

United Nations Committee on the Rights of Persons with Disabilities

Written submission on the Draft General Comment No. 6 on the right of persons with disabilities to equality and non-discrimination (article 5)

French version available here: https://eclj.org/eugenics/un/written-submission-on-the-draft-general-comment-no-6-on-the-right-of-persons-with-disabilities-to-equality-and-non-discrimination-article-5?lng=fr

November 30, 2017

The European Centre for Law and Justice (ECLJ) wishes to express its comments and amendment propositions to the Draft General Comment No. 6 ("the Draft") written by the Committee on the Rights of Persons with Disabilities ("the Committee") of the United Nations on the interpretation of Article 5 of the Convention on the Rights of Persons with Disabilities ("the Convention") regarding equality and non-discrimination.

The European Centre for Law and Justice is an international, Non-Governmental Organization dedicated to the promotion and protection of human rights in Europe and worldwide. The ECLJ holds special Consultative Status before the United Nations/ECOSOC since 2007.

The ECLJ engages legal, legislative, and cultural issues by implementing an effective strategy of advocacy, education, and litigation. The ECLJ advocates in particular the protection of religious freedoms and the dignity of the person with the European Court of Human Rights and other mechanisms afforded by the United Nations, the Council of Europe, the European Parliament, the Organization for Security and Cooperation in Europe (OSCE), and others.

The ECLJ bases its action on "the spiritual and moral values which are the common heritage of European peoples and the true source of individual freedom, political liberty and the rule of law, principles which form the basis of all genuine democracy" (Preamble of the Statute of the Council of Europe).

Grégor Puppinck Director General Priscille Kulczyk Anouck Barba Associate The ECLJ particularly draws the Committee's attention on the necessity to guarantee every human being, without discrimination based on handicap, an equal right to life (I), the latter being "a fundamental right, whose effective protection is the prerequisite for the enjoyment of all other human rights". ¹ It insists on the necessity to prevent any discriminatory infringement to the rights of disabled persons (II) and to promote a change of view on handicap within societies (III). Finally, recommendations will be proposed, based on these observations.

I. Guaranteeing every human being an equal right to life, without discrimination on the ground of disability

The need to link non-discrimination and the right to life of disabled persons

The ECLJ commends the relationship established in the Project (**Part VII**) of equality and non-discrimination (art. 5) with other rights provided by the Convention in its articles 6, 7, 8, 9, 11, 12, 13, 14, 19, 24, 27, 29 and 31. However, it regrets that the current Project does not refer to the right to life of disabled persons, even though it is affirmed in article 10 of the Convention: "States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others." It is not unusual for disabled human beings to be discriminated against in the enjoyment of this right, before as well as after birth.

Protecting disabled persons from discriminatory violations to the right to life before birth

In many countries, unborn children are subject to discriminatory treatment, because the protection of their right to life varies with their health condition. On the one hand, in many legislations, disability is a ground opening to abortion: a lot of unborn children with disabilities, even not serious, not life threatening or even treatable,² are thus eliminated. On the other hand, unborn children with proven or even only alleged disabilities can be aborted for a longer time period than healthy unborn children, sometimes until birth.³ In France, for example, therapeutic abortion (IMG) is allowed until birth,⁴ whereas voluntary termination of pregnancy (IVG) can be done until 12 weeks of pregnancy.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/652083/Abortion_stat_s_England_Wales_2016.pdf

¹ Human Rights Committee, General comment No. 36 on article 6 of the International Covenant on Civil and Political Rights, on the right to life, version of July 2017:

 $[\]underline{http://www.ohchr.org/Documents/HRBodies/CCPR/GCArticle6/GCArticle6_EN.pdf}$

