

« NEW GENERATIONS AT RISK »

Thematic Report Prepared for the United Nations Committee on the Rights of the Child

This report is presented by Alliance VITA as part of the civil society's contribution to the preparation of the List of Issues Prior to Reporting for the State of France



ABOUT US

WHO WE ARE

Alliance VITA was founded in 1993 in France at the time of the introduction of the first bioethical laws. The organization develops its action at the international level by providing trainings on **bioethical issues** and by engaging with international institutions (European Union, Council of Europe, United Nations...).

Alliance VITA held special Consultative Status before the United Nations Economic and Social Council (ECOSOC). Its president is François Xavier Pérès. The organization is funded exclusively by private donations.

WHAT WE DO

Alliance VITA operates based on **two major purposes:** aid for persons facing life's challenges and hardships; raising policymakers and public awareness on the protection of human life.

- Counseling and support services (through Internet, telephone, face to face meetings):
- "SOS Bébé" for questions about maternity (difficult or unplanned pregnancy, pre- or post-natal mourning, disability, miscarriage, voluntary and/or medical interruption of pregnancy, infertility): www.sosbebe.org
- "SOS Fin de vie" for questions about serious illness or death (risk of unreasonable therapeutic obstinacy, euthanasia, burn-out of loved ones or care-takers, mourning, suicide): www.sosfindevie.org
- Alerting and raising awareness. Alliance VITA:
- raises awareness among policymakers and the general public using national and international information campaigns, on the issues of protection of human life, respect for human dignity and protection of children.
- engages in national and international dialogue and discussion on contemporary bioethical issues.

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OVERVIEW

Following the United Nations General Assembly resolution <u>A/RES/68/268</u>,¹ the Committee on the Rights of the Child ("the CRC Committee") has made the simplified reporting procedure available to States parties, whose periodic reports are due from 1 September, 2019.

As part of the process of monitoring the progress made by the State of France in implementing the Convention on the Rights of the Child ("CRC" or "the Convention"), France has accepted to be reviewed under this procedure.

Alliance VITA presents this report as part of the stakeholders' written inputs to the preparation of the List of Issues Prior to Reporting (LOIPR).

This report aims to highlight emerging trends and critical issues that should be covered in the LOIPR and that France needs to address, as to fulfill its obligations to uphold children's rights.

RELEVANT DATA

- ➤ **25,614 children** were born in 2017 as a result of medically assisted reproduction and Assisted Reproductive Technologies (A.R.T.). This corresponds to 3.3% of the total births on this year in France.
- ➤ Half of the couples who used A.R.T. had no children as a result of the procedure.
- ➤ **246,263 human embryos** are kept frozen, one third of which are no longer part of a "parental project".
- ➤ The success rate for all methods of A.R.T. is 17%. On average, about 17 embryos had to be conceived for every 1 birth.
- ➤ **310,000 human embryos** were conceived in a test tube in 2016: 52% were destroyed, 22% frozen, 25% immediately used for attempts at implantation in the uterus.
- > 83% of pregnancies were serum tested for trisomy 21 (Down Syndrome).

Source: French Agency of Biomedicine

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¹ Resolution adopted by the General Assembly on 9 April 2014, Strengthening and enhancing the effective functioning of the human rights treaty body system.

KEY ISSUES ON THE PROTECTION OF THE RIGHTS OF THE CHILD

1/ ASSISTED REPRODUCTIVE TECHNOLOGIES AND THE RIGHTS OF THE CHILD TO KNOW HIS OR HER PARENTS AND TO PRESERVE HIS OR HER IDENTITY

Current legal framework and pending reform

The legal framework for medically assisted reproduction, including artificial insemination and *in vitro* fertilization with third party donors, was introduced in France in a manner intended to be strict, conformed to natural procreation. Thus, A.R.T. (« AMP » or « PMA » in French) is exclusively reserved to couples made up of a man and a woman, who are alive, of childbearing age, facing diagnosed infertility.

A bill reforming the French Bioethics Law is currently pending before the French Parliament.² As it is drafted today, this bill introduces major changes on A.R.T.'s legal framework, notably the dropping of the medical requirement of a diagnosed infertility to access A.R.T., the double donation of gametes, the lifting of donors' anonymity and more generally, a substantial overturning of the filiation rules. Such changes infringe multiple principles and rights enshrined in the Convention.

Convention's rights related issues

o Sustaining the child's parentage and identity in A.R.T.'s access (Articles 7, 8, 18 of the CRC)

In extending legal access to A.R.T. to single women and couples of women, the pending bill infringes the principle that "both parents have common responsibilities for the upbringing and development of the child".³ Allowing access to A.R.T. with donor but without a male partner results in intentionally and purposefully depriving the children born from such procedure of a father.

