

Stellungnahme

der europäischen Gruppe der Nationalen Menschenrechtsinstitutionen

im Verfahren vor dem

Europäischen Gerichtshof für Menschenrechte

Gauer und andere ./. Frankreich

(Beschwerde-Nr. 61521/08)

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AMICUS BRIEF IN THE EUROPEAN COURT OF HUMAN RIGHTS

Application No. 61521/08

Gauer & Others

APPLICANTS

V

France

RESPONDENT

WRITTEN COMMENTS

BY

THE EUROPEAN GROUP OF NATIONAL HUMAN RIGHTS INSTITUTIONS PURSUANT TO ARTICLE 36 § 2 OF THE EUROPEAN CONVENTION ON HUMAN RIGHTS AND RULE 44 § 3 OF THE RULES OF THE EUROPEAN COURT OF HUMAN RIGHTS

16 August 2011

Introduction	
Brief case related information	
The concept of legal capacity	
The principle of free and informed consent	<i>3</i>
The prohibition of torture and ill treatment	<i>5</i>
The right to respect for private and family life	7
The right of access to justice	<i>8</i>
The prohibition of discrimination	<i>8</i>
Conclusion	<i>9</i>

Introduction

- 1. In June 2011, the Court granted liberty to the European Group of National Human Rights Institutions ("the European Group") to intervene in *Gauer and others v. France* in the form of a written submission in accordance with Articles 36 § 2 of the European Convention for the Protection of Human Rights and Fundamental Freedoms ("ECHR") and Rule 44 § 3 of the Rules of the Court. Following the first intervention in the case of *DD v. Lithuania* in 2007 which is still pending, this is the second third party intervention by the European Group submitted to this Court (although some National Human Rights Institutions regularly do so in their individual capacity).
- 2. The European Group is a representative group of thirty five (35) National Human Rights Institutions ("NHRIs") within the Council of Europe, of whom, twenty two (22) are deemed to be fully compliant with the United Nations ("UN") "Paris Principles"¹. These principles govern independent NHRIs² and broadly set out the competences and responsibilities of NHRIs and the criteria under which they should function, namely:
 - Independence guaranteed by Statute or Constitution;
 - Pluralism, including in membership and
 - A broad mandate covering all human rights and based on universal human rights standards.
- 3. As a matter of information, it should be noted that the UN Convention on the Rights of Persons with Disabilities ("CRPD") provides that when States Parties establish the framework referred to in Article 33(2)³, including one or more independent mechanisms to promote and protect the rights of persons with disabilities and monitor the implementation of the CRPD in the national context, they should take the "Paris Principles" into account. NHRIs may be designated as the independent mechanism thereof and several members of the European Group have been so designated⁴. In the context of the Council of Europe, twenty eight (28) countries have ratified the CRPD. In particular, the respondent to these proceedings ratified the CRPD in February 2010.

Brief case related information

4. The proceedings before the Court concern five women with intellectual disabilities, each under guardianship, and who, it is claimed, underwent a process of ligation or removal of fallopian tubes without their informed consent. It is also claimed that such intervention was systematically used as a method of contraception by the centre providing them with work. An attempt by an advocacy group, *Association de défense des handicapés de l'Yonne (*Association of the Defence of the Handicapped of Yonne - "ADHY"), to bring proceedings on behalf of the women at domestic level was unsuccessful. The purpose of this submission is not to discuss whether tubal ligation (as opposed to removal) amounts to an irreversible sterilisation, but rather the implications of any such medical procedure in the light of international human rights standards.

- 5. Applicable French legislation in this matter can be found in two different codes. Article 16-3 of the French Civil Code provides that "The consent of the person concerned must be obtained previously except when his state necessitates a therapeutic intervention to which he is not able to assent". Therefore, a medical practitioner can act without consent only for therapeutic reasons and only where necessary. However, Article L.2123-2 of the French Public Health Code provides for the possibility of carrying out a tubal ligation on women with mental disability without their consent under specific conditions and following a special procedure⁵.
- 6. It is alleged that the treatment of the women in this case is in violation of Articles 3 (Prohibition of torture), 6 (Right to a fair trial), 8 (Right to respect for private and family life), 12 (Right to marry) and 14 (Prohibition of discrimination) of the ECHR. In relation to Article 3 it is claimed that there was an infringement of the women's physical integrity in that they were subjected to a medical procedure without the requirement for their consent and that same constitutes inhuman and degrading treatment. Pursuant to Article 8, it is claimed that the women's right to respect for their private lives has been breached, and in addition pursuant to Article 12, that their right to marry has also been impaired. In relation to Article 6 it is claimed that their right of access to the courts was denied in that they were not represented by a specially appointed guardian and that ADHY was deemed not to have standing to act on their behalf. It is also stated that the domestic proceedings and the refusal of their appeal was unfair. Finally, they allege a violation of Article 14 of the Convention in conjunction with Articles 3, 8 and 12, citing the discrimination they have suffered as the result of their disability. Subject to admissibility and findings of fact the case thus raises issues of fundamental importance concerning legal capacity and human rights.
- 7. In *Glor v. Switzerland*⁶, this Court noted that the provisions of the ECHR fell to be considered, *inter alia*, in light of European and international norms, noting both a 2003 Council of Europe Parliamentary Assembly Recommendation and the CRPD as evidence of the prohibition of discrimination on the grounds of disability⁷. This submission will address relevant European and international norms as they impact on the current application.

