

**IN THE EUROPEAN COURT OF HUMAN RIGHTS**

**(APPLICATION No. 61521/08)**

**JOËLLE GAUER AND OTHERS**

**APPLICANT**

**AGAINST**

**FRANCE**

**RESPONDENT**

**WRITTEN COMMENTS SUBMITTED JOINTLY**

**BY**

**CENTER FOR REPRODUCTIVE RIGHTS**

**EUROPEAN DISABILITY FORUM**

**INTERNATIONAL CENTRE FOR THE LEGAL PROTECTION OF HUMAN RIGHTS (INTERIGHTS)**

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## I. INTRODUCTION

1. These written comments are jointly submitted by the Center for Reproductive Rights, the European Disability Forum, the International Centre for the Legal Protection of Human Rights (INTERIGHTS), the International Disability Alliance and the Mental Disability Advocacy Center pursuant to leave granted by the President of the Fifth Section on 7 June 2011 in accordance with Rule 44(3)(a) of the Rules of Court.<sup>1</sup>
2. These comments set forth international human rights and medical standards on the issue of sterilisation, particularly as it affects women with disabilities. They demonstrate that informed consent is a critical component of any sterilisation procedure and that it is a violation of international human rights when sterilisation is performed on women with disabilities, a particularly vulnerable group, without their full and informed consent. International and comparative law standards discussed herein demonstrate that States have a positive obligation to apply stringent and effective safeguards so as to protect persons with disabilities from forced sterilisation.<sup>2</sup>
3. It is established that, in interpreting the provisions of the European Convention on Human Rights (hereinafter the ‘Convention’) and the scope of the States’ obligations in specific cases, the European Court of Human Rights (hereinafter the ‘Court’) will look “for any consensus and common values emerging from the practices of European States and specialised international instruments... as well as giving heed to the evolution of norms and principles in international law.”<sup>3</sup> It is respectfully submitted that international and comparative standards should inform the Court’s interpretation of Articles 3 (freedom from torture or inhuman or degrading treatment or punishment), Article 6 (right to a fair trial), Article 8 (right to respect for private and family life), Article 12 (right to marry and to found a family), and Article 14 (right to non-discrimination in the enjoyment of protected rights and freedoms) of the Convention in this case.

## II. BACKGROUND ON FORCED STERILISATION

4. 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,<sup>4</sup> but also continue to take place in modern democracies throughout the world. In the United States, a compulsory sterilisation programme started at the beginning of the 20<sup>th</sup> century, lasted until the mid-1970s, and resulted in the forced sterilisation of approximately 60,000 people.<sup>5</sup> Under the Swedish eugenic sterilisation program set up in 1934 and abolished in

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<sup>1</sup> For Interest of Interveners see Annex to the written comments.

<sup>2</sup> Forced sterilisation, also referred to as coercive or involuntary sterilisation, refers to sterilisation that has occurred without the consent of the affected individual. This includes instances in which sterilisation has been authorised by a third party, such as a parent or legal guardian, without that individual’s consent.

<sup>3</sup> *Opuz v. Turkey*, 33401/02, Eur. Ct. H.R., para. 164 (2009).

<sup>4</sup> G. ALY. ET AL., *CLEANSING THE FATHERLAND: NAZI MEDICINE AND RACIAL HYGIENE* 295 (1994) (It is estimated that approximately 400,000 people were forcibly sterilised by the Nazi regime).

<sup>5</sup> P. Lombardo, *Eugenic Sterilization Laws*, DOLAN DNA LEARNING CENTER, COLD SPRING HARBOR LABORATORY, [www.eugenicsarchive.org/html/eugenics/essay8text.html](http://www.eugenicsarchive.org/html/eugenics/essay8text.html) (last visited Aug. 12, 2011) (The principle targets of this programme were people perceived as “mentally ill, epileptic, blind, deaf, orphans, homosexuals,...” or persons with physical disabilities,

1976, tens of thousands of women with mental disabilities and women otherwise considered “inferior” were sterilised.<sup>6</sup>

5. Forced sterilisations of marginalised women have occurred in a number of other countries such as Switzerland, Japan,<sup>7</sup> India, China,<sup>8</sup> Puerto Rico, Peru, and Brazil.<sup>9</sup> Forced sterilisation of Roma women in the Czech Republic, Slovakia and Hungary has been an issue of great concern to human rights organisations<sup>10</sup> and United Nations treaty bodies<sup>11</sup> and cases related to such forced sterilisation are pending before the Court.<sup>12</sup> In the late 1990s, media and non-governmental organisations (NGOs) reports highlighted the practice of forced sterilisation of women with mental disabilities in France.<sup>13</sup> In 1997, it was revealed that 15,000 women had been forcibly sterilised in French institutions for persons with mental disabilities.<sup>14</sup> Another report showed that 211 disabled women or women in a difficult social situation were forcibly sterilised in French public hospitals in 1996.<sup>15</sup>

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etc.).

<sup>6</sup> See, e.g., *Sweden Admits to Racial Purification*, THE INDEPENDENT, AUG. 25, 2007,

<http://www.independent.co.uk/news/world/sweden-admits-to-racial-purification-1247261.html>.

<sup>7</sup> The Eugenic Protection Law permitted the forced sterilisation of persons with mental disability from 1948 to 1996 during which more than 16,500 women and men were sterilised against their will. T. Tsuchiya, *Eugenic Sterilizations in Japan and Recent Demands for Apology: A Report*, 3 NEWSLETTER OF THE NETWORK ON ETHICS AND INTELLECTUAL DISABILITY 1-4 (1997).

<sup>8</sup> L. Alvares et al., *Reproductive Health Justice for Women with Disabilities*, CENTER FOR WOMEN POLICY STUDIES (2011), available at

[http://www.centerwomenpolicy.org/programs/waxmanfiduccia/documents/BFWFP\\_ReproductiveHealthJusticeforWomenwithDisabilities\\_NOWFoundationDisabilityRightsAdvisor.pdf](http://www.centerwomenpolicy.org/programs/waxmanfiduccia/documents/BFWFP_ReproductiveHealthJusticeforWomenwithDisabilities_NOWFoundationDisabilityRightsAdvisor.pdf).

<sup>9</sup> R. Sifris, *Conceptualising Involuntary Sterilisation as Severe Pain or Suffering for the Purposes of Torture Discourse*, 28 NETHERLANDS QUARTERLY OF HUMAN RIGHTS 523, 530-31 (2010).

<sup>10</sup> See, e.g., Council of Europe Commissioner for Human Rights, *Recommendation of the Commissioner for Human Rights Concerning Certain Aspects of Law and Practice Relating to Sterilization of Women in the Slovak Republic*, COMMDH(2003)12, (Oct 17, 2003), available at

<https://wcd.coe.int/wcd/ViewDoc.jsp?Ref=CommDH%282003%2912&Language=lanEnglish&Site=COE&BackColorInternet=99B5AD&BackColorIntranet=FABF45&BackColorLogged=FFC679>; European Roma Rights Centre, PARALLEL SUBMISSION TO THE COMMITTEE ON THE ELIMINATION OF ALL FORMS OF DISCRIMINATION AGAINST WOMEN FOR THE CZECH REPUBLIC, 2010, <http://www.errc.org/cms/upload/file/cz-cedaw-sterilisations-errc-czech-republic.pdf>.

<sup>11</sup> See, e.g., Human Rights Committee, *Concluding Observations: Slovakia*, para. 13, U.N. Doc. CCPR/C/SVK/CO/3 (2011); *Slovakia*, para. 12, U.N. Doc. CCPR/CO/78/SVK (2003); Committee against Torture, *Concluding Observations: Slovakia*, para. 14; CEDAW Committee, *Concluding Observations: Czech Republic*, para. 24, U.N. Doc. CEDAW/C/CZE/CO/3 (2006); *Czech Republic*, para. 34-35, U.N. Doc. CEDAW/C/CZE/CO/5 (2010); *A.S. v. Hungary*, CEDAW Committee No. 4/2004, U.N. Doc. CEDAW/C/36/D/4/2004 (2006) [hereinafter *A.S. v. Hungary*].

<sup>12</sup> See, e.g., *I.G., M.K. and RH v. Slovakia*, 15966/04, Eur. Ct. H.R. (2009); *VC v. Slovakia*, 18968/07, Eur. Ct. H.R. (2009); *Ferenčíková v. Czech Republic*, 21826/10, Eur. Ct. H.R. (2010); *Červenáková v. Czech Republic*, 26852/09, Eur. Ct. H.R. (2009).

<sup>13</sup> *En France Aussi, on Sterilise des Handicapés*, ASSOCIATION FRANÇAISE CONTRE L'ABUS PSYCHIATRIQUE (Oct. 7, 2000), <http://afcap.free.fr/07%2010%2000%20st%E9rilisation%20des%20handicap%E9es.php>;

M. Muke, *La Stérilisation des Handicapés en France au Regard des Droits Humains*, FEMINISTES.NET, [www.feministes.net/sterilisation\\_handicapees.htm](http://www.feministes.net/sterilisation_handicapees.htm) (last visited Aug. 12, 2011);

J. Juilhard, *Handicapés – Maltraitance Envers les Personnes Handicapées: Briser la loi du Silence*, TOME 1, RAPPORT, RAPPORT DE COMMISSION D'ENQUÊTE, [www.senat.fr/rap/r02-339-1/r02-339-15.html](http://www.senat.fr/rap/r02-339-1/r02-339-15.html) (last visited Aug. 12, 2011).

<sup>14</sup> *Des Stérilisations de Handicapés Mentaux ont été Effectuées en France*, LE MONDE, (Sept. 11, 1997), cited in M. Muke, *supra* note 13.

<sup>15</sup> *La Stérilisation des Handicapés est Faible, Mais non Marginale, Selon l'IGAS*, LE MONDE, (Oct. 2, 1998), cited in M. Muke, *supra* note 13.

6. The reasons used to justify forced sterilisation of women with disabilities generally fall into three broad categories.<sup>16</sup> First, in order to eliminate the reproduction of children with disabilities, similar to eugenic policies and practices aimed at eliminating certain ethnic and marginalised groups.<sup>17</sup> Second, for the good of the State, community or family which is centred on the “burden” that disabled women and girls and their potentially disabled offspring place on the resources and services funded by the State and provided through the community. A related line of argument is the added burden of care that menstrual and contraceptive management<sup>18</sup> places on already overstretched families and carers. Third, the idea of the incapacity of women with disabilities for parenthood, which is based on widely held societal attitudes that women with disabilities are incapable and cannot be competent parents, leading to pressures to prevent women with disabilities from becoming pregnant.
  