Yet, a survey led by French Institute of Public Opinion⁴ showed that 93 per cent of French people believe that fathers have an essential part to play for the child. According to 61 per cent of respondents, "the need for every child to have a father must be prioritised by reserving medically assisted reproduction for male and female couples with infertility problems".

² In accordance with Article 46 of the Bioethics Law, the latter must be reviewed at least every seven years. The bill was voted in first reading in the National Assembly on 15 October 2019 and then in the Senate on 4 February 2020. It now awaits the second reading by the Parliament.

³ Article 18 of the Convention on the Rights of the Child.

⁴ IFOP survey on the French people and Paternity, June 2018, see https://www.ifop.com/publication/les-francais-et-la-paternite/ (in French).

The privation of a male referent, not only in childbirth but also in the development of the child's personality, disputes the deep desire of French people for their children.

In general, the donation of external gametes to the reproductive process causes injustice to the child. The latter would have access to his or her origins, but would still be deprived of his or her biological affiliation as long as the donor has no vocation to be his or her father, and the law itself forbids him to be so. Yet, knowing the identity of one's biological parent is different from knowing him and being raised by him.

This is an objective violation of the rights of the child, which does not stand for the child's interests, but rather for the fulfilment of one person's desire for a child. Thus, a child born from a gamete donation could engage the responsibility of the State whose legislation has organized and allowed his or her conception, in a way that does not respect his or her right to know his or her parents and be cared for by them.

The use of assisted reproductive techniques gives rise to another major ethical issue: that of supernumerary embryos frozen in the context of *in vitro* fertilization. Currently, 246,263⁵ supernumerary embryos are stored frozen. Almost a third of which are no longer part of a "parental project".⁶ And this number keeps increasing (+33% since 2011), even though the Bioethics Law provided initially to restrain the number of embryos stored.

About the best interests of the child and his or her rights (Articles 3, 16, 23, 24 of the CRC)

The CRC Committee - in its Concluding observations on the fifth periodic report of France -7 insisted on the best interests of the child asking the State to "strengthen its efforts to ensure that this right is appropriately integrated and consistently interpreted and applied" within the national system of protection of children's rights.

The best interests of the child shall be "a primary consideration" and, in this sense, must prevail over the self-interest of adults wanting to have a child. A shift in terminology from right « for the child » to right « to a child » represents a serious threat to children's privacy and human rights.

As pointed out in a Report of the French Senate in 2016, abolishing the requirement of medical infertility and sexual otherness would overturn the French conception of A.R.T., paving the way for "a right to a child" and for "procreation of convenience".⁸

⁵ French Agency of Biomedicine - Medical and Scientific Report 2017 (<u>Le rapport médical et scientifique de l'assistance médicale à la procréation et de la génétique humaines en France 2017</u> - French), published on September 2018.

⁶ These embryos can be donated to research, donated to another couple or destroyed after five years of storage. ⁷ <u>CRC/C/FRA/CO/5</u>, Concluding observations on the fifth periodic report of France, Committee on the Rights of the Child, 11-29 January 2016, §26.

⁸ Rapport d'information de M. Yves DÉTRAIGNE et Mme Catherine TASCA, fait au nom de la commission des lois n° 409 (2015-2016) – Sénat, 17 février 2016; available in French at http://www.senat.fr/notice-rapport/2015/r15-409-notice.html.

Acknowledging a larger framework of the medically assisted procreation beyond the sole therapeutic one would consequently lead to the recognition of a general "right to a child for all". Indeed, since there is no longer any reason to maintain the criterion of medical infertility for male/female couples, A.R.T. would become accessible to any adult without restriction.

France does not have to line up with "lowest ethical standard": The idea of a "right to a child" is not compatible with French ethical tradition regarding prohibition of the commodification of the human body and the protection of the child. The State of France must ensure the protection of the weakest against those who believe that might is right.

QUESTIONS TO BE INCLUDED IN THE LOIPR

It is now known that lifestyles or environmental issues, such as endocrine disrupters, can affect fertility. A report on the causes of infertility was submitted to the French Parliament in 2012. It appeared that research was disparate, with no guidelines.

- Eight years later, what is the follow-up policy?
- What are the policies for prevention and research for fertility restoration?

Currently, research is focused on improving the performance of A.R.T. rather than improving prevention or care. This is a worrying situation for women and men today and for generations to come.

- What prevention policy can the State of France implement today with young people to alert them to the biological clock and the advantages of having children at an earlier age?

2/ SURROGACY AND THE NEED OF AN EFFICIENT LEGAL FRAMEWORK TO PROTECT CHILDREN

Current legal framework

In France, surrogacy is strictly prohibited in its principle. Yet, developments in case law tend to accept its impacts on the child (civil status, adoption) when it is performed abroad.