The concept of legal capacity

- 8. The concept of legal capacity has been significantly developed under Article 12 of the CRPD and may be regarded as one of the cornerstones of that Convention.
- 9. It is essential to bear in mind that recognition of legal capacity is fundamental to human 'personhood' and freedom. It protects the dignity of persons as well as their autonomy; their ability to act, have legal recognition of their decisions on an equal basis with others, in other words, take charge of their own lives. These decisions span "all aspects of life" in both the private and public sphere such as the development of personal relationships, medical treatment, finance and asset management, the right to vote and be elected etc. The main obstacle to understanding disability rights generally and intellectual disability rights specifically is the all-too-easy assumption that disability simply equates with a lack of capacity. This assumption is then used to restrict the legal

capacity of persons with a disability, potentially in a discriminatory way. In large part this assumption rests on stereotypes and exaggerates the effects of disability. That is, it fails to see the person behind the disability and fails to treat the person as a rights-bearing "subject", rather than an "object" to be managed and cared for. Recognition of legal capacity under Article 12 of the CRPD may thus be viewed as a gateway to realising the dignity inherent in persons with intellectual disability which goes hand in hand with the principle of free and informed consent (see further below).

- 10. According to the CRPD, legal capacity entails the right to "recognition everywhere" as persons before the law (Article 12.1 CRPD) and it extends the right to be recognised before the law "on an equal basis with others" in "all aspects of life" (Article 12.2 CRPD). The entire thrust of Article 12 is a paradigm shift away from the negation or restriction of the legal capacity of persons with disabilities, towards the functional approach, where every person is assumed to have capacity irrespective of having a disability, whilst also recognising that the person may need "support" to exercise that legal capacity and that specific safeguards must be established, particularly where "supported decision making" occurs (Article 12.4 CRPD). 8
- 11. While there may be discussion as to whether Article 12 CRPD leaves any room for substituted decision-making on behalf of a person with a disability, and it is strongly arguable that it does not, it is clear from the analysis of various human rights standards below that there are a number of decisions which are so fundamental to the person that they are protected by human rights law in absolute terms. Any form of substituted decision-making, by which third persons (such as custodians), institutions (such as courts) or a combination of both replace or overrule the will of the person concerned or substitute the absence of free and informed consent in such decisions, is absolutely prohibited by the CRPD and may not be subject to any restriction.
- 12. The European Group of NHRIs respectfully submits that this is the case with sterilisation of a man or a woman who has not given free and informed consent, or objects to the procedure.

The principle of free and informed consent

- 13. Issues of medical treatment engage both Articles 3 (Prohibition of torture) and 8 (Right to respect for private and family life) and the issue of consent is an important component in this regard.
- 14. In principle, free and informed consent is a precondition to any medical intervention. The 1994 World Health Organization Amsterdam Declaration on Patients' Rights requires informed consent as a prerequisite for any medical intervention, guaranteeing also the right to refuse or halt medical interventions⁹. Most importantly, the European Convention on Human Rights and Biomedicine, which entered into force in 1999, states that "An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it 10. It should be noted that France has not ratified this Convention, even though French legislation contains clear