7. All of the above reasons are discriminatory in nature and act to exclude women with disabilities from the enjoyment and exercise of their rights. Further, regimes of substituted decision making imposed on persons with, in particular mental, disabilities, act to legally remove decision making and the exercise of rights from the individual and have them substituted by a guardian.<sup>19</sup> The presumption is that a guardian is better placed to make choices in the best interest<sup>20</sup> of the

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<sup>16</sup> L. Dowse, *Moving Forward or Losing Ground? The Sterilisation of Women and Girls with Disabilities in Australia*, WOMEN WITH DISABILITIES AUSTRALIA, (Sept. 8-10, 2004), <http://www.wwda.org.au/steril3.htm>.

<sup>17</sup> See, e.g., *Buck v. Bell*, 274 U.S. 200 (1927) (the majority opinion stating that “it is better for all the world, if instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind... Three generations of imbeciles are enough.”).

<sup>18</sup> See WORLD HEALTH ORGANIZATION (WHO), WORLD REPORT ON DISABILITY 78 (2011), available at [http://whqlibdoc.who.int/publications/2011/9789240685215\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf) [hereinafter WORLD REPORT ON DISABILITY].

<sup>19</sup> See MENTAL DISABILITY ADVOCACY CENTRE, GUARDIANSHIP AND HUMAN RIGHTS IN SERBIA: ANALYSIS OF GUARDIANSHIP LAW AND POLICY (2006), available at [http://mdac.info/sites/mdac.info/files/English\\_Guardianship%20and%20Human%20Rights%20in%20Serbia.pdf](http://mdac.info/sites/mdac.info/files/English_Guardianship%20and%20Human%20Rights%20in%20Serbia.pdf); MENTAL DISABILITY ADVOCACY CENTRE, GUARDIANSHIP AND HUMAN RIGHTS IN RUSSIA: ANALYSIS OF LAW, POLICY AND PRACTICE (2007), available at [http://mdac.info/sites/mdac.info/files/English\\_Guardianship%20and%20Human%20Rights%20in%20Russia.pdf](http://mdac.info/sites/mdac.info/files/English_Guardianship%20and%20Human%20Rights%20in%20Russia.pdf); MENTAL DISABILITY ADVOCACY CENTRE, GUARDIANSHIP AND HUMAN RIGHTS IN KYRGYZSTAN: ANALYSIS OF LAW, POLICY AND PRACTICE (2007), available at [http://mdac.info/sites/mdac.info/files/English\\_Guardianship%20and%20Human%20Rights%20in%20Kyrgyzstan.pdf](http://mdac.info/sites/mdac.info/files/English_Guardianship%20and%20Human%20Rights%20in%20Kyrgyzstan.pdf); MENTAL DISABILITY ADVOCACY CENTRE, GUARDIANSHIP AND HUMAN RIGHTS IN GEORGIA: ANALYSIS OF LAW AND POLICY (2007), available at [http://mdac.info/sites/mdac.info/files/English\\_Guardianship%20and%20Human%20Rights%20in%20Georgia.pdf](http://mdac.info/sites/mdac.info/files/English_Guardianship%20and%20Human%20Rights%20in%20Georgia.pdf); MENTAL DISABILITY ADVOCACY CENTRE, GUARDIANSHIP AND HUMAN RIGHTS IN HUNGARY: ANALYSIS OF LAW, POLICY AND PRACTICE (2007), available at [http://mdac.info/sites/mdac.info/files/English\\_Guardianship%20and%20Human%20Rights%20in%20Hungary.pdf](http://mdac.info/sites/mdac.info/files/English_Guardianship%20and%20Human%20Rights%20in%20Hungary.pdf); MENTAL DISABILITY ADVOCACY CENTRE, GUARDIANSHIP AND HUMAN RIGHTS IN THE CZECH REPUBLIC: ANALYSIS OF LAW AND POLICY (2007), available at [http://mdac.info/sites/mdac.info/files/English\\_Guardianship%20and%20Human%20Rights%20in%20the%20Czech%20Republic.pdf](http://mdac.info/sites/mdac.info/files/English_Guardianship%20and%20Human%20Rights%20in%20the%20Czech%20Republic.pdf); MENTAL DISABILITY ADVOCACY CENTRE, GUARDIANSHIP AND HUMAN RIGHTS IN BULGARIA: ANALYSIS OF LAW, POLICY AND PRACTICE (2007), available at [http://mdac.info/sites/mdac.info/files/English\\_Guardianship%20and%20Human%20Rights%20in%20Bulgaria.pdf](http://mdac.info/sites/mdac.info/files/English_Guardianship%20and%20Human%20Rights%20in%20Bulgaria.pdf).

<sup>20</sup> The principle of best interest, almost exclusively applied to children, is often used to justify the taking of decisions by third parties on behalf of persons with disabilities who are deemed to lack capacity, the purported aim being to protect such persons from harm in their “best interest” as interpreted by third parties. In the context of best interests, “the vocabulary used includes terms such as non/therapeutic, in/voluntary, un/authorised, un/lawful and non/consensual sterilisation. Each of these

individual concerned. The Court has previously held that a guardian's placement of a person who has a mental disability and has been deprived of his legal capacity in a psychiatric hospital solely based on the guardian's belief that the person requires hospitalization, against the person's will and in the absence of a judicial review, violates Article 5 of the Convention. In its *Shtukurov* judgment, the Court recognized that the will of a person placed under guardianship had to be taken into consideration when a restriction on a right as fundamental as the right to liberty is concerned.<sup>21</sup> In so doing, the Court recognized that a person whose legal capacity has been formally restricted may retain capacity to make medical and other decisions rather than having such decisions made by third parties.<sup>22</sup> Historically, however, the best interest approach and guardianship have often been used to perpetuate discriminatory attitudes against persons with disabilities as incapable. Such views may facilitate the practice of forced sterilisation against women with disabilities by assuming that their consent is neither necessary nor valid.

### III. INTERNATIONAL STANDARDS WITH RESPECT TO PERSONS WITH DISABILITIES AND INFORMED CONSENT TO STERILISATION

#### A. International standards with respect to persons with disabilities

8. In analysing the responsibility of States Parties in instances of forced sterilisation of persons with mental disabilities regard must be had to, *inter alia*, international standards, including the provisions of the United Nations Convention on the Right of Persons with Disabilities (hereinafter 'CRPD') and its guiding principles and values, which include respect for inherent dignity, autonomy, including the freedom to make one's own choices, independence, non-discrimination, full and effective participation in society, respect for difference, and equality of opportunity.<sup>23</sup>

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terms derive from particular perspectives which take as their starting point the gendered, disablist view that the menstruation, sexuality and reproductive lives of disabled women and girls are the legitimate domain of legal, medical or other experts to determine." L Dowse, *supra* note 16; See also R. Gupta, *Twin Tracking for Women with Disabilities in Disability Legislation*, CENTER FOR DISABILITY STUDIES, NASLAR UNIVERSITY OF Law, <http://www.disabilitystudiesnalsar.org/bcp-wwd.php> (last visited Aug. 12, 2011).

<sup>21</sup> *Shtukurov v. Russia*, 44009/05, Eur. Ct. H.R. (2010).

<sup>22</sup> *Id.* para. 94.

<sup>23</sup> Convention on the Rights of Persons with Disabilities, *adopted* Jan. 24, 2007, art. 3, G.A. Res. 61/106, U.N. Doc. A/RES/61/106 (entered into force May 3, 2008) [hereinafter CRPD]; The rights of persons with disabilities are grounded in a human rights framework. See Universal Declaration of Human Rights, *adopted* Dec. 10, 1948, G.A. Res. 217A (III), U.N. Doc. A/810 at 71 (1948) [hereinafter Universal Declaration]; International Covenant on Civil and Political Rights, art. 26, G.A. Res. 2200A (XXI), UN GAOR, 21<sup>st</sup> Sess., Supp. No. 16, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171 (*entered into force* Mar. 23, 1976) [hereinafter ICCPR]; International Covenant on Economic, Social and Cultural Rights, *adopted* Dec. 16, 1966, art. 2, G.A. Res. 2200A (XXI), U.N. GAOR, Supp. No. 16, U.N. Doc. A/6316 (1966) (*entered into force* Jan. 3, 1976), [hereinafter ICESCR]; Convention on the Elimination of All Forms of Discrimination against Women, *adopted* Dec. 18, 1979, art. 3, G.A. Res. 34/189, UN GAOR, 34<sup>th</sup> Sess., Supp. No. 46, at 193, U.N. Doc. A/34/46, U.N.T.S. 13 (*entered into force* Sept. 3, 1981) [hereinafter CEDAW]; Convention on the Rights of the Child, *adopted* Nov. 20, 1989, art. 2, G.A. Res. 44/25, annex, UN GAOR, 44<sup>th</sup> Sess., Supp. No. 49, U.N. Doc. A/44/49 (1989) (*entered into force* Sept. 2, 1990) [hereinafter CRC]; Committee on the Elimination of Discrimination against Women, *General Recommendation No. 19: Violence against women*, (11<sup>th</sup> Sess., 1992), in *Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies*, at 331, U.N. Doc. HRI/GEN/1/Rev.9 (Vol. II) (2008) [hereinafter CEDAW Committee, *General Recommendation No. 19*]; Committee on Economic, Social and Cultural Rights, *General Comment No. 5: Persons with Disabilities*, (11<sup>th</sup> Sess., 1994), in *Compilation of General Comments and General Recommendations by Human Rights*

9. The fundamental purpose of the CRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.<sup>24</sup> The CRPD is underpinned by the “social model” or “human rights” model of disability which upholds persons with disabilities as equal and active subjects of their rights. Article 12 of the CRPD mandates States Parties to recognise that persons with disabilities enjoy legal capacity on an equal basis with others.<sup>25</sup> This means that an individual’s right to decision-making should not be replaced by decision-making of a third party, but that each individual without exception has the right to make their own choices and to direct their own lives, whether in relation to living arrangements, medical treatment, or family relationships. In addition in the exercise of rights and decision making, an individual who so wishes may receive support and be provided with safeguards against the abuse of rights.<sup>26</sup> Additionally, in order to promote equality and eliminate discrimination, the CRPD requires States Parties to take all appropriate steps to ensure that reasonable accommodation is provided,<sup>27</sup> and recognises that the denial of reasonable accommodation constitutes disability-based discrimination.<sup>28</sup>
10. Article 12 is central to the CRPD because the exercise of legal capacity affects so many other fundamental rights. This Court has recognised the importance of legal capacity as a necessary prerequisite to exercising one's human rights, and has found violations of the rights of persons with disabilities whose legal capacity has been removed or restricted with respect to a number of rights, such as the right to liberty,<sup>29</sup> access to justice,<sup>30</sup> the right to an effective remedy,<sup>31</sup> the right to property,<sup>32</sup> the right to participate in child adoption proceedings as the child’s parent,<sup>33</sup> the right to private life<sup>34</sup> and the right to vote.<sup>35</sup>
11. The invisibility of persons with disabilities placed under guardianship and/or in institutions has meant that courts have had limited opportunities to consider the issue of human rights abuses of such persons. The United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment (hereinafter ‘Special Rapporteur on Torture’) has highlighted the invisibility of abuses occurring in institutional settings as one of the main reasons for the lack

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Treaty Bodies, at 17, U.N. Doc. HRI/GEN/1/Rev.9 (Vol. I) (2008) [hereinafter ESCR Committee, *General Comment No. 5*].