² In France, 90% of foetuses screened having Down Syndrome are aborted, some statistics indicating a rate of more than 95%: see B. Giudicelli, "Les interruptions de grossesse après 23 semaines", *Réalités en Gynécologie-Obstétrique, Performances médicales*, n° 167, January-February 2013 ; Comité Consultatif National d'Éthique pour les Sciences de la Vie et de la Santé, *Avis n° 107, Avis sur les problèmes éthiques liés aux diagnostics anténatals : le diagnostic prénatal (DPN) et le diagnostic préimplantatoire (DPI),* 15 October 2009, p. 12 et 13 ; Laurence Henry, « *On ne peut imposer ça à personne »*, Collection Carte Blanche, Salvator, 2013, p. 97. In England and Wales in 2016, cleft lip or cleft palate was the main reason for 9 abortions and 706 abortions were mainly motivated by Down Syndrome: see *Abortion statistics, England and Wales 2016*, p. 15, 16, 36 :

³ See G. Puppinck (dir.), *Droit et prévention de l'avortement en Europe*, LEH, 2016, p. 95-96.

⁴ French Public Health Code, article L-2213-1, § 1.

This discrimination on the ground of health conditions of unborn children, depending on a proven or alleged disability, strongly opposes article 5 of the Convention, as the Committee rightly recalled in its recent Comments in the Draft. The ECLJ reminds of its terms which it fully supports: "Laws which explicitly allow for abortion on grounds of impairment violate the Convention on the Rights of Persons with Disabilities (Art. 4, 5, 8). Even if the condition is considered fatal, there is still a decision made on the basis of impairment. Often it cannot be said if an impairment is fatal. Experience shows that assessments on impairment conditions are often false. Even if it is not false, the assessment perpetuates notions of stereotyping disability as incompatible with a good life." It is thus important to include it similarly in **Part VII** of this General Comment by dealing with discrimination in conjunction with the right to life, i.e. by linking articles 5 and 10 of the Convention.

This is even more essential as the Committee condemns, in **Paragraph 44** of the Draft, disability-selective antenatal screening policies which are the corollary and prerequisite for abortion of foetuses with proven or alleged disability. The Committee timely highlights that antenatal screening policies "go against the recognition of the equal worth of every person": the unborn child is thus recognised as a person. As the Committee notes, these policies maintain the stigmatization of disabled persons who are thus discriminated against in their right to life and their dignity is violated. This antenatal discrimination is build on the assumption that a disabled child would never be desired by nature and should be systematically aborted. Jean-Marie Le Méné, President of the Fondation Jérôme Lejeune, explains that these policies are based on "the technical feasibility, the savings officially calculated of the cost of the life of a handicapped person, the intolerance for imperfection. They validate the idea that the birth of an imperfect child being a "disorder" and a "misfortune", the avoidance through therapeutic abortion of such births re-establishes order in society and happiness in the family." Besides, this child would exist only because his disability would not have been detected before birth and could not be "avoided" by his parents, according to the recent statements by M. Ben Achour, a member of the UN Human Rights Committee.6

In this context, the question of the alternative between screening and research is asked. The need to guarantee as widely as possible non-discrimination in the enjoyment of disabled persons' right to life requires the States to encourage research on diseases for which unborn children are commonly eliminated, and to give priority to it over research on the means to facilitate such an elimination.⁷

⁵ Jean-Marie Le Méné, *Abortion and Eugenics*, in *Preventing abortion in Europe*, 22 June 2017: https://eclj.org/abortion/eu/european-seminar-preventing-abortion-in-europe-legal-framework--public-policies?lng=en

^{6 &}quot;...that does not mean that we have to accept to let a disabled foetus live (...), we can avoid handicaps and we must do everything to avoid them": Mr Ben Achour's statement during the debate in second reading on the Draft General comment No.36 on article 6 of the International Covenant on Civil and Political Rights, on the right to life, see https://youtu.be/WpGH9m5r2eE

⁷ Non-Invasive Prenatal Screening (NIPS) is particularly worrying. It consists in a simple blood test for the mother in the early stages of pregnancy, when voluntary termination of pregnancy can still be possible, thus becoming eugenic.

