

UNIVERSEL PERIODIC REVIEW – FOURTH CYCLE - FRANCE

A. THE PERPETUAL DISCRIMINATION AGAINST PEOPLE WITH DOWN SYNDROME...

1. Despite a militant discourse for the inclusion of people disabilities, the situation of people with Down syndrome has not really evolved in France. Since France's first universal examination, some efforts have been made in public representation, but people with Down syndrome still face problems of access to education, media representation and recognition of rights. The result is a profound inequality between people with Down syndrome and other citizens.

THE PERSISTENT SOCIAL EXCLUSION OF PEOPLE WITH DOWN SYNDROME

2. Although efforts have been made to achieve the objectives of schooling for people with disabilities, there are still many obstacles for these children. In practice, society finds it difficult to include them, especially those with Down syndrome, in the school environment or the labour market. The establishments are not adapted to allow the permanent schooling or the instruction of the carriers of trisomy 21. Every year, efforts are requested from the government to support this inclusion. Nevertheless, the social exclusion of people with Down syndrome does not stop there.
3. The European Court of Human Rights recently ruled "*inadmissible*"¹ the French CSA²'s ban on broadcasting a positive message delivered by people with Down syndrome in the video "*Dear Future Mom*"³. In 2014, this video was broadcast on French TV channels to raise awareness about people with Down syndrome. They showcase their joy of life by highlighting how their life can be similar to ours. "*Together, we can make it possible*"⁴. This message of inclusion, however was later censored by the CSA, which prevented its replay in 2017. The CSA, a governmental authority, has not reviewed its decision, thus continuing to deprive people with Down syndrome from their right of fair media representation. Their right to freedom of expression was restricted to limited programmes, because of their genetic characteristic, this video was labelled as a "*threat to the conscience*" of some people. However, personal issues of conscience should never interfere with the freedom of expression of people with disabilities, who are already under-represented in society. **The Committee on the Rights of Persons with Disabilities** has already recommended that France, in September 2021, "*adopt measures to increase the participation and visibility of persons with disabilities in public life and the public media*"⁵. By not reviewing its decision, France is clearly not considering these UN recommendations.

THE PERSISTENT MEDICAL STIGMATISATION OF PEOPLE WITH DOWN SYNDROME.

¹ [DE PRACOMTAL ET FONDATION JÉRÔME LEJEUNE c. FRANCE \(coe.int\)](#)

² CSA : Conseil Supérieur de l'Audiovisuel (*Superior Audiovisual Concil*), now ARCOM (Autorité de régulation de la communication audiovisuelle et numérique (*Regulatory Authority for Audiovisual and Digital Communication*)).

³ [DEAR FUTURE MOM | March 21 - World Down Syndrome Day | #DearFutureMom - Bing video](#)

⁴ 2:10 [DEAR FUTURE MOM | March 21 - World Down Syndrome Day | #DearFutureMom - Bing video](#)

⁵ Concluding observations on the initial rapport of France , October 2021 - [G2126972.pdf \(un.org\)](#)

4. French society, so little aware of Down syndrome, is still not adapted to the open acceptance of people with this condition. Indeed, the observation made by UNESCO in 2015⁶ has not changed: the introduction of the DPNI has led to a lack of interest in the care and support of people with Down syndrome. The solution is found in prenatal diagnosis, which allows births to be avoided until the end of pregnancy. The result is a discrimination, albeit unconscious, that lurks in the French society: parents who knowingly decide to bring a Down syndrome child into the world are responsible for the difficulties the child will encounter, since the State proposed an easy solution: the prenatal elimination⁷. The systematic use of prenatal diagnosis of Down syndrome does not encourage research into treatment. Recently, French researchers have discovered a potentially interesting molecule for curing Down syndrome patients⁸. This should be congratulated. But it should also be an opportunity for France to underline the good medical practices in the handicap announcement, and to be more truthful about the reality of trisomy 21⁹.

VIOLATION OF FRANCE'S INTERNATIONAL COMMITMENTS

5. By prohibiting the broadcasting of "Dear Future Mom", allowing the aforementioned medical practices to be performed and failing to combat false social prejudices about Down syndrome, France is breaching its obligations, undertaken by the ratification of the **Convention on the Rights of Persons with Disabilities**¹⁰, to "raise awareness throughout society, including at the family level, regarding persons with disabilities, [to] foster respect for the rights and dignity of persons with disabilities", to "combat stereotypes, prejudices and harmful practices relating to persons with disabilities", and to "promote awareness of [their] capabilities and contributions¹¹". It is clear that the attitude of the CSA does not help to combat stereotypes and directly denies "the capabilities and contributions of persons with disabilities".
6. Such an exclusion, made possible by the inaction of the State, is thus part of the discrimination against people with Down syndrome, prohibited by **Article 3 of the Convention on the Rights of Persons with Disabilities** and **Article 6 of the UNESCO Universal Declaration on the Human Genome and Human Rights**¹². Indeed, **Article 2 of the Convention on the Rights of Persons with Disabilities** states: "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 accommodation".