<sup>24</sup> CRPD, *supra* note 23, art. 1.

<sup>25</sup> CRPD, *supra* note 23, art. 12.

<sup>26</sup> *Id.* arts. 12(3), 12(4).

<sup>27</sup> CRPD, *supra* note 23, art. 5(3). “‘Reasonable accommodation’ means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms, ” CRPD, *supra* note 23, art. 2.

<sup>28</sup> *See* CRPD, *supra* note 23, art. 2 (definition of discrimination on the basis of disability).”

<sup>29</sup> Shtukurov v. Russia, *supra* note 21.”

<sup>30</sup> *Id.*; Berkova v. Slovakia, 67149/01, Eur. Ct. H.R. (2009); Salontaji-Drobnak v. Serbia, 36500/05, Eur. Ct. H.R. (2009).

<sup>31</sup> Berkova v. Slovakia, *supra* note 30.

<sup>32</sup> Zehentner v. Austria, 20082/02, Eur. Ct. H.R. (2007).

<sup>33</sup> X v. Croatia, 11223/04, Eur. Ct. H.R. (2008).

<sup>34</sup> *Id.*; Shtukurov v. Russia, *supra* note 21; Berkova v. Slovakia, *supra* note 30; Salontaji-Drobnak v. Serbia, *supra* note 30; Zehentner v. Austria, *supra* note 32.

<sup>35</sup> Alajos Kiss v. Hungary, 38832/06, Eur. Ct. H.R. (2010).

of judicial pronouncements on this issue. He noted, in particular, that the vulnerability of persons with disabilities means their access to judicial remedies is severely restricted.<sup>36</sup> He also noted that people with disabilities are often segregated from society for a long period of time in institutions, including prisons, social care centres, orphanages and mental health institutions.<sup>37</sup> As we will discuss below regarding positive obligations related to specific Convention articles, the CRPD attempts to address these gaps by imposing stringent obligations on States Parties to monitor violations of CRPD rights.

## **B. International standards on informed consent with regard to sterilisation**

12. International standards explicitly endorse the principle of informed consent as fundamental to the exercise of one's individual human rights.<sup>38</sup> Informed consent, which includes the right to information, is particularly critical to the life-altering procedure of sterilisation which seriously impacts upon an individual's human rights. Sterilisation performed without the full and informed consent of the individual violates numerous international human rights and international human rights monitoring bodies have repeatedly emphasised the need to obtain informed consent for sterilisation procedures.<sup>39</sup> For example, the Committee on the Elimination of Discrimination against Women (hereinafter the 'CEDAW Committee'), which monitors State compliance with the United Nations Convention on the Elimination of Discrimination against Women, has, on more than one occasion, expressed concern about and issued recommendations regarding forced sterilisations that result from the lack of full and informed consent. In its General Recommendation 24, the CEDAW Committee explains that "acceptable services are those that are delivered in a way that ensures that a woman gives her fully informed consent, respects her dignity, guarantees her confidentiality and is sensitive to her needs and perspectives."<sup>40</sup> The

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<sup>36</sup> M. Nowak, *Interim Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, para. 69, U.N. Doc. A/63/175 (July 28, 2008) [hereinafter *Special Rapporteur on Torture Interim Report 2008*].

<sup>37</sup> *Id.* para. 38 ("persons with disabilities are frequently subjected to unspeakable indignities, neglect, severe forms of restraint and seclusion, as well as physical, mental and sexual violence."); *Id.* para. 41 (such practices "remain invisible and are not recognized as torture or other cruel, inhuman or degrading treatment or punishment."); *See also Id.* para. 60.

<sup>38</sup> *See, e.g.*, CRPD, *supra* note 23, art. 15; 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 and Explanatory Report, *adopted* Apr. 4, 1997, art. 5, Eur. T.S. No. 164 (*entered into force* Dec. 1, 1999) [hereinafter *Convention on Human Rights and Biomedicine*] ("[a]n intervention in the health field may only be carried out after the person concerned has given free and informed consent to it"); Convention for the Protection of Human Rights and Fundamental Freedoms, *adopted* Nov. 4, 1950, art. 3, 213 U.N.T.S. 222, Eur. T.S. No. 5 (*entered into force* Sept. 3, 1953) [hereinafter *ECHR*].

("the free and informed consent of the person concerned" must be respected in the fields of medicine and biology).

<sup>39</sup> *See, e.g.*, Human Rights Committee, *General Comment 28: Equality of rights between men and women* (Art. 3) (68th Sess., 2000), U.N. Doc. CCPR/C/21/Rev. 1/Add.10, para. 11 [hereinafter *HRC, General Comment No. 28*]; Human Rights Committee, *Concluding Observations: Peru*, para. 21, U.N. Doc. CCPR/CO/70/PER (2007); *Slovakia, supra* note 11, para. 12; *Czech Republic*, para.10, U.N. Doc. CCPR/CZE/CO/2 (2007); CEDAW Committee, *Concluding Observations: Peru*, paras. 484-485, U.N. Doc. A/57/38 (2002); *Czech Republic*, paras. 23-24, U.N. Doc. CEDAW C/CZE/CO/3 (2006); *Hungary*, paras. 8-9, U.N. Doc. CEDAW//C/HUN/CO/6 (2007); Committee against Torture, *Concluding Observations: Peru*, para. 23, U.N. Doc. CAT/C/PER/CO/4 (2006); *Czech Republic*, paras. 5-6, U.N. Doc. CAT/C/CR/32/2 (2004); Committee on the Elimination of Racial Discrimination, *Concluding Observations: Slovakia*, para. 12, U.N. Doc. CERD/C/65/CO/7 (2004); *Czech Republic*, para. 14, U.N. Doc. CERD/C/CZE/CO/7 (2007); *See also* Report of the Working Group on the Universal Periodic Review: *Australia*, para. 86, U.N. Doc. A/HRC/17/10 (2011) (Several European States including Denmark, Belgium, UK and Germany made recommendations to repeal legal provisions allowing sterilisation of women and girls with disabilities and calling for its abolition in law and in practice).

<sup>40</sup> Committee on the Elimination of Discrimination against Women, *General Recommendation No. 24: Article 12 of the*

CEDAW Committee has urged States parties to “not permit forms of coercion, such as non-consensual sterilization ... that violate women’s rights to informed consent and dignity.”<sup>41</sup> It has also specifically called on a particular State party to “review its domestic legislation pertaining to the principle of informed consent and ensure its conformity with international human rights and medical standards, and monitor public and private health centres which perform sterilization procedures.”<sup>42</sup> It also recently called on a State to “adopt legislative changes on informed consent to sterilization as well as to provide justice for victims of such acts undertaken without consent.”<sup>43</sup>

13. With regards to persons with disabilities, the Committee on the Rights of Persons with Disabilities (hereinafter the ‘CRPD Committee’), which monitors State compliance with the CRPD, has expressed concern about the lack of clarity in the scope of legislation “to protect persons with disabilities from being subjected to treatment without their free and informed consent, including forced treatment in mental health services.”<sup>44</sup> The Committee specifically recommended that states “incorporate into the law the abolition of surgery and treatment without the full and informed consent of the patient, and ensure that national law especially respects women’s rights under article 23 and 25 of the Convention.”<sup>45</sup>
14. In addition to international human rights standards, several international medical bodies, including the World Health Organization (WHO) and the International Federation of Gynecology and Obstetrics (FIGO), have issued specific guidelines and considerations to ensure informed consent in cases of sterilisation. WHO clearly states in its Declaration on the Promotion of Patients’ Rights in Europe that “the informed consent of the patient is a prerequisite for any medical intervention.”<sup>46</sup> FIGO’s recently released guidelines on female contraceptive sterilisation stress that surgical sterilisation must be preceded by “the patient’s informed and freely given consent.”<sup>47</sup> The guidelines note that “[m]edical practitioners must recognise that, under human rights provisions and their own professional codes of conduct, it is unethical and in violation of human rights for them to perform procedures for prevention of future pregnancy on women who have not freely requested such procedures, or who have not previously given their free and informed consent.”<sup>48</sup>
15. Informed consent to sterilisation is particularly crucial for persons with mental disabilities as medical practitioners have been known to treat persons with mental disabilities as “objects of

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*Convention (women and health)*, (20<sup>th</sup> Sess., 1999), in *Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies*, at 358, para 22, U.N. Doc. HRI/GEN/1/Rev.9 (Vol. II) (2008) [hereinafter CEDAW Committee, *General Recommendation No. 24*].

<sup>41</sup> *Id.*

<sup>42</sup> CEDAW Committee: *Concluding Observations: Hungary*, para. 8, U.N. Doc. CEDAW/C/HUN/CO/6 (2007).

<sup>43</sup> CEDAW Committee, *Concluding Observations: Czech Republic*, para. 23, U.N. Doc. CEDAW/C/CZE/CO/3 (2006).

<sup>44</sup> CRPD Committee, *Concluding Observations: Tunisia*, para. 28, U.N. Doc. CRPD/C/TUN/CO/1 (2011).

<sup>45</sup> *Id.* para. 29.

<sup>46</sup> Regional Office for Europe, World Health Organization (WHO), *A Declaration on the Promotion of Patients’ Rights in Europe*, European Consultation on the Rights of Patients, Mar. 28-30, 1994, art. 3.1, WHO Doc. EUR/ICP/HLE 121 (1994) [hereinafter WHO, *Declaration on Patients’ Rights*].

<sup>47</sup> INTERNATIONAL FEDERATION OF OBSTETRICS AND GYNECOLOGY, *GUIDELINES ON FEMALE CONTRACEPTIVE STERILISATION*, para. 2, (2011) [hereinafter FIGO, *GUIDELINES ON FEMALE CONTRACEPTIVE STERILISATION*].