Protecting disabled persons from discriminatory violations to the right to life after birth

In 2012, the Office of the United Nations High Commissioner for Human Rights denounced "mercy killings" at birth or after as a practice originated by prejudices linked to disability. Likewise, "infanticide" was also recently condemned by the Special Rapporteur on the rights of persons with disabilities.9

While the euthanasia of disabled persons was widely condemned at the end of the Second World War as a crime against humanity, as well as in this Draft (§ 8), the ECLJ regrets that neonatal infanticide¹⁰ is not explicitly mentioned. Consisting in letting the newborn without care until his death or in euthanizing him, this practice is more insidious because it generally happens with an unsuccessful therapeutic abortion and it often affects disabled children.¹¹ Indeed, as therapeutic abortion can be practiced as the pregnancy is more advanced, when very premature babies can be saved,¹² the infanticide of a baby that one wishes to abort but who is born alive is favoured.

On the other hand, when the disability of the newborn was not screened during pregnancy,¹³ finding it at birth can favour such an infanticide which then constitutes a very extension of therapeutic abortion.¹⁴ The violations of human rights, including the 1989 International Convention on the Rights of the Child¹⁵ and the 1950 European Convention on Human Rights,¹⁶ is evident. Yet, as recalled by the paediatrician Michel Dehan, "The core principle of our approach is the recognition of the newborn. Whatever its

⁸ Report of the Office of the United Nations High Commissioner for Human Rights, *Thematic study on the issue of violence against women and girls and disability*, 30 March 2012, § 24: https://undocs.org/fr/A/HRC/20/5

⁹ A/72/133 Report of the Special Rapporteur on the rights of persons with disabilities, *Sexual and reproductive health and rights of girls and young women with disabilities*, 14 July 2017, § 34, http://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/Reports.aspx.

¹⁰ On this whole point, see G. Puppinck and C. de la Hougue, « Enfants survivant à l'avortement et infanticides néonatals en Europe », in G. Puppinck (dir.), *op. cit.*, p. 137-161.

 $^{^{11}}$ See E. Verhagen et P. J. Sauer, "The Groningen protocol, euthanasia in severely ill newborns", *N. Engl. J. Med.* 352 (10): 959–62, Mars 2005.

¹² For statistics from some countries on live birth during abortions, see G. Puppinck and C. de la Hougue, *op. cit.*, p. 147-150. Indeed, the limit of viability is defined by the World Health Organisation at 22 weeks, see *Ethical Issues In Obstetrics And Gynecology* by the FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, October 2012.

¹³ For a testimony revealing the case of a child with Down Syndrome not detected during pregnancy and euthanised at birth, see G. Puppinck and C. de la Hougue, *op. cit.*, p. 153.

¹⁴ Neonatal infanticides are sometimes called "after-birth abortion": see A. Giubilini and F. Minerva, « After-birth abortion: why should the baby live? », *Journal of Medical Ethics*, Febr. 2012.

¹⁵ The International Convention on the Rights of the Child states that "the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth" (Preamble), that "States Parties recognize that every child has the inherent right to life" and "shall ensure to the maximum extent possible the survival and development of the child" (art. 6) and that they "recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services" (art. 24); States committed themselves to respect and ensure the rights of children "without discrimination of any kind", including irrespective of birth (art. 2).

¹⁶ The European Convention on Human Rights guarantees the right to life (art. 2), prohibits inhuman (art. 3) and discriminatory treatments, but it is actually a discrimination in access to health care services on the ground of birth (inconsistent with art. 8 and 14).

weight, age, appearance, it is a human being, and this gives him, de facto, rights, particularly the right to receive health care".¹⁷

The need to denounce current eugenics

The practices denounced here are eugenics which includes elimination of persons selected according to physical characteristics allegedly inferior to a racial or sanitary "ideal" type.

The ECLJ recalls that abortion and euthanasia were employed in the XXth century as part of genocidal policies¹⁸ which are by nature discriminatory as they are led "with intent to destroy, in whole or in part, a national, ethnical, racial or religious group".¹⁹ For example, thousands of disabled persons were euthanized in Germany under the Nazi regime via gradual reduction of hydration and nutrition. These practices were clearly condemned during the Nuremberg Trials,²⁰ by the United Nations and the World Medical Association.