- provisions on the obligation to obtain consent before any medical intervention (see above paragraph 5).
- 15. Further, the obligation to obtain free and informed consent is enshrined in the Charter of Fundamental Rights of the European Union. Article 3 provides that "Everyone has the right to respect for his or her physical and mental integrity. In the fields of medicine and biology, the following must be respected in particular: the free and informed consent of the person concerned, according to the procedures laid down by law". 11
- 16. The UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health ("UN Special Rapporteur on the right to health") has given a purposive interpretation to consent stating that "informed consent in health [...] is an integral part of respecting, protecting and fulfilling the enjoyment of the right to health" 12.
- 17. The general principle of free and informed consent and its strict application takes on particular importance in cases of sterilisation. The UN Special Rapporteur on the right to health considers that "While consent for simple procedures may sometimes be implied by a patient, more complex, invasive treatments require explicit consent 13. Tubal ligation is clearly an invasive procedure, and has considerable consequences for the private and intimate life of the person concerned, directly affecting the right of a girl or a woman to birth control and to decide on matters related to sexuality and reproductive health, all intimate matters concerning the dignity and personality of the individual. The new Council of Europe Convention on preventing and combating violence against women and domestic violence, which has not yet entered into force, requires State Parties to take the necessary measures to ensure that "performing surgery which has the purpose or effect of terminating a woman's capacity to naturally reproduce without her prior and informed consent or understanding of the procedure" is criminalised. In its General Recommendation No.24, the Committee on the Elimination of Discrimination against Women (CEDAW Committee) confirms that "States Parties should not permit coercion, such as non-consensual sterilisation, [...] that violate women's rights to informed consent and dignity" 15.
- 18. In addition, the obligation on a medical practitioner to seek free and informed consent must be combined with the right of the patient to receive adequate information about his or her medical state and the medical treatment proposed 16. General Recommendation No.21 of the CEDAW Committee indicates that "Some reports disclose coercive practices which have serious consequences for women, such as forced pregnancies, abortions or sterilisation. [...] In order to make an informed decision about safe and reliable contraceptive measures, women must have information about contraceptive measures and their use, and guaranteed access to sex education and family planning services, as provided in article 10 (h) of the Convention. The same Committee found in a communication concerning the sterilisation of a woman of Roma origin that "the author has a right protected by article 10 (h) of the Convention to specific information on sterilisation and alternative procedures for family planning in order to guard against such an intervention being carried out without her having made a fully informed choice" 18.

- 19. While the application of the general principle of free and informed consent may be difficult to ensure in certain situations, for example in cases of urgency where the person concerned is unconscious, in which circumstance there may be justification for dispensing with consent, it should nonetheless be clearly underlined that this principle applies to persons with disabilities in the same terms as for a person without a disability and that the difficulty of overcoming practical barriers in securing free and informed consent cannot justify a law or practice that substitutes for the free and informed consent of the person concerned.
- 20. The CRPD clearly states that one of the principles on which it is based is "Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons" (Article 3). Article 12 of this Convention provides that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" and that "States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity". Further, according to Article 25(1)(d), "health professionals [must be required] to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care" (emphasis added).
- 21. In a recent document, the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment ("UN Special Rapporteur on torture") confirms that "Article 25 recognizes that medical care of persons with disabilities must be based on their free and informed consent". He further states that "Thus, in the case of earlier non-binding standards, such as the 1991 Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (resolution 46/119), known as the MI Principles, the Special Rapporteur notes that the acceptance of involuntary treatment and involuntary confinement runs counter to the provisions of the Convention on the Rights of Persons with Disabilities" Similarly, the UN Special Rapporteur on the right to health affirms that the CRPD obliges States to "provide persons with disabilities equal recognition of legal capacity, care on the basis of informed consent, and protection against non-consensual experimentation; as well as prohibit exploitation and respect physical and mental integrity"²⁰ (emphasis added). This is discussed further below.
- 22. The MI Principles set out detailed standards for ensuring a patient's informed consent after appropriate disclosure to the patient of adequate information in a form and language understood by the patient on:
 - a) The diagnostic assessment;
 - b) The purpose, method, likely duration and expected benefit of the proposed treatment:
 - c) Alternative modes of treatment, including those less intrusive; and
 - d) Possible pain or discomfort, risks and side-effects of the proposed treatment²¹.
- 23. Medical practitioners must ensure that consent is free from coercion from family members or other interested parties and that the presentation of health information is adapted to the specific needs of the patient in order to facilitate informed consent.

Information needs to be accessible and understandable and not merely imparted in a universal manner. This is critical in relation to persons with intellectual disabilities. Therefore it is essential that appropriate safeguards are in place to support free and informed consent and to protect the right to be involved in one's own medical decision making²².

24. Accordingly, if free and informed consent of the person concerned cannot be obtained, the sterilisation may not be carried out. It should be recalled that lack of consent may be due to the determination that the person is found not to be legally capable under national law.