<sup>48</sup> *Id.* para. 6.

treatment rather than rights-holders” and do not always seek their voluntary and informed consent when it comes to treatment.<sup>49</sup> The United Nations Special Rapporteur on the Right to Health emphasised that States have an obligation to respect, protect and fulfil the right to health of all individuals, including those with mental disabilities.<sup>50</sup> He recognised that “[f]orced sterilizations, rape and other forms of sexual violence, which women with mental disabilities are vulnerable to, are inherently inconsistent with their sexual and reproductive health rights and freedoms.”<sup>51</sup> The Special Rapporteur also stressed that “[c]onsent to treatment is one of the most important human rights issues relating to mental disability,”<sup>52</sup> and accordingly “it is especially important that the procedural safeguards protecting the right to informed consent are both watertight and strictly applied.”<sup>53</sup> According to the Special Rapporteur’s recently published report on informed consent and the right to health, informed consent is “not mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision, protecting the right of the patient to be involved in medical decision-making, and assigning associate duties and obligations to health-care providers, its ethical and legal normative justifications stem from its promotion of patient autonomy, self-determination, bodily integrity and well-being.”<sup>54</sup>

### Components of informed consent to sterilisation

16. Under international human rights and medical standards, there are certain objective criteria that medical providers must fulfil in every case of informing a patient about her or his proposed medical treatment. The Council of Europe’s Convention on Human Rights and Biomedicine obligates the medical provider to give each patient objective and comprehensive information about his or her contemplated treatment, including its purpose, nature, consequences and risks, in order to enable the patient to make an informed decision.<sup>55</sup> Information on risks should include those inherent in the type of intervention as well as any risks related to the specific characteristics of the patient.<sup>56</sup> Similarly, the FIGO guidelines, discussed above, specify that the physician who performs the sterilisation is responsible for ensuring that a woman has been counselled regarding risks, benefits, and alternatives to sterilisation.<sup>57</sup> Women must be made aware of and have the opportunity to consider alternatives to sterilisation, particularly family planning methods that are reversible.<sup>58</sup> Surgical sterilisation is recognised as a permanent contraceptive method by international medical bodies,<sup>59</sup> and while surgery to reverse sterilisation

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<sup>49</sup> OFFICE OF THE UNITED NATIONS HIGH COMMISSIONER FOR HUMAN RIGHTS & WHO, RIGHT TO HEALTH FACTSHEET NO. 31 16 (2008), available at <http://www.ohchr.org/Documents/Publications/Factsheet31.pdf>.

<sup>50</sup> P. Hunt, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, paras. 48-50, U.N. Doc. E/CN.4/2005/51 (Feb. 11, 2005).

<sup>51</sup> *Id.* para. 38.

<sup>52</sup> *Id.* para. 87.

<sup>53</sup> *Id.* para. 90.

<sup>54</sup> Secretary General, *Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, para. 9, U.N. Doc. A/64/272 (Aug. 10, 2009).

<sup>55</sup> Convention on Human Rights and Biomedicine, *supra* note 38, art. 5, para. 35.

<sup>56</sup> *Id.* para. 35.

<sup>57</sup> FIGO, GUIDELINES ON FEMALE CONTRACEPTIVE STERILISATION, *supra* note 47, para. 11.

<sup>58</sup> *Id.* para. 2.

<sup>59</sup> WORLD HEALTH ORGANIZATION (WHO), MEDICAL ELIGIBILITY CRITERIA FOR CONTRACEPTIVE USE 95 (2004), available at

exists, such procedures are costly, not widely available and have a low success rate.<sup>60</sup> The FIGO also lays out information that must be conveyed during counselling, including that sterilisation is intended to be permanent; that life circumstances may change as a result of the procedure; and that a person may later regret her state of sterility.<sup>61</sup> The FIGO also emphasises that “informed consent is not a signature but a process of communication and interaction.”<sup>62</sup>

17. In order for an individual to give full and informed consent, the information communicated should be provided in a manner that is understandable to her. The WHO explains that “information must be communicated to the patient in a way appropriate to the latter’s capacity for understanding, minimising the use of unfamiliar technical terminology. If the patient does not speak the common language, some form of interpreting should be available.”<sup>63</sup> The CRPD recognises that “communication includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.”<sup>64</sup> The FIGO Guidelines Regarding Informed Consent specifically note that the difficulty or time consuming nature of providing such information, for example, to patients who have had “little education,” does not absolve medical providers from striving to fulfil the criteria for informed consent.<sup>65</sup>

#### Health risk not an exception to full and informed consent in the case of sterilisation

18. International medical standards clearly state that patients must always give their informed consent to sterilisation procedures, even in cases in which sterilisation is being proposed due to a health risk. The WHO states that in situations where pregnancy poses a serious health risk and contraception is therefore recommended for medical reasons, sterilisation is often considered and that, as in other cases “these women should make voluntary, informed, well-considered decisions about contraception; family planning counselling is necessary...informed consent is necessary.”<sup>66</sup> The FIGO emphasises that “[s]terilization for prevention of future pregnancy cannot be ethically justified on grounds of medical emergency. Even if a future pregnancy may endanger a woman’s life or health, she will not become pregnant immediately, and therefore must be given the time and support she needs to consider her choice. Her informed decision must be respected, even if it is considered liable to be harmful to her health.”<sup>67</sup>

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<http://www.who.int/reproductive-health/publications/mec/mec.pdf>; FIGO, GUIDELINES ON FEMALE CONTRACEPTIVE STERILISATION, *supra* note 47, para. 11.

<sup>60</sup> R. A. HATCHER ET AL., THE ESSENTIALS OF CONTRACEPTIVE TECHNOLOGY: A HANDBOOK FOR CLINICAL STAFF, sec. 9-22 (1997).

<sup>61</sup> FIGO, GUIDELINES ON FEMALE CONTRACEPTIVE STERILISATION, *supra* note 47, para. 2.

<sup>62</sup> FIGO, ETHICAL ISSUES IN OBSTETRICS AND GYNECOLOGY BY THE FIGO COMMITTEE FOR THE STUDY OF ETHICAL ASPECTS OF HUMAN REPRODUCTION AND WOMEN'S HEALTH, GUIDELINES REGARDING INFORMED CONSENT, para. 4 (2009) [hereinafter FIGO, GUIDELINES REGARDING INFORMED CONSENT].

<sup>63</sup> WHO, Declaration on Patients’ Rights, *supra* note 46, art. 2.4.

<sup>64</sup> CRPD, *supra* note 23, art. 2.

<sup>65</sup> FIGO, GUIDELINES REGARDING INFORMED CONSENT, *supra* note 62, para. 3.

<sup>66</sup> See WORLD HEALTH ORGANISATION (WHO), FEMALE STERILIZATION: A GUIDE TO PROVISION OF SERVICES 72 (1992) available at [http://whqlibdoc.who.int/publications/1992/9241544341\\_\(part1\).pdf](http://whqlibdoc.who.int/publications/1992/9241544341_(part1).pdf).

<sup>67</sup> FIGO, GUIDELINES ON FEMALE CONTRACEPTIVE STERILISATION, *supra* note 47, para. 10.

#### IV. FORCED STERILISATION AS A VIOLATION OF HUMAN RIGHTS

##### A. Forced sterilisation of persons with disabilities constitutes torture and ill treatment (Article 3 of the Convention)

###### Forced sterilisation as a violation of the substantive limb of Article 3

19. Sterilisation without informed consent violates an individual's right to be free from torture or cruel, inhuman, or degrading treatment.<sup>68</sup> Forced sterilisation has long lasting physical and psychological effects, permanently robbing women of their reproductive capabilities and inflicting mental distress on them.<sup>69</sup> The removal of such a basic bodily function as the ability to reproduce seriously disrupts women's physical well-being and violates their physical integrity and bodily autonomy. In addition to physical pain, forced sterilisation causes women mental suffering. Experts recognise that the permanent deprivation of one's reproductive capacity without informed consent generally results in psychological trauma, including depression and grief.<sup>70</sup> Women subjected to forced sterilisation also suffer gross humiliation when a decision about their reproductive capacity is made with complete disregard for their values, preferences and experiences. Studies suggest that many people with an intellectual disability "understand the effects of sterilisation, maintain negative feelings towards the procedure, and ... exhibit signs of 'depression, sexual insecurity, symbolic castration and regret over loss of child-bearing ability.'"<sup>71</sup>
20. National courts and international bodies have also recognised numerous health consequences of forced sterilisation. Notably, the Supreme Court of Canada has stated that "[t]he grave intrusion on a person's right and the certain physical damage that ensues from non-therapeutic sterilization without consent, when compared to the highly questionable advantages that can result from it, have persuaded me [the Court] that it can never safely be determined that such a procedure is for the benefit of that person."<sup>72</sup>
21. Women with disabilities are particularly vulnerable to forced sterilisation, as they are often subjected to discrimination by virtue of their gender as well as their disability. This Court has recognised that the severity of a particular form of conduct should be measured in part by considering the specific status of the victim, including their sex, age and state of health.<sup>73</sup> The Special Rapporteur on Torture has incorporated this concept of vulnerability into his analysis of

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<sup>68</sup> The Human Rights Committee has indicated that the sterilization of women without their consent is a breach of article 7 of the International Covenant on Civil and Political Rights. See HRC, *General Comment No. 28*, *supra* note 39, para. 11.

<sup>69</sup> R. Sifris, *Conceptualising Involuntary Sterilisation as 'Severe Pain or Suffering' for the Purposes of Torture Discourse*, 28 NETHERLANDS QUARTERLY OF HUMAN RIGHTS, 523, 536-546 (2010). See also *A.S. v. Hungary*, *supra* note 11, paras. 2.4, 7.7.

<sup>70</sup> See S. GABBE ET AL., *OBSTETRICS: NORMAL AND PROBLEM PREGNANCIES* 704 (1996).

<sup>71</sup> R. Sifris, *supra* note 69, at 536-546 (citing P. Roos, *Psychological Impact of Sterilization on the Individual*, 1 LAW & PSYCHOLOGY REVIEW 45, 52 (1975); Dowse, *supra* note 16 (WWDA completed a national research study consulting women and girls with disabilities on their lived experiences of sterilisation and violations of their reproductive health rights).

<sup>72</sup> *E v. Eve*, [1986] 13 C.P.C. (2d) 6, para. 86; See also CEDAW Committee, *General Recommendation No. 19*, *supra* note 23, para. 22; *A.S. v. Hungary*, *supra* note 11, paras. 2.4, 7.7.

<sup>73</sup> See *Elci and Others v. Turkey*, 23145/93 & 25091/94, Eur. Ct. H.R., para. 633 (2003); *Ireland v. The United Kingdom*, 5310/71, Eur. Ct. H.R., para. 162 (1978).

what constitutes torture and cruel, inhuman and degrading treatment, noting that “the overriding factor at the core of the prohibition of CIDT [cruel, inhuman and degrading treatment] is the concept of powerlessness of the victim.”<sup>74</sup> The Special Rapporteur has stressed that, “given the particular vulnerability of women with disabilities, forced abortions and sterilizations of these women if they are the result of a lawful process by which decisions are made by their ‘legal guardians’ against their will, may constitute torture or ill-treatment.”<sup>75</sup>

### States’ positive obligations under Article 3

22. This Court has, through its case law, developed the concept of positive obligations by recognising that States are not only obliged to refrain from interfering with Convention rights but they also have a duty to take action to ensure such rights are not violated.<sup>76</sup> The positive obligations on States to protect against and respond to violations of rights under the Convention are most likely to apply, and where they do apply are heightened, in regard to the most fundamental Convention rights such as the right to be free from torture and cruel, inhuman and degrading treatment.<sup>77</sup> The Court’s jurisprudence regarding the content of the obligation of ‘due diligence’<sup>78</sup> has made clear that the State will be responsible where it ‘knew or ought to have known’ that there was a serious risk to the rights of the individual, and the State failed to take measures reasonably within its power to prevent a violation of those rights.<sup>79</sup>
23. The CRPD enjoins States Parties to take all appropriate measures to protect persons with disabilities from violence, exploitation and abuse and expressly requires them to provide assistance and support to prevent such rights violations from occurring.<sup>80</sup> This obligation extends to violations occurring both within and outside the home, the gender-based aspects of such

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<sup>74</sup> M. Nowak, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment: Civil and Political Rights, Including Questions of Torture and Detention*, para. 40, U.N. Doc. E/CN.4/2006/6 (Dec. 23, 2005) [hereinafter *Special Rapporteur on Torture—Civil and Political Rights 2005*]; See also *Special Rapporteur on Torture Interim Report 2008*, *supra* note 36, para. 50 (“In a given context, the particular disability of an individual may render him or her more likely to be in a dependant situation and make him or her an easier target of abuse. However, it is often circumstances external to the individual that render them “powerless”, such as when one’s exercise of decision-making and legal capacity is taken away by discriminatory laws or practices and given to others.”).