But be it imposed by a totalitarian State or encouraged by a liberal society, as in many countries today, eugenics has the same result with the same operating procedures because it is based on the same premise: a materialist conception of the human being whose dignity is reduced to its physical and intellectual capacities. Abortion and euthanasia are based on a reductionist conception of the human being, i. e. only its "spiritual" capacities (conscience, intelligence and will) would be properly human and thus worthy of protection. The foetus, all the more the disabled one, and the unconscious patient would not, or no more, be worthy to protect. This conception of humanity, where persons are distinguished according to their capacities, was precisely condemned in 1948 when the universality of human dignity was affirmed.

Human dignity, source of equality and non-discrimination

While the Committee rightly states that "The principle of universality of all human rights is based on this understanding that all human beings have equal worth and dignity and that all human beings should enjoy equal rights" (§ 7), these practices seriously conflicting with the principles of equality and non-discrimination deny the dignity inherent to every human being.

Dignity is said to be "inherent" to the human being, because it qualifies the *human nature* shared by every human being, whatever their physical and cultural characteristics. In this sense, Kant's famous formula is perfectly right: "Humanity itself is a dignity".²¹

¹⁷ Michel Dehan, « Grands prématurés : enjeux éthiques de la décision en néonatalogie », *Lettre de l'Espace éthique* n° 9-10-11, « Fin de vie et pratiques soignantes », 17 June 2003.

¹⁸ On abortion, see the conclusions of Prosecutor McHaney: *Opening Statement of the Prosecution in Trials of War Criminals Before the Nuremberg Military Tribunals Under Control Council Law No. 10. Vol. 4: United States of America v. Ulrich Greifelt, et. al.* (Case 8: 'RuSHA Case'), US Government Printing Office, District of Columbia: 1950. pp. 622-93. Part 1[Tr. pp. 24-125, 10/20/1947]. On euthanasia, see Hoche and Binding's theories: Robert Proctor, "Racial Hygiene: Medicine under the Nazis", p. 178.

¹⁹ 1948 Convention on the Prevention and Punishment of the Crime of Genocide, art. 2.

²⁰ On abortion, see *Nuremberg Trials Record: "The RuSHA Case"*, Opinion and Judgment, "*War Crimes and Crimes against Humanity*", Vol. V, pp. 152 to 154 and pp. 160-2. On euthanasia, see *Trials of the War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10, Nuremberg October 1946-April 1949*, Volume V, Washington, DC: Government Printing Office, 1950.

²¹ Kant, *Metaphysics of Morals* (1796), II, "The Doctrine of Virtue", § 38.

It is because dignity qualifies the common *human nature* that it is *universal* and shared equally by every person. Dignity is not attached to the capacities of a person, but to the shared human nature only, to the fact of "being human". Thus, this dignity is absolute, non-contingent and universal. Human rights' authority and universality also derive from the dignity of human nature.

Linking dignity to the capacities of individuals, rather than to human nature, undermines human rights, making them relative and contingent.

Human rights were proclaimed in 1948 on the basis of this dignity inherent to human being, in order to protect humanity against materialistic ideologies considering "life" only as a non properly human biological reality and acknowledging humanity only to those who share such a conception.

II. Preventing all discriminatory violations of the rights of persons with disabilities

As stated by the Committee in **Paragraph 8** of the Project, "throughout the ancient and contemporary history of the world, dignity, integrity and equality have been denied to persons with actual or perceived disabilities".

However, today, while human rights are at the heart of our modern civilization, persons with disabilities continue to be victims of blatant abuses of their rights and to be subjected to harmful and forced practices violating their integrity, such as forced sterilizations and forced and coerced abortions.²²

Forced sterilizations and abortions

The ECLJ greatly welcomes the Committee's explicit reminder to member States providing that they "have an obligation to respect, protect and fulfil the right of all persons with disabilities to non-discrimination and equality", identifying "non-consensual sterilization of women and girls with disabilities" as harmful practices that must be fought against (§ 32).

