Nepal, March 30, 2011; Human Rights Watch (2011), *Futures Stolen: Barriers to Education for Children with Disabilities in Nepal*. Available online at: http://www.hrw.org/reports/2011/08/24/futures-stolen.

<sup>4</sup> UN Committee on the Elimination of Discrimination Against Women (CEDAW Committee) (1992), General recommendation No. 19: Violence Against Women, Article 16 (and Article 5) of the Convention (Women and Health), para. 22.

<sup>5</sup> UN Human Rights Council, Promotion and Protection of All Human Rights, Civil, Political, Economic, Social and Cultural Rights, 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]. See also UN Committee Against Torture (CAT Committee), General Comment No. 2: Implementation of Article 2 by States Parties, 24 January 2008, CAT/C/GC2 [para.22]; UN General Assembly, Rome Statute of the International Criminal Court (last amended January 2002), 17 July 1998, A/CONF. 183/9 [Article 7(1)(q)].

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. These practices are framed within traditional social attitudes that characterize disability as a personal tragedy or a matter for medical management and rehabilitation.7 The difficulty some women with disabilities may have in understanding or communicating what was done to them increases their vulnerability to forced sterilization. A further aggravating factor is the widespread practice of legal guardians or others making life-altering decisions for persons with disabilities, including consenting to sterilization on their behalf.8

In many countries, the practice of forced sterilization continues to be debated and justified by governments, legal, medical, and other professionals, and family members and carers as being in the "best interests" of women and girls with disabilities. However, arguments for their "best interests" often have little to do with the rights of women and girls with disabilities and more to do with social factors, such as avoiding inconvenience to caregivers, the lack of adequate measures to protect against the sexual abuse and exploitation of women and girls with disabilities, and the lack of adequate and appropriate services to support women with disabilities in their decision to become parents. Such measures include making sexual education and parenting programs available and accessible, training in self defense and assertiveness, providing the necessary personal assistance and support services in the community that will reduce the risk of sexual abuse, monitoring closed settings in which women and girls with disabilities are often placed (such as orphanages, psychiatric hospitals, and institutions), and providing

alternative methods of contraception which are not irreversible or as intrusive as sterilization.

Safeguards to prevent forced sterilization should not infringe the rights of women with disabilities to choose sterilization voluntarily and be provided with the necessary supports to ensure that they can make and communicate a choice based on free and informed consent.

# **International Human Rights Standards**

The Convention on the Rights of Persons with Disabilities provides a basis for upholding the rights of persons with disabilities and contains specific articles of relevance to the issue of involuntary sterilization. Article 23 reinforces the right of people with disabilities to found and maintain a family and to retain their fertility on an equal basis with others. Article 12 affirms the right of persons with disabilities to recognition everywhere as persons before the law and to enjoy legal capacity on an equal basis with others, including access to the support they may require to exercise their legal capacity. Article 25 clearly articulates that free and informed consent should be the basis for providing health care to persons with disabilities. The Committee on the Rights of Persons with Disabilities recommended "the abolition of surgery and treatment without the full and informed consent of the patient" in one of its first recommendations to a state party.9

The Committee on Economic, Social and Cultural Rights has stated that forced sterilization of girls and women with disabilities is a breach of Article 10, protecting the family, of the *International Covenant on Economic, Social and Cultural Rights.*<sup>10</sup> The Human

Dowse, L. & Frohmader, C. (2001) *Moving Forward: Sterilisation and Reproductive Health of Women and Girls with Disabilities*, A Report on the National Project conducted by Women with Disabilities Australia (WWDA), Canberra.

<sup>8</sup> Open Society Foundations. *Against Her Will: Forced and Coerced Sterilization of Women Worldwide*. September 2011. Available online at: http://www.soros.org/ initiatives/health/focus/law/articles\_publications/publications/against-her-will-20111004/against-her-will-20111003.pdf.

<sup>9</sup> UN Committee on the Rights of Persons with Disabilities (CRPD Committee), Concluding Observations: Tunisia, para. 29, U.N. Doc. CRPD/C/TUN/CO/1 (2011).

<sup>10</sup> UN Committee on Economic, Social and Cultural Rights (CESCR Committee) General Comment No.5 [at par 31] states: Women with disabilities also have the right to protection and support in relation to motherhood and pregnancy. As the Standard Rules state, "persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood"....Both the sterilization of, and the performance of an abortion on, a woman with disabilities without her prior informed consent are serious violations of article 10 (2).

Rights Committee addresses the prohibition of forced sterilization in the *International Covenant on Civil and Political Rights* through Article 7, prohibiting torture, cruel, inhuman or degrading treatment; Article 17, ensuring the right to privacy; and Article 24, mandating special protection for children.<sup>11</sup> The Committee Against Torture has recommended that States take urgent measures to investigate promptly, impartially, thoroughly, and effectively all allegations of involuntary sterilization of women, prosecute and punish the perpetrators, and provide the victims with fair and adequate compensation.<sup>12</sup>

The Committee on the Rights of the Child has identified forced sterilization of girls with disabilities as a form of violence<sup>13</sup> and noted that State parties to the *Convention on the Rights of the Child* are expected to prohibit by law the forced sterilization of children with disabilities.<sup>14</sup> The Committee has also explained 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.<sup>15</sup>

The Committee on the Elimination of Discrimination against Women has considered forced sterilization a violation of a woman's right to informed consent, infringing on her right to human dignity and physical and mental integrity.<sup>16</sup> The Committee has clarified that except where there is a serious threat to life or health, the practice of sterilization of girls, regardless of whether they have a disability, and of adult women with disabilities in the absence of their fully informed and free consent, should be prohibited by law.<sup>17</sup>