<sup>75</sup> M. Nowak, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, para. 38, U.N. Doc. A/HRC/7/3 (Jan. 15, 2008) [hereinafter *Report of the Special Rapporteur on Torture 2008*].

<sup>76</sup> *X and Y v. the Netherlands*, 8978/80, Eur. Ct. H.R., para. 23 (1985) (where the Court held that there was an obligation on the State to adopt criminal-law provisions to secure the effective protection of individuals. This approach was later replicated in the case of *M.C. v. Bulgaria*, 39272/98, Eur. Ct. H.R., para. 149-150, (2003)); See also *Osman v. The United Kingdom*, 23452/94, Eur. Ct. H.R., para. 115-116 (1998); *Young, James and Webster v. The United Kingdom*, 7601/76 & 7806/77, Eur. Ct. H.R., para. 49 (1981).

<sup>77</sup> *M.C. v. Bulgaria*, *supra* note 76, para. 149-50.

<sup>78</sup> See Human Rights Committee, *General Comment No. 31: The Nature of the General Legal Obligation Imposed on States Parties to the Covenant*, (18<sup>th</sup> Sess., 2004), in *Compilation of General Comments and General Recommendations by Human Rights Treaty Bodies*, at 243, para. 8, U.N. Doc. HIR/GEN/1/Rev.9 (Vol. 1) (2008); Committee against Torture, *General Comment No. 2: Implementation of article 2 by States parties*, (44<sup>th</sup> Sess., 1992), para. 18, U.N. Doc. CAT/C/GC/2 (2008) [hereinafter CAT Committee, *General Comment No. 2*]; *Velásquez Rodríguez Case*, Inter-Am. Ct. H.R. (Ser. C) No. 4 (July 29, 1988).

<sup>79</sup> See *Osman v. The United Kingdom*, *supra* note 76, para. 116.

<sup>80</sup> CRPD, *supra* note 23, art. 15, 16, 17.

violations, and the duty of States Parties to investigate and prosecute those responsible.<sup>81</sup> In the context of social care institutions, States Parties are required to ensure that all facilities and programmes designed for persons with disabilities are effectively monitored by independent authorities.<sup>82</sup> These requirements are designed to facilitate a more structured and formal procedure through which persons who may not be able to assert their rights can be protected from procedures like forced sterilisation.

24. The State responsibility to take measures to ensure that individuals are not subjected to torture or inhuman or degrading treatment includes such ill-treatment administered by private individuals.<sup>83</sup> The Special Rapporteur on Torture emphasises that States' obligations extend into the private sphere and should be interpreted to include State failure to protect persons within its jurisdiction from torture and ill-treatment committed by private individuals, such as doctors, health professionals and social workers, including those working in private hospitals, other institutions and detention centres.<sup>84</sup> In effect, the failure of the State to exercise due diligence to intervene to prevent torture and provide remedies to victims of torture "facilitates and enables non-state actors to commit acts impermissible under [the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment] with impunity," and its indifference or inaction provides a form of encouragement and/or de facto permission.<sup>85</sup>
25. The Committee against Torture (hereinafter the 'CAT Committee'), which monitors State compliance with the United Nations Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, has also confirmed that States have a heightened obligation to protect vulnerable and/or marginalised individuals from torture and cruel inhuman and degrading treatment<sup>86</sup> and to "adopt effective measures to prevent public authorities and other

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<sup>81</sup> *Special Rapporteur on Torture Interim Report 2008*, *supra* note 36, para. 69; CAT Committee, *General Comment No. 2*, *supra* note 78; CEDAW Committee, *General Recommendation No. 19*, *supra* note 23 (Similarly, the United Nations Committee against Torture, in its General Comment No. 2, held that the prohibition of torture must be enforced in all sorts of institutions and States have to exercise due diligence to prevent, investigate, prosecute and punish such non-State officials or private actors. The CEDAW Committee in its General Comment No. 19 confirmed that "States may also be responsible for private acts if they fail to act with due diligence to prevent violations of rights or to investigate and punish acts of violence, and for providing compensation.").

<sup>82</sup> CRPD, *supra* note 23, art. 16 (provides that States parties are required to provide gender-sensitive measures to prevent exploitation, violence and abuse).

<sup>83</sup> *Opuz v. Turkey*, *supra* note 3, para. 159; *See Vo v. France*, 53924/00, Eur. Ct. H.R., para. 89 (2004); *Calvelli and Ciglio v. Italy*, 32967/96, Eur. Ct. H.R. (2002); *Powell v. the United Kingdom*, 45305/99, Eur. Ct. H.R. 2000.

<sup>84</sup> Also, article 1 of the Convention against Torture should be seen as reinforcing, and reinforced by: The Declaration on the Elimination of Violence against Women, G.A. Res. 48/104, U.N. Doc. A/RES/48/104 (1994); *Report of the Special Rapporteur on Torture 2008*, *supra* note 75, para. 31; *Special Rapporteur on Torture Interim Report 2008*, *supra* note 36, para. 51.

<sup>85</sup> CAT Committee, *General Comment No. 2*, *supra* note 78, para. 18; *See also* Report of the Special Rapporteur on Violence Against Women, its Causes and Consequences, *Integration of the Human Rights of Women and the Gender Perspective: Violence against Women, The Due Diligence Standard as a Tool for the Elimination of Violence against Women*, U.N. Doc. E/CN.4/2006/61 (20/01/2006) (The Special Rapporteur on Violence against women also supports the exercise of due diligence by States taking positive action to prevent and protect women from violence, punish perpetrators of violent acts and compensate victims of violence).

<sup>86</sup> CAT Committee, *General Comment No. 2*, *supra* note 78, para. 21 (which refers to a number of different statuses relevant to the application of the principle of non-discrimination in the context of torture and CIDT analysis: "race, color, ethnicity, age, religious belief or affiliation, political or other opinion, national or social origin, gender, sexual orientation, transgender identity, mental or other disability, health status, economic or indigenous status, reason for which the person is detained,

persons acting in an official capacity from directly committing, instigating, inciting, encouraging, acquiescing in or otherwise participating or being complicit in acts of torture....”<sup>87</sup> This vulnerability is heightened where people with mental disabilities are segregated from society for long periods of time in institutions, including prisons, social care centers, orphanages and mental health institutions.<sup>88</sup> It has been well documented that within such institutions “persons with disabilities are frequently subjected to unspeakable indignities, neglect, severe forms of restraint and seclusion, as well as physical, mental and sexual violence.”<sup>89</sup>

26. The CRPD requires States Parties to “maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation” of its provisions.<sup>90</sup> A proper legal framework to ensure protection of persons with disabilities from forced sterilisation should include national bodies with unrestricted access to places of detention of persons with mental disabilities along with their installations and facilities and with full access to all relevant information. Regular supervision of social care and other residential institutions by an independent outside body is critical in ensuring protection of persons with mental disabilities from torture, ill treatment and abuse. The European Committee for the Prevention of Torture has noted the “considerable importance to psychiatric establishments being visited on a regular basis by an independent outside body (e.g. a judge or supervisory committee) which is responsible for the inspection of patients’ care.”<sup>91</sup> It expressly recommended that the independent body be able to talk privately with patients, to receive directly any complaints which they might have, and to make any necessary recommendations.<sup>92</sup> The Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment requires the establishment of independent national bodies in accordance with its provisions and suggests the mandate of such bodies should include at the minimum the power “to regularly examine the treatment of the persons deprived of their liberty in places of detention [...] with a view to strengthening [...] their protection” and the power to “make recommendations to the relevant authorities” in order to advance its statutory objectives.<sup>93</sup>
27. Outside of institutions and places of detention the Human Rights Committee, which monitors State compliance with the United Nations International Covenant on Civil and Political Rights, has expressed concern at reports of forced or coerced sterilisation of Roma women, and has noted the State’s failure to implement “concrete measures to eliminate forced sterilization.”<sup>94</sup> The

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including persons accused of political offences or terrorist acts, asylum-seekers, refugees or others under international protection, or any other status or adverse distinction.” Discrimination plays a prominent role in an analysis of reproductive rights violations as forms of torture or cruel, inhuman and degrading treatment because sex and gender bias commonly underlie such violations).

<sup>87</sup> *Id.* para. 17.

<sup>88</sup> *Special Rapporteur on Torture Interim Report 2008*, *supra* note 36, para. 38.

<sup>89</sup> *Id.*

<sup>90</sup> CRPD, *supra* note 23, art. 33(2) (on national implementation and monitoring).

<sup>91</sup> Council of Europe, 8<sup>th</sup> *General Report on the CPT’s Activities Covering the Period 1 January to 31 December 1997*, CPT/Inf (98) 12 [EN] (1998).

<sup>92</sup> *Id.* para. 55.

<sup>93</sup> Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, adopted Dec. 18, 2002, G.A. Res. 57/199, UN GAOR, 57<sup>th</sup> Sess., U.N. Doc. A/RES/57/199 (entered into force June 22, 2006) [hereinafter CAT Optional Protocol].

<sup>94</sup> Human Rights Committee, *Concluding Observations: Slovakia*, para. 13, U.N. Doc. CCPR/C/SVK/CO/3 (2011).