Article 16-7 of the French Civil Code provides that "all agreements relating to procreation or gestation for the benefit of another are null." This article was introduced in the Bioethics Law of 1994 which defines several principles guaranteeing the respect due to the human body. According to Article 16-1 of the Civil Code, the human body is inviolable and as such, cannot be the subject of a property right.

The French Penal Code, in Article 227-12, punishes intermediaries: "Acting for pecuniary gain as an intermediary between a person desiring to adopt a child and a parent desiring to abandon its born or unborn child is punished by one year's imprisonment and a fine of €15,000." However, the Penal Code does not punish either the person or couple wishing to "have" a child or the surrogate mother herself.

There is a lack of vigilance on the part of the State of France who does not enforce the ban formally enough on its territory. Current legislation needs to be strengthened with clear, formal and enforceable provisions to prohibit surrogacy.

Convention's rights related issues

Surrogacy: turning children into commodities (Articles 35, 36 of the CRC)

Surrogate motherhood is contrary to many international conventions. The CRC prohibits the sale or trafficking of children "for any purpose and in any form". Yet, surrogacy constitutes the sale of a child and turns the child into a thing. Children are conceived and delivered under contracts, the surrogate mother is paid or "compensated", often with the intervention of intermediary services (agencies, insurance companies, banks). The mass surrogacy industry promotes babies as "high quality products". Babies may be aborted every time they do not "comply" with the requirements contracted between the buying partners and the surrogate mother. This notably occurs when the baby carries a disability or in case of multiple pregnancies.

⁹ Article 35 of the Convention on the Rights of the Child.

Since surrogacy is illegal in France, some nationals resort to it abroad. This phenomenon encourages the exploitation of foreign women who need to trade their bodies and children, sometimes for their own survival and that of their families. This constitutes a serious violation of the international treaties and efforts to fight against human trafficking.

o <u>Child's breakdown of parentage</u> (Articles 7, 8, 16 of the CRC)

In accordance with the Convention, the State of France must refrain from any legislative measure that prevents the child from knowing his or her parents and being cared for by them. Yet, this practice leads to the transcriptions of birth certificates for those children born from surrogacy procedures. Such certificates are intentionally inconsistent with the reality of the child's birth since they establish a false maternal affiliation. Indeed, the designated mother may not be the woman who gave birth, which is a violation of French law.

Surrogacy has breaking down impact on the child's parentage between the buying partners ("intended parents"), the surrogate mother, and often an egg donor. This breakdown of filiation leads to inextricable situations. Being cut off from part of one's genetic filiation is problematic to build one's own identity and constitutes an injustice causing serious suffering for the child.

Finally, it is unfair and abusive to equate surrogacy and adoption. Indeed, offering a family to a child who has been deprived from it remains fundamentally different from "producing" a child deliberately deprived from one of his or her biological ancestries, in order to satisfy a desire to have a child.

Therefore, surrogacy must be included as a special offence, which has nothing to do with the abandonment of a child as considered in adoption procedures.

QUESTIONS TO BE INCLUDED IN THE LOIPR

- What is France really doing to secure the prohibition of surrogacy at the international level?
- What protection is implemented against human trafficking?

3/ PRENATAL SELECTION AND EUGENICS

Current legal framework

In France, prenatal screening via prenatal diagnosis (PND) or pre-implantation genetic diagnosis (PGD) refer to medical practices, including obstetrical and fetal ultrasound, which aim to detect *in utero* a condition of particular gravity in the embryo or fetus.

In its current version, the Bioethics Law provides that the PGD is allowed only exceptionally when specific circumstances, attested by a physician, are met.¹⁰

Convention's rights related issues

Stigmatization of children with disabilities (Articles 2, 6, 23, 24 of the CRC)

While offering a better monitoring of pregnancies to assist the mother and the unborn child, prenatal screening procedures can also be completed with proposals for medical termination of pregnancy when the fetus is diagnosed with a condition of particular severity. In France, more than 7,000 medical terminations of pregnancy are performed annually. They can legally take place, at any time, during the pregnancy.

Many are concerned by the emergence of a new form of eugenics in France, stigmatizing children and persons with Down Syndrome in particular: 90% of fetuses diagnosed with Down Syndrome are eliminated through medical termination of pregnancy. Such stigma seriously impedes the right of children with disabilities to life, survival and development.