⁶ Report of the UNESCO International Bioethics Committee on Updating its Reflection on the Human Genome and Human Rights, 2015, page 26, paragraph 89.

⁷ As one doctor said about a 10-year-old child with Down syndrome: "With this one, we saw too many malformations on the ultrasound to keep him". Parents should not ask us to do too much for their son.

⁸ [Trisomie 21 : une nouvelle thérapie améliore sensiblement les fonctions cognitives chez des patients, selon une étude \(francetvinfo.fr\)](https://www.francetvinfo.fr/santitech/medecine/trisomie-21-une-nouvelle-therapie-ameliore-sensiblement-les-fonctions-cognitives-chez-des-patients-selon-une-etude_1181111.html)

⁹ Ifop poll for the Fondation Jérôme Lejeune, p. 30.

¹⁰ Convention signed by France on 30 March 2007 and ratified on 18 February 2010.

¹¹ Article 8 a), b), c) of the Convention on the Rights of Persons with Disabilities

¹² Declaration adopted by UNESCO in 1997 during the 29th General Conference. Hereafter: "UNESCO Declaration".

7. The inconsistency of the inclusion messages and this denial of media representation is a violation of **Article 4 of the Convention on the Rights of Persons with Disabilities**, which underlines that "*States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability*".

8. RECOMMENDATION

A) In accordance with Article 4 of the Convention on the Rights of Persons with Disabilities, France should order the CSA (now ARCOM) to reconsider its decision regarding the prohibition of broadcasting a video Ad showcasing persons with Down syndrome as a message of general interest. Indeed, by this agreement, it is committed to

a) "Adopt all appropriate measures [...] for the implementation of the rights recognised in the present Convention.

(b) To take all appropriate measures [...] to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities".

B) Furthermore, France should put an end to the trivialisation of discrimination against people with Down syndrome, through a public effective positive campaign. To do this, the State should respect its commitment, undertaken by ratifying the **Convention on the Rights of Persons with Disabilities, article 8**, to launch and carry out "*effective public awareness campaigns designed: (i) To nurture receptiveness to the rights of persons with disabilities, (ii) To promote positive perceptions and greater social awareness towards persons with disabilities*" as well as "*recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market*", which it does not sufficiently encourage in a State that is plagued by stereotypes about this disability at all levels: in the medical, educational and media environments.

B. ... WHICH PROMOTES FOR EUGENICS AGAINST PEOPLE WITH DOWN SYNDROME

9. Unfortunately, the lack of attention for people with Down syndrome in society does not remain an isolated problem. Their poor living conditions in France lead to the development of prenatal eugenics, the automatic exclusion of Down syndrome embryos: new eugenics.

DISCRIMINATORY PRENATAL DIFFERENTIAL TREATMENT OF EMBRYOS WITH TRISOMY 21.

10. In France, prenatal diagnosis specifically targets embryos with Trisomy 21. The systematisation and promotion of this diagnosis leads to the abortion of **96%** of children conceived and diagnosed with Down syndrome...
11. Indeed, the diagnosis of trisomy 21 is systematic, because trisomy is easy to detect, during pregnancy or in vitro¹³. And this test does not aim to better accompany parents in a care process¹⁴. On the contrary, testimonies of patients and families show that trisomy is often portrayed as unbearable by doctors, who push to abort or abandon the child¹⁵. It is obvious that the organisation of diagnosis cannot fail to have an incentive effect on pregnant women, who are then led to interrupt the pregnancy when the test is positive. And this systematisation is tending to develop in MAP procedures, where the aim is to diagnose chromosomal anomalies as early as possible not to give rise to them, with the still controversial PGD-A technique¹⁶.
12. However, disability cannot be the source of differential treatment, nor can genetic characteristics be the source of selection and discrimination encouraged by public policies¹⁷.

EUGENICS ASSUMED AND ENCOURAGED BY THE STATE

¹³ During pregnancy, women are systematically offered screening for trisomy. This test has been compulsorily offered to women since a decree of 23 June 2009, confirmed by a decree of 20 December 2018; doctors may even be prosecuted if they do not insist sufficiently on carrying out the test.

¹⁴ Ifop poll for the Fondation Jérôme Lejeune.