Committee urged the State to “adopt all necessary measures to investigate all alleged cases of coerced or forced sterilization, publicize the findings, provide effective remedies to victims and prevent any instances of sterilization without full and informed consent.”<sup>95</sup> Similarly, the CAT Committee has urged States to issue guidelines and training of public officials, including “on the criminal liability of medical personnel conducting sterilizations without free, full and informed consent, and on how to obtain such consent from women undergoing sterilization.”<sup>96</sup> The CEDAW Committee also recommends that States Parties “ensure that measures are taken to prevent coercion in regard to fertility and reproduction.”<sup>97</sup>

## **B. Denial of access to justice for persons with disabilities (Article 6 of the Convention)**

28. Persons with disabilities, particularly those with intellectual and psycho-social disabilities, may be denied effective access to justice because violations of their rights are not taken seriously if they are reported to the authorities.<sup>98</sup> This Court has recognised that persons whose legal capacity has been restricted may be denied the right to bring legal proceedings and even to participate in proceedings that directly concern them.<sup>99</sup> The inability of persons with intellectual disabilities and psycho-social disabilities to access justice can lead to impunity for violations of their rights.
29. A recent study concluded that the access to rights and justice in France and across Europe by people with intellectual/mental disabilities is by no means guaranteed.<sup>100</sup> It identified the lack of special measures available within the justice system to facilitate access for persons with intellectual disabilities, including accessibility of the procedures and information.<sup>101</sup>
30. There is little doubt that the right of access to justice is among the most important civil and political rights as it determines the extent to which individuals can secure and enforce their other substantive human rights.<sup>102</sup> The Court has extended to States a margin of appreciation including in the designation of the procedural arrangements that secure sound administration of justice and,

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<sup>95</sup> Human Rights Committee, *Concluding Observations: Slovakia*, para. 12, U.N. Doc. CCPR/CO/78/SVK (2003).

<sup>96</sup> Committee against Torture, *Concluding Observations: Slovakia*, para. 14, U.N. Doc. CAT/C/SVK/CO/2 (2009).

<sup>97</sup> CEDAW Committee, *General Recommendation No. 19*, *supra* note 23, para. 24(m).

<sup>98</sup> HOUSE OF LORDS HOUSE OF COMMONS JOINT COMMITTEE ON HUMAN RIGHTS, *A LIFE LIKE ANY OTHER? HUMAN RIGHTS OF ADULTS WITH LEARNING DISABILITIES: SEVENTH REPORT OF SESSION 2007–08 68-70* (2008), *available at* <http://www.bild.org.uk/humanrights/docs/A%20life%20like%20any%20other%20Vol%201.pdf>; MENCAP, *DON'T STAND BY, ENDING DISABILITY HATE CRIME TOGETHER: HATE CRIME RESEARCH REPORT* (2010), *available at* <http://www.mencap.org.uk/sites/default/files/documents/Stand%20by%20me%20research%20report.pdf>.

<sup>99</sup> *Shtukaturv v. Russia*, *supra* note 21; *Berkova v. Slovakia*, *supra* note 30; *Salontaji-Drobnak v. Serbia*, *supra* note 30.

<sup>100</sup> INCLUSION EUROPE, *JUSTICE, RIGHTS AND INCLUSION FOR PEOPLE WITH INTELLECTUAL DISABILITY 30* (2007), *available at* <http://www.inclusion-europe.org/documents/1081.pdf>.

<sup>101</sup> *Id.* at 28 (These findings are corroborated in a “Comparative Study on Access to Justice in Gender Equality and Anti-Discrimination Law” produced at the request of the European Commission in February 2011. Available on request from the European Commission DG JUST. These studies, as well as the report on “Access to Justice in Europe: an Overview of challenges and opportunities” published by the European Union Agency for Fundamental Rights around the same time, identifies ten EU and EEA countries – Austria, Cyprus, Czech republic, France, Latvia, Liechtenstein, Norway, Poland, Romania and Sweden – where the conditions for legal standing are considered to be excessively strict, requiring people to pass a double threshold: that of having a full legal capacity and of proving their direct interest in the matter. *See* EUROPEAN UNION AGENCY FOR FUNDAMENTAL RIGHTS, *ACCESS TO JUSTICE IN EUROPE: AN OVERVIEW OF CHALLENGES AND OPPORTUNITIES 2011*, *available at* [http://www.fra.europa.eu/fraWebsite/media/pr-230311\\_en.htm](http://www.fra.europa.eu/fraWebsite/media/pr-230311_en.htm).

<sup>102</sup> *Golder v. The United Kingdom*, 4451/70, Eur. Ct. H.R. (1975); *Airey v. Ireland*, 6289/73, Eur. Ct. H.R. (1979).

in the context of people with mental disabilities, the protection of the health of the person concerned.<sup>103</sup> However, the Court has made clear that this margin is limited and that any procedural measures should not undermine the very essence of the individual's right to a fair hearing as guaranteed by Article 6 of the Convention. The Court has also affirmed that States have a duty to ensure that such persons are afforded a fair hearing in relation to any interference with their civil and political rights occasioned by the curtailment of their decision making powers.<sup>104</sup> In assessing whether or not a particular measure meets the requirements of Article 6 all relevant factors are to be considered, including the nature and complexity of the issue before the domestic courts, and what was at stake for the individual in question.<sup>105</sup>

31. The CRPD expressly addresses the right of persons with disabilities to vindicate their rights through the justice system in Article 13 which, when read with Article 12, provides detailed provisions on the right of access to justice, including through the provision of reasonable accommodation. Failure to ensure that vulnerable persons have effective access to justice will perpetuate the abuses committed against them, contrary to the principle that the Convention "is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective."<sup>106</sup>

### **C. Failure to ensure free and informed consent to sterilisation as a violation of the right to respect for private and family life (Article 8 of the Convention)**

#### Forced sterilisation violates the right to respect for private and family life of persons with disabilities

32. Sterilisation performed without a woman's informed consent severely violates her right to respect for her private and family life. This includes the rights of individuals to decide freely on the number and spacing of their children, and the means necessary to enable them to exercise these rights.<sup>107</sup> According to the Court's established case-law 'private life' covers various aspects such as physical, psychological and moral integrity of a person, including his or her sexual life;<sup>108</sup> a person's ability to develop relationships with others,<sup>109</sup> to determine one's own personal identity,<sup>110</sup> and to develop a sex life free from any interference.<sup>111</sup> The Court has noted that "any interference with the physical integrity of a person must be prescribed by law and require the consent of that person."<sup>112</sup> Subjecting a woman to sterilisation without her free and informed

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<sup>103</sup> See, e.g., *Shtukaturov v. Russia*, *supra* note 21, para. 66.

<sup>104</sup> *Id.* para. 68-69.

<sup>105</sup> *Id.* para. 68.

<sup>106</sup> *Airey v. Ireland*, *supra* note 102, para. 24.

<sup>107</sup> FIGO, GUIDELINES ON FEMALE CONTRACEPTIVE STERILISATION, *supra* note 47, para. 1; See also CEDAW, *supra* note 23, art.16(1)(e); CRPD, *supra* note 23, art. 23(1)(b).

<sup>108</sup> See, e.g., *Glass v. The United Kingdom*, 61827/00, Eur. Ct. H.R., para. 70 (2004); *Y.F. v. Turkey*, 24209/94, Eur. Ct. H.R., para. 33 (2003).

<sup>109</sup> See, e.g., *Niemetz v. Germany*, 13710/88, Eur. Ct. H.R., para. 29 (1992).

<sup>110</sup> See, e.g., *Gaskin v. The United Kingdom*, 10454/83, Eur. Ct. H.R., paras. 36-7 (1989).

<sup>111</sup> See, e.g., *Dudgeon v. The United Kingdom*, 7525/76, Eur. Ct. H.R., para. 41 (1983).

<sup>112</sup> See *Y.F. v. Turkey*, *supra* note 108, para. 43.

consent deprives her of reproductive autonomy and bodily integrity and thus constitutes a violation of her right to private and family life.

33. The CRPD places an obligation on States to ensure that persons with disabilities are not subjected to arbitrary or unlawful interference with their privacy and family,<sup>113</sup> including all matters relating to marriage, family, parenthood and relationships.<sup>114</sup> The right to privacy under the CRPD is tailored to the specific autonomy needs of persons with disabilities in that decision-making capacity over personal information rests with them. It acknowledges that right on an equal basis with others with respect to all personal, health and rehabilitation information.<sup>115</sup> A recent report by the Council of Europe Commissioner for Human Rights noted the right of disabled persons to exercise general decision-making powers related to their private life.<sup>116</sup> Notably, the report found, following this Court's judgment in *Shtukaturov v. Russia*, that "[f]ull deprivation of legal capacity is a very serious interference with the right to private life protected by article 8 of the European Convention on Human Rights."<sup>117</sup>

### Positive obligations under Article 8

34. Article 8 of the Convention not only imposes restrictions on interfering with an individual's private life, but may also impose positive obligations on States to adopt measures designed to secure respect for private life.<sup>118</sup> The CEDAW Committee has recognized the positive obligations of States to take legal and other measures with regard to reproduction, recommending States to "...ensure that measures are taken to prevent coercion in regard to fertility and

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<sup>113</sup> CRPD, *supra* note 23, art. 22 (1).

<sup>114</sup> *Id.* art. 22.

<sup>115</sup> *Id.* art. 22 (2).

<sup>116</sup> COMMISSIONER FOR HUMAN RIGHTS, COUNCIL OF EUROPE, HUMAN RIGHTS AND DISABILITY; EQUAL RIGHTS FOR ALL 5 (2008), available at <https://wcd.coe.int/wcd/ViewDoc.jsp?id=1355349&Site=CM>. The 1999 Council of Europe Committee of Ministers "Recommendations on the Principles Concerning the Legal Protection of Incapable Adults," includes "maximum preservation of legal capacity" as one of its key tenets. The Recommendations allow for the restriction of legal capacity where it is shown necessary for the protection of the person concerned. Such a measure of protection does not, however, automatically deprive the person concerned of the right to consent (or refuse consent) to any medical intervention. See Council of Europe Committee of Ministers, *Recommendation No. R (99) 4 of the Committee of Ministers on the Principles Concerning the Legal Protection of Incapable Adults*, (Feb. 23, 1999), available at <https://wcd.coe.int/wcd/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=536854&SecMode=1&DocId=396848&Usage=2>.

<sup>117</sup> *Id.* at 10 (citing *Shtukaturov v. Russia*, *supra* note 21).