The UN Special Rapporteur on the Rights of Persons with Disabilities¹² warns about this situation: "When discussing issues such as prenatal testing, selective abortion and pre-implantation genetic diagnosis, there is a shared concern among disability rights activists that bioethical analyses are often used to give an ethical justification to a new form of eugenics, often referred to as "liberal" eugenics".¹³

¹⁰ This is the case when the couple, because of their family situation, has a high probability of giving birth to a child with a genetic illness of a particular seriousness recognised as incurable at the time of diagnosis. The diagnosis can have no other purpose than to find out about this condition and the means of preventing and treating it. By way of derogation, PGD may be allowed if the couple has given birth to a child with a non-hereditary genetic disease leading to death in the early years of life and recognised as incurable at the time of diagnosis.

¹¹ French Agency of Biomedicine, 2017, at https://rams.agence-biomedecine.fr/sites/default/files/pdf/2019-09/RAMS%202017%20DPN.pdf (in French), see Table DPN 11: a medical termination of pregnancy had been performed on 90% of the fetuses diagnosed with Down Syndrome and with a known pregnancy outcome.

¹² <u>A/HRC/43/41</u>, Report of the Special Rapporteur on the Rights of Persons with Disabilities, Human Rights Council, Forty-third session, 24 February-20 March 2020, §21.

¹³ Ibid., §21: "Contrary to the eugenics movement, liberal eugenics aims to expand reproductive choices for individuals, including the possibility of genetic enhancement. While there may be no State-sponsored coercive eugenics programmes, in a context of widespread prejudice and discrimination against persons with disabilities, the aggregate effect of many individual choices are likely to produce eugenic outcomes. Indeed, ableist social norms and market pressures make it imperative to have the "best possible child" with the best possible chances

Such practices have serious social consequences for children with disabilities and jeopardize their right to "enjoy a full and decent life, in conditions which ensure dignity". 14

In 2016, concerning the fifth periodic report of France, the CRC Committee had declared to be concerned about "persistent discrimination against children with disabilities", especially regarding "equality with others". ¹⁵

To this end, it recommended to the State of France to "undertake awareness-raising campaigns to combat the stigmatization of and prejudice against children with disabilities." ¹⁶ Regrettably, the French legislation did not improve the situation of those children, rather it encourages their stigmatization through practices like PND and PGD.

According to the Special Rapporteur, "such practices may reinforce and socially validate the message that persons with disabilities ought not to have been born. Legislative frameworks that extend the time frame for a lawful abortion or, exceptionally, permit abortion in the presence of fetal impairment aggravate this message. In addition, as the consequence is a smaller number of persons with disabilities being born, some fear a reduction in disability advocacy and social support for persons with disabilities." She calls for a change of perspective regarding disability, "the question is not about preventing or curing impairments, but how to ensure that all persons with disabilities enjoy the same rights and opportunities as everybody else." 18

o Eugenic selection of unborn children (Articles 3, 23, 24 of the CRC)

Through the recent introduction of new genetic tests, such as the non-invasive prenatal test (NIPT), a simple blood test from a pregnant woman allows the DNA of the fetus to be analyzed. This raises concerns about new practices that could lead to an increase in prenatal selection.

The pressure to carry out these increasingly precise tests reveals growing quality requirements, which are moving away from the reception of persons with disabilities and of vulnerability in general.

The measures in the draft bill, aiming for the promotion of genetic modification at the embryonic level, raise concerns about the real purpose they are intended to serve in the long term. These scientific techniques presented as research today could, once tested, lead to the birth of genetically modified babies.

at life. Some utilitarian bioethicists have further argued that genetic enhancement is a moral obligation and that it is ethical to give parents the option to euthanize their newborns with disabilities."

¹⁴ Article 23.1 of the Convention on the Rights of the Child.

¹⁵ CRC/C/FRA/CO/5, Concluding observations on the fifth periodic report of France, Committee on the Rights of the Child, 11-29 January 2016, §57.

¹⁶ *Ibid.*, §58 e).

¹⁷ A/HRC/43/41, Report of the Special Rapporteur on the rights of persons with disabilities, Human Rights Council, Forty-third session, 24 February-20 March 2020, §32.

¹⁸ Ibid., §19.

It is not only an insane risk to the physical and psychological health of these children, but it also profoundly disrupts the modalities of human procreation and ultimately, the integrity of the genetic heritage of future generations.

QUESTIONS TO BE INCLUDED IN THE LOIPR

The pending bill that intends to authorise genetic modifications on the embryo, may pose a risk, in the long term, to harm human dignity and the identity of children:

- What concrete barriers are considered to formally prohibit the birth of genetically modified children? Are there sufficient safeguards regarding these scientific practices that would alter the DNA of children without their consent, with the risk of transforming the genetic heritage of future generations?
- What measures does the State of France intend to implement to comply with its international obligation of non-discrimination and care of children with disabilities?