¹⁵ Interview of a mother of a young person with Down syndrome by the Youtubeur Tibo InShape, (278) TRISOMIA 21 HIS FIGHT! - YouTube 9:45

¹⁶ Pre-implantation genetic diagnostic of aneuploidies

¹⁷ France has committed itself to this by ratifying the Oviedo Convention: France ratified the Oviedo Convention on the Human Genome and Human Rights in April 1997. Article 11 of this Convention states that « Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited ». [CETS 164 - 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 \(coe.int\)](#)

13. The consequences of these diagnostic policies are a “birth expectancy” of **4%** for Down syndrome embryos in France. If **96%** of them are aborted, the general abortion rate in France in 2020 was **29.8%**¹⁸. This difference suggests the systemic exclusion of people with Down syndrome, even before they are born. And France, far from limiting or raising awareness of this worrying issue, seems to be promoting these acts of eugenics. In 2019, during the debates on the French bioethics law, a **French MP** spoke of the need to “*hunt down embryos carrying chromosomal abnormalities*”¹⁹, in front of the National Assembly! The French Parliament is becoming the defender of techniques for detecting these anomalies, with the aim of more easily eliminating a part of a population they deem unworthy and much more complicated to deal with. However, the **UN Committee on the Rights of Persons with Disabilities** has already expressed its concern about the “*negative stereotyping*” of people with Down syndrome, their “*devaluation [...] by the policies [...] underlying prenatal genetic screening for foetal impairment, particularly with regard to Down syndrome*”²⁰.

14. Moreover, the government does nothing to prevent eugenic advances and their implementation in biomedical research and clinical trials. Indeed, on the one hand, **the Agence de la biomédecine**²¹ authorised in March 2021 a research protocol aimed at improving the PGD-A technique, a technique that is currently banned in France because it is a source of serious eugenic abuses. **The Minister of Solidarity and Health** warned in 2019: “*This is the first potential drift of preimplantation diagnosis to search for aneuploidies: we are sliding towards a society that sorts embryos*”²². On the other hand, **the National Agency for the Safety of Medicines and Health Products**²³ has authorised the implementation of a clinical trial on PGD-A in March 2021. With these two decisions, two state agencies have endorsed a practice prohibited under French law, which allows targeted embryo sorting to avoid developing embryos carrying chromosomal abnormalities.

VIOLATION OF FRANCE'S INTERNATIONAL COMMITMENTS.

15. By systematising the tracking of Down syndrome embryos, by encouraging the development of these practices, and by allowing the elimination of **96%** of Down syndrome individuals before birth because of their chromosomal abnormality, France is violating its obligation of non-discrimination under the **Convention on the Rights of Persons with Disabilities** and the **UNESCO Declaration**²⁴.

More specifically, it also violates **Article 3 of the Convention**, which states that “*The principles of the present Convention shall be [...] b) Non-discrimination*”, and **article 4 of the same Convention** which states that “*States Parties undertake [...] e) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise*”.

16. Furthermore, **Article 1 of UNESCO Declaration** states that “*The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their*

¹⁸ [Avortements - Avortements, contraception - France - Les chiffres - Ined - Institut national d'études démographiques](#)

¹⁹ Official speech by Philippe Vigier at the National Assembly, 15 October 2019 - [\(21\) LCP sur Twitter : ""Dans cette loi de bioéthique, il y a des avancées, il y a des regrets, il y a des attentes", assure @VigierPhilippe \(Libertés et Territoires\). #DirectAN #PJBioethique https://t.co/mHH0EHM3KQ" / Twitter](#)

²⁰ Concluding observations on the initial rapport of France, October 2021- p.5 §17 - [G2126972.pdf \(un.org\)](#)

²¹ The Biomedicine Agency is a state agency

²² Hearing of Mrs Buzyn by the Special Bioethics Committee of the National Assembly, 9 September 2019 - [https://www.assemblee-nationale.fr/dyn/15/comptes-rendus/csbioeth/l15csbioeth1819033_comptereendu.pdf](#)

²³ Another state agency

²⁴ Article 3 of the CONVENTION ON THE Rights of Persons with Disabilities ; article 6 of the UNESCO Declaration.

inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity”.

However, by searching for chromosomal abnormalities in order to eliminate their carrier before birth, French medical practices do not recognise the diversity of human genetic characteristics. France allows and promotes the exclusion of people with Down syndrome from the human family, as they are systematically screened.

17. By explicitly authorising research and the application of techniques that improve the selection of embryos on the basis of their genetic characteristics, France is violating **Article 10 of the UNESCO Declaration**, which states that "*No research or research applications concerning the human genome [...] should prevail over respect for the human rights, fundamental freedoms and human dignity of individuals or, where applicable, of groups of people*".
18. However, by allowing the development and funding of this research, France is participating in the expansion of the idea that people with Down syndrome are less worthy of being born.

19. RECOMMENDATION

According to **the recommendation from the 3rd cycle of the Universal periodic Review of France by Costa Rica²⁵, not yet considered**, France have to "***review the policy of systematic prenatal detection of Down syndrome***", in line with the principles of the **Universal Declaration of Human Rights and international instruments**. France should do more to promote and fund research to better understand the medical needs of people with Down syndrome, and to improve their living conditions after birth.

In doing so, the government would be fulfilling its national and international obligation about the fight against discrimination based on genetic characteristics.

20. Our findings show that France does not sufficiently reconcile the need for research with respect for the ethical implications, and gives precedence to medical progress over respect for the dignity of all.

²⁵ Responses taken from 'Annex 1' of the Third Cycle, found here: <https://www.ohchr.org/en/hr-bodies/upr/fr-index>