<sup>118</sup> See, e.g., *Mosley v. The United Kingdom*, 48009/08, Eur. Ct. H.R., para. 106 (2011) (The Court has recognised the existence of positive obligations under Article 8 in a diverse range of circumstances, such as protection of persons from sexual abuse (*X and Y v. Netherlands*, *supra* note 76); official recognition of post-operative transsexuals (*Goodwin v. UK*, 17488/90, Eur. Ct. H.R. (1996)); access to personal information or other related data held by public authorities (*Gaskin v. UK*, *supra* note 110; *Roche v. The United Kingdom*, 32555/96, Eur. Ct. H.R. (2005)); duty to secure personal privacy by providing remedies to prevent publication of or revelations about an individual's private life (*Hannover v. Germany*, 59320/00, Eur. Ct. H.R. (2005)); legal recognition of the family relationship between parents and illegitimate children (*Marckx v. Belgium*, 6833/74, Eur. Ct. H.R. (1979)); reuniting children with their natural parents (*Ignaccolo-Zenide v. Romania*, 31679/96, Eur. Ct. H.R. (2000)); facilitating the traditional lifestyles of minorities (*Chapman v. The United Kingdom*, 27238/95, Eur. Ct. H.R. (2001)). This Court has held that the right to physical integrity is protected as part of respecting private life under Article 8 and can incur positive obligations on behalf of the State, *X and Y v. Netherlands*, *supra* note 76, paras. 22 - 23; *Pretty v. The United Kingdom*, 2346/02, Eur. Ct. H.R., para. 61 (2002); *Glass v. The United Kingdom*, *supra* note 108; *Storck v. Germany*, 61603/00, Eur. Ct. H.R., para. 150 (2005)).

reproduction...”<sup>119</sup>

35. In relation to persons with disabilities, the Court has accepted in principle that “the effective enjoyment of many of the Convention rights by disabled persons may require the adoption of various positive measures by the competent State authorities.”<sup>120</sup> It is submitted that where medical and health care personnel fail to provide full and accurate information on sterilisation and alternative forms of contraception to persons with disabilities such failure amounts to a violation of Article 8. The failure to give such information in relation to sterilisation is a particularly egregious violation of the right to private life, given the procedure’s permanent changes to a woman’s reproductive system, irreversible impact on a major bodily function, the ability to bear children and the impact that undergoing a procedure without consent has on the health and welfare of an individual and her family. The State also has an essential role to play in ensuring that steps are taken to facilitate the enjoyment and exercise of the right to private life by persons with disabilities, including by providing better support to families and carers of persons with intellectual disabilities, making available education programmes and information on sexual and reproductive health for persons with disabilities, developing inclusive public health and awareness raising campaigns about sexuality and parenthood,<sup>121</sup> in an effort to eliminate resorting to the practice of forced sterilisation. By putting in place an appropriate and effective legal framework that respects the right of persons with disabilities to reasonable accommodation States would reflect the core values and principles of the CRPD including respect for inherent dignity, autonomy and independence.<sup>122</sup>

#### **D. Depriving women with disabilities of their right to found a family (Article 12 of the Convention)**

36. Women with disabilities are often perceived as too dependent and weak to make fit parents and serve as good role models.<sup>123</sup> Such widespread attitudes limit the rights of women with

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<sup>119</sup> CEDAW Committee, *General Recommendation No. 19*, *supra* note 23.

<sup>120</sup> *Molka v. Poland*, 56550/00, Eur. Ct. H.R., para. 16 (2006).

<sup>121</sup> CRPD, *supra* note 23, preamble, art. 8, 16(2), 25(a); *See also* Committee on the Rights of the Child, *Concluding Observations: Uganda*, paras. 46-48, U.N. Doc. CRC/C/UGA/CO/2 (2005); *Costa Rica*, para. 72(d), U.N. Doc. CRC/C/CRI/CO/4 (2011); CEDAW Committee, *Concluding Observations: Uganda*, para. 46, U.N. Doc. CEDAW/C/UGA/CO/7 (2010); *Nepal*, para. 31, U.N. Doc. CEDAW/C/NPL/CO/4-5 (2011); *Zambia*, paras. 40 (a) (b), U.N. Doc. CEDAW/C/ZMB/CO/5-6 (2011); *Belarus*, para. 36(c), U.N. Doc. CEDAW/C/BLR/CO/7 (2011); *Liechtenstein*, para. 39(c), U.N. Doc. CEDAW/C/LIE/CO/4 (2011) (CEDAW and CRC Committee concluding observations on Uganda, calling for effective measures to be taken to ensure that women with disabilities have equal and non-discriminatory access to education and healthcare, including reproductive health; Nepal, expressing its deep concern on “the lack of access to family planning and the highest unmet needs for contraception of ... women with disabilities”; Zambia, with respect to women with disabilities to “adopt pro-active measures to encourage their participation and to eliminate discrimination against them including in the areas of health and reproductive health”; Belarus, recommending “to ensure that all women, including women with disabilities, ... as well as girls have free and adequate access to contraceptives and sexual and reproductive health services, including in rural areas, and to information in accessible formats”; Liechtenstein, recommending “to ensure that all women and girls, including adolescents, women with disabilities ... have free and adequate access to contraceptives and sexual and reproductive health services and information in accessible formats”; on Costa Rica, recommending to “ensure that education on sexual and reproductive health and rights is provided in age-appropriate and accessible formats and respectful of the dignity of students with disabilities.”).

<sup>122</sup> CRPD, *supra* note 23, art. 3, 2, 5(3).

<sup>123</sup> K. Wilde, *Gender and Disability*, WOMEN WITH DISABILITIES AUSTRALIA (1997), <http://www.wdda.org.au/kaliw.htm>

disabilities to experience sexuality, marriage and parenthood on an equal basis with others. The right of women with disabilities to found a family is still often impeded by prejudice about their parenting skills, violence against their bodily or mental integrity, discrimination and inaccessibility of services and facilities. Indeed, instances of denial of the right to family to women on the account of their disabilities have been well-documented by NGOs.<sup>124</sup>

37. Forced sterilisation deprives women with disabilities of the right to found a family, should they wish to do so. International law protects the right of persons with disabilities to “experience their sexuality, have sexual relationships and experience parenthood,”<sup>125</sup> “to decide freely and responsibly on the number and spacing of their children”<sup>126</sup> and “have the right to protection and support in relation to motherhood and pregnancy.”<sup>127</sup> Article 23 of the CRPD requires States Parties to take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others and specifically guarantees persons with disabilities, including children the right to retain their fertility.<sup>128</sup>

#### **E. Forced sterilisation as disability- and gender-based discrimination against women with disabilities (Article 14 in conjunction with Articles 3 and 8 of the Convention)**

38. According to this Court’s established case law, a “difference of treatment is discriminatory if it has no objective and reasonable justification, in other words, if it does not pursue a legitimate aim or if there is not a reasonable relationship of proportionality between the means employed and the aim sought to be realised.”<sup>129</sup> It is recognised that the State enjoys a certain margin of appreciation in assessing whether a difference of treatment is justified. However, the scope of this margin depends on the circumstances, the subject-matter and the background of a case.<sup>130</sup> In the past the Court has identified a number of particularly vulnerable groups including women and, most recently, persons with mental disabilities, in respect of which the State has a “substantially narrower” margin of appreciation when restricting their fundamental rights - the State must demonstrate “very weighty reasons” to justify such restrictions.<sup>131</sup>

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(paper was submitted to the Court Support Network in 1997); *See also* EUROPEAN DISABILITY FORUM, EDF INPUT TO THE GENERAL DISCUSSION OF THE CESCRR ON SEXUAL AND REPRODUCTIVE RIGHTS (2010), *available at* <http://www2.ohchr.org/english/bodies/cescr/docs/discussion/EuropeanDisabilityForum.pdf>; INTERNATIONAL DISABILITY ALLIANCE, IDA SUBMISSION TO THE COMMITTEE OF ECONOMIC, SOCIAL AND CULTURAL RIGHTS DAY OF GENERAL DISCUSSION ON SEXUAL AND REPRODUCTIVE HEALTH (2010), *available at* [http://www2.ohchr.org/english/bodies/cescr/docs/discussion/IDA\\_DGD15112010.pdf](http://www2.ohchr.org/english/bodies/cescr/docs/discussion/IDA_DGD15112010.pdf).

<sup>124</sup> COMITÉ ESPAÑOL DE REPRESENTANTES DE PERSONAS CON DISCAPACIDAD (CERMI), EUROPEAN CONFERENCE: RECOGNIZING THE RIGHTS OF GIRLS AND WOMEN WITH DISABILITIES: AN ADDED VALUE FOR TOMORROW’S SOCIETY (2007), *available at* <http://cms.horus.be>.

<sup>125</sup> ESCR Committee, *General Comment No. 5*, *supra* note 23.

<sup>126</sup> CRPD, *supra* note 23, art. 23(1)(b).

<sup>127</sup> ESCR Committee, *General Comment No. 5*, *supra* note 23, para. 31.

<sup>128</sup> CRPD, *supra* note 23, art. 23.

<sup>129</sup> *See, e.g.*, *Clift v. The United Kingdom*, 7205/07, Eur. Ct. H.R., para. 73 (2010); *Andrejeva v. Latvia* (GC), 55707/00, Eur. Ct. H.R., para. 82 (2009); *Sidabras and Džiautas v. Lithuania*, 55480/00 and 59330/00, Eur. Ct. H.R., para. 51 (2004); *D.H. and Others v. the Czech Republic*, 57325/00, Eur. Ct. H.R., para. 196 (2007).

<sup>130</sup> *Clift v. The United Kingdom*, *supra* note 129, para. 43.

<sup>131</sup> *Alajos Kiss v. Hungary*, *supra* note 35, para 42.

39. The Court has previously held that gender-based violence is an impermissible form of discrimination against women.<sup>132</sup> The case of *Opuz v. Turkey* emphasized the Court's approach to situations of violence against women generally, noting that such violence constitutes discrimination prohibited by international human rights law, and that the failure to adequately respond to such gender-specific violence amounts to discrimination under Article 14.<sup>133</sup> In so finding, the Court has relied on other international human rights bodies that have recognized violence against women as a form of inequality and stated that in its analysis of discrimination generally, including its scope and nature, it would have regard to relevant international standards.<sup>134</sup> These considerations have informed the analysis of forced sterilisation by the CEDAW Committee which, in a statement on violence against women, stated that "[c]ompulsory sterilization ... adversely affects women's physical and mental health..."<sup>135</sup> and noted "gender-based violence is a form of discrimination that seriously inhibits women's ability to enjoy rights and freedoms on a basis of equality with men."<sup>136</sup>

40. It is worth emphasising, in the context of discrimination, that the vulnerability of women to forced sterilisation is heightened where they have a mental disability. A recent European Union report recognised that persons with disabilities were often subject to multiple discrimination<sup>137</sup> and the CRPD has recognised this in expressing concern about the "difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination."<sup>138</sup> It is widely recognised and well documented that persons with disabilities suffer from widespread stigma and discrimination,<sup>139</sup> which may result in social exclusion and denial or restricted access to proper health care.<sup>140</sup> Such prejudice can entail legislative stereotyping which prohibits the individualised evaluation of their capacities and needs.<sup>141</sup> In *Glor v. Switzerland*,<sup>142</sup> this Court

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<sup>132</sup> *Opuz v. Turkey*, *supra* note 3, para. 200.

<sup>133</sup> *Id.*

<sup>134</sup> *Id.* para. 184-190 (The Inter-American system for the promotion and protection of human rights has also on a number of occasions characterised violence against women as a form of discrimination. For example, the Convention of Belém do Pará expressly recognises the relationship between gender-based violence and discrimination at the Preamble and in articles 4 and 6. See also *Maria da Penha v. Brazil*, Inter-Am. Ct. H.R., Case 12.051, No. 54/01 (Apr. 16, 2001)).

<sup>135</sup> CEDAW Committee, *General Recommendation No. 19*, *supra* note 23.

<sup>136</sup> *Id.* para. 1 (CEDAW Committee has elaborated that "based on gender" refers to acts that are either directed at a woman because she is a woman or that affect women disproportionately, *Id.* para. 6).