The United Nations Special Rapporteur on violence against women has asserted that forced sterilization is a method of medical control of a woman's fertility. It violates a woman's physical integrity and security and constitutes violence against women.<sup>18</sup>

The United Nations Special Rapporteur on torture has emphasized that forced sterilization of women with disabilities may constitute torture or cruel or inhuman treatment, and that forced sterilization constitutes a crime against humanity when committed as part of a widespread or systematic attack directed against any civilian population.<sup>19</sup>

The *Beijing Declaration and Platform for Action* identifies forced sterilization as an act of violence and reaffirms the rights of women, including women with disabilities, to found and maintain a family, to attain the highest standard of sexual and reproductive health, and to make decisions concerning reproduction free from discrimination, coercion, and violence.<sup>20</sup>

<sup>11</sup> Human Rights Committee (2000), International Covenant on Civil and Political Rights (CCPR), *General Comment No. 28: Equality of rights between men and women*, 29 March 2000, CCPR/C/21/Rev.1/Add.10, [at paras. 11 & 20 ].

<sup>12</sup> 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.

<sup>13</sup> UN Committee on the Rights of the Child (CRC Committee), *General comment No.* 13 (2011): Article 19: The right of the child to freedom from all forms of violence, 17 February 2011, CRC/C/GC/13 [paras. 16, 21].

<sup>14</sup> *CRC Committee General Comment No.9* [at para. 60] states: "The Committee is deeply concerned about the prevailing practice of forced sterilisation of children with disabilities, particularly girls with disabilities. This practice, which still exists, seriously violates the right of the child to her or his physical integrity and results in adverse life-long physical and mental health effects. Therefore, the Committee urges States parties to prohibit by law the forced sterilisation of children on grounds of disability."

<sup>15</sup> *CRC Committee General Comment No. 13* [at para. 61] states: "The Committee emphasizes that the interpretation of a child's best interests must be consistent with the whole Convention, including the obligation to protect children from all forms of violence. It cannot be used to justify practices, including corporal punishment and other forms of cruel or degrading punishment, which conflict with the child's human dignity and right to physical integrity. An adult's judgment of a child's best interests cannot override the obligation to respect all the child's rights under the Convention."

<sup>16</sup> Committee on the Elimination of Discrimination Against Women (CEDAW Committee) (1999), *General recommendation No. 24: Article 12 of the Convention (women and health),* A/54/38/Rev.1, chap. l; [para. 22].

<sup>17</sup> CEDAW Committee (2010) Concluding observations of the Committee on the Elimination of Discrimination Against Women: Australia. CEDAW Forty-sixth session, 12–30 July 2010. CEDAW/C/AUS/CO/7. See http://www2.ohchr.org/english/ bodies/cedaw/cedaws46.htm

<sup>18</sup> Radhika Coomaraswamy (1999), Report of the Special Rapporteur on Violence Against Women, its Causes and Consequences: Policies and practices that impact women's reproductive rights and contribute to, cause or constitute violence against women, (55th Sess.), E/CN.4/1999/68/Add.4 (1999), [para. 51].

<sup>19</sup> UN Human Rights Council, Promotion and Protection of All Human Rights, Civil, Political, Economic, Social and Cultural Rights, 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].

<sup>20</sup> United Nations, *The Beijing Declaration and the Platform for Action*: Fourth World Conference on Women, Beijing, China, 4–15 September 1995; A/CONF.177/20/ Add.1. [paras. 95–96]

#### Recommendations

In June 2011 the International Federation of Gynecology and Obstetrics (FIGO) issued new guidelines on female contraceptive sterilization and informed consent. The following recommendations expand on these guidelines with specific considerations for women and girls with disabilities. These recommendations should be reflected in laws and policies governing sterilization practices as well as in other professional guidelines and ethical standards.

- 1. The free and informed consent of the woman herself is a requirement for sterilization.
  - a) Only women with disabilities themselves can give legally and ethically valid consent to their own sterilization. Family members (including spouses and parents), legal guardians, carers, medical practitioners, and/or government or other public officers, cannot consent to sterilization on any woman's behalf.<sup>21</sup>
  - b) Perceived mental incapacity, including medically or judicially determined mental incapacity, does not invalidate the requirement of free and informed consent of the woman herself as the sole justification for the sterilization.
- 2. As part of any process to ensure fully informed choice and consent, women with disabilities must be provided with information that sterilization is a permanent procedure and that alternatives to

sterilization exist, such as reversible forms of family planning.<sup>22</sup>

- a) All information must be provided in language, including spoken, written, and sign, that a woman understands, and in an accessible format such as Braille and plain, non-technical language appropriate to the individual woman's needs.<sup>23</sup>
- b) The physician performing the sterilization is responsible for ensuring that the patient has been properly counseled regarding the risks and benefits of the procedure and its alternatives.<sup>24</sup>
- 3. Sterilization for prevention of future pregnancy does not constitute a medical emergency and does not justify departure from the general principles of free and informed consent. This is the case even if a future pregnancy may endanger a woman's life or health.<sup>25</sup>
- 4. Sterilization should not be performed on a child.
- 5. Women and girls with disabilities, including through their representative organizations and networks, must be included in the evaluation and development of legislation and other measures designed to ensure the enjoyment of all their rights, including sexual and reproductive rights and the right to found a family, on an equal basis with other women and girls.

- 23 FIGO Contraceptive Sterilization Guidelines, Principle 12, Recommendation 2.
- 24 FIGO Contraceptive Sterilization Guidelines, Principle 12.
- 25 FIGO Contraceptive Sterilization Guidelines, Principle 10, Recommendation 3.

21 FIGO Contraceptive Sterilization Guidelines, Principle 7.

## For more information, see www.stoptortureinhealthcare.org



<sup>22</sup> FIGO Contraceptive Sterilization Guidelines, Principle 1.