The ECLJ welcomes the Committee's numerous references to the various UN bodies that prompt member States to fight forced sterilizations, particularly the 2017 Report of the Special Rapporteur on the rights of persons with disabilities which recalls that "grave human rights violations such as forced sterilization, forced abortion and forced contraception are frequent", and that such medical procedures or interventions "are often performed without the free and informed consent of girls and young women with disabilities", most notably "forced contraception and forced abortion."²³

²² The Special Rapporteur on the Rights of persons with disabilities stresses that women and girls with disabilities "face significant challenges in making autonomous decisions with regard to their reproductive and sexual health, and are regularly exposed to violence, abuse and harmful practices, including forced sterilization, forced abortion and forced contraception. » See A/72/133 Report of the Special Rapporteur on the rights of persons with disabilities, Sexual and reproductive health and rights of girls and young women with disabilities, 2017, § 3.

²³ Ibid., §60 and § 31.

On this issue, the ECLJ invites the Committee to include forced abortions within the list of harmful practices, provided in **Paragraph 8**, since this form of discrimination, just as forced sterilizations, has been firmly condemned in international law.

Forced abortion was considered a crime against humanity at the Nuremberg trials during which Nazi leaders were sentenced for "encouraging and compelling abortions".²⁴ The World Conference on Women, held in Beijing, describes "forced sterilisation and forced abortion, coercive/forced use of contraceptives" as "acts of violence against women" (§ 115).²⁵ The Council of Europe's Convention on Preventing and Combating Violence against Women and Domestic Violence of 11 May 2011 required States Parties to criminalise abortions and forced sterilisation (Article 39). The European Court of Human Rights considers that sterilisation, when practiced without consent, is "incompatible with the requirement of respect for human freedom and dignity, one of the fundamental principles on which the Convention is based."²⁶ In 2011, PACE asked member States to "criminalise" the practice of forced abortions.²⁷ Similarly, in 2012 the European Parliament adopted a resolution that "condemns the practice of forced abortions and sterilisations globally".²⁸

Numerous other UN bodies have called upon member States to condemn such a practice. The Office of the High Commissioner for Human Rights thus recalled that "States have clear obligations under international human rights law to enact legislation prohibiting all acts of violence²⁹ against women and girls³⁰ with disabilities, including those to which they are more vulnerable, such as forced sterilization (...) and forced abortion." ³¹ In his 2017 Report, the Special Rapporteur on the Rights of Persons with Disabilities stressed that "During official country visits, [she had] received information about compulsory regular gynaecological checks and the use of forced abortion in institutions as a way to contain the institution's population."³²

Furthermore, the practice of forced abortions relies on a false and discriminatory stereotype saying that persons with disabilities would not be able to live a happy life and

²⁴ J. Hunt, St Joseph University, Philadelphia, "Abortion and the Nuremberg Prosecutors, a Deeper Analysis" in: Koterski, Joseph W., ed. *Life and Learning VII: Proceedings of the Seventh University Faculty for Life Conference*. Washington, DC: University Faculty for Life; 1998: 198-209.

²⁵ UN Women, the fourth World Conference on Women, Beijing, Dec 1995 Action for Equality, Development and Peace, available on: http://www.un.org/womenwatch/daw/beijing/platform/violence.htm#diagnosis

²⁶ ECHR, *V.C. v. Slovakia*, n°18968/07, 8 November 2011, § 107.

 $^{^{\}it 27}$ PACE Resolution 1829 (2011), Prenatal Sex Selection, October 3, 2011.

 $^{^{28}}$ European Parliament Resolution 2012/2712(RSP), 5 July 2012, in G. Puppinck (dir.), \textit{op. cit.,} p. 92-93.

²⁹ International law and human rights jurisprudence sets out States responsibilities to exercise due diligence in taking steps to end violence against women. See E/CN.4/2006/61.

³⁰ "The Committee on the Rights of the Child recognized that children with disabilities may be subject to particular forms of physical violence, such as forced sterilization (particularly girls)" § 9, A/HRC/20/5 Report of the Office of the United Nations High Commissioner for Human Rights, op. cit., 2012.

³¹ Ibid. § 28.