<sup>137</sup> EUROPEAN UNION AGENCY FOR FUNDAMENTAL RIGHTS, DATA IN FOCUS REPORT: MULTIPLE DISCRIMINATION (2010), available at [http://fra.europa.eu/fraWebsite/attachments/EU\\_MIDIS\\_DiF5-multiple-discrimination\\_EN.pdf](http://fra.europa.eu/fraWebsite/attachments/EU_MIDIS_DiF5-multiple-discrimination_EN.pdf).

<sup>138</sup> CRPD, *supra* note 23, preamble, art. 6(1).

<sup>139</sup> FROM EXCLUSION TO EQUALITY: REALIZING THE RIGHTS OF PERSONS WITH DISABILITIES, DEPARTMENT OF ECONOMIC AND SOCIAL AFFAIRS, OFFICE OF THE UNITED NATIONS HIGH COMMISSIONER FOR HUMAN RIGHTS, INTER-PARLIAMENTARY UNION 1-5 (2007), available at [www.ohchr.org/Documents/Publications/training14en.pdf](http://www.ohchr.org/Documents/Publications/training14en.pdf); *Pillay welcomes 100<sup>th</sup> Ratification of Treaty Designed to Cure Discrimination against People with Disabilities*, UNITED NATIONS OFFICE OF THE HIGH COMMISSIONER FOR HUMAN RIGHTS (May 13, 2011), available at <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=11016&LangID=E>; See generally, WORLD REPORT ON DISABILITY, *supra* note 18; CRPD, *supra* note 23, preamble.

<sup>140</sup> G. Thornicroft et al., *Discrimination in Health Care Against People with Mental Illness*, 19 INTERNATIONAL REVIEW OF PSYCHIATRY 113-122 (2007); EUROPEAN COMMISSION, DIRECTORATE GENERAL FOR EMPLOYMENT, SOCIAL AFFAIRS AND EQUAL OPPORTUNITIES, QUALITY IN AND EQUALITY OF ACCESS TO HEALTHCARE SERVICES (2008).

<sup>141</sup> *Alajos Kiss v. Hungary*, *supra* note 35, para. 42.

<sup>142</sup> *Glor v. Switzerland*, 13444/04, Eur. Ct. H.R. (2009).

recognised that Article 14 of the Convention encompasses discrimination based on disability. Referring in particular to the CRPD, the Court found that there existed a European and universal consensus on the need to protect persons with disabilities from discriminatory treatment.<sup>143</sup>

41. According to Article 5 of the CRPD “States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.” Provision of reasonable accommodations is a necessary component of the State’s obligation to promote equality and eliminate discrimination.<sup>144</sup> Article 6 of the CRPD recognises the multiple forms of discrimination which women and girls with disabilities face and obliges States Parties to take measures to ensure the full and equal enjoyment of their human rights. Article 12 of the CRPD expressly provides for the equal recognition of persons with disabilities before the law. The CRPD recognises, throughout its provisions, the importance of ensuring a gender-based perspective in promoting the fundamental rights of persons with disabilities and preventing discrimination.<sup>145</sup> Of particular relevance is Article 16 of the CRPD which emphasises a gender sensitive approach in protecting persons with disabilities from exploitation, violence and abuse and requires States to ensure “that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.”<sup>146</sup>
42. Article 17 of the CRPD guarantees the right of persons with disabilities not to be discriminated against in the enjoyment of their right to respect for their physical and mental integrity. In its first set of Concluding Observations concerning the protection of personal integrity, the CRPD Committee underlined the requirement of informed consent to medical treatment. It called for the legislative abolition of treatment without full and informed consent and for the law to particularly respect women’s rights to found a family and the right to health under articles 23 and 25 of the CRPD.<sup>147</sup> This recommendation addresses “gender inequalities reinforced by political, economic and social structures resulting in women being routinely coerced and denied information and autonomy in the health care setting,”<sup>148</sup> and confronts the particular risks which women with disabilities face. The Special Rapporteur on Torture has noted that “under article 23(c) of CRPD States Parties have an obligation to ensure that ‘persons with disabilities, including children, retain their fertility on an equal basis with others’ and to ensure their right to decide freely and responsibly on the number and spacing of their children.”<sup>149</sup>
43. The WHO in a recent report<sup>150</sup> relied on standards set out in the CRPD in relation to non-discrimination, and reiterated the right of persons with disabilities to retain their fertility and exercise their legal capacity in making healthcare decisions, including sexual and reproductive decisions.<sup>151</sup> The report specifically states that “[t]he presence of a particular health condition is

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<sup>143</sup> *Id.* para. 53.

<sup>144</sup> CRPD, *supra* note 23, art. 5(3).

<sup>145</sup> *Id.* at preamble.

<sup>146</sup> *Id.* art. 16(3).

<sup>147</sup> CRPD Committee, *Concluding Observations: Tunisia*, para. 29, U.N. Doc. CRPD/C/TUN/CO/1 (2011).

<sup>148</sup> *Secretary General, Right to Health 2008*, *supra* note 54, para. 54.

<sup>149</sup> *Special Rapporteur on Torture Interim Report 2008*, *supra* note 36, para. 60.

<sup>150</sup> WORLD REPORT ON DISABILITY, *supra* note 18.

<sup>151</sup> *Id.* at 78.

not sufficient to determine capacity. The assumption that people with certain conditions lack capacity is unacceptable, according to Article 12 of the CRPD.”<sup>152</sup> The report notes “there are many cases of involuntary sterilization being used to restrict the fertility of some people with a disability, particularly those with an intellectual disability, almost always women.... Involuntary sterilization of persons with disabilities is contrary to international human rights standards. Persons with disabilities should have access to voluntary sterilization on an equal basis with others.”<sup>153</sup> It also stated that legal frameworks and reporting and enforcement mechanisms, should be put in place “to ensure that, whenever sterilization is requested, the rights of persons with disabilities [should be] always respected above other competing interests.”<sup>154</sup>

44. The relationship between forced sterilisation of women with disabilities and discrimination is complex and mutually reinforcing. All international standards on forced sterilisation are underpinned by the principle of non-discrimination. Because the fundamental rights relevant to this case are often a precondition to the realisation of other human rights, failure to secure these fundamental rights to women with disabilities undermines the ability of this marginalised and neglected group to integrate into society and runs contrary to the principles of equality and human dignity that underpin the Convention.
45. Where the State fails to respond appropriately to forced sterilisation, structural inequalities are exacerbated and women with mental disabilities are further denied equal protection of the law. This case provides an important opportunity for this Court to confirm that where States fail to give meaningful effect to their obligation to protect in a way that overwhelmingly fails a particular class of applicants, they are not only in violation of the substantive provisions of the Convention as set out above, but also of the non-discrimination guarantee in Article 14 of the Convention, whether on the ground of gender, disability or both.

## V. CONCLUSION

46. Forced sterilisation of women with disabilities, and the inadequacy of State responses to it, represent grave violations of multiple human rights. States are obliged through the provision of an adequate legal framework, and its rigorous implementation, to exercise due diligence to protect individuals, and prevent the practice of forced sterilisation from taking place. Developments in international law and practice reflect that meeting these obligations in the context of forced sterilisation of women with disabilities requires States to take into account the vulnerability of such persons and to provide specific legislative, administrative and other measures to prevent the severe physical, psychological and emotional harm which can result from such procedures.

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<sup>152</sup> *Id.*

<sup>153</sup> *Id.*

<sup>154</sup> *Id.*

## ANNEX

### INTEREST OF INTERVENERS

*The Center for Reproductive Rights* (“Center”) is a non-profit legal advocacy organization dedicated to defending and promoting women’s reproductive health and rights worldwide. The Center’s International Legal Program, in collaboration with human rights advocates around the world, documents violations of reproductive rights, monitors and comments on laws concerning reproductive health care, and advocates before the United Nations and regional human rights fora, including the Council of Europe. The Center has previously served as a third party intervener in cases before the European Court of Human Rights, including *Vo v. France* (Application no. 53924/00), *Tysic v. Poland* (Application no. 5410/03) and *D v. Ireland* (Application no. 26499/02), *A, B and C v. Ireland* (Application no. 25579/05).

*The European Disability Forum (EDF)* is an independent non-governmental organisation which represents the interests and defends the rights of 80 million people with disabilities in the European Union, and is a member of IDA. EDF is the only European pan-disability platform run by persons with disabilities and their families. Created in 1996 by its member organisations, EDF ensures that decisions concerning persons with disabilities are taken with and by persons with disabilities.

*INTERIGHTS* is an international human rights law centre, based in London, which has held consultative status with the Council of Europe since 1993. It is a registered charity, independent of all governments. It works to promote the effective application of international human rights standards and procedures. A critical aspect of INTERIGHTS’ activities involves human rights litigation, including the filing of amicus curiae briefs before national and international courts and tribunals on points of law of key importance to human rights protection on which our knowledge of international and comparative practice might assist the court. INTERIGHTS has submitted amicus curiae briefs before this Court in many cases relating to the rights of persons with disabilities and women’s human rights, most recently in *Stanev v. Bulgaria* (Application no. 36760/06), *Kiyutin v. Russia* (Application no. 2700/10), and *Kawogo v. United Kingdom* (Application no. 56921/09).

*The International Disability Alliance (IDA)* is a unique, international network of global and regional organisations of persons with disabilities. Established in 1999, each IDA member represents a large number of national disabled persons’ organisations (DPOs) from around the globe, covering the whole range of disability constituencies, including persons with intellectual disabilities. IDA thus represents the collective global voice of persons with disabilities counting among the more than 1 billion persons with disabilities worldwide, the world’s largest – and most frequently overlooked – minority group. Currently comprising eight global and four regional DPOs,<sup>155</sup> IDA’s mission is to advance the human rights of persons with disabilities as a united voice of organisations of persons with disabilities utilising the Convention on the Rights of Persons with Disabilities and other human rights instruments.

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<sup>155</sup> IDA members are: Disabled Peoples’ International, Down Syndrome International, Inclusion International, International Federation of Hard of Hearing People, World Blind Union, World Federation of the Deaf, World Federation of the DeafBlind, World Network of Users and Survivors of Psychiatry, Arab Organization of Disabled People, Pacific Disability Forum, Red Latinoamericana de Organizaciones no Gubernamentales de Personas con Discapacidad y sus familias (RIADIS), and the European Disability Forum.

*The Mental Disability Advocacy Center (MDAC)* is an international human rights organisation which advances the rights of children and adults with intellectual disabilities and psycho-social disabilities. MDAC uses law to promote equality and social inclusion through strategic litigation, advocacy, research and monitoring and capacity-building. MDAC operates at the global level as well as regional and domestic levels in Europe and Africa. MDAC is headquartered in Budapest, Hungary and was founded in 2002. MDAC has participatory status with the Council of Europe and a special consultative status with the United Nations Economic and Social Council.