The prohibition of torture and ill treatment

- 25. The existence of a disability is sometimes determinative in assessing whether certain treatment is prohibited under Article 3: *Price v. The United Kingdom*²³. The UN Special Rapporteur on torture has linked medical treatment of persons with disabilities with torture or ill-treatment where the treatment is "of an intrusive and irreversible nature, when they lack a therapeutic purpose, or aim at correcting or alleviating a disability". Torture or ill-treatment will occur where the medical treatment is "enforced or administered without the free and informed consent of the person concerned"²⁴.
- 26. Sterilisation or tubal ligation are medical procedures of an intrusive and/or irreversible nature. Regardless of whether the motivation for such a medical procedure is benign, it will constitute torture or ill-treatment of a person with a disability unless the free and informed consent of the person is given. This is made clear by the Human Rights Committee in its General Comment No.28 where it states that the sterilisation of women without their consent is a breach of the prohibition of torture and ill-treatment guaranteed under Article 7 of the International Covenant on Civil and Political Rights ("ICCPR")²⁵.
- 27. The UN Special Rapporteur on torture has expressed concern that "intrusive and irreversible medical treatments without their consent (e.g. sterilisation, abortion and interventions aiming to correct or alleviate a disability, such as electroshock treatment and mind-altering drugs including neuroleptics) when perpetrated against persons with disabilities, remain invisible or are being justified, and are not recognized as torture, inhuman or degrading treatment" 16. The Special Rapporteur also recognises that "Innumerable adults and children with disabilities have been forcibly sterilized as a result of policies and legislation enacted for that purpose. [I Persons with disabilities, and particularly women and girls, continue to be subjected to forced abortion and sterilisation without their free and informed consent inside and outside institutions", stating also that under Article 23(c) of the 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 (art. 23 (b))" 27.
- 28. The absolute prohibition of torture set out in Article 3 of the ECHR is replicated in numerous universal and regional conventions. At the universal level, the prohibition is found in Articles 1 and 3 of the Convention against Torture and Other Cruel, Inhuman or

Degrading Treatment or Punishment ("CAT"), Article 7 of the ICCPR, Article 37 of the Convention on the Rights of the Child and Article 10 of the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families. This is reaffirmed in Article 15.1 the CRPD²⁸ which states "*No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation*".

- 29. The significance of Article 15.1 of the CRPD is that it amplifies the traditional prohibition of torture and cruel, inhuman or degrading ill-treatment concerning persons with disabilities by "providing further authoritative guidance"²⁹. The principles of respect for individual autonomy (Article 3 CRPD), the equal right to enjoy legal capacity in all areas of life "such as deciding where to live and whether to accept medical treatment" (Article 12 CRPD) and that medical care of persons with disabilities be based on their free and informed consent (Article 25 CRPD), thus reinforce and inform the prohibition of torture and ill-treatment against persons with disabilities. Article 15.1 also includes the prohibition of medical or scientific experimentation against persons with disabilities, while importing the concept of one's free consent as a constituent element of the right.
- 30. Article 15.2 of the CRPD requires State Parties to take positive effective measures (whether legislative, administrative, judicial or other) to protect persons with disabilities from torture or ill-treatment on an equal basis with others. Otherwise stated, this requires State Parties to "regulate" through all possible measures the treatment of persons with disabilities so that they are not only protected from torture or ill-treatment but also protected on an equal basis with others. These are self-reinforcing concepts which provide a practical means by which States can effectively prevent torture or ill-treatment of persons with disabilities.
- 31. This is reinforced further by General Comment No. 2 of the UN Committee against Torture which clarifies that State responsibility is engaged where acts or omissions are carried out by non-State actors: "Since the failure of the State to exercise due diligence to intervene to stop, sanction and provide remedies to victims of torture facilitates and enables non-State actors to commit acts impermissible under the Convention with impunity, the State's indifference or inaction provides a form of encouragement and/or de facto permission³⁰. The Committee also states that "Additionally, if a person is to be transferred or sent to the custody or control of an individual or institution known to have engaged in torture or ill-treatment, or has not implemented adequate safeguards, the State is responsible, and its officials subject to punishment for ordering, permitting or participating in this transfer contrary to the State's obligation to take effective measures to prevent torture in accordance with article 2, paragraph 1. The Committee has expressed its concern when States Parties send persons to such places without due process of law as required by articles 2 and 3^{r31}. Citing General Comment 2 of the Committee against Torture, the UN Special Rapporteur on torture has stated that the prohibition of torture "may apply to doctors, health professionals and social workers, including those working in private hospitals, other institutions and detention centres,"32. Hence States must "exercise due diligence to prevent, investigate, prosecute and punish such non-State officials or private actors"33.