³² L. Lin, J. Lin, C. M. Chu et L. Chen "Caregiver attitudes to gynaecological health of women with intellectual disability", Journal of Intellectual and Developmental Disability, vol. 36, no 3 (September 2011); A. Albanese et N. Hopper, "Suppression of menstruation in adolescents with severe learning disabilities", Archives of Disease in Childhood, vol. 92, no 7 (July 2007).

would not be capable of raising children properly. Yet, such an approach was precisely condemned by the current Committee in its Comments on the Draft.³³

Coerced abortions and medical and social pressures

When the foetus is identified as having a disability before his birth, he is most often eliminated. As this type of eugenic abortion falls now into a fairly broad social consensus, this increases the pressure on women and couples who, on the contrary, wish to keep the child. This pressure comes from medical professionals, relatives and, on a larger scale, society.

The Special Rapporteur stresses that, still in 2017³⁴, "girls and young women with disabilities are frequently pressured to end their pregnancies owing to negative stereotypes about their parenting skills and eugenics-based concerns about giving birth to a child with disabilities."³⁵

This issue has been largely documented by the ECLJ,³⁶ which echoed the same analysis. Thus, a mother claimed to have undergone so much pressure from the hospital staff, and because she already had a disabled son and knew how society treated these children, she did not have the strength to withstand the pressure.³⁷ Couples also expressed the difficulty to find a medical team willing to assist them during the pregnancy and birth of a child condemned to an early death.³⁸

Furthermore, forced abortion contravenes the Convention since it "does not seek to prevent disability (...) but rather to prevent discrimination on the basis of disability."³⁹ Thus, forced abortion must be combatted –the same way forced sterilizations are— as constituting a harmful practice that violates the rights of persons with disabilities.

However, this fight must necessarily be accompanied by a change in the way society perceives disability, specifically through the implementation of awareness raising campaigns by member $States.^{40}$

 $^{^{33}}$ Committee on the Rights of Persons with Disabilities, Comments on the draft General Comment No36 of the Human Rights Committee on article 6 of the International Covenant on Civil and Political Rights, § 1 "(...) the assessment perpetuates notions of stereotyping disability as incompatible with a good life."

See http://www.ohchr.org/EN/HRBodies/CCPR/Pages/GC36-Article6Righttolife.aspx

³⁴ A/72/133 Report of the Special Rapporteur on the rights of persons with disabilities, *op. cit.*, § 31, C. Harmful and forced practices.

³⁵ J. O'Connor, "Literature review on provision of appropriate and accessible support to people with an intellectual disability who are experiencing crisis pregnancy", National Disability Authority (Údarás Náisúnta Míchumais).

³⁶ G. Puppinck (dir.), *op. cit.*, p. 95 à 101.

³⁷ Beezy Marsh, « 66 babies in a year left to die after NHS abortions that go wrong », *Daily Mail*, 4 février 2008, available on: http://www.dailymail.co.uk/health/article-512129/66-babies-year-left-die-NHS-abortions-wrong.html

³⁸ See https://eclj.org/family/french-institutions/avec-pierre-marie--une-grossesse-particulire-?lng=en

³⁹ HR/P/PT/17 Office of the High Commissioner for Human Rights, *Monitoring the Convention on the Rights of Persons with Disabilities* - Guidance for human rights monitors - Professional training series No. 17, 2010, p. 23, http://www.ohchr.org/documents/Publications/disabilities training 17en.pdf

⁴⁰ Ibid., p. 23: "Campaigns to prevent accidents and promote safe childbirth and motherhood are relevant to public safety and health. However, when such campaigns are promoted in the context of persons with disabilities, disability is perceived in negative terms, shifting attention away from respect for difference and diversity as well as from combating discrimination –the primary focus of the human rights model."; See also

III. Changing views on disability to improve the social integration of persons with disabilities

The ECLJ shares the Committee's concern regarding the fact that "efforts carried out in States parties to overcome attitudinal barriers to disability have been insufficient to change the way societies view disability" (§ 2).⁴¹

As the Office of the High Commissioner for Human Rights asserted, "Respect for difference involves accepting others in a context of mutual understanding. This incorporates the acceptance of disability as part of human diversity and humanity. Despite some visible or apparent differences, all people have the same rights and dignity."⁴²

Yet, the ECLJ wants to warn the Committee against the excessive use of the idea, introduced in **Paragraph 11**, that disability would be a "social construct".⁴³ Such an approach of disability results in reducing the reality of what a disability is, namely a deprivation of physical or intellectual capacities human beings are ordinarily endowed with. This constructivist approach implies that health would be a "social construct", and so that the "human being" would also be a socially constructed notion. More concretely, such an approach amounts to denying the reality of disabilities and does not encourage the research of care.

Ensuring an equal access to media for awareness raising campaigns on disability

The ECLJ welcomes the Committee's injunction to member States to encourage awareness raising on disability within the media and to take action to combat the stigmatizations that discriminate persons with disabilities (§ 44).

The Committee's concern on this issue is of special importance today since, in some countries, it is problematic to see disabled children alive.

This is the case in France where an awareness raising spot⁴⁴ promoting a positive view on persons with Down syndrome, was censored by the French Higher Audiovisual Council (CSA)⁴⁵ while, interestingly, the same video was broadcasted in many countries and greatly awarded. Yet, the objectives in making such a video were precisely those promoted by the current Committee and the Office of the High Commissioner for Human

A/72/133 Report of the Special Rapporteur on the rights of persons with disabilities, op. cit., \S 62 i) and \S 40.

⁴¹ "The Committee assumes that, additionally, efforts carried out in States parties to overcome attitudinal barriers to disability have been insufficient to change the way societies view disability, as exemplified by the enduring prejudice, stigma and negative, humiliating stereotypes against persons with disabilities and the lasting misperceptions of disability as a burden for society or an individual problem."

⁴² HR/P/PT/17 Office of the High Commissioner for Human Rights, *op. cit.*, p. 22.

⁴³ "Inclusive equality corresponds to a new model of disability, the human rights model of disability, which leaves charity, welfare, and medical approaches behind and is based on the assumption that disability is not primarily a medical issue. Rather, disability is a social construct (...)" § 11, Committee on the Rights of Persons with Disabilities, Comments on the draft General Comment No36 of the Human Rights Committee, op. cit.

⁴⁴ Video Dear Future Mom (https://www.youtube.com/watch?v=Ju-q4OnBtNU&feature=youtu.be)

⁴⁵ The CSA refused to recognize the general interest of the *Dear Future Mom* spot on the ground that its "quite persuasive tone and because it addressed a future mother, a certain ambiguity appears regarding its aim which does not arouse a spontaneous and consensual support". (free translation)

Rights⁴⁶, namely to eliminate stereotypes of persons with disabilities as victims of their « *tragic and helpless situation* » or « *burden for society* ».⁴⁷ This case was brought by the Fondation Jérôme Lejeune and the ECLJ before the European Court of Human Rights⁴⁸.

The ECLJ suggests that the Committee on the Rights of Persons with Disabilities should ask the European Court to intervene in this case.

IV. Recommendations

Based on this developments, the ECLJ expresses the following recommendations to the Committee:

Adding a paragraph on the link between article 5 and article 10 of the Convention

The ECLJ recommends the addition of a paragraph regarding the link between article 5

and article 10 of the Convention (regarding the right to life), with the last part of paragraph 44 regarding the modern forms of discrimination.

"VII. Relationship with other specific articles of the Convention

v. Article 10 - Right to life

. As set out in the Committee's contribution to the general comment No. 36 on right to life of the Human rights Committee (2017), laws which explicitly allow for abortion on grounds of impairment violate the Convention on the Rights of Persons with Disabilities, particularly Article 5 on Equality and non-discrimination. Therefore, Article 5 is closely linked to Article 10 of the Convention on the right to life. In this sense, States parties shall/must remove from their national policy any law, regulation, or provision that explicitly allow for abortion on grounds of impairment, since this violates the Convention on the Rights of Persons with Disabilities (Articles 4, 5, 8). The life of unborn children with disability or presumed disability requires a specific protection and must not be discriminated against on the grounds of impairment or supposed impairment.