- 32. Article 2 of the CRPD prohibits disability-based discrimination and employs a similar definition of discrimination as found in other UN conventions: "Discrimination on the basis of disability means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination including denial of reasonable accommodation³⁴. General Comment No. 2 of the UN Committee against Torture clarifies that discriminatory treatment of girls or women with disabilities in "*medical treatment, particularly involving reproductive decisions*" is prohibited under that Convention³⁵. This suggests that in considering the medical treatment of persons with disabilities (particularly those with an intellectual disability) in circumstances where the said medical treatment may result in a person's sterilisation, the question arises as to whether the person is treated on an equal basis to a person without the disability. Where the effect of unequal treatment is significant, such as resulting in one of the four types of intervention listed by the Special Rapporteur³⁶, namely; a) abortion and sterilisation; b) electroconvulsive therapy; c) forced psychiatric interventions or d) involuntary commitment to psychiatric institutions, the treatment may amount to not alone prohibited discrimination under the CRPD, but also to torture or prohibited ill-treatment under the CAT and/ or the CPRD.
- 33. Thus, the Special Rapporteur on torture has stated that the requirement of intent present in Article 1 of the CAT (but not under Article 3 of the ECHR) can be effectively implied where a person has been discriminated against on the basis of disability³⁷. This is stated to be particularly relevant to the medical treatment of persons with disabilities "where serious violations and discrimination against persons with disabilities may be masked as "good intentions" on the part of health professionals." This is further reinforced by the joint statement of a number of UN committees on disability, that not only may "no exceptional circumstances ... be invoked for [the] justification of torture, and States have the obligations to prevent torture and other cruel, inhuman or degrading treatment or punishment, including of persons with disabilities", stressing also that "Forms of severe violence perpetrated by State or private actors directed at disabled persons can amount to torture since, if their purpose is discriminatory, they fall within the definition of torture in the Convention against Torture"
- 34. From the foregoing, it is clear that: a) even if an intrusive medical procedure is intended to be benign, it will constitute torture or ill-treatment of a person with a disability unless the free and informed consent of the person is given; b) the equal right of a person with an intellectual disability to enjoy legal capacity in all areas of life includes whether to accept medical treatment and c) there is no justification available to States in defending an allegation of torture or ill-treatment in those cases where the person has been subjected to a procedure of sterilisation and in this regard has been discriminated against on the basis of his or her disability.

The right to respect for private and family life

- 35. Sterilisation, in addition to the inherent violence of the intervention when practised without consent, has the potential of having considerable consequences for the private and intimate life of the person concerned.
- 36. The Convention on the Elimination of Discrimination Against Women ("CEDAW") requires "States Parties [to] take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular shall ensure, on a basis of equality of men and women: [...] (e) The same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.*
- 37. This right is replicated for persons with disabilities in the CRPD according to which: "States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that: (a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized; (b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided" 1.
- 38. Women with disabilities have the right to respect for private life, including matters related to family and children, without discrimination compared to other women. The Committee on Economic, Social and Cultural Rights⁴² confirms this by stating that: "Article 10 of the Covenant [on economic, social and cultural rights] (protection of family, mothers and children) implies, subject to the general principles of international human rights law, the right of persons with disabilities to marry and have their own family. These rights are frequently ignored or denied, especially in the case of persons with mental disabilities. In this and other contexts the term "family" should be interpreted broadly and in accordance with appropriate local usage. States Parties should ensure that laws and social policies and practices do not impede the realization of these rights". Further, "Women with disabilities also have the right to protection and support in relation to motherhood and pregnancy. [...] Both the sterilisation of, and the performance of an abortion on, a woman with disabilities without her prior informed consent are serious violations of article 10 (2)"⁴³.
- 39. Therefore, because of the impossibility to exercise their "right to decide freely and responsibly on the number and spacing of their children", persons (with disabilities) sterilised without prior consent, in addition to being subjected to torture and ill-treatment may also correctly view their right to respect for private and family life as being significantly interfered with.

The right of access to justice

- 40. Article 12 of the CRPD is also relevant to the right of access to the Courts under Article 6 of the ECHR. In principle under Article 12 a person with an intellectual disability must be presumed to have legal capacity, which entails having a right on the same basis as others to initiate proceedings in court in order to vindicate their fundamental rights. Article 12 is informed by Article 13 of the CRPD which provides that "States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations".
- 41. Thus, even if it has been properly determined, following an independent judicial process, that a person lacks decision making capacity according to national law, this should not deprive them of legal capacity to act in legal proceedings. Such a person should still have the right to bring legal proceedings to challenge any decision made that impacts on their health and welfare (such as sterilisation), albeit that this may necessitate adapting the legal proceedings and providing support in accordance with Article 12.3 to ensure that there is effective participation and representation of the person in the proceedings.

The prohibition of discrimination

- 42. As noted at paragraph 32 above, Article 2 of the CRPD prohibits disability-based discrimination and employs a similar definition of discrimination as that found in other UN conventions.
- 43. Article 1 of CEDAW defines discrimination against women as "any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field"⁴⁴.
- 44. In its General Comment No.18 on non-discrimination ⁴⁵, the Human Rights Committee employs a similar formulation as that set out in the Convention on the Elimination of all forms of Racial Discrimination ("CERD") and CEDAW. At paragraph 7 it defines discrimination as "... any distinction, exclusion, restriction or preference which is based on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, and which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedom.". It clarifies the scope of "discrimination" under Articles 2(1) and 26 of the ICCPR as pertaining to discrimination in law or in fact in any field regulated and protected by public authorities ⁴⁶. As with Article 14 of the ECHR, both direct and indirect discrimination is prohibited.
- 45. Article 3 of the International Covenant on Economic, Social and Cultural Rights ("ICESCR") provides for the equal rights of men and women. The Committee on Economic, Social and Cultural Rights in its General Comment No.20 expands on the interpretation of the general non-discrimination provision of Article 2(2) of the ICESCR

and includes: "... any distinction, exclusion, restriction or preference or other differential treatment that is directly or indirectly based on the prohibited grounds of discrimination and which has the intention or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of Covenant rights" Indirect discrimination is thus explicitly prohibited. Addressing disability, the Committee in its General Comment No.20 recalls that "In its general comment No.5, the Committee defined discrimination against persons with disabilities[] as "any distinction, exclusion, restriction or preference, or denial of reasonable accommodation based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights" General Comment No.5 affirms that "States [must] ... ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care as other members of society" All such services should be provided in such a manner as to "maintain full respect for their rights and dignity".

- 46. In relation to the right to health, enunciated in Article 12 of the ICESCR, this right is thus guaranteed to everyone, without discrimination on the basis of the person's status. In General Comment No.14 on the right to health, the same Committee "stresses the need to ensure that not only the public health sector but also private providers of health services and facilities comply with the principle of non-discrimination in relation to persons with disabilities" ⁵¹. Under specific legal obligations in paragraph 34 of General Comment No.14, the Committee states that "obligations to respect include a State's obligation to refrain from ... applying coercive medical treatments, unless on an exceptional basis for the treatment of mental illness or the prevention and control of communicable diseases. Such exceptional cases should be subject to specific and restrictive conditions, respecting best practices and applicable international standards, including the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care [MI Principles]. In addition, States should refrain from limiting access to contraceptives and other means of maintaining sexual and reproductive health..."52.
- 47. At the Council of Europe level, in its (2006)5 Recommendation, the Committee of Ministers recommended that the following specific actions be undertaken by member states: "i. To ensure that no disabled people are discriminated against in access to health care services and medical records...... iv. to ensure that women with disabilities have equal access to health care services, including in particular, ante-natal, gynecological and family planning advice and treatment; v. to ensure that gender specific aspects are respected in health care for disabled people; vi. to ensure that reasonable steps are taken to provide all relevant information regarding an individual's health care needs or services in a format understandable to the disabled person... ⁵³.
- 48. In *Glor v. Switzerland*⁵⁴, this Court found a violation on the basis of the Applicant's disability under Article 14 when read in conjunction with Article 8. As noted at paragraph 7 above, the Court stated that the Convention's provisions fell to be considered, *inter alia*, in light of European and universal norms, noting the international evidence of the prohibition of discrimination on the grounds of disability⁵⁵. The present submission fully endorses this approach.

11

49. Of importance here in considering the test to be applied under Article 14, is that disability was added by the Court as a suspect ground of discrimination in addition to previous formulations of sex and race and therefore attracts heightened scrutiny when considering the obligations of the State and how they were discharged to determine if discrimination occurred⁵⁶.

Conclusion

- 50. This submission considered the application of international human rights standards to the issues raised in this case and how such standards have been synthesised within the CRPD. In particular it is respectfully submitted that the recognition of the legal capacity of persons with disabilities, everywhere, and in relation to all aspects of life on an equal basis of others, as enshrined in Article 12 of the CRPD, is the normative standard which should inform this Court in determining whether there has been a breach of the rights invoked in the present case. It has been submitted by reference to the relevant international instruments and authoritative interpretations of same that sterilisation by whatever process without free and informed consent is never permissible and will constitute a breach of the right to be free from torture, the right to health, the right to respect for private and family life and the right not to be discriminated against in all circumstances.
- 51. If the Court is called on to determine in the present case whether there was, or was not, free and informed consent, it is again respectfully submitted that Article 12 CRPD provides a useful framework within which the question may be examined and addressed. Questions that may usefully be asked in this context are; whether there are circumstances under national law where the legal capacity of persons with disabilities may be restricted; if persons with disabilities have the same formal legal capacity on an equal basis with others under national law and what support structures are in place to ensure they can exercise their legal capacity effectively. In addition, Article 12.4 of the CRPD sets out a menu of safeguards that must be in place to ensure any system of supported decision making respects the person's right to recognition of their legal capacity.
- 52. Finally, Article 13 of the CRPD may be considered to be a discrete aspect of the right to equal recognition before the law under Article 12, insofar as it deals with the specific right of access to justice and how this right must be realised in practice. Again specific questions may be asked pursuant to Article 13 in relation to whether the applicants in the present case have been effectively refused access to justice, which in turn may inform an assessment of whether a breach of Article 6 alone or in conjunction with Article 14 ECHR has occurred.
- 53. The present case provides this Court with an opportunity to embed the human rights of persons with disabilities, as understood at an international level and respectfully set out in this submission, within the system for human rights protection elaborated under the ECHR.