. Likewise, States parties should address stigmatization through modern forms of discrimination, such as a disability-selective antenatal screening policy that go against the recognition of the equal worth of every person. States parties should take into account all factors, including the diversity of persons with disabilities and their identities and address multiple and intersecting discrimination when designing and carrying out awareness-raising measures.

CENTRE EUROPÉEN POUR LA JUSTICE ET LES DROITS DE L'HOMME 4, Quai Koch, 67000 STRASBOURG, FRANCE - Tél.: + 33 (0) 3 88 24 94 40 - Fax: + 33 (0) 3 88 24 94 47

⁴⁶ "States should promote a positive perception and raise awareness of the scope of equality and non-discrimination for persons with disabilities, including by combating stereotyping and stigmatization. In this sense, the Committee on the rights of Persons with Disabilities has recommended that States develop campaigns to fight discrimination against persons with disabilities (...). Eliminating barriers in attitude requires further efforts under article 8 of the Convention, and entails a critical approach to negative perceptions of persons with disabilities. In 2016, the Social Forum raised the importance of working with the media sector to increase their visibility and contribute to the elimination of existing stereotypes of them." A/HRC/34/26 Report of the Office of the United Nations High Commissioner for Human Rights, Equality and non-discrimination under article 5 of the Convention on the Rights of Persons with Disabilities, 2016, § 64, http://www.un.org/ga/search/view_doc.asp?symbol=A/HRC/34/26&referer=english/

 $^{^{47}}$ § 2 of the General Comment No. 6 of the CRPD on the right of persons with disabilities to equality and non-discrimination (Article 5), First draft as at 31 August 2017.

⁴⁸ The case is pending: *Fondation Jérôme Lejeune v. France*, n° 35133/17.

. In this sense, States parties shall adopt all appropriate measures to prevent euthanasia of disabled persons at or after birth⁴⁹.

Paragraph 1

The ECLJ recommends the following wording: "(...)The Committee routinely observes discrimination which includes: violation to the right to life from conception to natural death, violations to the right to access the built environment, transportation, information and communications on an equal basis with others; negative portrayals of disability in the media and harmful stereotypes; deprivation of the right to legal capacity; curtailments in access to justice, education, employment; and to the right to participate in cultural life, recreation, leisure and sport, to name but a few examples."

Paragraph 8

The ECLJ recommends the following wording: "Throughout the ancient and contemporary history of the world, dignity, integrity and equality have been denied to persons with actual or perceived disabilities and discrimination has occurred in all its brutal and less brutal forms, including non-consensual and/or forced mass sterilizations and medical or hormone-based interventions (e.g. lobotomy, Ashley-treatment), mass murder called "euthanasia", forced and coerced abortion, mutilation and trafficking in body parts, particularly of persons with albinism, and confinement."

Paragraph 11

The ECLJ recommends the suppression of the first two sentences of the paragraph and suggests the following wording: "11. Both the human rights model of disability and the medical approach commend that impairment must not be taken as legitimate ground for the denial or restriction of human rights."

In **paragraphs 21 and 37**, The ECLJ recommends to include unborn children as a category, a group whose protection is necessary in view of the particular and unique vulnerability of life before birth.

Paragraph 21

The ECLJ recommends the following wording: "On the basis of disability" includes not only persons -including unborn children- who presently have an impairment, but also who have had an impairment in the past, have a disposition to an impairment which lies in the future, and persons who are presumed to have an impairment or those who are associated with a persons with disabilities,³⁷ the latter known as "discrimination by association" (...)".

Paragraph 37

The ECLJ suggests the following wording: "States parties need to identify areas and subgroups of persons with disabilities that need specific measures to accelerate or achieve de facto equality, particularly those who are at the most vulnerable stage of their life, such as children before birth. (...)"

⁴⁹ Report of the Office of the United Nations High Commissioner for Human Rights, *Thematic study on the issue of violence against women and girls and disability*, 30 March 2012, § 24: http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session20/A-HRC-20-5 en.pdf