12

1 A NHDL is a State sponso

² National institutions for the promotion and protection of human rights, UN General Assembly Resolution 48/134, 1993.

⁴ For example of the German Institute for Human Rights, the Danish Institute for Human Rights, the UK Equality and Human Rights Commission, the Scottish Human Rights Commission and the Northern Irish Human Rights Commission, have been so designated.

⁵ Article L.2123-2 states that: "Ligating tubes or vas deferens for contraceptive purposes can not be performed on a minor. It can be performed on an adult whose altered mental status constitutes a disability and justifies its placement under supervision or guardianship <u>only when</u> there is an absolute medical indication against the methods of contraception or a proven inability to implement them effectively.

The operation is subject to a decision of the guardianship judge called for by the individual, the parents or legal guardian of the person concerned.

The judge decides after hearing the person concerned. <u>If the person is able to express his will</u>, his consent must be systematically sought and taken into account after he was given information appropriate to his level of understanding. Refusal or revocation of consent can not be ignored.

The judge hears the parents of the person concerned or his legal representative and any person whose views are deemed useful.

The judge collects the opinion of an expert committee of qualified people in the medical and representatives of disability organizations. The committee appreciates the medical justification for the procedure, its risks and its reasonably foreseeable consequences on the physical and psychological (Informal translation).

⁶ Glor v. Switzerland (App. 13444/04), Judgment 30 April 2009.

¹ A NHRI is a State-sponsored and State-funded organisation, with a constitutional or legal basis, with authority to promote and protect human rights at the national level as an independent agency.

³ Article 33 of the UN Convention on the Rights of Persons with Disabilities which concerns national implementation and monitoring states: "2. States Parties shall, in accordance with their legal and administrative systems, 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 the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights".

⁷ *Ibid.* at para. 53.

⁸ Article 12.3 of the CRPD creates particular State obligations in respect of supported decision making.

⁹ICP/HLE 121 (1994), Article 3.

¹⁰ Article 5 of the 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, Oviedo, 4.IV.1997.

¹¹ Article 3 of the Charter of Fundamental Rights of the European Union (2000/C 364/01)

¹²Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, August 10, 2009, A/64/272, at para. 18.

¹³ Ibid. at para. 13.

¹⁴ Council of Europe Convention on preventing and combating violence against women and domestic violence, Istanbul, 11.V.2011, Article 39.

¹⁵ CEDAW Committee, General Recommendation No. 24, *Article 12: Women and health*, (20th session, 1999) at para. 22. The CEDAW Committee is the supervisory body charged with monitoring

State compliance with the Convention on the Elimination of Discrimination against Women under Part V of that Convention.

- 16 Article 5 of the Convention on human rights and biomedicine. The ECtHR noted in K.H. V Slovakia. Judgment of 28 April 2009, a case concerning "effective access to information concerning [the applicants] health and reproductive status" (at para. 44) that "...protection of medical data is of fundamental importance to a person's enjoyment of his or her right to respect for private and family life as guaranteed by Article 8..." (at para. 55). In addition to a breach of Article 8, the Court also found a breach of Article 6 insofar as the Applicants were limited in their ability to bring a civil claim in relation to alleged forced sterilisation.
- ¹⁷ CEDAW Committee, General Recommendation No. 21, *Equality in marriage and family relations*,
- (13th session, 1994) at para. 22.

 18 Decision of the CEDAW Committee in the case of *Andrea Szijarto v Hungary* (Communication No. 4/2004), UN Doc. CEDAW/C/36/D/4/2004. See also Judgment of European Court of Human Rights in K.H. V Slovakia, op. cit.
- ¹⁹Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/63/175, July 28, 2008, at para. 44.
- ²⁰Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, August 10, 2009, A/64/272, at para. 72.
- ²¹ United Nations General Assembly Resolution, *The protection of persons with mental illness and* the improvement of mental health care, 17 December 1991, A/RES/46/119 at Principle 11(2).
- ²²Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, August 10, 2009, A/64/272, at para. 44.
- ²³ *Price v. United Kingdom* (App. 33394/96), Judgment of 10 July 2001; (2002) 34 EHHR 1285 at
- para. 24. ²⁴ Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/63/175, July 28, 2008, at para. 47.
- ²⁵ Human Rights Committee, General Comment No.28, The *equality of rights between men and* women (article 3) (29 March 2000), CCPR/C/21/Rev.1/Add.10 at para. 11.
- ²⁶Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/63/175, July 28, 2008, at paras. 40 to 41.
- ²⁷ Ibid. at para. 60. The Special Rapporteur on torture also cites the report of the Special Rapporteur on the right to the highest attainable standard of physical and mental health (E/CN.4/2005/51) at para. 12. ²⁸ This follows on from The Standard Rules on the Equalization of Opportunities for Person with
- Disabilities 1993 (adopted by UN General Assembly, 48th session, resolution 48/96, annex of 20 December 1993).
- ²⁹Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/63/175, July 28, 2008, at para. 44.
- ³⁰ Committee Against Torture, General Comment No. 2, Implementation of Article 2 By States Parties, Cat/C/Gc/2, 24 January 2008, at para. 18.
- ³¹ *Ibid.* at para. 19. Thus for example, any legal process such as guardianship of a person with an intellectual disability, which involves the transfer of the person concerned, who lacks legal capacity, to the care or control of an individual or institution will engage State responsibility.
- ³² Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/63/175, July 28, 2008, at para. 51. 33 Ibid.
- ³⁴ Article 2 of the CRPD defines "reasonable accommodation" as "...necessary and appropriate modification or 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".

³⁷*Ibid.* at para. 49.

⁴⁰ Article 16 of CEDAW.

⁴³ Committee on Economic, Social and Cultural Rights, General Comment No. 5, *Persons with Disabilities* (11th session, 1994) at paras. 30 to 32.

⁴⁴ Article 2 of CEDAW prohibits discrimination against women. See also Article 1 of the Convention on the Elimination of All Forms of Racial Discrimination (CERD).

⁴⁵ Human Rights Committee, General Comment No. 18, Non-discrimination (37th session, 1989).

⁴⁶ In addition, Article 3 of the ICCPR provides for the equal rights of men and women.

⁴⁷ Committee on Economic, Social and Cultural Rights General Comment No. 20, *Non-Discrimination in Economic, Social and Cultural Rights (Art. 2, para. 2)*, E/C.12/GC/20, 10 June 2009, (42nd session, 2009) at para. 7.

⁴⁸ Committee on Economic, Social and Cultural Rights, General Comment No. 5, *Persons with disabilities* (11th session, 1994), U.N. Doc E/1995/22, at para. 15. General Comment No. 20 gives the definition outlined in Article 1 of the CRPD: "Persons with disabilities include, but are not limited to individuals with "long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". This definition is similar to that found in other international conventions.

49 *Ibid*. at para. 34.

³⁵Committee Against Torture, General Comment No. 2, *Implementation Of Article 2 By States Parties*, Cat Cat/C/Gc/2, 24 January 2008, at paras. 20 to 22.

³⁶ Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/63/175, July 28, 2008, at paras. 60 to 65.

³⁸ *Ibid*.

³⁹ Joint Statement by the United Nations Committee against Torture, the Subcommittee on Prevention of Torture, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, the Committee on the Rights of Persons with Disabilities and the Board of Trustees of the United Nations Voluntary Fund for Victims of Torture, Geneva, 25 June 2009.

⁴¹ Article 23(1) (c) of the CRPD.

⁴² The Committee is the supervisory body charged with monitoring the implementation of the International Covenant on Economic, Social and Cultural Rights ("ICESCR") by virtue of Resolution 1985/17 of 28 May 1985 of the United Nations Economic and Social Council.

⁵⁰ *Ibid*.

⁵¹ *Ibid* at para. 26.

⁵² *Op. cit.*at para. 19.

⁵³ Recommendation Rec(2006)5 of the Committee of Ministers to member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015(Adopted by the Committee of Ministers on 5 April 2006 at the 961st meeting of the Ministers' Deputies), para.3.9.3.

⁵⁴ *Glor v. Switzerland (App. 13444/04)*, Judgment 30 April 2009.

⁵⁵ *Op. cit*.at para 54.

⁵⁶ See for example *Willis v United Kingdom* (2002) 35 EHRR 547, *Timishev v. Russia,* Judgment 13 December 2005 and the Judgment of the Grand Chamber in *DH v. The Czech Republic* (2006) 43 EHRR 923.